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HIV and AIDS and Aboriginal Communities in Canada.

A Socially Accountable Participatory Study.

by

Sally Ann Peberdy B.A. (Hons.)

A thesis submitted to

the Faculty of Graduate Studies and Research

in partial fulfillment of

the requirements for the degree of

Master of Arts

Department of Geography

Carleton University

Ottawa, Ontario

August 31, 1992

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Thesis Supervisor

Chair, Department of Geography

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ABSTRACT

Using a socially accountable participatory research methodology, this thesis examines the needs of Aboriginal people living with AIDS and HIV (PLWA/HIV) in Canada, and the vulnerability of communities to infection as articulated by PLWA/HIV and Aboriginal AIDS organisations involved in education, awareness and prevention programs and the provision of services and support. The problem is placed in the socio-geographic context of Aboriginal communities, which it is argued, affects the demand for, and the pattern of demand for services and support. At the same time it highlights differences in the needs of people and communities living on and off reserve.

The results identify common themes of concern which include: the need for education - for acceptance as well as prevention; income; housing; nutrition and medical treatments; appropriate service delivery; and funding. Overall participants enunciated a need for a holistic approach to education and health which can address the factors influencing risk to communities and the lives of PLWA/HIV and which emphasises the importance of traditional values and the healing process that is taking place in communities today, as well as a need for communities and PLWA/HIV to be in control of the development of programs for effective culturally relevant and community sensitive education and service provision.

ACKNOWLEDGEMENTS

I would like to acknowledge a number of people who have helped me throughout this process. To my family, and to my friends grateful thanks for their support, reassurance and forbearance. I would like to thank my supervisor, Professor David Knight for his encouragement and advice.

I am grateful to the Commonwealth Scholarship and Fellowship Plan for their financial support, and who not only enabled me to undertake this degree but funded the research.

I would also like to thank members of the Joint National Committee for Aboriginal AIDS Education and Prevention for their assistance, participation and interest. Most of all I would like to express my gratitude and give credit to the people that took the time to talk and patiently explain to me, and who shared their insights, in an effort to help me develop what understanding I have. Thankyou.

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CHAPTER 1

INTRODUCTION

1.1 STATEMENT OF THE PROBLEM

This thesis examines the needs of Aboriginal people living with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS), and the obstacles faced in meeting these needs, from the perspective of a human geographer who is cognizant of socially accountable participatory research. The potential vulnerability of Aboriginal communities¹ to HIV and AIDS is examined before the primary research question is addressed (see Glossary in Appendix 1 for definition of key terms).

There are significant differences between the social geographies of Aboriginal and non-Aboriginal communities in Canada. The unique attributes of Aboriginal communities affect the needs of Aboriginal people living with AIDS and HIV (PLWA/HIV) and patterns of demand for services and support. To be able to understand the needs of PLWA/HIV it is necessary for people and communities to voice their needs so they are met effectively and appropriately.

Disease is not simply a biological relationship between an organism and its

¹ In this study, the term Aboriginal includes Status Indians, non-Status Indians, Inuit and Metis people. Metis and Inuit communities have not been differentiated unless specified (see Glossary in Appendix 1).

host. The context in which a disease occurs may influence its transmission, spatial diffusion and etiology and thus its impact on communities and individuals. Populations are heterogeneous and thus the experiences of disease, ways of dealing with it, and conceptualisations of health are specific to communities. Affected communities and individuals need to be part of the process of developing programs to deal with infection so that they are appropriate to their needs and the environment in which they live.

HIV and AIDS are highly stigmatised. In the past the identification of specified populations as 'risk groups' has led to communities and individuals being identified as 'sources' and 'carriers' of infection, encouraging discrimination and isolation, and ignoring the real processes underlying transmission. By examining the potential risks of Aboriginal communities to HIV and AIDS the purpose is not to portray the population as a 'risk group'. In the words of Susan Beaver, Director of Two Spirited Peoples of the First Nations: "It has affected us because we are human beings and susceptible to disease and illness....There are no high risk groups when it comes to AIDS, there is only high risk behaviour" (7/7/92). Risk is a function of behaviour, not ethnicity. However, disease cannot be divorced from the context in which it exists. Data from around the world shows that it is the disadvantaged populations of both wealthy and poor countries which are being hardest hit by HIV and AIDS.

PLWA/HIV have specific needs which are consequent to infection and which are diverse, individual to each person, and change over the course of infection. Individuals' needs and the means of meeting them, may be shaped by themselves,

their relationship to the world around them, and where they live. In Canada the average social and economic situations, living conditions and health status of Aboriginal communities are significantly worse than those of non-Aboriginal Canadians. The demography, distribution and migration patterns of the Aboriginal population are notably different from those of the majority population. The living conditions and incomes of Native people in Canada indicate that for many people an environment exists which presents barriers to maintaining health.

This study examines the implications of these socio-economic and geographical factors for Aboriginal people in Canada. This thesis argues that these factors, which are a function of inequalities and discrimination in Canadian society, may increase the risk of transmission of HIV in Aboriginal communities and affect the needs of PLWA/HIV. The unique geography of the Aboriginal population creates a distinctive spatial pattern of diffusion of HIV and subsequently the pattern of demand for services and support.

While the thesis locates the experience of HIV and AIDS in Aboriginal communities in the context of the environment in which people live, communities or individuals are not deemed to be passive 'victims' of circumstance or of HIV and AIDS.² Communities and PLWA/HIV are responding to the epidemic, developing programs in the areas of education, prevention and awareness, as well as the provision of services and support. The problem is examined from the perspective of some of the

² The Denver Principles of the American national organisation of PLWA/HIV states "We condemn attempts to label us as "victims," which implies defeat, and we are only occasionally "patients" which implies passivity, helplessness, and dependence upon the care of others. We are "people living with HIV and AIDS"" (ACT/UP New York Womens Book Collective, 1990).

Aboriginal organisations and PLWA/HIV who have developed these initiatives. The majority of the data were gathered from interviews conducted in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario and Quebec.

1.2 ABOUT HIV AND AIDS

Human immunodeficiency virus (HIV)³ is thought to be the cause of acquired immune deficiency syndrome (AIDS). AIDS is a group of infections called opportunistic infections which develop in people who are immunosuppressed and which are associated with people who also test positive for HIV. HIV and AIDS are newly identified phenomena; there are considerable knowledge gaps, disputes about the nature and relationship between AIDS and HIV, and the etiology of both. The progression of the disease varies from individual to individual, and the environment in which people live is an important determinant of the progression of the virus after infection.

HIV is essentially a sexually transmitted disease. In Canada today, the primary means of transmission are unprotected penetrative or oral sex, needle sharing by injection drug users, and perinatal transmission.⁴ People who are infected with HIV usually show no noticeable signs of infection and can therefore remain unaware of

³ Two strains of HIV have been identified, HIV-1 and HIV-2. HIV-1 is the most common strain found in North America. I will use the 'generic' term HIV.

⁴ Since tests for HIV were developed in 1985 the probability of being infected by blood transfusions, blood products and transplanted organs and semen are virtually nil as all supplies are tested and donors screened.

their infection. People who do not consider themselves at risk may not be tested until they become ill. After infection the virus may remain inactive for an estimated one to nineteen years - or even longer.⁵ When activated HIV causes immunosuppression and AIDS. It is not known what stimulates the virus to attack the immune system. It is increasingly believed to be associated with cofactors. Montagnier has said,

...after a while - even from the beginning actually - we thought maybe, for the activation of that virus [HIV] in cells, we need some cofactors. HIV by itself - or some strains of HIV - are not sufficient to induce AIDS. Perhaps in order to have the disease, you need more than one agent, in order to have this burst of destruction of cells we see in AIDS patients (CBC, 1992:10-11).

It is not possible to say whether HIV always causes AIDS. John Scythes a researcher has said,

I think they will adjust their [the research establishment] thinking to include cofactors, and they may be right: maybe HIV is pathogenic only in the presence of cofactors. As I've said the persistence of its antibody in persons who are progressing, is compelling. An HIV antibody positive test is not a death sentence and, clearly, the epidemiology is pointing in that direction (CBC, 1992:11).

The clinical definition of AIDS is comprised of a series of infections which are commonly found in (some) people with AIDS. The definition was revised in 1987 and is currently being revised again. Although some infections are found in both men and women, there are gender differences in the most common infections found. Both the original and the current definitions excluded infections commonly found in women. The lack of an inclusive definition of AIDS has meant that many cases, particularly women, have gone unrecorded (Hankins, 1990).

⁵ It is estimated that approximately 50% people infected with HIV will develop AIDS in the ten years after infection, and around 5% will develop AIDS within two years.

Emotional responses to HIV infection and AIDS and personal support networks vary widely, creating individual needs for support from family, friends and service providers according to circumstance. A person with AIDS does not necessarily become ill overnight and stay that way, but may live in a continuing cycle of health and illness. Thus the needs of PLWA are constantly changing. Different opportunistic infections affect different people, so that medical and service needs are specific to each individual. The needs of a person who is losing their sight, or one who has cancers, or another affected by respiratory diseases, are obviously different.

Risk factors that enhance a persons risk of contracting HIV by directly increasing the risk of transmission or by affecting behaviour include: unprotected sex; sharing needles; being a partner of someone at risk; presence of sexually transmitted diseases (STDs), or a previous history of STDs; a stressed immune system; substance abuse (including alcohol); family violence; poverty and a lack of self esteem. Some postulated cofactors associated with the development of AIDS after infection are: stresses on the immune system (including STDs); substance abuse; general ill health; and emotional stress. Life expectancy after diagnosis with AIDS is related to: living conditions; stress; and general health status; nutrition; exposure to opportunistic infection; and early diagnosis. New medicines being developed to control some opportunistic infections can help to increase life expectancy after diagnosis with AIDS.

The environment in which the virus occurs is central to understanding its potential effect on communities, as well as individuals who have been infected and their needs. Thus the general socio-economic circumstances, health status and housing

conditions of Aboriginal population in Canada combined with the etiology of AIDS presents risks to Aboriginal people, creating greater vulnerability to infection as these risk factors and cofactors are disproportionately represented in Aboriginal communities and because they expose a person who has developed AIDS to more threatening living conditions.

1.3 RATIONALE FOR THE STUDY

Little research has been completed on the extent of HIV and AIDS in Aboriginal communities in Canada. No literature exists identifying the needs of Aboriginal PLWA/HIV. Only a small amount examines the needs of any PLWA/HIV in Canada, yet increasing numbers of people need support and services.

By July 1992, 6,650 cases of AIDS had been reported to the Laboratory Centre for Disease Control (LCDC) in Ottawa (HIV/AIDS Division, July 1992).^{6 7} Appendix 2 presents tables showing reported AIDS cases by gender and means of transmission by July 1992 in Canada.

Of the total reported cases of AIDS, 53 (or less than 1% of all cases) were Aboriginal people (Sutherland, personal communication, August 1992). The numbers

⁶ A record linkage study in 1988 found rates of under reporting of AIDS cases of 12% and 18%, which are similar to those of the United States and Britain (Calzavara *et al.*, 1990).

⁷ AIDS in Canada still appears to be primarily affecting gay white men. Of the total reported adult cases (6144), 94.1% were men, of whom 83% had contracted AIDS through homosexual/bisexual activity. However numbers of reported cases among men attributed to homosexual/bisexual activity are falling, but new cases attributed to other risk factors are increasing as are the number of new reported cases amongst women (HIV/AIDS Division, July 1992).

of recorded cases among Aboriginal people has jumped dramatically in the last three years. By the end of 1990 only 7 cases had been reported to the LCDC, in 1991 the cumulative total was 23. Dr Reckarts at the British Columbia Centre for Disease Control said that 7 new cases of AIDS in Aboriginal people were reported in the province between 1988-June 1991, but 9 new cases were reported in the three months of July-September 1991 (Reckarts, personal communication, June 1992).

These figures do not represent a true picture of the current extent of AIDS in Aboriginal communities. Information on ethnicity was not recorded in 3,053 of cases reported to the LCDC by July 1992. The HIV/AIDS Division of the LCDC have commented that available data for Aboriginal people are unreliable and that data on transmission rates are unrepresentative of risk in communities and therefore all data should be regarded with extreme caution (Sutherland, LCDC, personal communication, August 1992).⁸ Appendix 3 presents tables showing reported cases of AIDS among Aboriginal people by gender, means of transmission and over time.

Reported AIDS cases do not show the current epidemiology or extent of HIV infection. No Federal data are available on rates of HIV infection. Even if they were available HIV rates only identify people who have presented themselves for testing. The LCDC estimate that 30,000 Canadians may be infected with HIV (Ricketts, personal communication, August 1991). In 1990, the Joint National Committee for Aboriginal AIDS Education and Prevention estimated that as many as 6,300 Aboriginal people may be infected (JNC, 1990a)

⁸ A study in the US has noted that by being misclassified as non-Native, Native Americans are under-represented by as much as 50% in AIDS surveillance statistics (Metler *et al.*, 1991).

Seropositivity studies give indications of rates of HIV infection among selected populations.⁹ Of particular significance to this study, in 1989, researchers in Quebec found rates of infection were highest among babies born to women who were living in the poorest areas of Montreal island (1 in 216 compared to 1 in 559 for all the island) (Hankins *et al.*, 1990).¹⁰ Only one study in Canada has measured seropositivity among Aboriginal people, examining "street-involved people" tested by the AIDS Street Nurse Program in Vancouver. Tests were taken between 1988-1990. It found 6% of Aboriginal people tested positive for HIV compared to 4.2% of Caucasians and 3.7% of Hispanic people (Rekart, personal communication, June 1992). In the US, seropositivity studies of American Indians and Alaskan Natives show much higher rates of infection than are indicated by reported AIDS cases (313 or 1.8/10,000 in November 1991) (Centre for Disease Control (CDC), 1991:9). A study of seroprevalence among Sentinel Hospital patients between 1987-1990 found rates of HIV infection of 4/1,000 among American Indians/Alaskan Natives compared to 5.3/1,000 among all others tested (Chase, personal communication, January 1992). A study of seroprevalence in California between 1988-1990 found 5.4% of American Indians/Alaskan Natives tested positive for HIV compared to: 6.6% of Black people; 4.9% of Hispanic people; and 4.7% of Whites (*ibid.*). Preliminary results from a

⁹ Seropositivity studies test for HIV antibodies in blood usually collected in blind studies. When antibodies to HIV are found in the blood, the test is positive.

¹⁰ Studies of seroprevalence among pregnant women and newborn babies, have found ratios of infection of 1:1680 in Quebec; 1:3073 in British Columbia and the Yukon; 1:9090 in Manitoba; and 1:900 in Newfoundland (Hankins *et al.*, 1990; Schecter *et al.*, 1990; Sekla *et al.*, 1991; Canadian Press, 1992). Other seroprevalence studies will be referred to in subsequent chapters.

seroepidemiology survey conducted by the Indian Health Service between 1989-1991 show that HIV infection is present in rural isolated Aboriginal communities in the United States (*ibid.*).¹¹

The experiences of people in the US are not only distressing but are particularly germane to this study. The HIV/AIDS epidemic started several years earlier in the United States (US) than in Canada. By November 1991, Black and Hispanic people made up 45% of all reported AIDS cases, but constituted only 18% of the total population (CDC, 1991; Office of Minority Health, 1990).¹² The number of new reported cases of AIDS among Native Americans while smaller numerically than in other groups, are increasing at a greater rate. In 1984 one case of AIDS was reported every 3 weeks for American Indians/Alaskan Natives, by 1991 one case was reported every three days (Chase, 1991).

Studies show that women and Black and Hispanic people in the US live a significantly shorter time after diagnosis than white men. This has been attributed to differences in health status, access to health care, and later diagnosis (Deneberg, 1990; Sabatier, 1988).

Together with Native Americans, these communities share similar socio-economic conditions, poor health status, rates of STD infection, and high rates of substance abuse with Native Canadians (Indian Health Services, 1991; National Centre

¹¹ Seroprevalence among military recruits in 1988 was 0.8/1,000 (1.2/1,000 for all others) (Chase, personal communication, January 1992).

¹² A health professional has suggested that it is possible that there is an under reporting amongst whites in the US, due to family doctors "protecting" their patients by not reporting diagnosis (Knight, personal communication, August 1992).

for Health Statistics, 1991; Mortality and Morbidity Weekly Report (MMWR), 1992; Jeres, 1992). Appendix 4 shows AIDS cases by exposure category, race/ethnicity and gender for adults, reported by November 1991 in the US.

The American experience indicates that not only are risks of infection influenced by living conditions, but so are the lives of PLWA/HIV. There are obviously differences between the US and Canada, but the level of AIDS among Black Hispanic and Native Americans has serious implications for people in Canada whose life experiences are similar. In the light of the American epidemic of HIV and AIDS it is appropriate to discuss the implications of HIV and AIDS for the Aboriginal population of Canada. Given the lack of accurate data on the epidemic in Aboriginal communities it is necessary to discuss the risk to communities to understand the potential impact on communities and individuals and future demand for services and support. However, risk is no longer the primary issue. Many Aboriginal people are already living with HIV and AIDS and dealing with the issues it raises, yet no research has been done on what support they require to meet their needs. This study introduces some of the concerns that were raised by Aboriginal PLWA/HIV and Aboriginal AIDS organisations.

1.4 LITERATURE

Literature of particular relevance to this study includes that relating to: service provision for PLWA/HIV in Canada; use and access of Aboriginal people to health

services; and geographical literature relating to health care service provision.¹³

Literature relating to service provision for PLWA/HIV in Canada is extremely limited in any of the social science disciplines. Indeed, Smith and Mitchell comment, "In a review of the available literature we failed to find any study of the social organisation of the delivery of social services from the standpoint of clients" (1990:6). Two geographical studies have been made, one of a palliative care hospice in Toronto (Chiotti and Joseph, 1991), the other of housing needs of PLWA/HIV in Canada (Willms *et al.*, 1991). And a study in Toronto examined how Community Agencies were meeting the needs of youth living with HIV and AIDs (Radford *et al.*, 1991). A further study is under way interviewing PLWA/HIV in Toronto to find out how they are "hooking up" to service and support networks (Smith and Mitchell, 1990).

There is a similar deficiency in the literature relating to the use of services (particularly health services) by Aboriginal peoples (Shah, 1988). The literature that is available indicates that there is a different pattern of use (Morse, 1991; Thouez, 1990; Waldram, 1990; Shah, 1988; Weller and Manga, 1987; Shah and Farkas, 1985). Some literature indicates that Aboriginal people may have different conceptions of, and attitudes to health. Different communication patterns and familiarity with health care systems in cities have also been identified as barriers to access (Morse, 1991; Medicine, 1988; Shah, 1988; O'Neil, 1987; Roberts, 1987; Shah and Farkas, 1985; Farkas, 1984).

The majority of geographical literature relating to service provision examines

¹³ Further discussion of geographical and other studies on HIV and AIDS is presented in Chapter 2.

the problem in the context of time distance analysis (Joseph and Phillips, 1984; Eyles and Woods, 1983). The demographics and distribution of the Aboriginal population in Canada is different from the majority of the population and has implications for how and where services are delivered and the problems people have in reaching service and support networks. Although geographers are starting to take note of gender differences, there appears to be a lack of acknowledgement of the roles of culture and ethnicity in health service use (Thouez *et al.*, 1990; Jackson, 1989).

The present study represents a significant addition to existing literature given the lack of attention previously paid to the roles of ethnicity, community and culture on disease and health, and demand for and patterns of demand for services and support. Examining the problem of service delivery from the perspective of service users and specific service providers also represents a break with traditional approaches to determining the accessibility and utilisation of services. Much of the data presented on the socio-economic conditions of Aboriginal communities has not previously been gathered together in this form.

1.5 LIMITATIONS

Services and support to people living with HIV and AIDS are provided by a multiplicity of agencies in the public, non-governmental and private sectors. The compartmentalised nature of the health care system in Canada has led to fragmentation of health services. Its roots lie in a curative bio-medical model of disease and health,

which has left little room for the inclusion of alternative therapies, or an approach to service provision which encompasses the whole of peoples' lives. Available services vary widely in different locations across Canada, in cities and in rural areas. Therefore it was not feasible to examine specific services and support available to people living with HIV and AIDS. Although this may initially seem a large omission, the availability of services is irrelevant if they are not being used by potential clients, or if they do not meet their needs. It is more important to examine the needs of PLWA/HIV and the obstacles they face in finding the services and support they need and feel able to utilise.

While the study refers to the Aboriginal population of Canada, it is important to recognise that like all populations it is not homogenous. Communities are diverse, and considerable variations exist within, and between communities and individuals. The data expresses general conditions, not universal truths. A central theme of this thesis is to recognise that people and populations are not all the same and that these differences need to be accepted and acted on to ensure that peoples needs are met. Thus it is important to recognise that these variations exist.

The socio-economic and geographical issues underlying the transmission, diffusion and etiology of HIV and AIDS are examined. However, it is not possible in the scope of this study to examine the historical processes of colonialism, discrimination, marginalisation and lack of territorial control which have created them. A recognition of the history of the Indigenous people in Canada is central to understanding the issues discussed.

1.6 ORGANISATION OF THE STUDY

The study is presented in six chapters. This chapter has introduced the statement of the problem, the rationale for the study, and its limitations.

Methodological issues are discussed in Chapter 2. The use of a socially accountable participatory research methodology is considered and the means of data acquisition used are presented. Chapter 3 creates a context for discussion in subsequent chapters. It looks at the socio-economic and geographical dimensions of Aboriginal communities in Canada, and considers their implications for the transmission and diffusion of HIV in this population, and for people living with HIV and AIDS. Chapter 4 identifies known risk factors for the transmission of HIV and their extent and significance for the future of HIV and AIDS in Aboriginal communities. Chapter 5 considers the needs of Aboriginal people living with HIV and AIDS, and some of the obstacles to meeting these needs. The issues are examined from the perspective of Aboriginal organisations providing education and services and support, and PLWA/HIV and presented as far as possible in their own words. It communicates common themes of concern that emerged during the interviews. Chapter 6 concludes the thesis.

CHAPTER 2

METHODOLOGICAL ISSUES AND RESEARCH DESIGN

2.1 INTRODUCTION

The purpose of research is to produce information which contributes to answering, or leading to greater understanding of a research problem. Selected methodologies provide the way of approaching a problem that the researcher finds most appropriate to the context in which the problem is situated.

This study is based on a socially accountable participatory research methodology. The data were gathered by using interviews, a questionnaire, published statistical information and other secondary sources. The methodology was approved by the Research Ethics Committee at Carleton University. The chapter first defines what is meant by a socially accountable research methodology, and describes the data acquisition methods for each part of the research problem. It concludes by placing these in the context of the literature on participatory research.

2.2 SOCIALLY ACCOUNTABLE PARTICIPATORY RESEARCH

A socially accountable participatory research methodology can be characterised as one which allows the research process to be accountable to the participants and

community being researched, and in which they play an active part in the research process.¹

Such a methodology contrasts with the "traditional" approach to research involving people, which has emphasised a 'professional' distance between the researcher and the participants (Kirby and McKenna, 1989; Maguire, 1987; Lockhart and McCaskill, 1986). In the latter context the accent has often been on attempting a 'scientific' or objective approach, which has removed control from the participants and their communities (Kirby and McKenna, 1989; O'Brien and Page, 1990; Griffiths and Nance, 1986; Lockhart and McCaskill, 1986). Research problems and methodologies have usually been defined by the researcher and not by the communities or people being researched (O'Brien and Page, 1990; Griffiths and Nance, 1986; Lockhart and McCaskill, 1986).

This is certainly true of much of the research by non-Natives into issues pertinent to the Aboriginal people of Canada, which has often been exploitative, voyeuristic, and disempowering (ACUNS, 1988; Brody, 1988; Lockhart and McCaskill, 1986; O'Brien and Page, 1990; Griffiths and Nance, 1986). The Association of Canadian Universities for Northern Studies (ACUNS) remark that:

¹ Participatory research emerged in the early 1970's. There are strong bodies of literature in the fields of education, feminist epistemology, and development. Feminist geographers have emphasised the use of participatory research. Participants in the relevancy debate in geography had a complementary understanding of some of the problems associated with traditional research and a similar desire to find new ways of conducting interactive research (Koybashi and Mackenzie, 1989). It has attempted to incorporate a section of the population who have been excluded from the research process and from the institutions directing the research. Some authors include: Kirby and McKenna (1989); Personal Narratives Group (1989); International Development Research Centre (1988); Harding (1987); Maguire (1987); Bowles and Klein (1983).

...researchers have worked in isolated communities without regard for the people who live there. Communities have been disrupted, and essential local resources used without consultation. Privacy is difficult in small communities, creating additional problems for participants (ACUNS, 1988:3).

This study is hopefully not part of that tradition. I have adhered to the Ethical Principles for the Conduct of Research in the North outlined by ACUNS (*ibid.*). These principles identify some of the pitfalls of inappropriate research methodologies.

Using an appropriate methodology is important to ensure that this study is legitimate not only in the eyes of the University, but also the community of people participating in the inquiry. It is particularly important here as I have sought personal and sensitive information from people who are facing many other problems.

Techniques and methods traditionally deemed appropriate research tools by academe may not be appropriate when examining issues pertinent to people who have been not been part of the development of these institutions. If the study is to be useful to the people participating in it, it is important that it is accountable to them (Kirby and McKenna, 1989; O'Brien and Page, 1990; Hedley, 1986; Lockhart and McCaskill, 1986).

There is a growing body of research examining appropriate methods for conducting research in Aboriginal communities. Attempts to create partnership models between universities and communities being researched have been developed by Aboriginal community leaders and academics at the Universities of Trent, Windsor, and British Columbia (O'Brien and Page, 1990; Hedley, 1986; Griffiths and Nance, 1986). Lockhart and MacCaskill (1986:1) note that their objective was,

In an effort to combat the socio-culturally cooptive ideology of the established academic tradition, the authors argue for pre-developmental assessment and a community-based partnership model.

Using a socially accountable participatory research methodology can help to ensure that the communities and 'subjects' of the research are participants with some control over the research process, and in doing so, may overcome some of the problems associated with more traditional approaches. It can help to ensure that participants are not exploited, misrepresented, and that the problem is relevant to them.

The initial research problem became apparent when I was examining the literature relating to AIDS in Canada. There appeared to be a paucity of information relating to Aboriginal communities in Canada. The literature was dominated by socio-medical approaches which concentrate on HIV infection among gay men, injection drug users and the potential for HIV infection amongst the heterosexual population. The literature relating to HIV and AIDS in Africa and the USA identified HIV as a virus that disproportionately affects people who are disadvantaged, marginalised and those who are poor and have poor health. I could see little recognition of the implications of these analyses for Aboriginal people in the Canadian literature.

The only literature I could identify which dealt directly with HIV infection in the Aboriginal population of Canada were the "Findings" and "Recommendations" documents produced by the Joint National Committee for Aboriginal AIDS Education and Prevention (JNC) (1990a; 1990b). These created a background and identified a number of outstanding research problems. I approached the JNC expressing an interest in doing research in this area. Through discussion we identified a research problem

which would be useful to them, which I felt capable of doing and which would be of geographical interest. This is the research problem described in Chapter 1. Members of the JNC have acted as representatives of the community being researched.² It consists of representatives from eleven national Aboriginal organisations. The JNC was formed in 1989:

... to research and report its findings to the Minister of National Health and Welfare Canada and make recommendations on the issue of AIDS as it affects Aboriginal people in Canada (JNC, 1990b).

We agreed that I would consult the JNC at each stage of the research process. If they felt that aspects of my inquiry or method were inappropriate, I agreed that I would not use them or approach the problem in that way. I also agreed that any comments which they wanted to make on my final thesis would be incorporated into the final draft, either acknowledged in the text or in an appendix - whichever was deemed most appropriate. Input, approval and advice from members, has been sought at each stage of the thesis. The thesis has been submitted to them for their comments. Chapter 5 was sent to interview participants for their comments and to ensure that they had not been misrepresented nor their confidentiality been breached. All of this stated, I remain accountable for decisions on the project (ACUNS, 1988:3).

² Because of the need to respect the confidentiality of potential participants, it was not possible to be directly accountable to them in the identification and construction of the research problem and methodology.

2.3 DATA ACQUISITION

AIDS is a health problem which reaches into many areas of interest, including geographical, ethical, methodological, medical, or psychosocial. It is difficult to separate them without losing sight of the whole context which is important to conceptualising the disease. Consequently I have looked at a wide range of literature from different disciplines and perspectives. This literature included published statistical data gathered by the Federal and Provincial Governments of Canada, and by the CDC and the Federal Government in the USA. Other sources include articles published in geographical, social science, scientific and medical journals and books. The primary data were gathered by using interviews and questionnaires.

The problem as identified has two parts: the current and possible future extent of the epidemic in Aboriginal communities, and the needs of Aboriginal PLWA/HIV and some of the obstacles to meeting those needs.

2.4 PART 1

Methods used to attempt to answer the first part of the problem can be broken down into those appropriate to finding out the current extent of HIV infection and AIDS among Aboriginal people and those appropriate to predicting the future of the epidemic and the potential vulnerability of Aboriginal communities.

To identify the present extent of the epidemic, I used available published statistical data and seropositivity studies. Current statistics on the number of AIDS

cases was released by the LCDC after they had received the authorization of the JNC.³ I had hoped the questionnaire would build a demographic profile of HIV infection in Aboriginal communities, unfortunately this was not possible.

To examine the possible future of the epidemic I had originally intended to compare the extent of HIV infection, in the United States, particularly among Native Americans and Black and Hispanic Americans with the Canadian experience. Unfortunately there was insufficient reliable data (from Canada) to allow me to do this.⁴

To probe the potential vulnerability of Aboriginal communities, I have examined the extent of identified risk factors in the population, using published data largely from government sources and the insights of interviewees. The risk factors include economic status, indicators of self esteem, STD infection rates, levels of substance abuse, and health status indicators.

2.4.1 Limitations

Limitations to the data include problems with the quality and scope of available data. Firstly, as related to Aboriginal people in Canada:

- i) there is confusion over the actual number of Aboriginal people in Canada. This confusion arises because the official ethnicity of Aboriginal Canadians is determined by statute. Non-Status Indians,

³ The LCDC does not release statistics broken down by ethnicity without authorization.

⁴ Kramer and Weller (1989), in a comparative study of the health of Canadian and American Aboriginal people comment on the lack of comparable data.

Metis and Inuit people are often excluded from official figures. Some bands do not participate in government counting schemes.

ii) the Federal government will only assume responsibility for Status Indians living on reserves, which excludes non-Status and Status Indians living off-reserves. The majority of studies relate only to people living on reserves (Shah, 1988; Shah and Farkas, 1985);

iii) in Canada many statistics gathered on a provincial or federal basis do not identify ethnicity. Ontario and NWT have a statutory prohibition against recording data on ethnicity (Ricketts, personal communication, August 1991);

iv) recording of ethnicity is voluntary. Information on ethnicity was not recorded in 46% of reported cases of AIDS (3,053) in Canada by July 1992 (Sutherland, personal communication, 1992); and

v) ethnicity is reported by doctors, so unless people identify themselves as Aboriginal, (this fact of their identity may be ignored or missed by doctors), the ethnicity of many Aboriginal Canadians may go unreported. It is estimated that Native American ethnicity has been under reported by as much as 50% in AIDS reporting procedures (Metler et al., 1991);

Other problems in obtaining accurate statistical data include:

i) differences in collecting methods (Schwager et al., 1989:5-8);

ii) no official records made of HIV infection are available in

Canada;

iii) national data masks local variations;

iv) AIDS is a new disease. Information relating to its progression and associated risk factors is constantly being updated. Many health reporting methods predate AIDS. Therefore relevant statistical data are not always available, or are gathered in ways which make it difficult to use (Schwager *et al.*, 1989:5-8);

v) some of the risk factors are difficult to quantify except on a local basis, e.g. sexual behaviour (Schwager *et al.*, 1989:5-8);

vi) data relating to risk factors are not always broken down by ethnicity;

vii) the definition of AIDS has changed since 1981, many people, especially women, were excluded prior to the revision in 1987. The present definition (currently being revised), still excludes people from being officially diagnosed with AIDS.

2.4.2 Literature

Mathematical models and computer simulated models are used in many different aspects of AIDS research to predict future prevalence rates within populations. Mathematical models fall into three categories (Shannon *et al.*, 1991; Schwager *et al.*, 1989).

(1) Direct extrapolation models use existing data. These models are limited in that they cannot account for changing patterns of infection among different

communities or within one community. They also require accurate data relating to the number of known AIDS cases which are not available for Aboriginal people in Canada (Schwager *et al.*, 1989:9-10).

(2) Back calculation models are also based on the number of known cases. These are combined with the estimated time lag between infection with HIV and the development of AIDS. They have been found to be very sensitive to changes in the length of the incubation period (*ibid.*:11). The time lag is not uniform, and no information is available on time lags in Aboriginal communities in Canada.

(3) Dynamic transition models or epidemiological models are more sophisticated. They examine the distribution of factors related to aids infection (*ibid.*:14-15). For accurate modelling the levels of statistical information required are unavailable in Canada.

An article in Science in 1991 identified three of the most important computer simulation models which have been developed for use in developing countries (Culotta, 1991). They all require high levels of knowledge about the population being studied which not only makes them unwieldy, but without which they are inaccurate (Bulatao, personal communication, 4/1/92; Bulatao and Bos, 1991; Culotta, 1990)

The mathematical and computer simulated models are problematic for similar reasons, as each requires a sophisticated level of statistical data. The information required to generate the models is not available in Canada, and particularly not for the Aboriginal population of Canada.

Geographers have produced diffusion and network models showing the spatial

diffusion of AIDS.⁵ These analyses are descriptive models and are not predictive. Their utility for this thesis is limited. Network analysis requires detailed information about the numbers and locations of AIDS cases or people who have tested positive. They have been useful in identifying initial patterns of infection, but are only as useful as the information available. Two important studies using this method were conducted in Finland and Iceland, countries with small populations and a high level of available data (Loytonen, 1991; Haraldsdottir, 1990).⁶ Diffusion models have used existing data to plot the diffusion of AIDS world-wide and within the United States.

Neither of these types of analysis is useful for this study. In Canada there is no accurate data on the number of AIDS cases in Aboriginal communities and distributional data even on the Provincial and Territorial level is not publicly available to preserve confidentiality (Ricketts, personal communication, 1991).

Wallace (1991a, 1991b) has developed a theoretical mathematical model which examines the diffusion of HIV along "a low-dimensional 'socio-geographic' network". His model is significant for this study because it places the spread of HIV in a social context, examining a range of socio-economic, geographical, behavioural, and historic variables which are not included in the other models (1991a, 1991b, 1990). His recognition that different communities may have a different socio-geographic pattern

⁵Including: Loytonen (1991); Shannon *et al.* (1991); Haraldsdottir (1990); Kirby (1988); Gould (1989); Shannon and Pyle (1989); Gardner *et al.* (1989); Wood (1988); Dutt *et al.* (1987). The work of Shannon and Pyle is controversial because of their dubious obsession with the geographical origins of HIV and analysis of the epidemic (Newman, 1990; Watts and Okello, 1990).

⁶ Schoepf (1991:751), discussing the utility of network analysis comments that, "Useful in the epidemics early stages, the method and the target group notion are no longer adequate to the complex problems of prevention"

of infection which are related to levels of "social disintegration", "out-migration and residential instability" is of particular significance to this thesis (1991a). Its utility is in his conceptualisation of the problem as the model is designed largely as a theoretical instrument. The conclusion to his paper is particularly important to the approach taken in this thesis:

These and other questions raised by, and the policy implications of, this (or any) modelling exercise cannot truly be either answered or refuted by 'better' or 'more complete' mathematical models, but only by the more sophisticated collection and analysis of real data about real communities in space, 'social network space' and time. It is just such work which this paper in fact seeks to encourage (1991b, p.851).

This thesis cannot make a significant contribution to the collection of epidemiological data about Aboriginal communities, other than providing an unofficial figure of the number of Native people who are in contact with contacted service organisations and who are infected with HIV and living with AIDS. However it can elucidate the factors which make communities vulnerable to infection.

2.5 PART 2

The purpose of this part is to examine whether Aboriginal PI.WA/HIV have distinct needs, and to identify the obstacles to meeting them. The problem has been approached by asking service users and service providers to answer the research question. They were approached through questionnaires and interviews.

2.5.1 The Questionnaire

The questionnaire was designed to provide basic demographic and geographic information about Aboriginal PLWA/HIV, the size of the communities they live in, and their reasons for living there, as well as their income, housing conditions, and the services and support that they receive. It was difficult to design the questionnaire in a way which would provide sufficient information without being too long or complicated to complete. The questionnaire is in Appendix 5.

The questionnaire was distributed by agencies providing services to Aboriginal PLWA/HIV. It was sent with a letter to the organisation explaining the purpose of the study, letters of introduction to participants, a consent form, and a stamped addressed envelope (see Appendix 5).

The letter of introduction to the participant described the study and its purpose. Participants were asked to call me collect if they:

- i) wanted to participate, but did not want to, or could not complete the questionnaire;
- ii) had completed the questionnaire, but still felt that they had more to say about their experiences;
- iii) if they had any questions about the study;
- iv) or wished to receive a copy of the relevant sections of the thesis so that they make comments.

An important aspect of the letter was to explain that the confidentiality of participants would be preserved by having all information collated and written in a

composited form to ensure that it would not be possible to identify them from the information that they provided. The consent form is self explanatory. It stated clearly the right of participants to withdraw at any stage.

Distribution

Services to PLWA/HIV are provided by many agencies in both the statutory and non-statutory sectors. These could not all be contacted due to time and cost constraints. The agencies chosen were those who were feasible to contact and who would probably be providing services to Aboriginal PLWA/HIV. The following organisations were chosen to be asked if they were providing services to Aboriginal PLWA/HIV and, if so, if they would be willing to distribute the questionnaire:

- i) organisations affiliated with the Canadian AIDS Society (CAS) (see list in Appendix 6);
- ii) Feather of Hope Society - an Aboriginal AIDS organisation with branches in Alberta (Calgary and Edmonton) and Saskatchewan (North Battleford); Healing Our Spirit (Vancouver); the Manitoba Aboriginal AIDS Task Force; Two Spirited Peoples of the First Nations; and Anishnawbe Health. These organisations provide education, prevention and awareness programs and support and services to PLWA/HIV. (Appendix 6);
- iii) referrals by the above organisations to other agencies providing services and support to Aboriginal PLWA/HIV in their area (Appendix 6);

iv) Reserve health programs listed in the Aboriginal Resource Directory, published by the Assembly of First Nations (see list in Appendix 7).

The organisations listed in Appendix 6 were first contacted by telephone. I explained the purpose of the study and asked if they were providing services or support to Aboriginal people in their area. If they were, they were asked to distribute the questionnaire, and how many they would need.⁷

The health centres were contacted by a letter which explained the purpose of the study and asked them to contact me to send them questionnaires if they were providing services to PLWA/HIV in their area. Due to the large number of centres it was not feasible to make initial contact by telephone with each centre.

The questionnaire and letters were submitted to the JNC for their approval and comments. The comments made have been incorporated.

Limitations

The questions asked on the questionnaire were to provide information relating to the participants' income, housing conditions, the support they receive from family and friends, the kinds of services they use, or wish to use, and the barriers to access. The questionnaire was limited as it circumscribed the number of services that a participant could describe. The problems faced by the participant may not be the problems identified by the questionnaire. The questionnaire could not deal with the changes in demand for services over time that PLWA/HIV experience as their health

⁷ A similar method was used by Haraldsdóttir (1991), who contacted doctors in Iceland to provide her with information about the location and movement of people who had tested HIV+. The Ontario Native Womens Association in a study of family violence (1991) also used a third party to make contact with participants.

Status changes.

There was a bias and limitation in the method of distribution as it excluded any Aboriginal PLWA/HIV who were not in contact with these organisations. These may be the people who need but do not receive services or support. PLWA/HIV living in remote and rural areas are most likely to have been excluded as few of the distributing organisations are readily accessible to them. Given that there are approximately 2,114 Reserves in Canada, it has not been possible to contact each of these. However, all First Nations health centres providing general medical services listed in the Assembly of First Nations Directory were contacted, but many reserves with programs may have been missed.

Although the study has limited the number of Aboriginal PLWA/HIV it could reach, I believe it has attempted to contact the maximum number of people given the time and cost constraints. It is important to remember that the experience of those who are not included in the study may be different from those who were contacted by or who are in contact with participating organisations.

Questionnaires are often associated with traditional methods of research because they do not allow participants to speak for themselves. However, a number of participatory researchers have used them. In these cases, the questionnaires have usually been developed with the help of the population being studied (Kirby and McKenna, 1989:74-76). For this study, the questionnaire was approved by the JNC, and comments made by members were incorporated. It also seemed to be a suitable research tool as it allowed potential participants to remain totally anonymous if they

wished to. In addition a questionnaire potentially facilitates contact when going through a third party.

2.5.2 Response to the Questionnaires

The number of returned questionnaires was very low, although this was not entirely unexpected.⁸ Of 248 questionnaires sent out at the request of organisations, only 10 had been returned by July 1992. Composited results are shown in Appendix 8. There are a number of possible reasons for the low response rate. Some of these were identified by interview participants, including:

- HIV and Aids are highly stigmatised, few people are open about being infected and may not have wanted to potentially expose themselves or talk about their infection.
- They have other things to be doing than answering personal questions about their lives. Many Aboriginal people are resistant to taking part in research projects for reasons outlined earlier - in the words of several people "We're tired to death of being studied".⁹

⁸ A study of family violence conducted by The Ontario Native Womens Association had a 15% response rate to the 680 questionnaires they sent out. They identified the following as factors influencing the response rate: sensitivity of the subject matter; fear of talking about the situation; shame; length and density of the questionnaire; and the number of forms which Aboriginal people have to fill out (1988:14).

⁹ Brody comments, "Indians who have endured anthropological or other scrutiny might envy the people of northeast B.C. for having had a fortunate escape from intrusive questions and their mysterious, even dubious purposes. It is never easy to know why research is being done or whose interests in the end will be served. The accumulation of knowledge about colonial tribal populations is often a facet of control and exploitation - even when the researchers firmly believe otherwise. To be neglected by science might well be a blessing" (1988:xxi).

Organisations may have over estimated the numbers of questionnaires they could distribute and I have no way of knowing if they were distributed. Low levels of literacy may also have been a problem.

The low response rate meant that it was not possible to base the analysis only on the knowledge of PLWA/HIV, so I relied more heavily on interviews with service providers.

2.5.3 Interviews

As it had not been possible to gather information directly from PLWA/HIV reached through the questionnaire, I contacted non-governmental organisations which had been established by Aboriginal people (and in each case initiated by PLWA/HIV), to meet needs in their communities. Some of the people working with these organisations are living with HIV and AIDS themselves. I also contacted people from non-Native organisations who were providing services to Native people in their community. These were the primary interviews conducted. Appendix 9 lists the organisations and some of the people interviewed.

I also talked to people about the research question when contacting organisations to distribute the questionnaire. I attended the First Quebec Aboriginal AIDS Conference in February 1992. This not only gave me the opportunity to talk to a number of individuals, but to listen and learn as well. The Conference was intended as a forum for education and exchange of ideas for people who are currently, or would in the future be providing AIDS education in their communities and/or providing services

for PLWA/HIV.

Owing to time and cost constraints, it was not possible to interview as many people as I would have liked and who were willing to talk to me. However, the people I interviewed are people who have largely developed their organisations to service their own community because they could see that needs were not being met by existing services. I interviewed people in street outreach organisations to allow the perspective people servicing a distinct group of people at risk to be heard. I met with people in Toronto, Ottawa, Winnipeg, Regina, Saskatoon, North Battleford, Edmonton and Vancouver.

The primary interviews were tape recorded when the permission of interviewees was given. Informal interviews were used, to allow participants to voice the issues that they felt were important, not just the ones that I thought may be significant. After introducing myself and explaining the purpose and methodology of the study, I identified the four primary areas that I was interested in:

- i) the development, activities and funding base of their organisation.
- ii) whether they felt Aboriginal people were more vulnerable than the majority of the Canadian population. And, if yes, why?
- iii) what services and support did they think were needed by Aboriginal PLWA/HIV? If yes, what, where and provided by whom?
- iv) whether there are differences in the needs of people living in reserve and off reserve communities, and rural and urban areas.

The same areas were covered in each interview, but not necessarily in the same

order. During this process common areas of concern or themes emerged. Different emphases were at times placed on different issues. Some of the themes that emerged were unexpected. There were slight variations in the areas covered in talking to street outreach programs.

Limitations

Time and cost constraints meant the interviews were largely confined to non-statutory Aboriginal AIDS organisations. I was not able to talk to Aboriginal Outreach Workers in CAS-affiliated organisations and other people providing services to PLWA/HIV in non-statutory and statutory sector organisations. However, given the overall consensus in issues facing Aboriginal communities and Aboriginal PLWA/HIV, and the particular insights that the people interviewed were able to give, I feel that the issues they raised voiced common concerns.

The geographical area was limited in two ways. Firstly, I was unable to interview people initiating education programs and providing services on reserves. However, all of the people interviewed are themselves educators and have been involved in education and prevention programs on reserves. Secondly, the primary interviews were conducted only in cities west of Ottawa. There are no organisations like those interviewed involved in education or providing support and services in excluded areas. Thus this study cannot speak for people living in excluded areas.

The other major limitation is that not only am I non-Native, but I am English and have been in Canada for less than two years. I had and still have a great deal to learn about the issues faced by Aboriginal people in Canada.

2.5.4 Confidentiality

Preserving the confidentiality of participants has been an essential part of this study. AIDS is still a highly stigmatised disease. PLWA/HIV are often discriminated against and rejected, whether by their families, friends, communities or employers. The confidentiality of participants has been preserved by:

- i) the method of distributing the questionnaire, as I had no knowledge of the people receiving/or returning it unless they wished to provide it;
- ii) the questionnaire did not ask for any identifying information;
- iii) information has been collated and written in an aggregated form to ensure that it is not possible to identify an individual from the description of the replies on the questionnaire or from interviews;
- iv) the emphasis has been on ensuring that participants had control over the extent of their involvement with the study, and the information they chose to share;
- v) any possibly identifying information from the interviews about someone who did not want to be identified has been attributed to "Anon".

2.5.5 Literature

Although geographers have made significant contributions to the understanding of the distribution and barriers to access to health services (Joseph and Phillips 1989), they have only just started to look at the distribution of services to PLWA/HIV. As

Chiotti and Joseph observe,

...there seems only to be limited interest on the part of geographers in the provision of health care and housing for persons living with AIDS. This is surprising given, for instance the established interest in locational issues within medical geography (Joseph and Phillips, 1984). It is even more surprising that, in outlining future research agenda for geographers interested in contributing to the AIDS literature, both Wood (1988) and Gould (1989) omit consideration of both the design of health care delivery systems and the location of constituent facilities. This is unfortunate in light of the very distinctive social geography of the disease (Chiotti and Joseph, 1991:1).

Currently only four studies examining the provision of services to PLWA/HIV living in Canada exist. Of these, two are essentially geographic, examining the provision of housing to PLWA/HIV in Canada. Chiotti and Joseph (1991) examined the location process of a hospice for PLWA/HIV in Toronto, while Willms *et al.* (1991), looked at the availability of affordable accessible housing. Radford *et al.* (1991) examined how the needs of HIV infected youth in Toronto are being met. A study of how PLWA/HIV living in Toronto "hook up" to social services is currently underway (Smith and Mitchell, 1990).

Ostensibly the studies relating to the location and accessibility of services will be of more interest to this study. Different approaches to this problem have been made. Most are rooted in time/distance analysis. Although they may include variables relating to ethnicity, socio-economic status and other variables which may influence the behaviour of users, the emphasis is usually on the unequal spatial distribution of services to these communities, rather than the spatial implications of these variables on the use of services (Thouez *et al.*, 1990; Thouez, 1987; Joseph and Phillips, 1989).

Few attempts appear to have been made to examine the needs and wants of

service users from their perspective. Thouez (1990:25) in a study examining "Correlates of Health-Care Use" among Inuit and Cree people in Northern Quebec comments,¹⁰

The notion of needs is a central concept which cannot be reduced to the traditional socio-geographic and economic categories of accessibility to health-care. An analysis of health-care should include all the factors that facilitate or limit the use of health services by potential users. The precise meaning of needs in relation to health and disease differs between individuals and from one social group to another. Also the definition of needs changes over time and with change in living conditions.

This thesis thus attempts to discover the barriers to access to services of Aboriginal PLWA/HIV. Although cultural differences in use may be recognised, geographers do not seem to have attempted to understand how cultural differences in residence and migration patterns may affect access (Thouez *et al.*, 1990; Jackson, 1989). This study attempts to do so.

Ecological approaches to medical geography emphasise the need to understand the whole of peoples' lives to understand their health; this will be an important component of this study. Barriers to access may be due to distance, but may also be affected by cultural and other (e.g., socio-economic circumstances) which determine the distance a person is willing and able to travel to use a service. Rather than emphasise the distribution of services, it is perhaps more useful to ask the service users what problems they face in maintaining their health.

¹⁰ A series of studies of this community has examined health and health care delivery in the context of factors affecting health status and health care use by Cree and Inuit people living in Northern Quebec (Thouez *et al.*, 1990).

2.6 SUMMARY

This thesis attempts to combine an ecological and holistic approach to medical geography with a socially accountable participatory research methodology.

Ideally, in a socially accountable participatory research methodology, the participants would be part of the process of identifying the research problem, designing the research methodology and tools, and the analysis. The JNC played the role of participant, acting as it did as representative of Aboriginal PLWA/HIV. As noted above, all interview participants have been invited to comment on what has been written and to have their comments included and acknowledged in the final copy. Given the limitations and scale of the study I feel that every effort has been made to promote participation in the process.

The examination of the utility of mathematical and computer based predictive models may be seen by some as a departure from a participatory research approach which was developed to overcome the problems of quantitative analytical approaches (Clark and Wilson, 1989). However, there two old sayings which are particularly appropriate: "don't throw the baby out with the bath water" and "don't cut off your nose to spite your face". As stated in the introduction, methods are tools to create a greater knowledge base. Just because a method is traditionally associated with a particular paradigm it should not necessarily be rejected if it can be used in the task at hand.

While this study is rooted in the concept of participatory research there are a number of departures from the previous experiences. These departures are a

consequence of using the research model to examine a particular problem, and adapting it to the problem, rather than attempting to fit the problem to the methodology.

Rees in his analysis of the "Dene-Gondie" study, which looked at the effects of the Norman Wells Oilfield Expansion and Pipeline Project on the Dene community makes a comment which is particularly pertinent to this study:

A fundamental underpinning of the study was our belief that the residents of a developing region have unique qualifications to document and interpret the impacts of such development on their personal and communal lives. We also believed that the most significant contribution of university researchers in such circumstances was to assist people in the credible documentation of impacts, in developing independent analytic capabilities, and in finding ways of giving voice to their concerns (Rees, 1986:143).

It is important that Aboriginal service providers and users voices are heard, for this surely is a significant aspect of providing services to Aboriginal people in Canada. Compared to the majority of the Canadian population, Aboriginal people often have quite different life experiences, different residential and migratory patterns, and different health experiences. It is PLWA/HIV, and the organisations that they have initiated to meet their needs, who can best express the impacts that HIV and AIDS has had on their lives, the needs it has created or emphasised, and the possible solutions. This study attempts to document their views and give voice to their concerns. I will not be attempting to provide my own solutions to the problems outlined

CHAPTER 3

SOCIO-ECONOMIC AND GEOGRAPHICAL DIMENSIONS OF HIV AND AIDS

3.1 INTRODUCTION

**Yes, AIDS is colour blind. It doesn't care who you are. But native communities are smaller. It's like dumping a rock in a little pond or a big pond. The waves are bigger in the little pond.
(Dr. Jay Wortman, AIDS consultant for Medical Services Branch, quoted by Certenig, 1992:A3).**

This chapter provides a context for subsequent chapters by means of outlining important socio-geographic aspects of the Canadian Aboriginal population and by identifying their implications for the transmission and diffusion of AIDS among this population and specifically on the lives of PLWA/HIV. It is demonstrated that many Aboriginal people live in different circumstances and different places than the majority of the Canadian population, which may determine the vulnerability of communities to infection and create distinct needs for services, support and education. The first part of the chapter looks at the income, housing conditions and health status of Aboriginal communities in Canada and their implications for the transmission of HIV and for people who are living with the virus. The second part examines how population distribution and migration patterns affect the diffusion of HIV and the provision of services to people who are living with HIV and AIDS.

Literature from the United States and Africa examining the relationship between poverty and the transmission of HIV and the role of migration in diffusion of HIV has provided a background for this chapter. The data have been gathered from secondary sources. The most recent Canadian data available have been used however many of the health statistics relating to Aboriginal people are dated.¹ The experience of interviewees is also included.

3.2 THE SOCIO-ECONOMIC CONTEXT

All you have to do is find any group that is politically, socially and economically disenfranchised and that group will certainly have a higher percentage of HIV infection than the rest of society. Historically epidemics have always affected the poor rather than the rich (Nils Claussen, AIDS Regina, 29/5/92).

Around the world AIDS is disproportionately affecting poor disadvantaged and marginalised communities. Although communities are diverse, on average Aboriginal communities in Canada are poorer and significantly disadvantaged when compared to the majority of the Canadian population. These inequalities in Canadian society need to be seen in the context of the history of Aboriginal people in North America.

Socioeconomic, housing and health inequalities may affect the transmission of HIV. People who are in poor health and whose immune systems are already activated are more susceptible to the virus (Kaplan, 1991; Packard and Epstein, 1991; Ankrah, 1989; Sabatier, 1988). Poverty and marginalisation may place constraints on behaviour.

¹ Indicative of the problem is that Statistics Canada in a 1991 presentation to the Royal Commission on Aboriginal Peoples were using data from the 1986 census (Statistics Canada, 1991).

Wallace comments,

Research on factors influencing transmission of HIV infection has tended to ignore questions of context, yet each individual contracting the disease is deeply enmeshed in constraints defined by socio-economic, geographic, historical and other contexts. These constraints may profoundly influence or even determine behaviour patterns associated with risk of acquiring disease, and can determine as well the magnitude of that risk for a given population (1991a:847).

Socioeconomic disadvantage also has implications for people who have contracted HIV. The primary known means of controlling HIV and AIDS are through maintaining a healthy and stress free living environment. The health status, socio-economic conditions and housing of PLWA/HIV may affect the progression of HIV infection in three ways.

Firstly, the health status of someone who is HIV positive can have a significant impact on the length of time it takes for AIDS to develop after infection with HIV (Willms et al., 1991:11-12; Radford et al., 1991:25). Secondly, once a person has developed AIDS, they are likely to live longer if they minimise their exposure to opportunistic infection, eat well and keep warm (Willms et al., 1991; Radford et al., 1991). Thirdly, an increasing number of researchers and scientists believe that HIV requires a cofactor for AIDS to develop. Some postulated cofactors include immunosuppression through infection and/or substance abuse, poor health or the presence of specific, but as yet unidentified infection (CBC, 1992; Montagnier, 1991).

The needs of people living with AIDS and HIV are individual and change over the course of infection. They include emotional and social support, housing, nutrition,

medical and social services, and sufficient income to meet these needs.²

3.2.1 Income

The incomes of Aboriginal men and women both on and off reserve are considerably lower than the national average.³ In 1985, the average income of Aboriginal men was 68% of that of all Canadian men, Aboriginal women earned on average 77% the income of all Canadian women (Statistics Canada, 1991).⁴

Income in Canada is largely a function of employment status. Aboriginal people are more likely to be unemployed, and less likely to be in the labour force (see Table 3.1).⁵ These figures mask local differences. On some reserves, 90% of the population may be unemployed.

² A person with HIV may need no more medical support than monitoring of T-Cells. They may require emotional support to deal with the diagnosis, as well as sufficient income and adequate housing to maintain health. A person with AIDS does not become ill and stay that way, but may be intermittently affected by different opportunistic infections, before their immune system is no longer able to fight opportunistic infections and they require more intensive medical services.

³ In 1981, 43% of off-reserve Indian households in Metropolitan areas were low income households compared to 18% of non-Indian households. In Toronto, Calgary, Edmonton, and Vancouver the percentage of low income households was double non-Indian. In Winnipeg, Regina and Saskatoon, Indian people were 3 times more likely to be living in low income households than non-Indian people (Clatworthy and Stevens, 1987:42).

⁴ In 1985, 43 of Aboriginal men aged over 15 years earned less than \$7,000 compared to 24% of all Canadian men. For women the percentages were 60% and 47% respectively (Statistics Canada, 1991).

⁵ A person is unemployed if they do not have paid employment, but are actively seeking work. Unemployment figures are underestimates, as people who have been out of work for a long time may have given up seeking work. People who are not in the labour force are not employed or seeking employment (Statistical Data Technical Working Group, 1991:24). People pursuing traditional ways of living are counted in this group, although they do not meet Statistics Canada's criteria for employment they are working.

TABLE 3.1

Labour Force Activity of Aboriginal people and all Canadians, 1986(as a percentage of the population 15 and over)⁶

	<u>Employed</u>	<u>Unemployed</u>	<u>Not in Labour force</u>
Total Canadian	59.6	6.9	33.5
Indians on-reserve	28.2	15.1	56.7
Indians off-reserve	36.8	16.8	46.4
Inuit	40.1	14.4	45.5

Source: Statistical Data Technical Working Group, Statistical Profile of Native Mental Health, Background Report #1, Ottawa:Medical Services Branch:23.

Aboriginal people are more likely to be dependent on welfare (social assistance) than the majority of the population. In 1987, 19.2% of status Indians living on-reserve were receiving social assistance, compared to 7.2% of the total population (Statistical Data Technical Working Group, 1991:19). Transfer payments as a percentage of income of Aboriginal people living off reserve (24% in 1985), were more than double the percentage for all Canadians (McDonald, 1991: 5).⁷ The majority of people living with HIV and AIDS are receiving welfare or disability payments. In their 1990 Report, the National Council of Welfare (1991:50) said,

The income provided by most provincial and territorial welfare programs is grossly inadequate for the vast majority of recipients. Most

⁶ Statistics Canada in their presentation to the Royal Commission on Aboriginal People reported that the unemployment rate of Aboriginal people was 23.5% (28% off reserve) compared to 10% of all Canadians (Statistics Canada, 1991).

⁷ Aboriginal people are more dependent on transfer payments (19.1%), than the total Canadian population (11.7%) (Statistics Canada, 1991).

welfare incomes are far below the poverty line.⁸

Aboriginal people are more likely to be employed in unskilled jobs, primary occupations and service industries, and therefore more likely to be seasonally employed (Statistics Canada, 1991).⁹ Seasonal employment and levels of employment imply that people may be more likely to move to find work. Low income and lack of employment opportunities determine the ability of individuals to support healthy lifestyles and living conditions.

3.2.2 Housing

Housing has a significant impact on health status. Living in a healthy environment is particularly important for people with HIV and AIDS to maintain health.

Persons with HIV have compromised health status and it is important to their individual well being to live in an environment that is easy to keep hygienically clean, warm, dry, safe from violence and secure in tenure. These conditions seem important and reasonable for every Canadian and yet we know that these conditions are not being met for the majority of persons with HIV (Willms et. al.,1991:1).

The housing conditions of Aboriginal people are considerably worse than those of the majority of the Canadian population.

Poor community infrastructure, especially inadequate housing, is

⁸ The report notes that welfare incomes in all provinces and territories are below the poverty line; it is just a question of degree (National Council of Welfare, 1991).

⁹ Aboriginal people are more likely to be employed part-time or part-year. In 1986, 60% of employed aboriginal men and 66% of women worked part-time or part year compared to 42% and 58% of non-Aboriginal men and women (Statistics Canada, 1991).

strongly associated to poor physical/mental health. Four main indicators reflect the substandard living conditions of Indian people: building structure, heating system, indoor bathroom, and living space (Assembly of First Nations (AFN), 1988:22).

Aboriginal people are almost 14 times more likely to live in overcrowded conditions than all Canadians.¹⁰ In 1986, 30% of Status Indians living on-reserve, 11.3% of Status Indians living off-reserve and 31.1 % of Inuit people lived in overcrowded dwellings, compared to 1.8% of the total Canadian population. Rates of overcrowding on-reserve are generally 11 times higher than rates in nearby non-reserve communities (Statistical Data Technical Working Group, 1991:15-16).

Housing conditions of Indian people living on reserve are particularly severe (see Table 3.2). The First Nations Task Force on Indian Housing reported that in 1985, reserve housing was 27 times more likely to lack complete basic amenities than non-Indian housing and was 16 times more likely to fail minimum standards (AFN, 1988:22).¹¹

In 1988, only 82.3% of homes on-reserve had an adequate water supply and only 72.2% had sewage disposal.¹² In 1986, 37.5% of dwellings on-reserve and 9.5% of dwellings of Status Indians living off-reserve lacked central heating, compared to

¹⁰ Overcrowding is defined as any dwelling occupied by more than one person per room (Statistical Data Technical Working Group, 1991:15).

¹¹ 38% lacked some or all components of basic amenities (ie. running water, indoor toilet), and 48% failed to meet minimum standards set by the Canada Mortgage and Housing Corporation (AFN, 1989:22).

¹² Adequate water supply and sewage mean access to water and sewage facilities, but not necessarily running water in the dwelling.

5.4% of all Canadian homes (Statistical Data Technical Working Group, 1992).¹³

Housing problems are worst on remote reserves, where two thirds of dwellings have multiple housing problems compared to 47% of all reserve housing (First Nations Task Force on Indian Housing, 1989:13-14).

TABLE 3.2
Differential housing conditions of reserve and all Canadian Housing in 1985. (as percentage of dwellings)

	<u>Reserve Dwellings</u>	<u>All Canadian Dwellings</u>
Major repairs required	23	7
Complete bathroom	63	98
No bathroom facilities	32	2
Lacking running water or indoor plumbing	38	1

Source: First Nations Task Force on Indian Housing, **National Report - 1989**, 1989, Ottawa: Assembly of First Nations:14.

Little information is available on the housing conditions of Aboriginal people living off-reserve (Clatworthy and Stevens, 1987:1). People with low incomes will obviously have less disposable income to spend on housing and are therefore more likely to live in poor quality housing (Willms et al., 1991). Clatworthy and Stevens (1987:xxiii), found,

Off reserve Indian households are also much more likely than non-Indian households to acquire housing which is in need of major repairs, lacks basic facilities or is too small to accommodate their space needs.

¹³ The First Nations Task Force on Indian Housing found 50% of on reserve dwellings lacked central heating (AFN, 1989:14).

Not only do many Aboriginal people live in poor housing, they face considerable problems paying for it. A study in 1987 found that the incidence of housing affordability problems was 17 times higher in Registered Indian households than in all Canadian households (First Nations Task Force on Indian Housing, 1989:14). Housing deficiencies are linked to income. The incidence of deficiencies is lower among higher income Aboriginal households (*ibid.*; Clatworthy and Stevens, 1987).

3.2.3 Health Status

The health status of Aboriginal people is considerably worse than that of the majority of the Canadian population. The Assembly of First Nations (AFN) comment "...it is obvious that the poor living conditions of the Indian population contribute to higher rates of diseases and disorders" (1988:19).

Poor health status in Aboriginal communities causes concern in two areas. Some authors suggest that people with already stressed immune systems have a higher probability of contracting HIV if they come into contact with the virus. After infection it is important that people minimise the stress on their immune system and exposure to opportunistic infections. Aboriginal PLWA/HIV are more likely to come into contact with infections which may compromise their immunity and health, and more likely to have health problems when they contract HIV.

Infant mortality rates, death rates, life expectancy and mortality rates are common indicators of the health status of populations. Between 1980-1985, the infant

mortality rate in Native communities was double the Canadian rate (19.5/100,000 compared to 9) (AFN, 1988:10). The life expectancy of Aboriginal people in 1986 of 65.9 years was 9 years less than the national life expectancy (AFN, 1988:9). In 1985, The death rate per 100,000 population was 1.04 for Registered Indians, but only 0.71 for all Canadians. The AFN identify poor housing, poor sewage and water facilities, and poor access to medical services as contributing factors (AFN, 1988:8).

Some infections and diseases also indicate poor health. Rates of diabetes mellitus in the Aboriginal population are two to five times higher than rates for the total Canadian population (Kewayosh, 1991:3).¹⁴ Parasitic diseases and nutritional, metabolic and immunity disorders are also more prevalent among Aboriginal people.¹⁵ Death rates due to parasitic and infectious diseases are about five times the national rate (Postl *et al.*, 1987:219; Health and Welfare Canada, 1988:24).¹⁶

Deaths due to respiratory diseases eg., pneumonia and bronchitis, are also more common. In 1985 in Registered Indian populations, the death rate due to respiratory ailments was almost double the national rate (Health and Welfare Canada, 1988:25).¹⁷

¹⁴ A study of diabetes prevalence in Southwestern Ontario found an age adjusted rate of diabetes of 14.7% for Registered Indian participants, compared to a rate of 2.2% for Caucasian participants (Evers *et al.*, 1987).

¹⁵ A study in the Northwest Territories following a program to improve water and sanitation services, found that shigellosis and salmonella occurred 2-6 times more frequently than in the national population, as are other parasitic diseases like toxoplasmosis, trichinosis and toxocara (Postl *et al.*, 1987:219-220).

¹⁶ In 1985 they were 18.5 per 100,000 in registered Indian populations, but only 3.8 per 100,000 nationally (Postl *et al.*, 1987:219; Health and Welfare Canada, 1988:24).

¹⁷ 95 per 100,000 compared to a national rate of 55 per 100,000 (Health and Welfare Canada, 1988:25).

Although tuberculosis (TB) is no longer ravaging Aboriginal communities as it did in the past, during the 1980's death rates due to TB have been consistently at least ten times higher among Aboriginal people than in the total Canadian population (Assembly of First Nations (AFN), 1988:18; Kue Young and Casson, 1988:302-305). Following a fairly consistent decline in the number of TB cases during the 1980's, there was a 20.1% increase in the number of new and reactivated TB cases among the Registered Indian population between 1988-1989 (Canadian Centre for Health Information, 1990:19).

Continuing high rates of TB in Aboriginal communities are worrying for two reasons. Firstly, studies have found that people who are HIV positive with latent TB "are at high risk for progressing to clinically active disease" (Daley, *et al.*, 1991:651). Secondly, in the United States, after a steady decline in rates of TB from 1953-1985, there has been a significant increase in the rate of infection in recent years. The increase has been linked to increases in homelessness, poverty and AIDS (Jeres *et al.*, 1992; Slutkin *et al.*, 1988:23; CDWR, 1986:28). Highest rates of increase have been found among Black and Hispanic Americans whose communities are most affected by AIDS.

Kramer and Weller (1988:20) in a comparative study of the health of Canadian and American Native communities comment,

In analysing the health status of Native peoples in both countries it is important to realize that the causes of, and therefore the remedies for, the high mortality and morbidity rates are not rooted in the relative absence or presence of modern medical treatment centers but rather in the most basic of social, political and economic factors affecting every aspect of family and community life.

3.3 POPULATION DISTRIBUTION AND MIGRATION PATTERNS

The Aboriginal population in Canada has a distinctive spatial distribution. Aboriginal people in Canada are more likely to live in small, rural and remote communities and are more mobile than the majority of the population.¹⁸ These issues have implications for the diffusion of HIV and for the provision of services and support to Aboriginal PLWA/HIV. Two aspects of the literature contribute to an understanding of how population distribution and migratory patterns can affect transmission of HIV, and pose a significant risk to Native communities in Canada.

Literature examining the transmission of HIV and AIDS in Africa has emphasised the role of migration, and patterns of migration in accelerating the transmission of HIV and AIDS, as well as its diffusion to rural communities. Of particular concern to the future of many small communities is the documentation of the devastation wrought by AIDS on small rural communities once AIDS has entered the community (Ankrah, 1991; Sabatier, 1988; Brokensha, 1988:171). George Poitras a Program Director of Feather of Hope observed,

People on the reserve level live in very much Third World conditions, you see the shanty towns in African countries. I was in Africa a few years ago, and I felt so much at home, because they were a poor people. They didn't have a lot, they had the bare necessities to survive....They didn't have fridges full of food, and almost on a daily basis never knew where their next meal was going to come from. Their health care services were poor. Basically resources were not available to them.

And I think of AIDS and how its affecting the African population. I equate it right smack with the Aboriginal population in North America.

¹⁸ Remote areas lack access to road transport to urban areas; rural areas are more than 60 miles from the nearest urban centre (Frideres, 1989:156).

I had the opportunity a few months ago to participate in a programme with South African educators. And just being able to communicate with them and through our conversations and their making me aware of what things are like in their country today and how AIDS is rampant among the heterosexual population and that they are a poor population and don't have a lot of resources.

That makes me cringe, because we're talking about AIDS and how its rampant in Africa and that's the exact same scenario that's going on in Canada and North America among Aboriginal people and on reserves (12/6/92).

As discussed in Chapter 2, the majority of geographical literature is concerned with diffusion of AIDS on a global or national (usually the USA) basis.¹⁹ However Potterat *et al.*, and Wallace, demonstrate the possibilities of diffusion in marginalised minority populations (Potterat *et al.*, 1991; Wallace 1991a, 1991b).

Potterat *et al.* examining the diffusion of gonorrhoeal infection among gay men found that it occurred in "small socially definable segments of the population", who knew each other and lived and socialised in the same places forming a socio-geographic network of infection (*ibid.*:30).

Wallace (1991a) used their work to examine the implications for HIV diffusion in minority communities. He comments,

The possibility of rapid, silent HIV transmission along sociogeographic networks seems especially significant for the traditional, and now rapidly expanding residential zones of the socioeconomically marginalised urban and rural poor in the United States. For poor American urban communities highly dense and geographically centred resource sharing socioeconomic networks are particularly essential to individual and family strategies for survival as well as to community stability.

He argues that minority, marginalised ,and impoverished communities develop social

¹⁹ Loytonen (1991); Haraldsdottir (1991); Shannon *et al.* (1991); Gould (1989); Shannon and Pyle (1989); Gardner *et al.* (1989); Wood (1988); Dutt *et al.*, 1987.

networks for survival. Once HIV infection enters this network, the rate of transmission is likely to be higher than in a more diffuse social network. If migration occurs, or the community is dispersed, then HIV will diffuse through the social network and geographically. He notes that there may be a connection between apparently high and rapid rates of infection among gay men and IDUs, as both form marginalised communities with "highly constrained patterns of geographic and social interaction" (Wallace, 1991a). This view is reinforced by rapid rates of increases among IDU populations within cities (MMWR, 1991:465; Alary and Castel, 1990:25).

Wallace also examined the role of migration in the diffusion of HIV within mobile communities with strong social networks that are marginalised (1991b).

Significantly his model implied that,

...rates of disease transmission along networks of particularly susceptible communities may be strongly affected by patterns of out migration from them, or residential instability associated with life in them. Such consonance may be driven by social disintegration, ...or result from inherent structural factors,... (Wallace, 1991b:1160).

Wallaces' work is important as it not only has implications for the transmission of HIV in and between Aboriginal communities, but may help explain the prevalence and significance of other risk factors, particularly the high rates of STD infection among young Aboriginal people.

3.3.1 Distribution

According to the 1986 Census, 712,000 people reported that they were of aboriginal origin (2.8% of the total Canadian population). Of these, 74% identified

themselves as being of North American Indian ancestry, 18% as Metis, and 4.5% as Inuit. People qualifying for Status (443,884 in 1988) under the Indian Act of 1876 and the amendment Bill C-31, comprised 1.7% of the total population (Statistics Canada, 1991).²⁰

There are 596 Bands in Canada and around 2,241 reserves.²¹ Reserves vary in size and population density. Prior to Bill C31 most bands had populations of less than 1000 (39%), and about one third had a population of between 101-300 people. Only 16 bands had populations over 2,000. The largest is Six Nations which had over 8,200 members in 1981 (Frideres, 1988:150-154). There are 200 bands in British Columbia living on 1,600 reserves. Metis and Inuit people do not live on reserves but may or may not hold rights to land. Non-Status Indians do not have any land rights.

In 1986, Aboriginal people were twice as likely to live in rural areas (46%) than non-Aboriginal people. They were less likely to live in large urban areas (71% of urban Aboriginal people live in urban areas with populations over 25,000 compared to 82% of all Canadians) (Statistics Canada, 1991). Non-Aboriginal people are twice as likely to live in cities with populations over 100,000, (52% and 24% respectively) (Shah, 1988:5).

There is some discrepancy in the estimates of the proportion of the Status Indian population who live off-reserve, the Assembly of First Nations (AFN) estimate

²⁰ As a result of Bill C-31 the Registered Indian population increased from 374,200 in 1986 to 443,884 in 1988 (Statistical Data Working Group, 1991:6).

²¹ The number of Bands and reserves may vary (Frideres, 1988:150).

that around 60% of Status Indians live on-reserve (1988:5).²² About 50% of Status Indians living off reserve live in urban areas (Clatworthy and Stevens, 1987:xxi; McDonald, Ryan J.,1991:6). The introduction of Bill C31 may mean that a higher proportion of the Status Indian population will live off-reserve and in larger urban areas.

Approximately 70% of Status Indians living on-reserve, live in remote and rural areas, (30% in remote areas). Inuit people are even more likely to live in remote and rural areas (Frideres, 1989:156). Shah noted that non-Status Indians and Metis people are most likely to live in urban areas, 70% and 60% respectively, compared to only 20% of Inuit people and 30% of Status Indians (1988:6). People living in rural and remote areas are likely to have less access to health services (Kramer and Weller, 1988:9).

3.3.2 Migration

Some of the concerns or reasons for the vulnerability for our population to HIV include that a large majority of the native population live off reserve. There's a lot of transiency from the reserve to the city, from the reserve to reserve, not only in one direction going to the city, but coming back. That happens a lot. I believe that therefore, for the native population there's no boundaries, Alberta, Saskatchewan, B.C., and not only Canada, but the United States....

And the transiency that goes on, not only people that are moving from one reserve to another, or from one reserve to a city, or people moving back, like short term living arrangements. Not only that

²² Statistics Canada in their presentation to the Royal Commission on Aboriginal Peoples said only approximately 30% of those of people of Aboriginal origin lived on-reserve. and that 53% of people of Native American origin lived on-reserve (1991). This discrepancy may be attributable to the introduction of Bill C-31. This study includes those who cannot register under the Indian Act, and peoples without reserves.

transiency, but there's transiency of people coming for services, or coming for recreational activities, baseball, volleyball tournaments, ice hockey tournaments, there's a lot of that transiency that goes on. The leadership travels quite a bit....

And because our population is in that way a transient one, our concern of transmission occurring that way is a high concern, a big big concern for us (George Poitras, 12/6/92).

The distribution pattern of Aboriginal peoples is reflected in migration patterns.²³ Rates of movement among Aboriginal people are higher than in the non-Aboriginal population (Shah, 1988; Peters, 1984; Frideres, 1988; Clatworthy, 1987). High rates of movement between reserves and cities, and between reserves, increase the rate of diffusion of HIV, especially to small rural and remote communities. Young single people are over represented in the migrant population - the people most at risk for HIV infection (Shah, 1988; Frideres, 1988; Clatworthy, 1987).

The 1986 Census found that 61% Aboriginal people living off-reserve had moved in the five years preceding the Census compared to 44% of the total Canadian population.²⁴ Over 40% of Aboriginal people had moved from another community (McDonald, 1991:3). Around 25% of migrants in one study moved residence between three and five times in five years (Frideres, 1989:154). Shah reports another study which found that on average, Native people move every 18 months compared to every 54 months for non-Natives (Shah, 1988:11).

²³ Migration maybe a misnomer as it implies permanence, while transiency implies itinerancy, and thus neither accurately describe the movement taking place in aboriginal communities or encompass the wide variety of factors underlying it.

²⁴ Inuit people are least likely to migrate, in 1986, 12% of Inuit people were living in a different community from where they had lived five years previously (20% of all Canadians). Lower rates of migration have been attributed to dominance of home languages (28% off Inuit people spoke only Inuktituk), and geographical isolation (Signer, 1989).

However, Peters observes that many urban residents are permanent residents (56% in her study). Many moves may be visits to the city for services in the city, or to visit family whether in the city or on reserves (Peters, 1984, 27-28). The National Association of Friendship Centres in their presentation to the JNC said,

Our people move to the cities from the reserves and rural communities for a large number of reasons. They come to complete their education, find jobs, seek medical help, to escape strained home environment and so on....

They retain their contacts with home, be that their reserve, or rural community of birth or where their relations live, and visit home regularly....

The urban population is a highly mobile population travelling frequently from the cities to the reserves and back throughout the year. They are also a young people with a high fertility rate....(JNC, 1990:47).

Studies quoted by Shah report that the primary reason that people move is to find employment (Shah, 1988:9). Aboriginal people are more likely to be seasonally employed, contributing to rates of movement (Peters, 1984:27).

Rates of out-migration are highest from small bands (less than 400 members), where there are few employment opportunities, in semi-rural areas with road access to urban centres and where there is a "poorly formulated band government" (Shah, 1988:10). Jerome Yellowdirt of the Alberta Indian Health Care Commission expressed the need for services in communities so that people don't have to travel to get what they need,

Transiency. It's a major problem, because of the lack of services and facilities in communities, lack of programs in communities. We have the problem of the native Indian population, the Aboriginal First Nations people coming into the cities because they don't have nothing out in the communities, no services available. So what's the next best thing to do, but come to the city to find out what kind of services are available....

What is there to do on the reserve that you can't do in the city? They have all the niceties in the city. Sure myself I'll come to a movie. I'll come to a fancy restaurant, I'll come to watch the Edmonton Oilers play hockey. These are the things that they come for (12/6/92).

The socio-economic status of many native people, and the age of many migrants compounds the problem. People coming to urban areas from rural areas have to adjust to living in a city and may have left their support system behind. Albert McLeod commented,

What happens to a person if they come to Winnipeg if they haven't even been here before? People go to the south because there are more resources, but that's only the physical part, there's the emotion, part too.... Their friends and family are in the north and that's where support is.

There's a lot of people that use chemicals to substitute for emotional support and strength when they're in the city (25/5/92).

Young people are particularly at risk (JNC, 1990a) and make up the largest proportion of migrants. If they are unable to find work (or too young), poverty may lead some people (particularly if they use drugs or alcohol) to use their bodies to buy food, to put a roof over their heads or for drugs (JNC, 1990a:45). The Street Youth and AIDS study found that approximately 80% of Native youth in the study had come from reserves, 44% from rural or remote communities (King, 1989:22).

Street outreach workers commented that many street youth go back to their reserves to 'dry out',

Some of the people that we know that use [injection and other drugs] go home to the reserve to dry out and get clean and healthy (Laurel McTavish, 26/5/92).

Kids leave the north to come to Winnipeg for education and Jobs and get involved in prostitution. In the summer they go home and go back to who they really are. So no one knows and they don't think

about the prostitution and risk - because they are who they really are (Albert McLeod, 25/5/92).

Street youth and substance abusers are only a part of the migrant population. But as the mobile population is young, it is probable that people will engage in sexual activity both on and off-reserve with important implications for rural and remote communities and the transmission and diffusion of HIV.

3.4 SUMMARY

The discussion above creates a background to discussing the vulnerability of Aboriginal communities to HIV, and the services and support that are needed by Aboriginal people living with HIV and AIDS.

The movement of Aboriginal people is significant for two reasons. Firstly it means that it is possible for HIV and AIDS to diffuse out from areas of relatively high prevalence to small, rural communities which are not normally considered at high risk and who may not consider themselves at risk because they are distant from centres where HIV may be prevalent. Secondly, the high concentration of on-reserve populations in small, rural communities where risk factors exist could allow these communities to be disproportionately affected and impacted by HIV.

The living conditions of Aboriginal people living on reserve are worse than people living off reserve. But Aboriginal people living in cities are most likely to live in inner city communities where HIV rates are likely to be highest and living conditions poor. The dispersal of Aboriginal people in small, fragmented, remote and

rural communities and small urban areas, mean they have less access to services and support networks for education, prevention and health care.

The connection between disadvantage, marginalisation ethnic minorities and HIV is significant for Aboriginal communities. Poverty not only creates conditions conducive to the transmission of HIV, but has serious implications for people who are trying to maintain their health after infection.

These inequalities are particularly disturbing when seen in the context of the epidemic in the United States. In Canada rates of infection among gay men are falling, while rates of infection among injection drug users are rising. This follows changes in patterns of infection in the United States. George Poitras commented,

There's a very low increase of that population [gay men], being infected with HIV today. I think that the second wave of HIV infection is going to occur with people who are poverty stricken, people who are socially disadvantaged, economically disadvantaged. The inner city population who are practising alcohol and drugs, the inner city population who have a vast majority of native people, prostitution going on.... People who are abusers of alcohol, and people who live below the poverty level. Which is a primary target for the Aboriginal population (12/6/92).

Studies from the US have shown that men and Black and Hispanic people have on average shorter lives after diagnosis with HIV and AIDS than white gay men. This has been largely attributed to poor health status, living conditions, and substance abuse (late diagnosis may also play a role) (Sabatier, 1988; Denenberg, 1990).²⁵ This is significant to native communities in Canada, who like ethnic minorities in the USA, and as this chapter shows, have lower incomes, poorer housing and worse health status

²⁵ Sabatier notes, "Poorer access to health care means that after diagnosis with AIDS, a black or latino man in the US lives for only one fifth of the time of a white male adult." (1988:19).

than the majority population. Susan Beaver observed,

And I know a lot of people who have been around this city for a long time but have only tested positive within the last 2-3 years. Now maybe they've been carrying it all this time, maybe they were in the window period. I don't know. Its only 2-3 years. We don't know any people in the native community who have been alive for 10 years, 12 years who are healthy, who are managing it, we just don't have them (Susan Beaver, 7/7/92).

The costs to small communities of providing health care to people living with AIDs and the loss of people in the most productive age group of the population who are most likely to be care givers cannot be dealt with here, but may be of great importance to Aboriginal communities in the future.

CHAPTER 4

RISK FACTORS AND RISK BEHAVIOUR

4.1 INTRODUCTION

The previous chapter placed the transmission and diffusion of HIV within the context of the social geography of Aboriginal communities in Canada. This chapter considers some known risk factors for the transmission of HIV, and outlines their extent and implications for the future of HIV and AIDS in Aboriginal communities. The risk factors considered are: unprotected sexual intercourse; sexually transmitted diseases (STDs); substance abuse, including injection drug use (IDU); and self-esteem.

The issues discussed in this chapter involve the behaviour of individuals, however behaviour cannot be divorced from the context within which it takes place. Ankrah (1989:272) commented on the need to place the behaviour of individuals in context when she said,

Behaviour is the operative risk determinant to HIV transmission. Therein, too, economic factors are of critical import. Risky behaviours such as intravenous drug use and prostitution are closely correlated with low incomes and social deprivation, limited access to health care and housing, and to racial or other discrimination. Behaviours take on differing meanings in differing socio-economic contexts.¹

¹ Wallace (1991:1161) comments, "We suggest sexual activity, the sex industry and/or forms of substance use and abuse, and even the ability to respond to 'education and publicity' do not exist in a social vacuum, but are strongly determined and finely patterned by political, socioeconomic and sociogeographic contexts which are themselves manipulable and whose control may provide powerful tools for either accelerating or slowing transmission of HIV."

While the factors will be examined individually, it is important to remember that they are interrelated and do not stand alone. Levels of risk in Aboriginal communities are intrinsically linked to the socio-economic inequalities outlined in Chapter 3 and the history of exclusion and marginalisation that produced them. Their impact needs to be considered in the context of the distinct population characteristics, distribution and migration patterns described in the previous chapter.

The majority of data have been gathered from secondary sources, but insights of interviewees have also been included. HIV and AIDS were only identified in the past ten years, and understanding of the processes underlying transmission is constantly changing. Although it is a relatively new area of study, a copious amount of literature already exists. I have drawn on geographical, sociological and medical sources. It is often difficult to distinguish between disciplinary boundaries in the literature as the issues raised spill over conventional categories.

Comparison of data is problematic because different recording procedures may be used; data may be disaggregated in ways which are not directly comparable; and Federal, Provincial and Territorial governments do not usually record data by ethnicity. Appendices 3-5 show exposure categories in reported cases of AIDS in Canada, Canadian Aboriginal people and the US.

4.2 SEXUAL TRANSMISSION

HIV is essentially a sexually transmitted disease (STD). However, Schoepf

(1991:752) remarked that if sexuality and sex are seen as biological processes,

...it fosters the illusion that HIV spreads simply as a result of the behaviour of individuals while neglecting the social conditions which produce the epidemic.

Sexual transmission of HIV is strongly associated with the presence of STDs.

Transmission routes are officially identified by homosexual/bisexual activity and heterosexual activity, however, it is unsafe sex that determines vulnerability to HIV, not sexual orientation.

4.2.1 Unprotected sex

Homosexual/bisexual activity is still the predominant recorded exposure category of the total reported AIDS cases in North America.² It accounted for 78% of reported AIDS cases in Canada by July 1992 (83% of men), and 38 (76%) of reported cases among Aboriginal Canadians (HIV/AIDS Division, July 1992). By November 1991, in the United States, "men who have sex with men" accounted for 58% of known adult cases, and 55% among American Indian/ Alaskan Natives (Centre for Disease Control (CDC), 1991).

Gay men were the first community to be hit by the epidemic in North America. Behavioural changes among gay men combined with the development of the epidemic into other sections of society is reducing the significance of homosexual/bisexual activity as a route of new transmission (Anderson and Roy, 1992:58). In Canada since

² Reported transmission routes in recorded AIDS cases are misleading because of the time lag between infection with HIV and developing AIDS. As HIV is associated with gay men many heterosexual people may not present themselves or testing as they may not see themselves as being at risk for infection.

1989 the number of new cases of AIDS attributed to homosexual/bisexual activity has fallen (HIV/AIDS Division, 1992).³ In the United States, among "Black not Hispanic" and "Hispanic" people "men who have sex with men" accounted for only 35% and 40% of cases respectively. For "White, not Hispanic" it accounted for 76% of AIDS cases (CDC, 1991).

In July 1992, heterosexual activity accounted for at least 8% of all reported AIDS cases in Canada, but 58% of female cases, and for 3 cases of AIDS in Aboriginal people (HIV/AIDS Division, July 1992). In the United States "heterosexual contact" accounted for 6% of reported adult AIDS cases, 36% of cases among women, and 4% among American Indian/Alaska Natives by November 1991 (CDC, 1991).

The chances of contracting HIV through unprotected vaginal sex are about 1 in 100 per contact for men, and about 20% higher for women (Heyman *et al.*, 1990:3, Johnson and Laga, 1990:15; Peterman, 1990:56). The probability of contracting HIV through unprotected anal sex is about 2.3 times higher than through vaginal intercourse (Johnson and Laga, *ibid.*; Peterman, *ibid.*).

The influence of organised religion and other European influences has been associated with a denial of homosexuality among some Native communities and people, despite a historical tradition of acceptance.⁴ The JNC Findings Document

³ This has been attributed to changes in behaviour, and (in the USA, at least), the epidemic has reached the peak of its infectious curve. A survey of gay men in Toronto found 55.5% had been tested for HIV, (13.5% of participants were HIV positive) (Myers *et al.*, 1991:32). Thus many of the people at risk in this population may have already been tested.

⁴ "The Humming Bird Society, Winkie, Berdache, Ogokwe, 2-spirited, the basket and the bow: These are all symbols and words use to describe the sacred people known as lesbians and gay men....It is well known that before the Europeans, most indigenous societies had names for homosexuals and far more than just identify us, these names reflected a recognition of the sacredness of 2-spirited people. We were

notes that,

While many Aboriginal people continue to deny the existence of homosexuals, bisexuals and lesbians within their population, the emergence of four Aboriginal gay and lesbian organisations across the country dispute this claim (JNC, 1990:33).

The denial of homosexuality and bisexuality, and an unwillingness to accept gay people was identified by most of the people interviewed as a barrier to awareness in communities.⁵ Bisexuality and anal sex in heterosexual relationships are not generally acknowledged in non-Native and Native societies. Yet a study of female North American university students found 22% of them reported having had anal intercourse at least once (Haley, 1992). A study of gay men in Toronto found 13% of respondents were currently bisexual (Myers *et al.*, 1991:14).

An increasing body of literature argues that the transmissibility of HIV may be enhanced by immunosuppression. Immunosuppression is linked to poor health status and substance abuse (Ankrah, 1991; Kaplan, 1991; Packard and Epstein, 1991; Padian, 1990; Molgaard *et al.*, 1988; Patron, 1991). Aboriginal people (like Africans, and ethnic minority populations in the USA), are more likely to be in poor health than the majority of the Canadian population, and rates of substance abuse are high, increasing vulnerability to HIV infection.

The prevalence of unprotected sexual activity whether homosexual,

respected and vital parts of our societies. We were medicine people, warriors, healers and visionaries. It is said that 2-spirited people will walk where everyone else is afraid to and we will go where no one else will" (Beaver, 1992:2).

⁵ A study of gay men in Toronto found 13% of respondents were currently bisexual, 48.1% had only had sex with men in their lifetime, and 31.4% had had sex with a woman in the previous five years (Myers *et al.*, 1991: 14)

heterosexual or bisexual is indicated by STD rates and teenage pregnancy rates.

Knowledge, attitude and behaviour (KAB) studies reveal the extent of sexual activity and unprotected sex.

4.2.2 Knowledge, attitudes and behaviours of Canadians

Four Canadian KAB studies are of particular interest.⁶ They show the general extent of behaviour change and levels of knowledge in Canada.

A study of Canadian adults found that between 80-90% of respondents could give a description of AIDS and primary routes of transmission, but 15-25% held important misconceptions, particularly regarding risk prevention (Ornstein, 1989:11-32).⁷ No significant behaviour changes were recorded (*ibid.*:46-48).⁸

The Canada Youth and AIDS Study and its offshoot, Street Youth and AIDS, found that about 73% of youth gave correct answers to questions about AIDS and HIV transmission (King *et al.*, 1988; Radford *et al.*, 1989).⁹ However, they knew little

⁶ They are: AIDS in Canada: Knowledge, Behaviour and Attitudes of Adults (Ornstein, 1989); Canada Youth and AIDS Study (King *et al.*, 1988a); Street Youth and AIDS (King *et al.*, 1988b); and Men's Survey'90 (Myers *et al.*, 1991).

⁷ Of respondents, 24% did not know that HIV can be transmitted by someone who shows no signs of infection and that it cannot be cured. Using a diaphragm and washing genitals after sex were rated as "very effective" in preventing transmission of HIV by 15% of respondents (Ornstein, 1989:16-17).

⁸ As many as 41% of men and 27% of women had had sex with out using a condom with someone they did not know well in the previous 5 years; people with more partners were more likely to participate in risk behaviour (*ibid.*:46-49).

⁹ Street youth were the best informed (75% correct answers), Grade 11 students were the least knowledgeable (67%), followed by university students (70%). Native Street youth were less informed than their peers (70%) . Understanding of transmission routes was similar for all groups.(Radford *et al.*, 1989:75-80)

about other STDs, and a significant number did not know how to protect themselves.¹⁰ The majority did not see themselves at risk and were not contemplating changing their behaviour to protect themselves. The Street Youth and AIDS study found that Native youth were less informed, less educated, had poorer mental health, were less likely to be employed but more likely to be prostitutes, and were more likely to use drugs and alcohol regularly than their peers (Radford et al., 1989).

Canadian youth are at risk given that by age 16, 50% had had sex, while three quarters of older adolescents were sexually experienced. Only 20% of youth said they always used condoms, while 30% said they never used condoms. Street youth were least likely to protect themselves (Canadian Public Health Association, 1991:149-150, King et al. 1988a:107-119).¹¹

Men's Survey '90 was conducted among gay and bisexual men in bars and bath houses in Toronto, Canada (Myers et al., 1991). Four percent of respondents identified themselves as being of Native origin. The authors note that "The knowledge of risk involved with specific sexual activities among gay and bisexual men is generally good" (ibid.:42). Despite knowledge of risk, 20.7% of respondents reported having unprotected anal intercourse in the previous 3 months.¹² However, the report

¹⁰ Of those having regular sex, less than 25% used a condom, and nearly 50% did not know that condoms used with spermicide provide protection.. Only 14% of college and university students said they always used a condom (Canadian Public Health Association, 1992:148-150; Radford et al., 1989:78-80).

¹¹ This is reflected by those reporting having had an STD: 22% of street youth, 4% of college and university students (CPHA, 1992:149-150, King et al., 1988a:107-119).

¹² The study did not record how many times unprotected anal intercourse had taken place over the previous three months.

notes that "Comparison with previous studies in the Toronto area suggests,...dramatic increases in the use of condoms have occurred since the beginning of the epidemic" (ibid.:40).

Although these studies have largely identified the knowledge attitudes and behaviours of non-Aboriginal Canadians,¹³ there is no reason to believe that Aboriginal peoples knowledge attitudes and behaviours are likely to place them at less risk. It is significant that each study found that lowest levels of knowledge, and changes in attitudes and behaviours occurred among people with least education, income and occupational status. This implies that sections at least of Aboriginal populations may be less informed and are less likely to have changed their behaviour. No attempts have been made to measure differences in the knowledge, attitudes and behaviours of people living in urban and rural areas.

Little is known about Native Canadians attitudes to sexuality. It is one of the areas identified by the JNC as needing further study (1990b). Two HIV and AIDS specific KAB studies in Aboriginal Communities in Canada were identified. A study conducted by the Ontario First Nations HIV/AIDS and Healthy Lifestyle Research Project in partnership with the University of Toronto is in the process of completion (Myers, 1992:6). The second was an unpublished study undertaken by the Swampy Cree Tribal Council and,

...began with a needs assessment of grade five, and seven through twelve students who were surveyed for behaviour, attitudes, and

¹³ Men's Survey'90 notes Ornsteins observations "that telephone surveys, commonly used in probability sampling of the general population, receive a high response rate, but underrepresent ethnic and high risk groups" (Myers et al., 1991:3).

knowledge. Key informant interviews were carried out among the adult population to get their sense of the communities' strengths and weaknesses concerning AIDS. All interviewees believed the threat was real (Procyk, 1992:10).

Pickering and James (1991) by examining the attitudes and knowledge of women and girls to the prevention of STDs (including AIDS) and teenage pregnancies among James Bay Cree offer some useful insights. They found that "although people did not feel it [AIDS] was an immediate problem everyone felt it could become a problem, and that people should be educated about it" (1991:6). People were reasonably well informed about HIV and AIDS, but uncomfortable talking about sexuality.¹⁴ The study indicated that in this community, sexual activity often starts at 13-14, that condoms are not usually used, and that teenage pregnancy although viewed negatively is not heavily stigmatised.¹⁵

Dr Emmett Chase of the Chief Coordinator of the Indian Health Services (IHS) AIDS program has said that there is evidence to show that a larger proportion of the Native American population is sexually active, particularly women of childbearing age, than in all US races. He argues that this is verified by the high rates of teenage pregnancy, STDs and births (Chase, 1991:2). Native American KAB studies indicate that in excess of 30% of those interviewed are engaging in multiple sexual partner

¹⁴ Credit for levels of knowledge was given to CHRs, public health officers, NNADAP workers and media with the Quebec Module and Cree Board of Health for education (Pickering and James, 1991:24). These people are part of the James Bay Cree AIDS Awareness Program which started in 1990, as a result of the continuing success of this program levels of awareness and behaviour change may have developed further since the study was conducted.

¹⁵ This study also interviewed older women about sexual attitudes and behaviour in the past (Pickering and James, 1991:7-11).

activity (*ibid.*).¹⁶

The prevalence of STDs is a strong indicator that people are practising unprotected sex.

4.3 SEXUALLY TRANSMITTED DISEASES

Sexually transmitted diseases are not only indicators of sexual behaviour, but also facilitate the transmission of HIV (Heyman *et al.*, 1990; Peterman, 1990 and others). People with a history of STDs are more likely to test positive for HIV than people without.¹⁷ Furthermore, communities with high rates of STDs are more vulnerable to rapid transmission of HIV. In Canada, STD rates published by the Federal government are not broken down by ethnicity, but rates of STDs are reported to be between three to seven times higher in Native communities than in the total population (Henna, 1990; Haugeneder, 1990; Health and Welfare Canada, 1988).

Caution should be exercised when comparing rates of STD infection as rates are affected by control programs, and reporting methods (Gully, 1992).

National rates of STD infection in Canada have not shown significant rates of

¹⁶ A KAB study conducted in Northwestern USA found 7% of respondents were at "high risk, and 30% were at "middle risk". In other studies, 2% of Hispanic people, 4% in the black population, and 3% in the general population were classified at "high risk". Of over 700 respondents, 75% were female. The "high risk" category was made up of men who had sexual relations with other men and IDUs. The "middle risk" group were people who had two or more partners in the previous year or had been involved with someone they did not know well (Hall, 1990:876).

¹⁷ A seroprevalence study in Manitoba conducted 1990-1991 found rates of HIV of 41.4 for men, and 3.7 for women for people having routine tests for syphilis; rates for people with STDs and their contacts were 128.0 for men and 3.9 for women (Sekla *et al.*, 1991:180).

decline. Table 4.1 shows rates of infection of gonorrhoea, hepatitis B and syphilis over time. The declining rate of gonorrhoeal infection has been attributed to improvements in control programs (Gully and Rwetsiba, 1991a:105).¹⁸

TABLE 4.1

Rates of infection of selected reportable STDs in Canada over time. (per 100,000)

	<u>1985</u>	<u>1986</u>	<u>1987</u>	<u>1988</u>	<u>1989</u>
Gonorrhoea	161.0	138.0	113.0	81.0	75.0
Hepatitis B	9.2	9.3	12.0	12.0	13.2
Syphilis	10.3	8.6	9.2	n/a	n/a

Sources: Gully Paul, Rwetsiba Daphne, 1991a, "Trends in Gonorrhoea in Canada: 1980-1989", CDWR, 17(21): 105-109; Carter, A.O., Walsh, P. "Hepatitis B in Canada," CDWR, 17(31):166; Canadian Public Health Association AIDS Education and Awareness Program, 1992, A Resource Manual for AIDS Educators, Canadian Public Health Association:Ottawa.

The national rates shown in Table 4.1, mask underlying trends. Declining male rates of STDs have been attributed to gay men changing their sexual behaviour. Of particular concern is an increase of some STD's among young women.¹⁹ STDs are most prevalent among people aged 15-29 years - the age group at greatest risk for HIV infection.

¹⁸ Genital warts (human papillavirus) are found in 4-5% of people aged 15-24 years visiting STD clinics in Canada. Herpes simple virus infections are also common, but rates of infection are unknown in Canada (Gully, 1992:43).

¹⁹ Between 1985 and 1986 rates of syphilis in women aged 22-29 increased 22.8%, while the overall male rate fell 42.6%. In the following year there was a 50% increase in reported cases among women aged 15-19 (Canadian Public Health Association, 1992; Canada Diseases Weekly Report (CDWR), 1988:86). Women are more likely to be infected by Hepatitis B when younger than men.

Chlamydial infections have been called "one of the most common and most important of all STDs because of their high incidence and long term consequences" (Gully and Rwetsiba, 1991b:282). Chlamydia was not included as a reportable disease until 1990. Available data for 1989-1990 showed a 7.9% increase in cases (Masse *et al.*, 1991:954).

TABLE 4.2

Rates and ratios of chlamydial infection by gender in Canadians aged 15-29, 1989-1990. (per 100,000)

	<u>male</u>	<u>female</u>	<u>male:female ratio</u>
15-19	236.4	1578.6	1:6
20-24	520.5	1525.8	1:3
25-29	243.8	532.7	1:2
total pop.	102.3	315.6	all 216.8

Source: Gully Paul, Rwetsiba Daphne, 1991b, "Chlamydial infection in Canada", CDWR, 17(51):286.

Chlamydial infection can be asymptomatic and remain so for long periods.²⁰ It is an indicator of heterosexual activity, as unlike other STDs it is less commonly found in gay men (Gully and Rwetsiba, 1991b:290). High rates of infection in Canada demonstrate that condoms are not being used, and shows how an a-symptomatic STD can spread through a population. Rates and ratios of chlamydial infection by gender in Canada are shown in Table 4.2. The dramatic male female discrepancy has been at least partially attributed to under diagnosis.

²⁰ A study of young women attending routine gynaecological examinations in Montreal found around 70% of infected women were a-symptomatic (Masse *et al.*, 1991:954).

4.3.1 STD's and Aboriginal Communities

As stated above, rates of STD infection are believed to be five to seven times national rates, yet there may also be significant local variations. For example, in 1989 the rate of chlamydial infection in the total population of an Ontario reserve was ten times the provincial rate (1721.4/100,000 compared to 174). Rates of gonorrhoeal infection were 2.5 times the Ontario rate (22.4 and 87.8/100,000 respectively) on the same reserve (Anon., personal communication 21/1/92). Randy Lewis coordinator of the Native AIDS Awareness and Prevention Centre in British Columbia says more than ten times as many Natives as non-Natives in the Lower Mainland contract syphilis, and in Northern communities, about seven times as many Natives contract gonorrhoea as non-Natives (Hanna, 1990:C6).

American Indians and Alaskan Natives are five to ten times more likely have a history of STDs than White non-Hispanic Americans (Patron, 1991:58).²¹ Les Hanson the program director at the American Indian AIDS Institute in San Francisco, has said,

...the high rate of STDs has to do with reservations being concentrated areas. If one person is exposed, then through 'snagging' - what we call sleeping around - they will transmit it to a lot of others. Plus there's this connection between substance abuse and sexual practices. In that type of situation, under the influence of alcohol or drugs you are more likely not to use a [condom] (Patron, 1991:58).

In the USA there was a 75% increase in primary and secondary syphilis

²¹ Indian Health Services (IHS) in the USA report finding in excess of 25% positive screenings for chlamydia among teens (Chase, 1991:2). In 1982, a study of Navajo prenatal patients found 25% were infected with chlamydia. In 1986, 30% of Inupiat women receiving prenatal care were infected, ten times the local non-native rate (Toomey, *et al.*:566-7). Between 1981-1989, rates of gonorrhoea and syphilis in Native Americans were more than double the rates among White non-Hispanic Americans (*ibid.*, 1989:566).

between 1985-1990, a 126% increase among Black men and a 231% increase among Black women. These upwardly spiralling rates have been linked to a growth in drug use (MMWR, 1991a:321; Gully, 1992:42). While they may not be replicated in Canada, they serve as a reminder of how quickly an epidemic can develop and the strong links between STD's and deteriorating socio-economic conditions. As one commentator noted:

Declines in socioeconomic and education levels (eg. among people of lower income levels in inner cities) are associated with higher unemployment, drug use, prostitution, and family disruption, conditions conducive to the spread of syphilis (MMWR, 1991a:322).

4.4 PROTECTION

Using condoms reduces the risk of penetrative sexual transmission of HIV and other STDs. People need to be taught how to use them. Feather of Hope Saskatchewan commented:

And then most of the kids don't know how to use condoms. So "the hell with putting a condom on, we'll do it like that." So those are the realities (2/6/92).

Even if people know how to use them, they may not be available. Getting condoms on reserves may be difficult:

We talk about the native population on the reserve level. There's not many places for people to shop. There's no such thing as a drug store on the reserve. The place to get your condoms on the reserve is the medical health unit and you'll have to ask somebody. They won't display the condoms and have them available in a basket in the waiting area. You'd more than likely have to ask the nurse for condoms....The native population are not very....They feel very intimidated by white

people. We're a very shy population. When we talk about going into the health unit to ask for condoms, that's impossible. We won't do that. The accessibility to safer sex information or even resources like condoms is practically impossible.

When we think of the urban areas its less of a problem because we have the needle exchanges who roam the inner cities where our population hangs out. Who makes needles available to them. Who gives condoms out. People in cities are less shy. People have more access to these resources like condoms and needles.

But the reserve levels, no, no such thing (George Poitras, 12/6/92).

Pickering and James (1991:14), also comment on the need for condoms to be made more readily available, they note,

It is even more difficult in a small community, where your friends and family may well guess your reasons for being seen in the clinic. The use of condoms presents many of the same problems as the use of the birth control pill. First one has to go and ask for it, either at the clinic or at the store. Since one usually knows both the clinic and store staff, this is more difficult than going anonymously to a drug store in a large city.

If free condoms are not available, buying condoms may not be an option for people with little money to spare,

And you think about buying condoms. People have no money to eat for many days out of the month. What more spend three, four, five dollars on a box of condoms? (George Poitras, 12/6/92).

Using a condom requires consent between partners.²² Women particularly do not always have control over the use of condoms in a sexual relationship.²³ A study

²² The study Men's Survey '90 commented "The study showed that one fifth of episodes where condoms were not used were because a partner did not want to use one. This suggests that even within gay relationships there are possible power differentials and condoms are not used because individuals lack assertiveness...and self efficacy..."(Myers *et. al.*, 1991:41).

²³ An article on the Eighth International Conference on AIDS (July 1992) reported, "Dr Jonathan Mann of Harvard University said the growing number of infected women also reflects their subservient status. He said women often are unable to demand that their partners use condoms...."(Associated Press, 1992:A5).

on family violence in Aboriginal communities in Ontario estimated that eight in ten Aboriginal women have experienced family violence at some point in their lives, compared to one in ten of all Canadian women (Ontario Native Women's Association, 1989:19). These figures indicate the problem of control that some women may experience with a partner who is unwilling to use a condom. Below are the comments of two women interviewed who work with women.

How can you say use a condom when you have sex when if they ask the husband or boyfriend to use a condom they'll get beat up (Margaret Akan, AIDS Regina, 29/5/92).

Its not a perfect society. You take a woman whose husband who may be putting her at risk. How do you get some negotiation for safer sex in the relationship - the guy's going to bash her. Its very difficult. Women often don't know that they are at risk or deny it. The thought that their husband is having an affair with god knows who... (Anne Katz, Village Clinic, 26/5/92).

Pickering and James in their study found that although most respondents thought birth control was the responsibility of both partners, "...none of the young girls interviewed thought it was realistic for a girl to ask her boyfriend to wear a condom" (1991:14).

Sexual relationships are not always consensual. Like non-Native communities, no firm data exists on the extent of sexual abuse.²⁴ The effect of residential schools has been seen as particularly damaging (Statistical Data Technical Working Group, 1991:36).²⁵ Healing Our Spirit commented, that as communities heal themselves

²⁴ Pickering and James found that gang rape had happened in each community and that most interviewees were aware of incidents of sexual abuse of children, commenting that their study could not measure the extent of sexual abuse (1991:16).

²⁵ The report of the Special Advisor to the Minister of National Health and Welfare on child sexual abuse in Canada is quoted as saying "...many Aboriginal leaders see them [residential schools] as the origin of the sexual abuse of children in Aboriginal communities, as well as a prime cause of a

sexual abuse issues need to be addressed,

They [Aboriginal communities] are at risk because of the fact that a lot of the communities have sexual abuses in the communities and have at risk groups in the communities.

After the "Europeans" arrived and their religions were pushed, it took away the culture. And a lot of that sexual abuse is kept quiet, that's in the communities. Not talked about because a lot of them are relatives and they don't want to send their relatives to jail and stuff like that.

We ask the communities to look at the issues of sexual abuse, and use that to look at the issues of drugs and alcohol and start addressing them.

We think that the community is in a healing process (Healing Our Spirit, 10/6/92).

Studies have indicated that people who do not consider themselves at risk do not practice safer sex (Ornstein, 1989; Radford *et al.*, 1989). Prostitutes will use condoms with clients (90%, but not with partners (18%) (JNC, 1990:41; King *et al.*, 1988). Until people, both native and non-Native - consider themselves at risk, they are unlikely to change their behaviour. People are also less likely to use condoms when high on alcohol or drugs (Myers *et al.*, 1991:30). This is particularly relevant to the transmission of HIV, since alcohol abuse is also a common component of family violence and sexual abuse (Ontario Native Women's Association, 1989:22).

4.5 SUBSTANCE ABUSE

Another factor influencing our population of contracting HIV through STD's is alcohol and drug use. Which realistically we know we are a population who is probably the most affected in North America by

deterioration in parenting skills in Aboriginal communities" (Statistical Data Technical Working Group, 1991:36).

alcohol abuse and we're seeing more IV drug use amongst our population too.

The transiency that may occur to the reserves and to the urban areas is also influencing our population contracting HIV through alcohol and drug use, while they are transient. So alcohol and drugs is a very big cofactor in making our population very vulnerable to being targeted for this disease (George Poitras, 12/6/92).

Substance abuse is identified as a risk factor in the transmission of HIV. Firstly because of the effect of alcohol and drugs on behaviour,²⁶ and secondly, because injection drug use often involves needle sharing which facilitates the transmission of HIV. Substance abuse also causes immunosuppression affecting susceptibility to HIV infection and the development of AIDS after infection. When considering substance abuse, it is important to see it within the context in which it is occurring, Kaplan (1991:278) commented,

If sexual and drug abuse patterns are implicated in exposure in HIV the full understanding of the social causation of the HIV infection requires an understanding of the factors that influence sexual behaviour and drug abuse patterns.

4.5.1 Injection drug use

Rates of reported cases of AIDS are growing fastest among injection drug users (IDUs) (Pagliaro, 1992:5). Partners of IDUs are also at risk (Pagliaro, 1992:5; MMWR, 1991c:885). In July 1992, injection drug use (IDU) accounted for 2% of reported AIDS cases in Canada and for 3 reported cases among Aboriginal Canadians. IDU is strongly associated with reported AIDS cases in minority communities in the

²⁶ Not only does drug and alcohol use impair judgement, but drug users may use their bodies to get money for drugs or in exchange for drugs (Armstrong *et al.*, 1992, MMWR, 1991c)

US. By November 1991, IDU accounted 22% of all reported cases, 18% of cases among American Indians and Alaskan Natives, 39% of cases among Black people, and 40% among Hispanic people. IDU among Native Americans with AIDS is around two times higher than among white non-Hispanics, and accounts for the majority of cases among women (Rowell, 1991:22).²⁷

In 1990, a seropositivity study of 242 IDUs in Toronto aged between 16-26 years found that 5% were HIV positive (Radford *et al.*, 1991:3). A study of IDUs in Alberta (Pagliaro *et al.*, 1992) has found,

... 8-10 percent of native addicts reported they are HIV+ compared to 1 or 2 percent of non-natives. He [Pagliaro] noted however that many were in prison, where the HIV rate is higher than among the general population (Certenig, 1992:A3).

Once HIV has entered a drug using community studies indicate that seropositivity can rapidly expand (DesJarlais *et al.*, 1990; Ford *et al.*, 1990). Des Jarlais *et al.* state that "when seroprevalence reaches 10-15% there will be a rapid rise to 40% or more over the next three years" (1990:142).²⁸ A seroprevalence study in Quebec found HIV seroprevalence among IDUs increased from 4.2% in 1988 to 19% in 1990 (Alary and Castel, 1990:25).²⁹ IDUs are not isolated from communities they live in, high levels

²⁷ A study of a Hepatitis B (HVB) epidemic in two Native American communities found 88% of people with HVB were IDUs (Harding, 1992:13).

²⁸ In Edinburgh the seropositivity rate of IDUs increased from 2% to 50% in two years (Ford *et al.*, 1990:469). In American urban areas, HIV seroprevalence rates for IDUs is between 10-65% (MMWR, 1991b:465).

²⁹ This study of people presenting themselves for HIV antibody testing in Quebec found that HIV seropositivity was associated with: the presence of HIV related symptoms (prevalence odds ratio [POR] 36.5), homosexuality or bisexuality (POR 8.4), intravenous drug use (POR 4.2), male sex (POR 2.8), previous sexually transmitted disease (POR 1.8). (Alary and Castel, 1990:25).

of HIV in IDU populations can diffuse into non-drug using populations.

The Addiction Research Foundation (ARF) have estimated that 25,000 to 50,000 Canadians are at risk of HIV infection from needle sharing (Ford et.al., 1990:469).³⁰ As many as 50% of street youth may have injected drugs (Taylor, 1991).³¹ Little literature addressing IDU in Native Canadian and American communities is available (Rowell, 1991:2). Street Youth and AIDS reported a lower rate of IDU (12%), of these IDU, 50% had shared needles. Native youth were most likely to have shared needles (Radford et al., 1989:120-122). Available KAB studies involving Native Canadian and Americans show a significant level of IDU (Rowell, 1991:22).³²

In Canada, data available from needle exchanges and street youth organisations indicates that native people are over represented in their clients.³³ National Association of Friendship Centre (NAFC) sponsored needle exchanges in Vancouver and Edmonton report that since 1991 over 50% of users are native (see Table 4.3) (NAFC, 1992:1-2). In a study by Street Links in Winnipeg of their clients, 78% self

³⁰ An estimated 250,000 Canadians have injected illicit drugs (CPHA, 1992:153). The ARF estimate that between 15,400 and 22,800 Ontario high school students have injected drugs at least once (Ford et al., 1990:469).

³¹ Rates of use of some drugs by street youth were, alcohol - 95%; cannabis - 92%; LSD - 70%; cocaine- 64%; ecstasy - 13% (Taylor, 1991).

³² A study conducted in Idaho, Washington, and Oregon in 1989, where 7% of respondents reported they had injected drugs not supplied by a doctor. In a study of Native Americans in chemical dependency programs 13% reported using needles to get high (Rowell, 1991:31,33).

³³ Needle exchanges provide new needles in exchange for used needles, cleaning equipment and condoms. The purpose is to make needles readily available to prevent sharing, and reduce risk of transmission in a vulnerable sector of the population.

identified as native. Laurel McTavish, a nurse working in the project said,

One area, where the majority of clients we're seeing are, probably most are under 20 years, 95% are under 24 years and 99% are native - mostly solvent abusers Laurel McTavish, 26/5/92).

TABLE 4.3

Percentage of users of HIV/IDU prevention services by race and type of service used, February 1992.

	<u>Edmonton</u>	<u>Vancouver</u>	<u>All</u>
All users (number)	995	716	1711
Native	54%	46%	51%
Caucasian	44%	50%	46%
Asian	1%	2%	1%
Other	1%	2%	2%
Needle exchange only	54%	18%	38%
Needle exchange/ bleach and/or condom	44%	31%	39%
Condom only	2%	51% ³⁴	22%

Source: National Association of Friendship Centres (NAFC), HIV/IDU Prevention Program, February Report, 1992:1-2.

Of all clients in Edmonton and Vancouver, nearly 50% were women and the same proportion were in their twenties (NAFC, 1992; Personal Communication, April 8, 1992). Street Links estimate 60% of users are females³⁵ and 30% are males, (10% are "trannies") and 40% of clients are 15-19 years old,

³⁴ Of this 51%, 67% were females.

³⁵ "They are females - certainly not women, not by a long shot, they're too young" (Laurel McTavish, 26/5/92).

Only 1% are younger than 15 - but it's staff evaluated so we probably miss some younger ones because you don't want to think that this is a 13 year old dressed up as a 17 year old working the streets, so there are probably a lot more under 15 (Laurel McTavish, 26/5/92).

Needle exchanges also provide bleach and teach kits, condoms and lubricants, basic health care, information, bad trick lists, and can give people advice or refer them where to go for help. Street Links survey (McTavish, 26/5/92) found,

- 48% of users came for condoms
- 24% for the needle exchange
- 24% for information about AIDS or other information
- 12% for advice referral or help
- 12% for bad trick information.

In Edmonton about 50% of users do not take condoms, implying they are not protecting themselves against sexual transmission.

Needle exchange programs are available in most major cities in Canada, (none in Saskatchewan). The availability of needle exchange facilities may help to reduce the transmission of HIV transmission by needle sharing. A study by Pagliaro *et al.* (1992), is attempting to discover the "prevalence and the characteristics" and knowledge, attitudes and behaviours of IDUs in Alberta. From results of interviews with Native IDUs in Edmonton, they have found that although IDUs have high levels of knowledge about HIV and AIDS, they continued to share needles, practice unsafe sex, and did not perceive themselves to be at risk (*ibid.*:7).³⁶ The study is disturbing because they have found that despite the existence of needle exchanges, needle sharing

³⁶ 83% of Native male IDUs, and 69% of females, said that they thought their "chances of getting the AIDS virus were "somewhat unlikely" or "very unlikely" (Pagliaro *et al.*, 1992:7).

continued among "chronic" or "hard core" IDUs (*ibid.*:6-7).³⁷

A high percentage of Native people in Canada live in rural and remote communities where there are no needle exchange programs, and needles are less likely to be available. Anecdotal evidence from needle exchange programs shows that IDU does take place in rural communities, as does needle sharing (Feather of Hope Saskatchewan, 2/6/92; Anon. 21/2/92; Ford *et al.*, 1990:470).³⁸

Rates of diabetes are 2 to 5 times higher in the Aboriginal population of Canada (Kewayosh, 1991:3). Rowell argues that

There is another danger for [Native Americans] ...the use of disposable needles and syringes by diabetics which may be reused by IV drug abusers in the same household (1991:35).³⁹

Feather of Hope in Saskatchewan reiterated this argument when they commented,

And the other problem that links into it is that we have a lot of diabetics, so there's a lot of needles kicking around that kids get a hold of. But they don't get hold of enough. They can't steal from Mum ten needles because she's going to know. They might steal one and then they'll share it (2/6/92).

³⁷ Reasons given included that IDUs exchanged new needles and syringes for drugs; shared as part of the "ritual of fixing"; could not wait for a new needle; were too wasted to know what they were doing; and because of "laziness". (Pagliaro *et al.*, 1992:6-7). Service providers in interviews noted that needle sharing between IDUs is also part of a culture and behavioural norm, and a way of expressing friendship. These reasons for needle sharing may be harder to affect (Radford *et al.*, 1989).

³⁸ A study of IDU in Kingston, Ontario revealed there were an estimated 600 IDUs in the community, that needles were not easy to get, and that needle sharing was taking place usually in groups of 3-5 people, and occasionally in groups of 10-12 people. In 1988, 4 out of the 40 people who were infected with HIV in Kingston were IDUs (Ford *et al.*, 1990:470).

³⁹ From informal interviews conducted in 1988, The National Native American AIDS Prevention Centre said that the issue of needle/syringe reuse in diabetic households by IDUs was significant enough to warrant educational intervention (Rowell, 1991:35).

4.5.2 Other substance abuse

Non-needle using substance abusers are also at increased risk for HIV infection. Alcohol and drug abuse, is associated with behavioural changes, loss of judgement and subsequent participation in risk behaviour (Rowell, 1991:22; Patron, 1991:58 Ostrow, 1990:49).⁴⁰ Dr Emmett Chase of IHS has said that,

Substance abuse is a major contributing factor in exposure to sexually transmitted disease including HIV,It is reasonable to expect that substance abuse will be a major cofactor to further spread HIV in American Indian and Alaskan Native communities. For American Indian and Alaskan Native women, substance abuse is already documented to be a major cofactor to transmission of HIV (Chase, 1991:2).

Alcohol abuse in Canadian and American Aboriginal communities has been well documented (Rowell, 1991:21). Alcohol abuse is a more severe problem among Native peoples than non-Native peoples in both countries, and is worse in some communities than in others.⁴¹ American Indian youth show higher rates of drug use than their peers (Harding, 1992:14; Chase, personal communication, February 6, 1992). A health assessment study in the NWT showed a higher rate of drug use (not IDU) in native communities (Imrie, 1988). A Native American AIDS Manual has commented,

Most of us are aware that alcohol abuse is responsible for most of the top ten causes of death for Native people...Studies have shown that the use of alcohol and other drugs is positively associated with high-risk sexual behaviour. Those who abstained from alcohol and other drugs during sex were found not to have engaged in high risk sexual behaviour. Those who combined sex with alcohol and drug use were

⁴⁰ A study quoted by Ostrow found that people using alcohol or another drug were 2 to 3.5 times more likely to be at high risk for infection (1990:49). Molgaard *et al.* (1988) note the link between alcohol abuse among gay men to increased susceptibility to HIV infection due to immunosuppression and risk behaviour.

⁴¹ Alcohol accounts for four of the top ten causes of deaths of Native Americans (Rowell, 1991:21).

most likely to have had a history of high-risk sexual behaviour over the previous year (JNC, 1990:32).

Chase of Indian Health Services in the United States has said,

And I don't think that we're ever going to be able to prevent HIV transmission unless we prevent alcohol and substance abuse in Native Communities. That's the bottom line, and that's what makes me think HIV is going to eventually become endemic (Patron, 1991:59).

Studies have also shown that both IDU and non-IDU substance abusers may use sex to get drugs or money for drugs (MMWR, 1991c:887; MMWR, 1992:143).⁴²

Substance abusers are more likely to have a history of STDs.

Substance abuse in Native communities cannot be separated from wider problems faced by First Nations communities. Studies show rural and remote communities and those which have undergone massive changes tend to be most severely affected (Shkilnyk, 1985). Over the past ten years, alcohol abuse has declined in many communities as Native controlled treatment programs have been introduced. Most communities are now 50% sober (Big Canoe, personal communication, February 1992).⁴³ Alcohol and substance abuse does not only affect users,

In some communities everyone is profoundly affected by alcohol, regardless of whether they personally drink. This is because people in their family and/or community do abuse alcohol, and this abuse affects the health and well-being of everyone (Kramer and Weller, 1988:19).

⁴² A studies of women in drug treatment programs in the USA found an average of 60% had ever exchanged sex for money or drugs (some programs as many as 75%) (MMWR, 1992b:143; Fordyce et al., 1992:141). Another study found that 25% of female partners, and 21% of male partners of IDUs had exchanged sex for money or drugs (MMWR, 1991c:887).

⁴³ Notable is the story of Alkali Lake in B.C., where over 15 years the number of people drinking fell from 95% to 5% (Big Canoe, personal communication, February 1992).

This thesis cannot address the issues underlying substance abuse in Aboriginal communities. It is important to understand the inter-relationship between substance abuse and other risk factors outlined here.

4.6 SELF ESTEEM

There is starting to be recognition. But if I took you when you were three or four years old and whacked everything out of you, your culture, all your belief systems, everything and put a bottle in front of you you're going to take it because you have nothing. No sense of self-esteem, no culture, who the hell are they? "I'm no good." Its not the alcohol and drugs - its the whole being and its not going to change in a few years. It's going to take a lot of work (Aian LaRoque Kennard, 9/6/92).

Dr Jay Wortman of the Medical Services Branch AIDS Program has identified the lack of self-esteem among people in Aboriginal communities as a barrier to changing risk behaviour. If a person does not care about themselves and their life they are less likely to take precautions to preserve their life or the life of others.⁴⁴ In interviews, service providers in Aboriginal AIDS education and prevention organisations have consistently said - "you can give out all the condoms you want, but if people don't care enough about themselves, they won't use them".

Self-esteem is an intangible concept and difficult to quantify. Substance abuse, suicide and homicide rates can be used as indicators of a lack of self-esteem and self care (Radford *et al.*, 1989; Seigel *et al.*, 1989). Wallace observes,

⁴⁴ A study of gay men practising "risky and safer sex" found that self-esteem and alcohol "approached significance" in continuing unsafe sexual practices and risk taking (Siegel *et al.*, 1989).

Thus both homicide and suicide may, under certain circumstances of rapid urban decay and associated forced migration, be closely related expressions or indices of certain aspects of rapid social disintegration, and may, for some populations, often be functionally difficult to distinguish (Wallace, 1990:804).

Suicide rates of Registered Indian people in Canada are approximately 3 times higher than the Canadian rate, and account for 15-20% of all violent deaths among this population. Between the ages of 10-29 Registered Indians are 5-6 times more likely to commit suicide than the rest of the population (Statistical Data Technical Working Group, 1991:45; Steering Committee for First Nations and Inuit Mental Health, 1991:8-9).⁴⁵ High rates of suicide among young Native people are serious as they are most at risk for HIV infection.⁴⁶ Significant differences exist in suicide rates between communities, and can change rapidly over time.⁴⁷

Some of the factors identified as contributing to the high rates of suicide in Native communities in Canada are depression, loss of employment or unemployment, social dislocation and disruption, social isolation, and substance abuse (McNamee and Steering Committee for First Nations and Inuit Mental Health, *ibid.*; Frideres, 1989:140; National Task Force on Suicide in Canada, 1989:35). The Grand Chief of the Nishnawbe-Aski Nation said that the high rate of suicide in youth,

⁴⁵ It is believed that suicide in Native communities is significantly under reported, in some communities it is thought that up to 25% of deaths attributed to accidents were suicides (McNamee and Offord, 1990:1227; Statistical Data Technical Working Group, 1991:45; National Task Force on Suicide in Canada, 1987).

⁴⁶ Indian men aged 20-29 years are 4.6 times as likely to die from suicide compared to Canadian men of the same age, males aged 10-19 are 5.3 times more likely to commit suicide, while females 10-19 are 7.5 times more likely to commit suicide (Statistical Data Technical Working Group, 1991:ii).

⁴⁷ Suicide attempts in Sioux Lookout Zone increased from 70 in 1987 to 143 in 1990, in a population of approximately 14,000 (Plauter, 1991:A1).

is a multifaceted complex phenomenon, what reasons there are rooted in the lifestyles - and Third World conditions that the people find themselves in" (Platier, *ibid.*:A2).⁴⁸

Homicide rates in Aboriginal Canadian communities are also disproportionately high. In 1988, Aboriginal people in Canada were ten times more likely to be charged with murder, and are eight times more likely to be homicide victims (Statistical Data Technical Working Group, 1991:43).

Death rates for Registered Indians aged 10-39 years are over three times higher than the national rate in Canada. Albert McLeod commented, "Young people are dying all the time anyway from suicide, alcohol, and violence. So it's hard for people to see AIDS" (25/5/92). Kramer and Weller (1988:12) comment,

The effects of the very high death rates over long periods from the ravages of infectious diseases on the present health status of the native populations is often forgotten and usually underrated....Disease as much as conquest and relocations undercut morale, that is one's sense of self worth and the ability to control one's own or the community's destiny.

Although HIV and AIDS can affect anyone, two aspects of Aboriginal populations are of concern.

4.7 YOUTH

A high proportion of the Aboriginal population is in the high risk age group for HIV infection and AIDS. In 1991, DIAND estimated that approximately 30% of Native Canadians are aged between 15-29 years, compared to 22.5% of the total

⁴⁸ A survey presented in 1991 found 1 in 5 Native American teenage girls and 1 in 8 boys had attempted suicide (Brown, 1992:A3)

population. This discrepancy is not likely to change significantly in the foreseeable future (Statistical Data Technical Working Group, 1991:8). Young Aboriginal people are disproportionately at risk because rates of other risk factors are highest in this age group (e.g., sexual activity, STDs, suicide, mobility, etc).

A survey of Native American teenagers released in 1992 found that according to the co-author Robert W. Blum,

For every risk factor [for HIV infection] with the exception of homicide, the Native kids are in far worse shape than African-American kids (Brown, 1992:A3).

Native American teenagers were more likely: to have lost a parent, have been victims of sexual abuse, to drink regularly, use marijuana and to have attempted suicide (*ibid.*). There is no reason to believe that Native Canadian youth do not exhibit the same degree of risk. Glen Murray, Director of the Village Clinic in Winnipeg in his presentation to the JNC said,

Native Youth in Manitoba appear to be at increased risk for contracting AIDS because of high rates of sexually transmitted diseases amongst the population; part of the street culture, use injection drugs; are the least educated; suffer from systemic racism; lack access to health care and often are in conflict with the law; come from dysfunctional families or are rejected by their families; lack income and engage in sex for survival; poor physical health and malnutrition; lack of youth support systems (JNC, 1989:37).

Street youth face particular problems and have needs which cannot be dealt with in the context of this thesis.

4.8 PRISON POPULATIONS

If we look at our population in the federal and the provincial penitentiaries, or smaller security prisons, again a very vast majority of the native population is inside that population. And we know that people are contracting HIV as a result of being in penitentiaries. we know that there is sexual activity going on in the native population or in the penitentiary population. So we know our population is vulnerable that way, from being in the prisons, the alcohol and drugs... (George Poitras, 12/6/92).

The transmission of HIV in prison populations is of increasing concern.

Aboriginal people make up 9.6% of federally incarcerated inmates. Aboriginal women comprise 14.7% of federally incarcerated women. A consultant working with incarcerated inmates suggests that if non-Status Indian, Metis and Inuit people are considered, 30-40% of federal inmates are Aboriginal (JNC, 1990c).⁴⁹

A seroprevalence survey of incarcerated men in Quebec undertaken in 1990 found 3.6% (CI 95%) were HIV positive. A study of women in prison found a rate of infection of 7.2% (Hankins, 1991:233). Sexual activity and IDU occurs in prison populations, often in abusive situations.⁵⁰ It is probable that incarceration is a source of risk for many Aboriginal people.

4.9 SUMMARY

Chapter 3 examined some of the social and geographical factors which place

⁴⁹ He said that in any one year as many as 15,000 to 20,000 aboriginal men are incarcerated in federal, provincial/ territorial and municipal prisons (JNC, 1990c).

⁵⁰ In the United States, AIDS is the leading cause of death in many prisons (Pagliaro and Pagliaro, 1992).

Native communities at risk. Having now examined the prevalence of risk factors in Aboriginal communities it is possible to see that communities are vulnerable. Therefore provision needs to be made to provide services and support to people who are and will be infected with HIV.

At present the only way to prevent HIV infection is through education awareness and prevention programs. Aboriginal communities are developing education programs targeted at their communities and tailored to meet community needs. Barriers to education, awareness and prevention programs are discussed in Chapter 5. The existence of needle exchanges and outreach programs in some cities may help to reduce the transmission of HIV through IDU. They also provide an opportunity to distribute condoms and information. Although free condoms and needle exchanges may be more readily available in some cities they are not in rural communities. Drug use, prostitution and sex occur in rural communities, prevention programs need to be addressed to them as well.

Sharon Day the Executive Director of the Minnesota Native American AIDS Task Force, has said,

The more work I do, the more I know prevention cannot just be the mechanics of cleaning a needle or using a condom. If we want people to change behaviours, to be healthy, we have to give them reasons to do that. When you consider the racial and political pressures the Indian population has been subjected to for the last 500 years, it stands to reason that if you're told continually that you are inferior, you tend not to care about yourself. The way to restore health to a community is for people to have a positive self image and to understand the positive values and behaviours that have traditionally been part of their culture (Patron, 1991:58-59).

CHAPTER 5

MEETING THE NEEDS OF PEOPLE LIVING WITH HIV AND AIDS

5.1 INTRODUCTION

I thought about what you were asking before I came here, and what I need most is respect (Anon.).

Chapters 3 and 4 outlined the potential vulnerability of Aboriginal communities to HIV and AIDS. It is apparent that despite current education efforts not only do Aboriginal communities remain vulnerable to infection, but present levels of infection are much higher than the reported cases to the LCDC would indicate. This chapter examines some of the needs of Aboriginal people living with HIV and AIDS, from the perspective of Aboriginal organisations providing education and services and support, and people living with HIV and AIDS themselves. The chapter does not examine the actual provision of services, but relates common themes of concern that developed during the interviews.

I had originally hoped to gather this information almost entirely from Aboriginal people living with HIV and AIDS. For reasons that were outlined in Chapter 2, this has not been possible. Information from returned questionnaires has been included (see Appendix 8). The majority of organisations interviewed were developed in conjunction with, or by, people who had been infected and who saw needs that were not being met by mainstream AIDS organisations (see Appendix 9).

As members of their communities who had seen (and continue to see) gaps in provision, and are often PLWA/HIV themselves, their insight is significant.

Many of the issues raised are faced by non-Native as well as Native PLWA/HIV. However, the history of Aboriginal people in Canada has led to inequality, social and economic deprivation, poorer health status and lesser health services for many communities (as outlined in Chapter 3). These factors exacerbate problems for people dealing with infection in Native communities. The size and geographical location of communities present particular difficulties for service delivery, and can intensify problems of stigma and confidentiality. Cultural differences, and different patterns of use of health services, affect how services should be delivered and by whom.

Despite commonalities in needs of PLWA/HIV, this chapter demonstrates that Aboriginal PLWA/HIV and their communities have specific needs which need to be met in distinct ways.

There are differences between communities, provinces and cities. Location may affect levels of income, as well as the availability of services and medical treatment. It appears that the needs of women, particularly those acting as care-givers may be significantly different (Willms *et al.*, 1991; Manthorne, 1990; ACT UP/New York Womens Book Collective, 1990; Hankins, 1990; Campbell, 1990).¹ Street youth also

¹ Given that women tend to be poorer and have worse living conditions than men as well as roles as care givers their needs are not only likely to be greater but different (Margaret Akan, 29/5/92; Susan Beaver, 7/7/92; Donna Reed, 2/6/92; Alan LaRoque Kennard 10/6/92; Willms *et al.*, 1991:22). Relevant literature includes Manthorne (1990); ACT UP/New York Women and AIDS Book Collective (1990); Hankins (1990); Campbell (1990).

have different issues to deal with (Radford *et al.*, 1991).² Owing to the few numbers of women and street youth who participated in the research, it is not possible to comment on any distinct needs they may have.

The chapter is structured around themes that emerged during the course of the research. Where possible these themes are articulated in the words of the people interviewed. Before embarking on the interviews I had thought that the discussion would probably centre around practical problems, or physical needs of PLWA/HIV. Although these were seen as important, the stigma attached to HIV and AIDS emerged as an overarching problem affecting where people could live, access to services, the quality of services, and support from family and friends. Thus the need for and obstacles to education in communities and for service providers is included in this discussion.

5.2 EDUCATION, AWARENESS AND STIGMA

The stigma, myths and blame attached to HIV and AIDS have been described by many authors. Stigma and blame affect people who have been infected in many ways, for instance, their self-esteem, their willingness to access services, the attitudes of service providers, and increasing the need for confidentiality, as well as affecting the ability of their family and friends to provide support (Smith and Mitchell, 1990:1; Radford *et al.*, 1991:35-36; Willms *et al.*, 1991:11).

² Some are outlined by Radford *et al.*, (1991), Willms *et al.*, (1991) and were raised by participants.

The effect on individuals is important. Stress affects peoples health and people dealing with serious illnesses need the support of their partners, family and friends. People need to be able to go home. They need to feel accepted when they seek services.

5.2.1 Community respect

The healer I see said I have to learn to accept myself, but how can I do that when my community doesn't accept me (Anon.).

The lack of community acceptance places strains on individuals and their families. It may make people scared to say that they have the virus. I will start by giving the story of a young man who has tested positive (his name has been changed).

John was living away from his reserve and adoptive and birth families. When he tested positive for the virus, he did not feel able to tell anyone but his partner for over a year. When he was hospitalised with severe pneumonia he decided that he should tell his families.

They came to where he was in hospital. The same day someone on his reserve had heard that he was in hospital and knew that he was gay. This person got on the reserve radio and announced that John was in hospital with AIDS.

His adoptive family have been accepting and supportive. However, since then the Band Council have been directly deducting the costs of his parents travel to his hospital bedside from their wages. These costs would normally be met by the Band Council. The Council will not fund any education programs that his mother (as the CHR) has tried to initiate.

The home of his adoptive family is regularly spray painted with slogans like "AIDS Lovers" . Their car windows have been smashed in. When he visited his family a brick was thrown through the front window with a note attached "...that said things I can't tell you because I don't even want to think about them."

John said that when he visits the store on the reserve it's normally wall to wall people, "But when I walk in I always have four

feet of space around me. If I'm walking down an aisle and someone is coming the other way, they'll always change direction."

John continues to live off the reserve, but his family are still living there.

Similar stories were recounted by other people. As a service provider said,

When you have glaring examples like these, I don't blame people for not being open. You have to weigh up where your losses are going to be (Anon.).

Despite distressing stories of rejection there are many other people who have been accepted into their own and other communities. John talked of visiting a reserve as an educator and when he left,

I thought lots of people must be getting on the plane out, or somebody really important must be leaving because everybody was there. But they were there to see me off...I still get letters from them and only yesterday I had a message on the answering machine from some of the kids to say they were thinking of me.

Many people said that PLWA/HIV often wanted to return home. Some of the questionnaire responses to the query "Have you moved since testing positive - if yes, why?" included,

I needed to move closer to my family and support and away from influences that would hinder my health (Anon.).

Not initially. I stayed away from my reserve for four years before moving home (Anon.).

I moved closer to home, or closer to home from where I have been tested at (Vancouver)(Anon.).

Answering the question "Would you rather live somewhere else - if yes, where and why?" one respondent said, "On my home reserve - to be with my people" (Anon.).

Awareness and education programs can help communities to accept people

without blame, fear or stigma. They may help families, friends and partners be supportive. Four of the questionnaire respondents said they felt that they needed more emotional support. Only three felt that they were getting the support they needed from their families, and five said that they were not getting enough support as opposed to needing more. Friends appeared to be more able to provide support, however six of the respondents said that they needed more support from friends, or were not getting enough support. People affected by HIV may need support themselves. One respondent to the questionnaire expressed it this way,

Family support. I think my family need some kind of support, and they need it to be able to help me by supporting me (Anon.).

If you are a Native brother or sister or father or mother of somebody with AIDS who do you go to? If you are a gay man in Toronto there is a support group no matter who you are, but there is not a comparable situation here (Nils Claussen, AIDS Regina, 29/5/92).

Organisations do try to help partners families and friends,³

With the families coming through. We try to assist as much as possible and hopefully down the road we'll be able to address these needs. That's one of our goals to ensure that the families who do usually end up as care givers do not have to deal alone with the stress of someone whose dying..." (Healing Our Spirit, 10/6/92)

Public stigma also affects peoples' access to services (Radford *et al.*, 1991:42).

It may mean that people do not use services for fear other people will find out that they are infected,⁴

It takes a lot of courage to come through the doors...People are

³ Healing Our Spirit has a "closed circle group" for PLWA/HIV and their families and friends.

⁴ Donna Reed of AIDS Saskatoon gave this as a reason for choosing their location in an office block where nobody would know if a person was visiting the office (2/6/92).

scared to come here because they feel that they will either be identified as having HIV infection or as being gay. So that can be a problem. We are starting to see more infected IV drug users, so it's changing (Anne Katz, The Village Clinic, 26/5/92).

Nils Claussen of AIDS Regina said,

And I think because the numbers are relatively low, people living with HIV and AIDS are not likely to go to an agency and say I have a problem because that will identify them as having HIV or AIDS. I think that in small communities that's a problem....

We get very few people in Regina who are public about it. Certainly there are people who are HIV positive and would not come to our office because they think that will identify them...(29/5/92).

5.2.2 Services and stigma

AIDS is not only associated with death,⁵ but with homosexuality, drug use, promiscuity and a whole host of things which are viewed negatively by the society we live in. People may be scared to approach service providers because they are scared of the reception they might (and sometimes do) receive. A service provider related the story of a client,

There is a real fear of being discriminated against with the HIV on top of everything else. I am thinking of a woman that I see who was an IDU and who has been clean and sober for 18 months. Every day is a battle. She has such low self-esteem...she feels that everyone knows about her. She's scared to go places because she feels people will know [that she has HIV]. It's very traumatic for her because if she has to go to see the specialist she thinks that they will treat her badly because she must be a whole list of other things (Anon.).

Her fears may not be unfounded. People from Regina are attending clinics in Saskatoon because not only is there a specialised clinic, because they are

⁵ "Stigmatising. AIDS is still a death sentence in most peoples minds. But it's no longer considered a death sentence, but a chronic disease" (Alan LaRoque Kennard, 9/6/92).

uncomfortable with the treatment they receive in Regina (Donna Reed, AIDS Saskatoon, 2/6/92). Nils Claussen commented,

Lack of awareness and understanding, may affect the way service providers or the organisations they work in respond to people living with HIV and AIDS. This may be because of fears of infection, homophobia, or feeling that people are to blame for the situation they are in. Someone with HIV would not necessarily want to tell the intake worker that they are HIV positive, and if you don't disclose it then you can't get any of the special allowances for people with disabilities.

Of course there is the general problem that if you disclose HIV to an intake worker it depends on the personality of the intake worker as to the treatment you will receive....I have come across some homophobic bigots... (29/5/92).

Most of the organisations interviewed are providing education participating in education programs for CHRs, NNADAP workers and other community workers on reserve.⁶ Many of these workers have themselves been instrumental in setting up education programs on reserves.⁷ Other Native organisations in urban areas are also participating in education programs (Tasaka, 1987; MAATF, 25/5/92; Anne Katz, 26/5/92; Margaret Akan, 29/5/92; Healing Our Spirit, 10/6/92; Susan Beaver, 7/7/92; Janice Trudeau, 8/7/92). However, a need for more education for people who may be providing services to infected people was identified.⁸ Janice Trudeau at Anishnawabe Health in Toronto voiced this when she said,

⁶ Jerome Yellowdirt a Community Health Liaison Worker at the Alberta Indian Health Care Commission in Edmonton commented on the problems faced by CHRs who face many demands on their energy and time, "They're there to assist the nurse, the elderly, they're there to assist people in looking after themselves. I feel sorry for these CHRs because they don't even get paid enough to do the work they do. Often they are putting in overtime and not getting paid for it. A lot of them are doing it from the goodness of their hearts" (12/6/92).

⁷ Most education programs on reserve are being initiated and organised by or through CHRs and NNADAP workers (Lowes, 1992; Procyck, 1992; Valverde, 1992; Wortman, 1992).

⁸ Radford *et al.* also identified a need for education for service providers (1991:42-43).

I think there is a need for the community to respond rather than to react....Some of our social support organisations find out that they have, or will be getting somebody who is HIV positive, so right away it is a reaction not a response. We get a panic call, "We need AIDS 101 for our staff, the community this, the community that, what can we do?"

Where when they are a-symptomatic there is nothing, but there is still this aversion, this fear of AIDS and HIV. And they need education, and they still do, and there's a lot of homophobia, and I think this is something, more education for them.

To coordinate, do education, get something in place with their staff, with their policies for whatever organisation they have. To have them in place, so "Oh, this persons HIV positive, so there's no - they can have the same utensils." Not separate, which has happened in some places, and different things.

We've had calls from Native social support organisations who've had a panic reaction because now they're dealing with HIV positive people, clients.... I'm sure they had them before, but now they know. But there should have been this net in place. This is what we're working to through education, so they respond rather than react to a client who is HIV positive (8/7/92).

Feather of Hope in Saskatchewan commented,

First of all we have to have educators to educate the educators on the reserve who'll look after those children. Like the education staff on most reserves are not even aware of what takes place.. (2/6/92).

Susan Beaver talked about calls she gets from Native Outreach Workers,

They generally want a lot of support around issues like sexuality, and being two spirited, or being gay and lesbian....There's lots of people who are really hung up on issues of sexuality who are in AIDS work. People in our organisations who can't deal with their sexuality. And when you start talking about condoms and penises, and anal penetrative sex and all of that stuff....And they've never heard the word lesbian. It's really difficult.

I'm not saying we've got a handle on everything. But I think we're a bit more in touch with a lot of Native communities than some other organisations are. And I'm not saying it's necessarily the fault of the people who are there. But the system was set up in a very specific way. The systems and even the AIDS systems that have been set up to support Native people aren't allowing them access to develop (7/7/92).

The need for organisations to be proactive, to respond rather than react was argued by

all the organisations interviewed.

5.2.3 Confidentiality

Until attitudes of people to HIV and AIDS change confidentiality is essential. It can be particularly difficult to maintain confidentiality in small communities although as Janice Trudeau working in Toronto observed,

And you have to respect that, that this [confidentiality] is an issue. And it's not just with HIV too, it's like "Did you hear so and so is pregnant?" or something like that. It's something that needs to be addressed at the reserve level.

But even here we deal with the Native community and we're really stringent in the confidentiality. Down here even though we are a large Native community, it's still small enough that you know families.... (8/7/92).

Fear of a lack of confidentiality may prevent people from finding services or from being tested.⁹ Albert McLeod of the Manitoba Aboriginal AIDS Task Force (MAATF) talked about the dilemmas of some people living in reserve communities,

There are hospitals in the North which can test, and nurses and CHRs are being trained to do testing and pre and post test counselling. But a lot of people don't want to be tested in their own communities because they are worried people will find out. People are usually flown to Winnipeg for testing which can be difficult for them (25/5/92).

Healing our Spirit in Vancouver said,

We know confidentiality is important. When we go to these communities we say, "You know you have to make up your own mind, you can get tested here, you can go to the city, you can go to another community." Some people may be more comfortable in their own community because they have the support there (10/6/92).

⁹ Men's Survey '90 reported that "For a substantial proportion of this study population concern about the confidentiality and anonymity of HIV testing and perceived effectiveness of treatment remain important issues" (Myers *et al.*, 1991:42).

The problems in small communities may be particularly severe, Margaret Akan from AIDS Regina and Feather of Hope - Saskatoon observed,

I think that if someone wants to go back to the reserves, maybe the confidentiality isn't very good. For instance if you're sister-in-law is the Community nurse....You know it's just the little things that happen in little communities that could make things very hard (29/5/92).

Perhaps the solution to this problem is education, without stigma the concerns over confidentiality may be minimised.

5.2.4 Obstacles to education and awareness

The most common obstacles to adequate provision of education (and at times, services) expressed were, lack of funding, homophobia, a reluctance to discuss sexuality openly, and a need for leadership from Band Councils and elders. Religion was recognised as being important to peoples spirituality, but at times a barrier to discussing issues around sexuality and safer sex.

Homophobia presents particular problems for gay and lesbian or Two Spirited people. Attitudes that see AIDS as a "gay white mens disease" hampers prevention efforts and leads to assumptions that all people with HIV and/or AIDS are gay. Susan Beaver commented that,

We don't have a lot of options because our community [two spirited people], our issues around safety and where we feel comfortable are very, very specific ones. Because we walk into a Native centre, which for a lot of people is a very strong part of their identity, and you have probably already been rejected from one Native community in your lifetime. So to walk into a Native organisation to do it all over again is asking a bit much of a person...(7/7/92).

Healing Our Spirit felt that at least in the education process homophobia need not

present a problem.

See the workshops it's not directed to homophobia - its lack of education because people don't know. We think it may be in the way a person carries themselves, how they present themselves to a community and there is then a difference in how the community responds to them. What we try not to do is say that they are this or that. What we try to say is we give direction on how to go about reducing risk.

We had to look at that issue when we started and how we were going to deal with it (10/6/92).

However, other organisations including MAATF, Feather of Hope, Vancouver PWA felt homophobia presented a barrier to education, acceptance and service provision. MAATF said that people do not like homosexuality to be discussed because they don't want to acknowledge it exists in their communities, putting people at risk and preventing people from receiving education (25/5/92). An educator related the story of an educational initiative,

We have a video, Harnessed by the Moon, which deals with gay and lesbian First Nations. We showed it at a workshop of a Tribal Council organised to teach about pre and post test counselling because its something that CHRs and NNADAP workers will eventually have to do. So we showed the video. One lady got up and said "that does not happen in my community, there are no gays and lesbians and that's not how my tribe was long ago." I talked about the historical respect for two spirited peoples who used who hold a special place in our society because of the knowledge they held from having two spirits. The woman was quite upset with it.

Recognition needs to be made of the role played by gay and lesbian people as initiators and educators in the education and awareness process. Most people voiced that people are uncomfortable talking about sexuality and sexual issues, yet they are an

essential part of AIDS education, however that does not mean people cannot learn,¹⁰

Native and white people don't want to talk about sexual issues. For Aboriginal people it's even worse because drug and alcohol abuse are involved. (Alan LaRoque Kennard, Vancouver PWA, 9/6/92)

Sexuality is one of the biggest barriers that we face both in our individual lives and as part of the larger community. And as an organisation and particularly as an organisation doing AIDS work. There are such barriers to talking about sexuality and the church has such a stranglehold on a lot of peoples views that it makes it that much more difficult to deal with. It affects the kind of information that they are getting, and getting the information there in the first place.

So that's one of the things that we also try to do to show people that we are really comfortable with our sexuality, and we are really comfortable with our sexuality. We don't mind talking about masturbation, and we can say words like that, and it doesn't bother us. But a lot of people and a lot of AIDS educators aren't comfortable necessarily that comfortable with their sexuality. I think that's why actually there are a lot of two spirited people who are doing this. It's because our sexuality is a big part of our lives and its something we've had to deal with. And in a very honest way. So we are able to talk about these issues and we are able to do condom demonstrations and make them non-threatening and fun and all of these different things (Susan Beaver, 7/7/92).

It was said that older members of communities (and others) are often reluctant to have sex discussed in explicit terms, in street language which may be graphic but is used by youth.

There are two sorts of leadership in Aboriginal communities, the political leadership and elders (roles which may overlap). Political leadership, particularly on reserves may have a lot of power in determining the allocation of resources and the

¹⁰ "Eighteen months ago not only were there no Crees doing AIDS education in the communities, most of those now doing AIDS education were too embarrassed to say the word spichinaakin (condom) out loud. Now these same people are giving presentations for students and parents, condom demonstrations and radio listeners" (Valverde, 1992).

content of education programs.¹¹ They can also set an example.

I guess it just depends who the person is on the reserve, how the people working on the reserve, the band councils or whatever, how they react to the whole situation. They have a lot of power to make changes. If say reserves are very negative to a person who wants to come back who has HIV or AIDS - if the Chief and Council and the workers at the Band Office plan on doing an AIDS education workshop on the reserve to educate them on exactly what this person is going through, basic information on AIDS, then I'm sure they'd be more accepted into the community.

I think in reserves it depends on who is in power there with the Chief and the Council and the Band staff. If they have that power to do the education and to make the community understand someone who wants to come home and live then it'll be OK (Margaret Akan, 29/5/92).

There is a lot of conflict on some reserves over who gets what in terms of resources. The Band Council has a lot of sway, and if they don't want to help someone they can block it (Albert McLeod, 25/5/92).

Talking about the role of a wider leadership Susan Beaver said,

Political leadership is definitely an issue in our lives as Native people. And I say Native people, because that's the community in which I live and function. It's a problem in everybody else's communities as well....

And our leadership...I have very little patience for. Everyone's wrapped up in the Constitutional issues now and they are very important, they are talking about the future of our people and self-government and all of those things, but there are other issues...meanwhile people are dying.

And I feel very strongly that people do look up to our leaders...We do look up to our leadership, and our leadership quite frankly hasn't been setting the kind of examples that they could....

And one of the statements that we've made is that we are asking the leadership to present themselves as a role model in their universal acceptance of all Native people, with all of our issues and all of our complexity and not try to come up with simple solutions for a complex people, for a complex issue (Susan Beaver, 7/7/92).

¹¹ One interviewee pointed out that one of the leading members of his Band Council is the same person who beat him up several years ago for being gay. As he said it makes it difficult for him to approach the council for assistance and support.

Some felt that although issues like sexuality, homophobia and religion played a role in denial, the social pressures of communities makes the political leadership reluctant to see yet another stigmatised problem.

Again I don't know why, but we don't like to look at AIDS. We can't even begin to look at AIDS now. We are talking about a population who is undergoing so much social disadvantage, who are looking at so many social issues on the reserve level. We are looking at housing problems, a population who lacks a lot of housing on the reserve level. We look at a people who are very sick and trying to govern themselves. We look at our leadership who are quite often a sick leadership. By sick I mean still practising alcohol abuse. Who have issues themselves, who can't even begin to look at AIDS as another social issue coming into our populations. So we're ignorant that way. Not necessarily intentionally. It's just because it's another social issue and something that is stigmatised as being something that is homosexual or a gay man's disease. How could we possibly want to concern ourselves with it?

So we have a leadership who are not very proactive in supporting or taking the initiative to begin any type of AIDS services on their reserves (George Poitras, 12/6/92).

I think that they won't address the need because maybe they don't want to look at their behaviours...And also they would rather wait until it starts happening in their communities and look at it then (Healing Our Spirit, 10/6/92).

Jerome Yellowdirt talked of a leadership that took the time to learn,

In my area we had Chiefs that said, "We don't want anybody in our community that's going to have a relationship with,...that's going to have contact with HIV and AIDS. We'll accept people that are clean." Which I respect, but they don't know what the people are going through that have that contact. They don't know that experience of that relationship. In community they got people to come out and speak. The chief and council were there asking questions. They understood that you're not going to catch it by shaking hands or hugging a person, or standing close. They didn't understand that before. They are quite aware of it now and my hat's off to them because they took the time to learn (Jerome Yellowdirt, Alberta Indian Health Care Commission, 12/6/92).

The elders also have a strong role in communities, and many have been important to

promoting AIDS education and healing in communities,

The elder population is a good advocate for AIDS education. My concern with the elder population, and I give that population a lot of credit for being able to advocate on our behalf....

But there is a concern that I have had with our elder population and that is the fact that a lot of our elders are very devout religious people. Not only the Catholic religion, but other religions that have been brought back by the churches. So they are very devout thinkers that way. A lot of them are Native spiritual believers, believers in the spirituality of Native people. But a lot of it is incorporated both with the church and with Native spirituality.

So our elders have been very largely affected by the church and the churches beliefs and the church has a lot of influence on the way they believe. Which is very unfortunate. Because when the church came to our population they began to teach them the church rules. This is what God says.. this is what God thinks you should not do. And one of the biggest concerns of that today in our area of work is the fact that because they've been taught that homosexuality is bad. That homosexuality is something that god will punish you for if you live that lifestyle.

... The populations prior to them and prior to white men coming to our population believed in,...or there was a place for the homosexual man or the homosexual woman in our society. Which was a very, very respected and honoured position for homosexual men or women.

So our advocates - the elder population today says "yes we have to learn avoid AIDS, we have to learn how to stop it. We have to teach it to the young people alike." But when it comes to dealing with homosexuality which goes hand in hand with AIDS education, because everyone thinks it is a gay mans disease, and it'll be brought up time and time again in our educational initiatives (George Poitras, 12/6/92).

Symposiums to discuss issues around AIDS have been organised by elders. Despite their contributions there was still a feeling that some elders need to know more. The problem of young people sharing knowledge about AIDS with elders whom they respect was raised,

One thing that we would like to see through the Feather of Hope [Saskatchewan] is that a provincial conference be organised that is specially geared to our elders and to our spiritual healers, our medicine men, to be involved with the conference, and to talk only about AIDS.

These are the people we have a lot of respect for in the Native communities, these are the ones that we listen to a lot. So if we can get them going on the issues of AIDS then there will be a lot going for it.

It's a touchy subject to deal with, especially with older people, especially as sex is something you're not supposed to talk about. As a younger person it's difficult (Margaret Akan, 29/5/92).

I've been in situations where I've had to deal with the elder population. Not necessarily educating them about the Two Spirited People and how they're related to our society prior to settlers and the influence of church and so on. But I've had to deal with elders who've thought that AIDS is a punishment from god for the homosexual population. Because they don't know about the two spirited peoples. They don't know how they lived in our society prior to the church because they've been influenced by the church.

In this certain scenario where I had to do some quick talking and I had to be respectful at the same time. It was very difficult for me to sit there and to say "did you know?" when they are supposed to be the teachers and I'm supposed to be the person whose learning...It was a very difficult situation because we were taught to respect our elders. So that's another barrier that we have to cross (George Poitras, 12/6/92).

Having presented this backdrop I now examine the more physical needs voiced by interviewees and questionnaire respondents before examining the issue of access to services and identifying the specific problems of rural and urban communities and funding.

5.3 INCOME

PLWA/HIV need good nutrition, warmth, accessible appropriate housing, and to minimise their exposure to opportunistic infections. They may also need medical treatment and/or complementary therapies. Assistance may be needed for help with transport costs and telephone services if their health deteriorates. To meet these needs

they need sufficient income.

The majority of PLWA/HIV are on welfare or disability. Levels of these vary provincially, but no where appeared sufficient to meet the needs of recipients. All of the questionnaire respondents relied on welfare or disability payments as their source of income. Only one respondent to the questionnaire had an income of over \$1000 per month, and one had an income of less than \$500 per month. Nine of the respondents reported that lack of money is a constant worry, the tenth was the person whose income is over \$1000, who said that money is sometimes a worry.

Warmth is important to maintaining health and resisting disease, yet six people had problems paying hydro bills, and eight people said they did not have enough money to buy winter clothes. Two had problems meeting rent payments. Five respondents reported that they could not access services they needed, as they wanted to because they could not afford travel costs or the service itself. One response to the question "What other services and support do you need?" was,

Extra money for foods, special bills etc. \$575 per month does squat (Anon.).

Many of the organisations interviewed also commented on the problems associated with low income. Donna Reed of AIDS Saskatoon in response to my question asking what she thought was needed most said,

There is so much needed in the way of services. Starting with the levels of assistance from social services. That's absolutely the first priority, because 90% of the HIV population is on social assistance. Certainly in Saskatchewan. So that's the first thing, those levels have to go up....I think the basic need is for more money from social services, because they just can't make it on what they have (2/6/92).

While Janice Trudeau at Anishnawbe Health observed,

It depends on where they live, even people living in Toronto, they have a hard time with finances. Even if they get FBA, FBA is not very much money. And there's a real void for people who are HIV positive that applies to economics, housing and access to medical services, because there's only so much that uninsured medical benefits will cover. And then it's a real long red tape processes (8/7/92).

Alan LaRoque Kennard said,

It's called Gains here, which is \$550 per month. There's also disability which is only a couple of hundred more. It's horrible - it's half the poverty level...The quality of life is one thing we're trying to get over to people. That you must allow people to have a decent income to create the quality of life. You take people, even if they were making a decent living you impoverish them, you subject them to all kinds of junk questions, a second grade way of living, homelessness, levels of care are not there. It's horrible (9/6/92).

The issue of poverty is exacerbated for many PLWA/HIV because many are in the 20-45 year age group, and therefore have not had sufficient time to build savings.

If you are poor and have HIV, then you have all the problems that you would have if you weren't HIV positive, plus the medical condition (Nils Claussen, 29/5/92).

I don't know, if you're sick, you're suddenly poorer... (Anne Katz, 26/5/92).

I mean some people go from working...This hits people, mainly people in their twenties and thirties who haven't built a career, who haven't built a pension plan or anything. And all of a sudden here's this HIV process in front of you, and sometimes it takes 3-4 years to deal through this process (Alan LaRoque Kennard, 9/6/92).

The majority of PLWA/HIV, whether Native or non-Native live on welfare or disability allowances. However the situation of Native people is likely to be worse as they are more likely to be poor before they get infected (see Chapter 3).

Again its not so much as people are HIV positive, although

that's a factor definitely, and its not so much that they are gay, although that's also a factor, its where we come from as Native people. And how we are as Native gay and lesbian people. And that has to do a lot with the places where we come from, self-esteem, education levels, all of these things....

So we have some members who have probably never held a steady job, haven't - don't have a lot of years in the european education system, those people have been accessing welfare long before they tested positive. And so they are making like \$450.00 per month....And its ridiculous (Susan Beaver, 7/7/92).

5.4 NUTRITION AND MEDICAL TREATMENT

Nutrition is important to maintaining health. Of the people who responded to the questionnaire only three reported having sufficient income to buy the food they needed. One respondent reported that they used food banks.

Nutrition is a very big area. We're starting to look more closely at it because we're seeing members - like now we have one member in particular, who doesn't drink alcohol. He eats very well. He doesn't eat any junk food. He takes very good care of himself just in terms of nutrition...he is the healthiest member of our community

There's other people who are taking their AZT or whatever, and they're not eating properly, you can just see them physically in the last 3 months or year or what ever, that they are weakening much faster than he is. So that's something we are getting into. Nutrition is a big issue within our communities, and that all goes back to self-esteem and all those issues (Susan Beaver, 7/7/92).

Medications are not always covered by drug payment schemes if they are not approved by Provincial or the Federal Governments. Some people wish to use complementary therapies (e.g., homeopathy, massage, etc.) which may not be covered by medical treatment plans. Native people are more likely to have diabetes and other illnesses, thereby adding stress to their health status and adding to their medical costs.

If people do not have Status, the problem is exacerbated, (six out of the ten questionnaire respondents were not "Registered"). Janice Trudeau commented,

They are not eligible. Oh yes sure it is a problem. Like FBA will only carry so much again for medicine, and it depends on their individual conditions, and because it is a syndrome it is combination of several things, not just diabetes, not just arthritis. It's all of them. Whatever, Kaposi's, rashes....(8/7/92).

Some alternative therapies are paid for, but basically anything that isn't prescription drug approved by the government isn't available...We have a program here which covers up to \$75.00 per month for every member for additional things, like massage, or vitamins and so on (Alan LaRoque Kennard, 9/6/92).

Many organisations with funding for service provision can make nutritional supplements available for people who have run out of money or who are ineligible for nutritional supplement financial assistance. They may also provide groceries or grocery money for people in emergencies. Some help with payments for medications not covered by drug plans and complementary therapies. Some organisations provide clothes. Native organisations who are not receiving funds for services and support are unable to provide direct help.

People are coming to us with problems accessing social services. We have a health care fund to cover expenses which aren't covered by health care programs. We get requests for help with nutritional supplements, complementary therapies, that sort of thing (Nils Claussen, 29/5/92).

Sometimes people run out of grocery money at the end of the month. We help with that. Generally people know to access that. We keep a stock of canned goods and Boost so if anyone comes through and they are hungry we can help. We have clothes. People will arrive in winter with only the clothes on their back. Basically people are OK, but there is nobody who is comfortable. People can't dress warmly - it happens all the time that they come in without adequate clothes.

We [also] have an emergency fund - which comes from

charitable donations and fundraisers. People can apply to the emergency assistance fund. But basically they have to have a damn good reason (Anne Katz, 26/7/92).

To people who are struggling with illness and dealing with a stigmatised disease it is not only demeaning to have to seek this kind of assistance, but significant that people do not have sufficient income to buy it for themselves.

5.5 HOUSING

Adequate housing is likely to be a significant problem for Native people given their overall poor housing conditions in both urban and rural communities (see Chapter 3). Willms et al. identify four significant housing concerns for PLWA/HIV. They note that,

Persons with HIV who have little or no income must cope with their medical problem and with Canada's incomplete housing system. If they do not already have a secure place in the housing system before their HIV infection develops into AIDS, they will certainly face a severe problem finding appropriate housing -- housing which is adequate, accessible, affordable and available (Willms et al., 1991:16).

Adequate housing for people with HIV should "be warm, dry, mould free, easy to keep hygienically clean and offer a safe quiet and secure environment," to help maintain health and to minimise the possibilities of infection in people who are immunosuppressed (Willms et al., 1991:18). It should be accessible to support (whether from family and friends or supportive organisations), and services. People with AIDS suffer from fatigue, so homes need to be physically accessible, and of course people need to be able to afford this housing.

Appropriate, affordable, safe housing was identified as a significant need, particularly in large urban centres where rents are high and accommodation scarce. In replying to the question in the questionnaire, "What services do you feel you need most but don't get? Three respondents said that they needed affordable housing. Three were sharing a room with somebody who was not a partner, and one person lived in a rooming house.¹²

The housing situation is complicated because the housing needs of individuals change during the course of infection. If a person starts to develop infections, they need a home where they can receive home care services. Some people may require palliative care if they cannot get help in the home. As one respondent to the questionnaire with housing problems said, "We need affordable housing for independent living with leeway for sickness."

In some cities affordable housing is not available. The problem appeared less severe in Prairie cities.¹³ But in Vancouver,

Housing is a real problem here. This is one of the most expensive cities in Canada. Toronto and Vancouver have a lot of the same problems... One of the main things I'm trying to emphasise to people is that you must allow people to have their own home. To have that level of comfort. That it has a great deal to do with healing (Alan LaRoque Kennard, 9/6/92).

and Toronto,

They need housing, especially if you are HIV positive, getting

¹² Two others were receiving housing subsidies.

¹³ In Winnipeg an organisation called AIDS Shelter Coalition facilitates people getting housing through the Manitoba Regional Housing Authority. People are fast tracked through the allocation system. People can be placed in a week. This appeared to be a unique program.

sick, or even if you're a-symptomatic. If you're gay and Native, housing that's both safe and affordable is a big issue in Toronto. Housing that's affordable and user friendly for people that are HIV positive is a whole other issue....

Affordable housing in Toronto is a contradiction in terms. There is no such thing. There are like housing and provincial housing,... but there are all sorts of social issues that go along with that. It's hard to say, it could be months, on average months, especially if it's something like Ontario housing. (Susan Beaver, 7/7/92).

Susan Beaver also commented on the isolation of some people in big cities like Toronto,

I think probably the biggest problem in terms of housing that's comfortable for them once they start getting sick, is that they tend to be isolated from each other...I find Toronto in itself isolating. Native people are scattered all over the city. We don't have a neighbourhood. We don't have whatever. I think that's probably one of the biggest issues for our people in terms of their housing" (7/7/92).

The income levels of PLWA/HIV mean that unless subsidised housing can be found, only housing at the low end of the market will be affordable. This is most likely to be in poor condition. People may have to rely on friends or relatives,

Affordable housing. I know a lot of people, in a group of friends, one person will have a job and an apartment or whatever, and a lot of people end up staying with them. That's our idea of affordable housing. Someone else has a job, so they help to support you. (Susan Beaver, 7/7/92).

One person said,

It depends on how sick they are in some cases. A lot of times what's happening is that people are living with each other. So if somebody has a stable household there may be 2 or 3 people. Like my lover and I we have stable housing, we have somebody staying with us, and I don't know the last time he had his own address. He's also HIV positive. He's also a very good friend of mine (Anon.).

As health needs deteriorate it may be necessary to have help in the home, or

have adaptations made to fit changing needs, or move to hospital.¹⁴ The stories below illustrate this,

It is an issue. I know one person who is living up the street in an apartment building whose going into the hospital because there's nothing in between his apartment and more supportive housing that he's comfortable with. So his only option really is to go to a hospital (Anon.).

One person who was living around here, and got sick, or was getting sick, his health was deteriorating... he got a dishwasher because he couldn't stand at the sink all day doing his dishes. So his landlord tried to get him thrown out because he said that was against something that he'd signed in his lease. So there's those kinds of issues...they're not available, they're not equipped to deal with people who are HIV positive, people who are getting sick.(Anon.)

Deteriorating health can cause other problems. In some cities group housing for people with HIV is available, however, often people cannot remain there when they become sick,¹⁵

I mean we've had people, I mean I'm thinking of one person in particular who was in a house for people who are HIV positive and he was too sick for them. They wanted him to leave, and he didn't really have anywhere else to go. Which was a struggle, because they wanted to throw him out. He at this point wasn't able to himself look for an apartment, move or even just deal with the whole mental stress and all that to move. So we had to argue very strongly to even let him stay there. (Anon.)

Home care may be available, but people need a home and family and friends to help support it (Willms *et al.*, 1991:26). They can be complex and difficult to arrange

¹⁴ "A problem arises when the lack of appropriate housing for individuals with HIV to go to...it means that hospitals are turned into housing"(Willms *et al.*, 1991:46).

¹⁵ Willms, *et al.*, note that non-specific group homes are rarely successful housing placements for PLWA/HIV, and that even designated group homes can be a hard adjustment for independent people and people dealing with other problems (1991:27).

and sustain (Anne Katz, 26/5/92). The alternatives to home care are hospitalisation and palliative care. Palliative care for PLWA/HIV is extremely limited. (Willms, et al., 1991:46).¹⁶ Hospices for PLWA/HIV exist in Montreal, Toronto and Vancouver, but places are limited.

Many people choose to stay at home - maybe because they don't have any choice. But some people can't be at home. Some people don't have family and friends to help (Anne Katz, 26/9/92).

Hospitals are not necessarily appropriate places for people to end their lives. Sometimes bureaucracy can make it difficult for people to access traditional healers and allow traditional ceremonies. Susan Beaver related some of their experiences,

We spend sometimes more energy dealing with their bureaucracy than dealing with the person who is sick or dying. And may want a healing circle, or may want smudge, or different things that don't fit into the structure of their institution, and don't fit into their bureaucracy. So if you burn sweetgrass it's against the anti-smoking by-laws. Which is a complete load of bullshit. It's true. It's happened on a couple of occasions (7/7/92).

The Two Spirited Peoples of the First Nations in conjunction with other Native groups in Toronto are starting a fundraising initiative to build a hospice in the city.

Many of these housing problems are common to all PLWA/HIV. However, the housing conditions of Native people living both on and off reserve are considerably worse than those of non-Native people in Canada. Thus Native people are likely to start out in a disadvantaged position when trying to protect their health.

¹⁶ "Palliative care is a problem in the province. In Winnipeg there are 2 beds out of 20 reserved for PWA" (Anne Katz, 25/5/92)

5.6 SERVICES AND SUPPORT

Persons with HIV require health care, social services and housing support - services which are not provided under any integrated ministry in any province.(Willms *et al.*, 1991:16).¹⁷

Income, housing, education, medical and support services are offered by a wide variety of service organisations.¹⁸ In urban centres they may be met by Native AIDS organisations; CAS affiliated AIDS organisations; PLWA/HIV groups; Native and non-Native health centres; hospitals; doctors; housing organisations; Native and non-Native social service agencies; government social service agencies; Native and non-Native substance abuse programs etc.¹⁹ On reserves, services and support and education may be provided by Band Councils and attached services; health centres; CHRs and NNADAP workers.

5.6.1 Accessing services

The lack of Native run services education programs for PLWA/HIV was

¹⁷ Sandy Cooke of Adolescent Youth Services commented that there are ten Ministries in the British Columbia which have some responsibility for young people. (10/7/92).

¹⁸ Lee (1991:158) notes, "Available care remains fragmented between different institutions, disciplines, and settings, confined within a rigid medical division of labour, and provided largely in isolation from community-based services and programs. Medical expertise and resources are also concentrated in relatively few facilities and practices, largely in the major cities".

¹⁹ In response to the question "What kind of organisations do you go to for support and services?" Responses included (in no particular order): Toronto PWA Foundation; Two Spirited People of the First Nations; AIDS Committee of Toronto; AIDS Saskatoon; PLWA Saskatoon; AIDS service organisations; government social services; PWA Office; AIDS Vancouver; Vancouver PWA Support; food banks; AIDS Committee of Toronto; my sisters; praying, I'm a Roman Catholic; AIDS Vancouver Island (support groups); personally, through friends and family; Anishnawbe Health; Manitoba Aboriginal AIDS Task Force; Health Science Centre support groups.

identified as a big problem for several reasons. These include that many Native people do not access white run services; non-Native services often do not meet the needs of Native people; many people when they become infected wish to connect with their culture; the need for communities to develop programs to suit their own particular needs; and the need for holistic education, service and support programs which can take the whole person into account.

Native people do not access services in the same way as non-Native people do, particularly when they are run by white people (Morse *et al.*, 1991; Thouez *et al.*, 1990; Medicine, 1988; Shah, 1988; Young, 1987; Roberts, 1987; Shah and Farkas, 1985; Farkas, 1984).²⁰ A number of organisations articulated this problem,

And just walking into an office and being surrounded by all of these white faces..it puts a person off right there. And also our history of Native people, particularly if you grew up on the reserve, is that all of your authority figures in your life are white. Your doctors, your dentists, and the police, and everybody, the teachers, they're all white. So they have this like, these are the authorities, and we don't want to walk into another organisation, and expect.... I mean we think, well of course we're going to be treated like inferiors they're all white. This organisations all white for a reason, it didn't happen by accident. And so why should we even go in. People aren't comfortable going through that door. It's difficult (Susan Beaver, 7/7/92).

They [Aboriginal people] won't say what's lacking. They'll go in to social security or wherever and get as much as they can, but because we are a shy people if they don't get what they need they go away. A lot of people have been trained not to ask. When they are asked if they need more they say "no, its OK" (Healing Our Spirit, 10/6/92).

And whether we like it or not there is an Indian/White barrier,

²⁰ Thouez *et al.* (1990:32), found "...a negative attitude was observed in both cases with regard to relationships with health care personnel; this was also the case in terms of individual perceptions and evaluation of the health care systems in general".

and that is there. A young Indian person probably has not the face to go to AIDS Saskatoon because there's no Indian person there that they can relate to. So all those things are combined, and it's causing us problems for the Native workers (Feather of Hope - Saskatchewan 2/6/92).

Native people are particularly hard to get at. There was a Native group here for over a year, but they wouldn't access it. They wouldn't walk through the door, because this is a white based organisation and it was white people setting up this program for Indians. White programs that people have set up for Indians have always screwed them up and so they learned not to come through the door.

In the last 6 months this has been a program set up with and by Aboriginal people and people are gradually getting to know its here (Alan LaRoque Kennard, 9/6/92).

Three of the respondents to the questionnaire said they did not feel comfortable using a specified service, in each case it was an non-Native run service. Organisations providing services by and for the community, for PLWA/HIV can provide a safer environment which people may feel more free to access.

The situation is compounded because CAS-affiliated community AIDS organisations are often perceived to be closely linked to the gay white male community, which can make some people reluctant to approach them, or feel that they can't help them. One interviewee said,

I need emotional support, badly. But I'm not gay and therefore not comfortable with existing support groups, I'm Native and not comfortable with non-Natives. I'm alone (Anon.).

Gay Native people may also feel uncomfortable accessing these organisations, Dr Wortman of MSB has commented,

AIDS Vancouver and PWA are great organisations, but they are mainstream organisations in terms of homosexual politics....They are generally organisations of white, middle class, well-educated gay men. Gay Aboriginal people - and there are just as many of them as there are in any other population - don't feel a part of that group. They are more

Aboriginal than they are gay (Hanna, 1990:C6).

Susan Beaver also articulated some of the problems with white AIDS organisations,

We call it the gay white male model. And it doesn't work in most cases, and in some cases it doesn't even work for gay white men. There's lots of issues, particularly around class and education levels and so on....As the face of AIDS changes, organisations are trying to keep up, and I'm being generous when I say that. I mean people are sort of making attempts to be more inclusive....They don't know what to do with these people, they don't know how to work with different communities. They only know how to work with different communities within their own organisations (7/7/92).

However other people like George Poitras articulated more positive experiences with AIDS community organisations,

I give credit to a lot of the Native people who are very proactive in this area of providing this AIDS awareness. I give a lot of credit to a lot of AIDS service organisations and people who are working with mainstream AIDS service organisations who see our population as being very vulnerable and who take it upon themselves to acquire the proper funds to fund a Native liaison person to reach that population.

I give credit to the Executive Director at the AIDS Network of Edmonton Society who saw it as a very important thing that needed to be dealt with. Who houses us for no money at all. Who gives us a lot of use of their computer, of their photocopier, and a lot of their resources. People who see the need to do something (George Poitras, 12/6/92).

5.6.2 Bureaucracy and hoops

Not only do people have to deal with issues around stigma, and trying to access services that they may not feel comfortable using, they are often trying to find their way through mazes of bureaucracy, red tape and the multiplicity of agencies which may be able to help them (Radford, *et al.*, 1991:42, Smith and Mitchell, 1990:6). This can be a particular problem for people who are becoming ill and/or lack

mobility. Accessing bureaucracy is also difficult for people who are not literate or used to the processes,

I think the major problem is that people with AIDS are people who very often have never been sick in the past and are people who have never had to access any social services or deal with the federal bureaucracy.

If you happen to be Native or semi-literate, then its all the more difficult to access that service (Nils Claussen, 29/5/92).

Many organisations see that they have an important role to play in helping people negotiate the system,

I think its really the socio-economic circumstances. Somebody who is not assertive and doesn't know how the system works is going to have a hard time. Depending on which social assistance office you go to then they make you jump through a lot of hoops. That's where I come in. I do a lot of [of advocacy]. I think they give applicants a hard time generally, but if another professional calls they tend to buckle down and do it (Anne Katz, 25/5/92).

Some people need assistance just dealing with the general bureaucracy that's been set up to deal with some of their issues. Whether its in the lesbian and gay community or the Native community its not so important. They might not necessarily be looking for tons of help. But what I can do if I hear their particular horror story, I can call up somebody and say "Look this is a member of our community who is HIV positive etc...and who has had a really bad experience with your organisation. What are you going to do about it? And how are we in future going to have a better relationship where I can feel comfortable in referring our members to you? And by the way we're members of the Native community too." So we can do those sorts of negotiating so that people don't have to fight the whole system that they're dealing with (Susan Beaver, 7/7/92).

5.7 HEALING THE WHOLE PERSON, AND IN THE WHOLE COMMUNITY

There was strong agreement that HIV and AIDS cannot be disassociated from other issues facing Aboriginal communities and individuals. The emphasis on the need

to deal with the whole of peoples lives and on healing in the whole community was seen to be part of the process of healing that is taking place in communities, and which fosters a holistic approach to health and which was seen as central to prevention and care initiatives.

People with HIV and AIDS often need to deal with more than their diagnosis. Many people may have to deal with alcohol and drug abuse and other issues in their lives. Chapter 4 outlined the extent of substance and other abuses in Native communities. George Poitras of Feather of Hope in Edmonton describes the situation of many Native people trying to deal with their diagnosis,

I think when we talk about what are some of the needs for Aboriginal PLWA/HIV and AIDS I think of a lot of the people that I've worked within the last, almost two years that I've been working in this area. I think of my conversations with them and what I feel that they need as Aboriginal people living with AIDS and HIV. I look at the lifestyle that they live and I look at the lifestyle that they used to live, and that a lot of them are still living although they've been diagnosed as being HIV positive.

There's lots of dysfunction as a result of growing up in alcoholic environments, as a result of growing up in abusive homes, as a result of growing up in foster homes because their parents weren't caring for them. As a result of growing up in residential schools where a lot of abuse has gone on with the residential owners who were primarily the church.

A lot of abuse as a result of a population that has been oppressed by the white population in general. That has been oppressed by the white governments who have basically made our people a very dependant people on the government system. I could go on about this but I won't....

When I look at these people who are living with HIV today, the dysfunction continues to a large extent for a lot of them, a lot of them die with the indignity, a lot of people... they need to [to be able to] die with dignity. By the need to die with dignity I mean recovering from a lot of dysfunction. People never looking at their sexual abuse issues and dying like that. People never looking at their alcohol and drug addictions which are always a result of something else. We recognise

that alcohol and other addictions are just symptoms of something else that has gone wrong in their lives. Never really looking at any issue that could have resulted in their childhood or upbringing in very dysfunctional environments.

So a lot of our Aboriginal people die with HIV in very sad situations.

I can't imagine what it would be like mentally for an Aboriginal person of my age [mid-twenties] or younger, who would not only have to hopefully look at all these issues in terms of recovering their life, to begin a new life, but an Aboriginal person of my age or younger who is HIV positive and who is still practising alcohol or any other kind of addiction. Who never even begins to look at any of these issues to start with, how they can deal with and accept their diagnosis of HIV?

So we're looking at a situation which is very complex and it's very, very frustrating when I have to work here 8 hours a day and think of 160,000 people who is in our jurisdiction to provide services to and I see my population being the most infected on a daily basis. And we have no resources to do anything about it (12/6/92).

Susan Beaver at Two Spirited Peoples voiced it this way,

People want support in all aspects of their lives because to be honest we're an unhealthy community. And when I say unhealthy I mean all of those things, physically, spiritually, mentally, emotionally, all of these different things. All of these different needs we've been living with all our lives as a people, as part of our culture, as part of a history, that's devastated our people. People need support in every aspect of their life.

I try to tell our funders that when you look at HIV you can't just look at the fact that someone has tested positive and going through that whole grief process, going through the physical dying process. All of us, you have to look at this person as a complete individual, and all the issues that go along with whoever that person may be (7/7/92).

The story of one person was related,

It brings up a lot of things. I know one person tested positive and he came to me and he went through the whole gamut of crying and being angry within a week, and then we started talking a bit more deeply and he still hadn't finished properly grieving for his mother who had passed away when he was 15 years old. So we looked at that particular situation and why he hadn't grieved for his mother and it had a lot to do with him being a survivor of sexual abuse....They all come together because they all affect his mental well being. And he's thinking

about all of these things because quite rightly he's going to die. Probably within the next 10 years. He also feels an immediacy, he has to deal with it now or he's not going to deal with it (Anon.).

So services and support programs are needed which can assist people by addressing interrelated issues affecting them not just HIV,

Anyone who is going through a healing process has to deal with numerous issues rather than just the one. I mean whatever issue brings them to look for healing, life is not so simple, there are a lot of areas that have to be looked at and dealt with (Janice Trudeau, 8/7/92).

The thing with some of them too, they have addiction problems. Which encompass also another form of healing that they have to go through and look at. And that's one issue that a lot of people like us we try to address, these addiction issues. We need programmes that make people look at the drug problem to deal with this... (Healing our Spirit, 10/6/92).

That's part of a whole that when we talk about AIDS, and when we talk about taking care of yourself, and when we talk about living a healthy life and when we talk about all those aspects that make a person a healthy person. Which includes their mental state, their spiritual, as well as their physical well being.

When we talk about AIDS - and this is something that's been really difficult to convey to other organisations, and its been difficult to convey to our funders is that when we look at HIV in our community, we can't just zero on in there. And I can't just sit here and do counselling around someones' [HIV] status. It doesn't work like that.

I always tell them that nobody's born a junkie, nobody's born an alcoholic, there's all these other things. Why are these people in the situations they're in? So we start dealing with all these things. So I do counselling around drug and alcohol abuse as well as their HIV status as well as incest abuse, ritual abuse, incest survivors all of these things. They start coming out. And that has more to do with the history of Canada than it has to do with Native people per se. And I always try to emphasise that... (Susan Beaver, 7/7/92).

Educators also voiced a need for education programs to include all aspects of communities' lives which influence peoples health and vulnerability to HIV,

When we talk about educational initiatives on reserves, we focus

of course primarily on HIV, but we also take into consideration all the issues. We can't as educators go into the reserve and expect to pound into these peoples brains HIV. We have to look at other issues and cofactors that influence people to contract the virus. We have to look at alcoholism and how it affects our populations. When we go into our reserves that's talking about the vast majority of the population.

In our educational initiatives we have to be able to remind people that HIV is contracted through high risk behaviour, through influencing cofactors like alcohol and drug addictions. That because teenage pregnancies in Aboriginal populations is about 3-4 times higher than in the mainstream population, we have to talk about teenage pregnancies. We have to talk about alcohol addiction, we have to talk about sexual abuse issues. We have to talk about everything (George Poitras, 12/6/92).

We have to look at other social issues, sexual abuse issues, and how we can't only look at HIV, we have to look at how all the other dysfunctional issues are part of our lives and how we're going to deal with it....(Healing Our Spirit, 10/6/92)

So you need to deal with all the problems facing a community, not just HIV. MAATF are developing a package which includes drugs outreach and offering social services, to included all aspects of people (MAATF, 25/5/92).

5.8 RECONNECTING

To help deal with their diagnosis, both people responding to the questionnaires and people taking part in the interviews said that reconnecting with their cultural identity was an important part of the healing process.²¹ Returning to traditional values and approaches to health were seen as the foundation of the healing that is taking

²¹ Morse *et. al.*, examined the differences between Cree healing practices and western health care, "Western culture usually views physical health, mental health, and spiritual health as different areas of life, each with its own set of beliefs, practices and practitioners. Because of this separation of the body, healing of the mind, and healing of the spirit Native people are frequently dissatisfied with the Western health care system" (1991:1365).

place in communities and which allows the whole of HIV and AIDS to be addressed in communities as well as individuals. One of the respondents to the questionnaire to the question "What other services and support do you think you need?" said, "First Nations cultural events and sweat lodge healing circle" (Anon.). Other questionnaire participants commented,

I feel that culturally appropriate services should be made more readily available to gay and lesbian Natives. It should also be a safe place for two spirits to access without fear of racism or homophobia (Anon.).

Being HIV positive has definitely changed my life...At first it was devastating. Then I learned to use it as a powerful tool. The more I turned back to my Native ways, the more I got in tune with myself...I would love to see more Native cultural practice in urban areas (Anon.).

While interviewees observed,

The people we've been dealing with so far who have been dying of AIDS, have been looking at recapturing their identity. In other words they're looking at an identity that they have pushed aside because of what education and everything that's happened to Natives has done. It's something to be ashamed of. And many of them, as they are dying, want their identity back.

So we try to address those needs as they come along with people who are dying. And it benefits people who are HIV. We try to get them into involvement with their traditions as much as possible,... (Healing Our Spirit, 10/6/92).

And so our population is dealing with our problem today. And dealing with alcohol addiction is a very big step for many people. And being able to recognise the other issues and to deal with them, by and large has brought our people to recognise who they are as people indigenous to this land. People who are very culturally and spiritually grounded - very good beliefs, very strong values. Coming back and dealing with our issues and being able to have these values, these spiritual beliefs as part of our lifestyles today is a very, very strong thing for our population. And if the Aboriginal PLWA/HIV could develop that same mode of recovery, then yes I believe that there is a good part of HIV, and that is what Ken speaks about when he refers to HIV as a gift... (George Poitras, 12/6/92).

Like I said nobody's born a born a junkie. So we try to deal with all of these issues as much as possible, and we deal with them in a way that is specific to our culture, and the knowledge that we as First Nations people were given. And approach health and life and death and all of those things from that perspective (Susan Beaver, 7/7/92).

For this to be possible organisations need to exist which can provide that. In the words of Healing our Spirit,

We try and incorporate as much traditional culture as possible, not only in our workshops, but in whatever we do. And non-Native organisations can't do that (Healing Our Spirit, 10/6/92).

5.9 REMOTE AND RURAL COMMUNITIES

The needs of people living in remote, rural and urban communities may be distinct. People in remote and rural communities, whether living on or off reserve may have problems with access to services,²²

We're finding that a lot of these people either rapidly go through the disease and die, or commit suicide. Because there's no help. They have no place to live. They can't go home. Nobody understands what's happening to them. Either then they are sick or its a plague as far as some people are concerned. That's some of the education we're talking about. But reality is that there is no place to go. There is no sort of self help group in the community that can offer any kind of assistance. Its tough...(Feather of Hope - Saskatchewan)

Some of the problems for people living on reserve or in rural communities included lack of knowledge about, and inaccessible testing facilities, a lack of pre and post test counselling, poor access to medical treatment, poor housing, and problems

²² Rounds discusses some of the challenges facing rural communities noting "Fear, intolerance and stigma are not unique to rural areas. However, given the lack of confidentiality and the homogenous nature of most rural communities these attitudes are much more pronounced and their effect much more strongly felt" (1988:362).

with confidentiality in small communities. Sometimes services just aren't available or accessible.

[The biggest problem] is Saskatoon and Regina, they have free counselling and testing, and there's post test counselling. Well we don't have any of that service here [North Battleford, Prince Albert area]. I feel it's the highest population of Indians has no service.

That's where Feather of Hope is at least trying to fill the vacancy, the vacuum of non-service in these areas. And there is still a non-service. Sure there's STD Clinics, but how do you get there? First of all coming out of a rural community, how do you know where to go? Do you have transport? The field nurse that we have can't even transport patients to start with. And they don't have the skills to pre counsel. And even if the testings done, there is still post counselling and the process [of dealing with infection] takes a long time (Feather of Hope - Saskatchewan, 2/6/92).

George Poitras in response to a question asking about differences in the needs

PLWA/HIV on and off reserve commented,

I think the treatment and care would be the difference. When I think about our Aboriginal people who are now living in the urban centres they have access to homes, they can live in the home.

People going to the reserve level will more than likely be living with their families. Usually in a situation where the homes are overcrowded. So when I think of the reserve level, even though there's no accommodation specifically for Aboriginal people living with HIV in urban areas, I think we also need it for the reserve level, an extended care type of facility. And the care and the treatment has to be available to them.

A lot of times we're finding today with the mainstream population. A lot of the medications aren't available to rural mainstream population people living with HIV. The urban centres like Edmonton and Calgary are fortunate to be centres that have treatment and equipment available for people living with HIV.

People in the rural areas have to come in for their medical attention. So we talk about our population on the reserves. There is not a lot of accessibility for medication to them. Or people qualified to administer medication or the medical treatments.

So we're looking at qualifying people who will be able to provide the medical attention to these people that are on the reserve. We are talking about accommodation that needs to be made available to them.

Care and accommodation are very big goals for Aboriginal people living with HIV. Care and accommodation which takes into consideration a lot of the issues that I've talked about (12/6/92).

Getting adequate medical treatment can be difficult. Except for people living in cities or off-reserve, health services to Registered Indians and Inuit people have been provided by the Medical Services Branch (MSB) of National Health and Welfare Canada. Control of health services is being transferred to communities. Health facilities provided by MSB include nursing stations, health stations, health centres and general hospitals. The AFN report that in 1987 a minimum of 57,000 First Nations people did not receive services from Community Health Representatives (CHR) of the MSB. The number of clients per CHR in 1987 was 568, compared to a federal standard of 500:1. In some areas the ratio was two to three times higher (AFN, 1988:24-25). An MSB (1991:18) report on First Nations and Inuit mental health found that there was "a lack of both financial and human resources" for mental health services in First Nations and Inuit communities, commenting,

Culturally and community appropriate mental health services for First Nations and Inuit are virtually non-existent.

Interviewees identified getting adequate, informed and effective medical treatment as a significant problem for people living in remote and rural communities,

The problem we're having right now with a woman. She's not on reserve, she's in a small community. The doctors don't know what they are doing, how to treat her. They've been giving her medications. She is just a walking pharmaceutical, she's got all kinds of medicines. Which is probably more harmful to her than anything else. But the doctors don't know that, and she doesn't know that because she hasn't had the education to understand that she doesn't need all this. It's hard to work with that because she's from a small community with no direct links, in terms of having someone there to assist her, and empower her to say

no to some of these drugs, to say I can do things (Anon.).

Coming into cities for medical treatments is costly and can be difficult for people without support in the city,

What happens to a person if they come to Winnipeg and they haven't been here before? It can be a big shock for people coming from the reserve for the first time. People go to the south because there are more resources, but that's only the physical part, there's the emotion part too, if friends and family are in the north, that's where their support is. There's a lot of people that use chemicals to substitute for emotional support and strength (Albert McLeod, 25/5/92).²³

People need temporary housing,

I have a couple of people who live on reserve and come in for their medical appointments and it costs a fortune. Either it costs the individual something to come 500 miles or it costs the taxpayer money. Then they come to the city - where do they stay when they come to the city. I would like to see some kind of a place where people can hang out. Some kind of clean safe accommodations for people with HIV and AIDS, so that they can at least get breakfast.

Many of them have friends or relatives. Some guys may come and go to the bar and pick up someone so that they have somewhere to stay (Anne Katz, 26/6/92).

People in the rural areas have to come in for their medical attention. We are talking about accommodation that needs to be available. We've got nothing now to be made available to them (Feather of Hope - Saskatoon, 2/6/92).

Educational initiatives may be dependent on the enthusiasm of the band leadership and finances of the community. Programs in some communities, like those of the James Bay Cree, and Swampy Cree and the Ontario First Nations, are showing

²³ Ken Ward (a person living with AIDS) when talking about being diagnosed said "I was really concerned about what was lacking for our own people, in the health services. A response team, specifically with HIV and AIDS. We...I had to meet with individuals who were non-natives. They were great. You know, I felt the support. But again I can imagine someone coming from further north and feeling very alone and afraid (CTV/CJOH, 1990, May 9, 1990 Canada A.M.)

the way forward, however other communities are only just starting to take their first steps towards educating their communities. Fly-in communities face particularly high costs.

...and no money absolutely. In my opinion if we had a budget to allow us to travel which would make it a proactive type of organisation, we could choose our population.

For instance in 1991 our organisation provided presentation workshops to 12 reserves in Alberta. That's from being able to go there on their request, on their invite and them picking up the cost from transport to meals to accommodation. And sometimes if possible they will make a donation to our society.

If we had funds where we could direct our focus - to the populations which are more remote and not so accessible to other AIDS service and prevention organisations. We could choose them and be able to go there and focus not on 12 but maybe 20 or 30 communities (George Poitras, 12/6/92).

Jerome Yellowdirt of the Alberta Indian Health Care Commission talking about funds available to reserves,

And we have a hard time sometimes dealing with that, for the fact that there's not enough money and development programs out there...community health development programs. There's not enough in the area of education, there's not enough in the area of prevention, so there's not a whole lot of money available for awareness programs...we just have a hard time obtaining funds. And personally I think more money needs to be pumped into communities. I think it needs to be pumped in more at the social level (12/6/92).

Although more services may be available in cities there is a distinct lack of "culturally appropriate" services available to Native people living in cities (Shah, 1988).²⁴ The federal government and Medical Services Branch do not provide

²⁴ Lee (1990:163) comments "...PLWA face serious institutional barriers within the medical delivery system. Primary care physicians who care for PLWAs, and hospitals and other facilities that provide treatment are generally terribly overstretched in the major centres and largely unavailable in other areas."

funding to Native programs off reserve,

That's been a big thing in our lives, is whose jurisdiction do you fall under? Everyone, it's like well if you go to the Province they say "What are you doing here, why don't you go to the Federal?" and once you go to the Federal, they say "Ah well, you're not on reserve, so you're Provincial." So a lot of people get caught in those kinds of cracks. Or it's very easy to get caught in those kinds of cracks. You can negotiate around it, but it generally takes time (Susan Beaver, 7/7/92).

Many people living in urban centres do not have Status and are therefore excluded from benefits available to other Aboriginal people.

5.10 FUNDING

The discussion above outlines the distinct needs of Aboriginal PLWA/HIV, the problems they have accessing services, and the inability of non-Native services to meet their needs - although they may be able to meet some. Out of the Aboriginal organisations interviewed, only Anishnawbe Health, Two Spirited Peoples of the First Nations and Vancouver PWA were receiving funds earmarked for providing services and support to Aboriginal PLWA/HIV.²⁵

The primary obstacle that participants expressed was the urgent need for more funding for those groups that do exist, to allow them to pursue effective education programs (particularly in reserve communities), and to allow them to provide services and support to Aboriginal people in their communities affected by the virus. Funding appears to be woefully small and inconsistent. In the words of these organisations

²⁵ Despite this groups without funding do what they can to support PLWA/HIV, their partners, families and friends, organising support groups.

themselves:

Feather of Hope - Alberta,

The thing that I see as being the biggest barrier to us as an Aboriginal organisation providing AIDS education is funding. We have very limited funding available to us. In the first year since the establishment of the FOH the society got \$30,000. The second year - the last fiscal year, the society got \$90,000. This fiscal year we probably won't be getting more than \$90,000.

In the first year we were able to find one person who would work for a very low salary to coordinate the projects. That means coordinating workshops and presentations to 54 Indian Reserves in Alberta with a budget that didn't allow for any of the volunteer educators or the employee to travel.

The second years funding allowed us to employ myself as a program director [in Edmonton] and another man in Calgary, Robert Welsh who is our program director in the Southern part of the province. There was enough funding from that \$90,000 to provide for our salaries and very, very minimal other costs for us to continue our day to day operations.

The costs went to Board development and operating costs for the office, but again no money for travel. So basically we've been operating reactively as opposed to being pro-active and going out and providing the education, choosing the reserves which are very isolated and remote and basically don't have the resources to provide their own educational initiatives.

Basically we've been operating on a day to day basis. Our salaries for our positions basically allow us to stay here to provide some service to urban organisations. Because we're in the city we can travel to the different agencies to provide the education.

We don't have the money to go out - to choose the reserves. To be able to go out and to provide the education which we would like to....Our approach has always been in my opinion anyway a very proactive one otherwise I don't think we would be here today dealing with an issue which is basically considered taboo by the Native population.

We see the need for us to be a proactive type of body and good people who are willing to work in this area of off HIV and AIDS to provide the education, and the awareness to the general population and hopefully very, very soon in the near future we'll be able to go into support programmes.

Support basically meaning counselling of HIV individuals. Support being hopefully to be able to have the resources to provide

whatever they may need financially. Because of our lack of funds I think its been very difficult for us to look at even beginning to organise or to develop new programmes for our population because, one, we've only got enough funds to provide for 2 persons in the province of Alberta who are paid to provide education for a population of approximately 160,000 Aboriginal people. Who we are responsible for to provide education (George Poitras, 12/6/92).

Feather of Hope - Saskatchewan,

With this we put in a budget of over \$100,000, because we felt it was needed, because we identified the areas that it was needed. But today we get \$26,000 now how far is that going to go? What are you going to do with something like this? So its frustrating. To top it all off we're not supposed to pay anyone to do this work. They make it that so we don't hire anybody.... Basically that's what it comes out with....But each and everyone of us around the table has to work to be able to survive. So everyone of us has a job. But nobody is working for those kids are they? We've identified the problem and the like to get \$100,000 for two of us to be employed in that area so we can do something - but now we can't do that.

That's what we asked for in our proposal, a secretary and sort of a coordinator. Somebody to coordinate the whole thing. At the same time we're not going to get it so.... So you continue working, but for how long? How long can you afford it? It seems like they are saying to us "Well, its your problem you look after it."

I think what we're fighting is that we have no real organisation set up [around here] that can say we have some authority in education, we have some authority in prevention. We don't have that. Therefore people don't give a damn because there is not that credible organisation that can say "yes we can deal with the kids on needle exchange or needle abuse." Talk to the kids about condoms or sex education which the schools are supposed to do and the churches are supposed to do but they are not doing it. And that's the problem we see....

And that's the kind of organisation we're trying to set up. Nobody wants to help it get off the ground....It pisses me right off. It's so frustrating (Feather of Hope, Saskatchewan, 2/6/92).

Healing Our Spirit,

What we need is money. Money, money, money. We get government funding for education, but the government does not give money for support (Healing Our Spirit, 10/6/92).

Susan Beaver at Two Spirited Peoples of the First Nations,

One thing my organisation really needs it to triple it's budget in the next six months....And we need money, lots of money....We need more money, did I say that? (7/7/92)

MAATF also expressed a need for more financial support,

Money. We need more funding to be able to do the education. To go out to communities. To provide support to people. We can't do any thing now. How do we get to communities. We can only go if they can pay. We have no money to produce pamphlets and things (25/5/92).

Alan LaRoque Kennard of Vancouver PWA, in response to the question, "What do you think is needed" said,

More money. Directly given to Aboriginal people to service their own as opposed to keeping a lot of bureaucracies alive to keep people in jobs. They're not making the kind of marks we are. What we are doing is working, what most of the white services are doing are not (Alan LaRoque Kennard, 9/6/92).

5.11 SUMMARY

The discussion above indicates some of the distinctive needs of Aboriginal PLWA/HIV. When these are placed in the context of the location and size of Native communities it is apparent that there is an urgent need not only for education and awareness programs, but the development of services to meet the needs of Aboriginal PLWA/HIV, in reserve and off reserve communities, in rural areas and in cities. The healing that is taking place in communities and increasing emphasis on traditional values is essential for both prevention of HIV and AIDS, as well as for providing a supportive atmosphere for PLWA/HIV. It is evident that PLWA/HIV face considerable

obstacles in trying to sustain a healthy lifestyle. The consequences are more severe than discomfort, they mean people may die before they need to. The different needs of different communities indicate the need for community based initiatives. This aspect of the interviews is discussed in the concluding chapter.

Although a need for more education and prevention programs has been identified, considerable progress has been made since the First Canadian Conference on AIDS and Related Issues in the Aboriginal Community in 1989 when only a few programs existed (Wortman, 1992). Aboriginal PLWA/HIV have been instrumental in promoting this work, sharing their experience, working as educators, starting initiatives and fostering initiatives to protect their communities.

CHAPTER 6

SUMMARY AND CONCLUSION

6.1 SUMMARY

The study has examined the needs of Aboriginal PLWA/HIV from the perspective of Aboriginal AIDS organisations and PLWA/HIV. Owing to the inadequacy of official data on the extent of HIV and AIDS in Aboriginal communities, the vulnerability of communities to HIV was examined first showing that there are already PLWA/HIV who have needs that have to be met and that the number of people needing services and support is likely to increase in the future. The study focused on the distinctive socio-geographical aspects of Aboriginal communities and their effect on risk to communities and the lives of PLWA/HIV. The emphasis on geographical issues has shown that there will probably be a higher demand for services and support in remote and rural areas than among non-Aboriginal communities as a consequence of higher rates of migration, and that people living in remote and rural areas encounter particular problems in meeting their needs. Stigma and misconceptions about HIV and AIDS were found to affect access to services, education and acceptance of PLWA/HIV.

Central themes emerged during the course of the study that encompassed all aspects of the research question including the research process. These included: the

need to contextualise disease and health; the distinctiveness of communities and individuals; and issues relating to control of research, education, and support and service delivery.

Issues of control in the research process were examined in Chapter two, which outlined the use of a socially accountable participatory research methodology, explaining the role of the JNC and interview participants in developing the research problem and their input into the writing process. The methods of data acquisition and their limitations were described and the inadequacy of official data and the failure of the questionnaire as an effective research tool were identified.

Chapter three brought together information on the incomes, employment status, housing conditions, and health status of the Aboriginal population of Canada, showing that for each, Aboriginal communities are on average in a disadvantaged position compared to the majority population. It showed that Aboriginal people are more likely to live in small rural or remote communities than the majority population, and have distinctive migration patterns. Transiency was identified as a significant factor in the increasing the rate of diffusion of HIV to small rural communities where risks would normally be considered low. As a consequence the pattern of demand for services and support is affected. This chapter provided the background to discussion in chapters four and five by identifying the importance of these factors for the lives of PLWA/HIV as well as the transmission and diffusion of HIV.

The connection between these factors and risk behaviour and other factors affecting the transmission of HIV were identified in Chapter four. The chapter

presented evidence to show that risk factors for HIV infection are over-represented in Aboriginal communities, and cannot be separated from the issues raised in the Chapter three. It noted that STD rates are higher than in the majority population, as well as the effects on risk behaviour of substance abuse (including injection drug use) and low self esteem. Barriers to using condoms were identified including access, cost, and unequal sexual relationships. It is apparent from the data presented that Native communities are disproportionately vulnerable to infection, and while there is already a demand for services and support from PLWA/HIV, demand is likely to increase significantly in the future in the absence of effective education programs which will need to encompass more than education given the issues underlying risk behaviour.

The primary research question was addressed in Chapter five, where the results of interviews and the questionnaire were presented. Interviewees were remarkably accordant in identifying common areas of concern. Education emerged as a tool not only for prevention and awareness, but also for building acceptance and understanding of PLWA/HIV in their communities, for themselves, and by organisations from whom they might seek services and support. Barriers to effective education identified by participants included a lack of effective leadership, homophobia and a reluctance to address or talk about sexuality. Effective political leadership was seen as a significant influence on the education process and on communities willingness to accept and support people wanting to live on Reserve. It was felt that supportive leadership from Band Councils and elders was essential to the development of successful education and health care programs and to allowing PLWA/HIV to be respected and accepted in

their communities.

The income of all PLWA/HIV who rely on welfare or disability is inadequate. People are unable to meet even their basic needs on these levels of income. Aboriginal people are less likely to have savings or families which can help or support them financially. If people do not have enough money to feed themselves properly, keep warm, and for the medication they need, it has a detrimental effect on both their physical and mental health.

Finding adequate housing in a supportive environment that could meet the changing needs of PLWA/HIV was identified as a serious problem for many people, affecting both physical and mental health. Without sufficient income people have less access to suitable housing.

Participants identified that issues faced by Native PLWA/HIV are different, and that people may not feel comfortable using non-Aboriginal services. So even if non-Native run services are available they may not be seen as accessible by PLWA/HIV. The need to reconnect with their cultural identity was seen as an important part of the healing process for many individuals and is something which cannot be provided by non-Aboriginal service providers.

Funding emerged as a significant problem for all organisations interviewed. Only Anishnawbe Health (an already established health centre), Vancouver PWA (a non-Native organisation), and Two Spirited Peoples of the First Nations received funding for the provision of services and support. Funding for the other organisations was limited to education programs and even for that funding appeared to be

insufficient to enable organisations to develop the proactive initiatives that they see as essential to dealing with HIV and AIDS. Organisations are dependent on reserves to fund educational initiatives.

Many of the issues raised in the study, in both the areas of risk and of services and support to PLWA/HIV, apply to both Native and non-Native communities. However, the study has shown that inequalities in Canadian society and the history of Aboriginal communities has exacerbated problems and created distinct needs for Aboriginal communities and PLWA/HIV. The location and size of remote and reserve communities was said to present specific barriers to accessing support and medical services.

The unique needs of communities was reflected in the common themes that emerged from the interviews which emphasised the necessity for community control and the importance of learning from the experiences of PLWA/HIV to developing of appropriate and effective services.

6.2 METHODOLOGICAL IMPLICATIONS

A number of concerns emerged from using a research process based on a socially accountable participatory research methodology. The need for the community to being researched to have some control during the research process arose from both the nature of the problem and the history of exploitative research in Aboriginal (and other) communities. It was particularly important to emphasise participation because I

believe in this circumstance it would have been unethical to ask people to contribute their time, energy and ideas for the sake of a qualification. Reconciling these issues has been part of the research process.

The methodology has proved effective in that it has allowed input from participants and the JNC in defining the research problem, and the research process. Passing relevant sections to interview participants has allowed them to take part in the process and has ensured that they have not been misrepresented. Time constraints limited the time available for consultation, but by the completion of the thesis no changes had been requested by participants or the JNC.

The role of the JNC was questioned by a number of interview participants, and thus raised questions about its appropriateness as a representative of the community in the context of this study. During the year of the research process the JNC has been restructuring and redefining its mandate. The reservations expressed by interviewees concerning the role of may stem from its apparent lack of direction during this time. Some of the comments included,

The JNC in itself, not that the people aren't committed, not that the people don't care,...they are a very typical top level kind of thing, where "we're going to decide what the issues are and we're going to find out what's needed, and we're going to make these recommendations to the government", and most of the time they exclude community based organisations from this process. When they are the people who are dealing with it every day of our lives (Susan Beaver 7/7/92).

I think of the JNC, who in my opinion are not a very active organisation who are probably primarily responsible for providing the services to our population in Canada, or even advocating or lobbying on behalf of our population....But they don't know the realistic concerns of HIV and how its impacting our population....For them to recommend programs which are going to study my population and how its going to

affect my population really perturbs me. Not only do I want to be able to advocate for my population which I'm doing here and struggling with,...I would have the real concerns, I would have the concerns of the PLWA/HIV, as opposed to people advocating for my population who don't know realistically how it is being impacted by the disease (George Poitras, 12/6/92).

Frustration that the experience of PLWA/HIV and Aboriginal AIDS organisations is not being drawn on sufficiently is relevant to the conclusion of the thesis. It is important to note that a recent meeting of the JNC (held in July 1992), did include service providers and PLWA/HIV, including Two Spirited Peoples of the First Nations and Feather of Hope- Alberta. Some people articulated the need for its role to be more clearly defined, not only by current members, but in concert with PLWA/HIV and people who are working day to day in the provision of education, support and services. Susan Beaver commented,

....I do think we need some kind of national level organisation that can do our lobbying with the Federal Government, or whatever. So that we can have more access. I think we definitely need a national way of sharing information. I think ideally that's what the JNC is for. I think we definitely need a way of supporting each other on a national basis. And looking at whose strategies or what, and how effective these strategies have been in your particular community. That I think would indeed be really ideal.

I think the JNC should be something that is flexible and able to respond to our needs. Our needs are changing and who is testing positive is changing - so we need a national organisation that is sensitive to things like women testing positive with children, street kids, and at the same time not seeing women only in so far as they can bear children, but as individuals who need treatment and a certain quality of life as well (Susan Beaver).

She was not alone in seeing the importance of the JNC as a national organisation.

Despite the reservations of participants, the JNC is the national organisation with responsibility for developing research initiatives. Certainly members shared insights

with me which were useful to developing the study and hopefully the study will be of use to the Committee. Perhaps these issues are a reflection of the difficulties of attempting to develop initiatives in an area which is new and constantly changing.

The use of unstructured interviews allowed participants to develop the issues that they felt were important. Brody has commented,

Sometimes they addressed social problems or social ills, but they were placed in the people's own terms of reference. In this way I, the researcher, was taken away from research schemes and agendas, and sometimes far away from familiar kind of enquiry."(1988:xx)

This is certainly appropriate to my experience. Unfortunately the time, space and format of a Masters Thesis have not allowed me to explore many of the insights that people took the time to share with me. Although they may not be here in print, they have helped develop my understanding of the research problem. The academic demands of a thesis, while perhaps laudable, do not always allow the information to be presented in a way which participants can readily use. Therefore after this thesis is completed I will prepare a report for participants which may be more useful for their needs and which may allow the inclusion of some of the issues that lay outside the scope of this thesis.

The low return rate of the questionnaire, demonstrated the problem of faceless research on a sensitive issue in a population which has been "researched to death", and certainly brings in to question the utility of questionnaires as an effective tool in this type of research. Nevertheless, the information from the ten returned questionnaires was useful.

Time and cost constraints prevented me from interviewing people who were

willing to talk to me and whose insights would have been useful, particularly people involved with initiatives on reserves. However, interviewees have been part of these initiatives, helping to develop programs and acting as visiting educators, so they could provide useful insights on issues at the reserve level.

During the course of the interviews it became apparent that many people, especially women, are not in regular contact, or any contact with the agencies approached. This would indicate that these people may be facing specific issues which have not been articulated here. Significantly, women have remained largely invisible in this study, though some of the issues faced by women are likely to be unique¹

Its hard to know where to start. Like there's womens' relationship with the medical establishment and with the medical profession and their relationship with doctors who generally have a history of not taking them seriously, not taking their health seriously, not taking women's concerns seriously....There are women who are refused tests by their doctors because they say they're not in a high risk group, they are not seen as being at risk at all. Women in terms of the research that's being done, and the drug trials and so on, women are not being included in a lot of these things. And you know it's only recently that they've expanded their list of opportunistic infections of AIDS to include women. Ten years into the disease.

Then there's women's economic status in society and their status as primary care givers for children. Women if they have to get a sitter, then they're not going to go to the doctor. Women generally are poor, quality of health care again. Housing condition are probably not as good as others...

The women and children will be a big issue in our native community (Susan Beaver, 7/7/92).

Although I interviewed people working with Aboriginal street youth with HIV and AIDS, I did not feel that the information gathered was sufficient for the issues raised

¹ Manthorne, 1990; ACT UP/New York Women and AIDS Book Group, 1990; Campbell, 1990; Hankins, 1990. Susan Beaver commented,

to be discussed effectively in the framework of this study. The needs of women and street youth are areas that warrant further investigation.

As a researcher, inadequate data on the extent of HIV and AIDS in Aboriginal communities, and uneven data on factors affecting the vulnerability of communities to the virus presented a problem. Seropositivity studies would show levels of infection most accurately, knowledge attitude and behaviour studies may also be useful for targeting education programs. However George Poitras was not alone when he said,

We are recommending funds to provide the government with statistical things, like what's happening with our population, why is our population vulnerable. We don't need to do any more feasibility studies to see how our population is going to be affected. We don't need to be doing seroprevalence surveillance testing in Sioux Lookout Region to see how our population is being affected by this disease. We know our population is being affected by this disease. We know that our population is the most vulnerable in this country and continent.

Direct the funds where they are going to be used to prevent HIV amongst our population. Direct the funds to educational awareness, to where we need care and accommodation programs for people already living with HIV (George Poitras, 12/6/92).

6.3 IMPLICATIONS OF THE FINDINGS.

I do not feel qualified to make concrete recommendations, nor would it be appropriate to the way the problem has been approached for me to attempt to do so. However during the interviews common needs were articulated in several areas.

Interviewees were united in seeing the need for services to be delivered by Aboriginal organisations which can recognise and address the diversity of communities, in the framework of a holistic approach to health and education which is

culturally relevant. Communities are not homogenous,

...people have to get the idea that native people aren't one homogenous lump of brown flesh. We all have different experience, we all come from different places, we all have different ways of dealing with illness, with all of these things...(Susan Beaver, 7/7/92).

The need for responses to reflect this diversity and which are appropriate to local and individual needs was articulated by all interviewees. To do this the involvement of communities and individuals in the development of programs was seen as essential,

We have to go sort of into the nucleus of the community to work outwards instead of working inward, and that process never takes place. Its always worked on the outside coming in.

We seem to know what programs the communities need but we don't really know what they really need because they don't tell us. And its our job to go in there and find out. You, me, we have to work from inside out. In a lot of cases we don't. We just say, "Oh there's ten communities out there that need this." Well, why do they need it? Maybe one community doesn't have any HIV prevention programs and may be one has ten going, you see.

So in a lot of cases we seem to work coming from the outside, never going in and working out. (Jerome Yellowdirt, 12/6/92).

This organisation grew out of two very similar principles that native people have to take responsible for our own lives. We are responsible for our own communities and we are quite capable of taking care of our own community...It's knowing your community. I think we know what people respond to and I think its pretty accurate What has to happen is that we have to come together as a community to deal with this. And we as a community have to look at our issues, and we as a community have to get the support from whatever government happens to decide that they are going to rule us. Ultimately we have to get that support, that room to deal with it as a community because other solutions are not going to work. That's the biggest thing (Susan Beaver 7/7/92).

Education and prevention programs developed by the Swampy Cree Tribal Council and the James Bay Cree AIDS Awareness Program have been extremely

successful. They were developed on a community based approach which as allowed each community "to set its own objectives and activities "which is necessary to ensure community control and cultural relevance" (Valverde, 1992:12; Procyk, 1992). It has not been possible in the framework to identify the many programs that communities have undertaken. While the focus of many of the activities of the organisations interviewed is education, largely a result of available funding, they identified a pressing need for the issue of services and support to PLWA/HIV to be addressed,

And a lot of what they're talking about, and a lot of their strategies and so on, deal with education and prevention....At the same time we have a certain number of people who are already living with AIDS for who education and prevention isn't going to help them a whole lot (Susan Beaver, 7/7/92).

Ken Ward, a person living with AIDS who was instrumental in the establishment of Feather of Hope is organising a meeting this autumn (1992) of PLWA/HIV to discuss issues that they see as important.

The theme of the need for culturally relevant programs developed by communities to meet local needs provided a framework for more specific recommendations which included:

- 1) income - government financial support urgently needs revision so that people can afford to buy their basic needs, including housing;
- 2) housing - sufficient income to be able to access suitable housing; group homes for Aboriginal PLWA/HIV; increased home care services; palliative care²; accommodation for PLWA/HIV making temporary

² Two Spirited Peoples of the First Nations and other organisations in the Native Community in Toronto are starting a project to raise funds to establish a hospice for Aboriginal PLWA/HIV.

visits to cities for medical treatment and other services;

3) education - peer education for leadership and elders; more education for organisations that may provide services to PLWA/HIV and communities; more culturally appropriate education materials (printed and other media) in the language of communities;

4) people affected by AIDS - support for families, partners and friends of PLWA/HIV so that they can provide support; temporary housing for people visiting people in hospitals etc.

5) remote and rural areas - the provision of services and support to PLWA/HIV living in these areas needs specific attention.

The lack of financial support for Aboriginal organisations, particularly in the area of services and support is possibly a function of the Federal (and provincial governments') attitude that their responsibility for services and support begins and ends on reserves. Yet at least half of the population do not live on reserve. Non-Status Indians and Metis people face many of the same issues as Status Indians and Inuit people, but are excluded from Federal programs. There seems to be little recognition from the government for the need for Aboriginal communities to control AIDS initiatives, yet it has been accepted in NNADAP and mental health programs.

Lack of funding to support Aboriginal organisations and to allow communities to develop their own initiatives is a serious barrier to program development. Reconnecting with cultural identity, leadership, community control and culturally relevant programmes are essential for communities to be able to combat infection and

to support PLWA/HIV.

A holistic approach has been used to address the research question. While I am not qualified to discuss the problem in the context of traditional conceptions of health, traditional conceptions which encompass emotion, spiritual, mental and physical health were identified as pertinent to understanding and dealing with AIDS education and the provision of services and support. HIV and AIDS cannot be separated from the conditions which encourage transmission and affect their etiology. All participants identified the need for education, and service and support programs which encompass the whole of peoples lives, not just the virus; which can incorporate traditional strengths and are culturally relevant. Without addressing the factors and issues that underly the vulnerability of communities to HIV and which threaten the lives of people living with the virus, education awareness and prevention programs can only have a limited effect. People with HIV and AIDS are often not only dealing with the virus, but issues in their own lives. Disease does not exist in a vacuum, health is not just a biological condition.

Placing the transmission and etiology of HIV and AIDS in a structural context can be seen as disempowering. However, perhaps the most powerful concept that emerged from the interviews was that AIDS need not be seen as a catastrophic force and a harbinger of death, but if used properly is a learning tool, "a gift" to help communities to address social and other issues that they are trying to deal with. If used positively it can become a constructive force in communities and the lives of PLWA/HIV, not a destructive force, and thus a part of the healing process in

communities,

I was asked if I was sorry about having HIV. I had to think hard because some of me is glad, because what it is teaching our communities and teaching me (Leonard Johnston, 10/6/92).

I first began to get involved in a serious way, about two, three years ago. And I looked at AIDS and how you protect yourself, how you get it. Looking at our communities, and I thought that AIDS has a message to bring around a healthy lifestyle. I thought that AIDS could be the conduit for healing a lot of issues in our lives as native people, looking at issues of self esteem, looking at ways we express our sexuality. The role of women in our communities, how men and women are interacting, and lesbians and gay men, and all of these things.

I thought that this could be the way to a healthy life. AIDS is bringing us a healthy life ultimately. and then I talked to one of our spiritual advisors - only she probably wouldn't want to be known as that because she says she's only just learning herself - but she is for me very much a spiritual advisor and she said AIDS is a gift to our communities.

And I think that's very true....AIDS has made us look at a lot of things, and if we can look at those things and we can start to address those things, we can start to heal them. So I very much feel that AIDS is a gift and it has made changes in my life. And I am simply a person who is affected not infected. Not that that's important. But in a way it is. Its affected how I look at life and people who I have known and have lived with and watched pass on they have taught me an awful lot of things as well (Susan Beaver, 7/7/92).

And so our population is dealing with our problem today. And being able to recognise the other issues and to deal with them, by and large has brought our people to recognise who they are as people indigenous to this land. People who are very culturally and spiritually grounded - very good beliefs, very strong values. Coming back and dealing with our issues and being able to have these values, these spiritual beliefs as part of our lifestyles today is a very, very strong thing for our population. And if the Aboriginal PLWA/HIV could develop that same mode of recovery, then yes I believe that there is a good part of HIV and that is what Ken speaks about when he refers to AIDS as a gift (George Poitras 12/6/92).

AIDS can be used positively if it is part of the healing taking place in communities.

Communities and individuals need to be able to develop programs which address the issues raised by HIV and AIDS as well as the virus.

6.4 CONCLUSION.

The study has provided an introduction to an issue which has not previously been addressed and which urgently needs attention. The magnitude of the factors involved in the provision of services and support to PLWA/HIV mean that I have only been able to initiate an understanding of the issues that people are facing and some possible solutions. However the study has shown that the needs of Aboriginal PLWA/HIV and the vulnerability of individuals and communities to HIV are influenced by the unique socio-geographical aspects of Aboriginal communities. The distinctive geography of the Aboriginal population of Canada, and its manifestation in the differences in issues faced by people living in remote and rural areas and people in cities highlights the need for geographers to pay attention not only to the geography of health care delivery, but to the geography of users and their needs as well. The kinds of information that have been revealed give insight into community views which could not have been obtained by any other method. By using socially sensitive research in the human geography of disease and health care the study has demonstrated the effectiveness of this approach and that further work along these lines deserves further exploration.

Disease affects communities and individuals in distinctive ways and cannot be

separated from the context in which it occurs. In turn this affects how communities and individuals respond to both risk and infection. Responses to risk and infection need to be controlled by communities and affected individuals so that their specific needs are met in the context of the environment which they are part of. Perhaps the most basic need is for people to have the opportunity to define and meet their own needs. The question of control is part of the political and territorial changes and taking place in Aboriginal communities in Canada today.

The inability of bio-medicine to effectively control HIV or AIDS emphasises the need for a holistic approach to health, which can address both prevention and care. The factors underlying the risks of infection to communities and individuals are closely tied to the health of communities. Preventative and caring initiatives that exist in communities today reflect the importance of traditional values, not just as they relate to perceptions and approaches to health, but which are central to the healing process which is taking place in Aboriginal communities and which allow a holistic, caring and positive response to HIV and AIDS.

The initiatives that exist today are heavily dependent on the work and courage of PLWA/HIV who have taken risks to disclose themselves, and who have shared their time, energy and knowledge to initiate and to help develop them. Hopefully attention will be paid to the provision of services and support, and the voices of people living with HIV and AIDS and communities will be listened to.

BIBLIOGRAPHY.

ACT UP/NY Women and AIDS Book Group, editors (1990). Women AIDS and Activism. Boston: South End Press.

Alary, M. and J. Castel (1990). "Risk factors for HIV seropositivity among people consulting for HIV antibody testing: a pilot surveillance study in Quebec," Canadian Medical Association Journal, 143(1):25-31.

Alexander, Nancy; H.L. Gabelnick; J.M. Speiler (1990). Heterosexual Transmission of AIDS. New York: Alan R. Liss.

Anderson, R.M. and R. May (1992). "Understanding the AIDS Pandemic" Scientific American, 266(5):58-66.

Ankrah, M.E. (1989). "AIDS: Methodological Problems in studying its prevention and spread." Social Science and Medicine, 29(3):265-276.

Ankrah, M. E. (1991). "AIDS and the Social Side of Health," Social Science and Medicine, 32(9):967-980.

Armstrong, K., L. Samost, and D.R. Tavis (1992). "HIV risk behaviours of sterilized and non-sterilized women in drug treatment programs - Philadelphia, 1989-1991," Mortality and Morbidity Weekly Report, 41(9):149-152.

Assembly of First Nations (AFN) (1991). Aboriginal Resource Directory. Ottawa: Assembly of First Nations.

----- (1988). Current Indian Health Conditions: A Statistical Perspective. Ottawa: Assembly of First Nations.

Associated Press, (1992). "Virus spreading among women." Globe and Mail, July 21, 1992:A5.

Association of Canadian Universities for Northern Studies (1988). Ethical Principles for the Conduct of Research in the North. Ottawa: Association of Canadian Universities for Northern Studies.

Beaver, S. M. We Are Part of a Tradition. A Report to The Royal Commission on Aboriginal People. Presented June 25, 1992.

Big Canoe, Loraine (1992), Program Consultant, Addiction Research Foundation. Personal communication, February, 1992.

Bowles G., and P.D. Klein, editors (1983) Theories of Women's Studies. London: Routledge.

Brody, H. (1988). Maps and Dreams: Indians and the British Columbia Frontier. Douglas & McIntyre: Vancouver, 1988.

Brown, D. (1992). "Survey presents bleak circumstances of Native American teenagers." Washington Post, March 25, 1992:A3

Bulatao, Rudolpho A., World Bank. Personal communication, January, 1992.

Bulatao, R. A. and E. Bos (1991). Projecting the Demographic Impact of AIDS. Unpublished. 1991.

Calzavara, L.M., R.A. Coates, K.J.P. Craib, M. Math, M.T. Schechter, T.N. Le, P.L. Nault, and K. Elmslie (1990). "Underreporting of AIDS cases in Canada: a record linkage study." Canadian Medical Association Journal, 142(1):36-39.

Campbell, C.A. (1990). "Women and AIDS." Social Science and Medicine, 30(4):407-415.

Canada Diseases Weekly Report(CDWR) (1988). "Sexually Transmitted Disease in Canada" 14(20):85-88.

Canada Diseases Weekly Report (1986). "Tuberculosis, Final Data - United States, 28-30

Canadian Centre for Health Information (1990). "Tuberculosis Statistics." Health Reports Supplement No.10, 12(4):19.

Canadian Press (1992). "HIV tests urged for pregnant women." Globe and Mail, July 23, 1992:A4.

Canadian Broadcasting Company (CBC), Ideas (1991). What Causes AIDS? A Second Look. Transcript of program aired November 6-7, 1991.

Canadian Public Health Association (CPHA) AIDS Education and Awareness Program (1992). A Resource Manual for AIDS Educators. Ottawa: CPHA.

Castillo-Chavez, C. (ed.). (1989). Mathematical and Statistical Approaches to AIDS Epidemiology. Berlin: Springer-Verlag.

CBC,IDEAS "What Causes AIDS? A Second Look ", 6,7 November, 1992.

Center for Disease Control (CDC) (1991). HIV/AIDS Surveillance: US AIDS cases reported through November 1991, Atlanta: CDC.

----- (1990). STD Surveillance (1990), personal communication January 30, 1992.

Certenig, M. (1992). "Sharing of drug needles a valued ritual, study finds." Globe and Mail, July 15, 1992:A3.

Chase, Emmett Dr., Chief AIDS Coordinator, Indian Health Service. Personal communication, February, 1992; April, 1992.

Chase, E. (1991). "AIDS among American Indians and Alaska Natives." Tribal Activities Bulletin, Issue 1:1-3.

Chiotti, Q. and A. E. Joseph (1992). "Casey House: A Commentary on the Location of an AIDS Hospice in Toronto." Unpublished.

Clark, M. and A. Wilson (1989). "Mathematical models in human geography: twenty years on." in New Models in Geography, Vol.1, eds. R. Peet and N. Thrift London: Unwin Hyman:30-40.

Clatworthy, S. and H. Stevens (1987). An Overview of the Housing Conditions of Registered Indians in Canada. Ottawa: Department of Indian and Northern Development.

Culotta, E. (1991). "Forecasting the Global AIDS Epidemic." in Science, 253(5022):852-54.

Daley, C.L., G.F. Schecter and G.W. Rutherford (1991). "Tuberculosis outbreak among persons in a residential facility for HIV infected persons - San Francisco." Mortality and Morbidity Weekly Report, 40(38):649-652.

Denenberg, R. (1990). "Unique Aspects of HIV Infection in Women." in eds. ACT UP/NY Women and AIDS Book Group op. cit.:31-43.

Des Jarlais, D.C., S.R. Friedman and J.S. Woods (1990). "Intravenous Drug Use and AIDS." in (ed.) D.G. Ostrow, op. cit.:139-155.

Dutt, A. K., C.B. Monroe, H.M. Dutta and B. Prince (1987). "Geographical Patterns of AIDS in the United States." The Geographical Review, 77(4):456-471.

Evers, S., E. McCracken, I. Antone, G. Deagle (1987). "Prevalence of Diabetes in Indians and Caucasians in Southwestern Ontario." Canadian Journal of Public Health, 78:240-243.

Eyles, J. and K.J. Woods (1983). The Social Geography of Medicine and Health. London: Croom Helm.

Farkas, Carol, Personal communication, October 1991.

Farkas, C.S., (1983). Nutrition Education Planning for Native Canadians: an Application of the Ethnography of Communication, Doctoral Thesis, University of Toronto.

Feldman, D.A., editor (1990). Culture and AIDS. New York: Praeger.

First Nations Task Force on Indian Housing (1989). National Report - 1989. Ottawa: Assembly of First Nations.

Ford, P.M., E. Ford and L. Lightfoot (1990). "IV drug use and HIV infection: Perspective from a small city," Canadian Medical Association Journal, 142(5):469-471.

Fordyce, M., M.Jones, R.S. Hopkins, G. Halpin, A. Kline, K. McNally, K.C. Spitalny (1992). "Childbearing and contraceptive use plans among women at high risk from HIV infection - selected US sites, 1989-1991," Mortality and Morbidity Weekly Report, 41(8):135-144.

Frideres, J.S. (1989). Native Peoples in Canada: Contemporary Conflicts. Scarborough: Prentice Hall Canada.

Gardner, L.T., J.F. Brundage, D.S. Burke, J.G. McNeil, R. Visintine, and R.N. Miller (1989). "Spatial Diffusion of the Human Immunodeficiency Virus Infection Epidemic in the United States, 1985-1987." Annals of the Association of American Geographers, 79(1), 1989:25-43.

Gould, P. (1989). "Geographic Dimensions of the AIDS Epidemic." Professional Geographer, 41(1):71-78.

Griffiths, C.T., and M. Nance (1986). "Beyond advocacy: The Northern Conference as an educational model." Canadian Journal of Native Studies, VI(1):241-251.

Gully P. and D. Rwetsiba (1991a) "Trends in Gonorrhoea in Canada: 1980-1989." Canada Diseases Weekly Report, 17(21):105-109.

----- (1991b). "Chlamydial infection in Canada", Canada Diseases Weekly Report, 17(51):282-291.

Gully, P. (1992). "Sexually transmitted disease control," Canadian Journal of Infectious Diseases, 3(1):42-43.

Haley, N. (1992). HIV in Children and Adolescents. Presentation at First Quebec Native AIDS Conference, April 7, 1992.

Hall, R., D. Wilder, P. Bodenroeder and M. Hess (1990). "Assessment of AIDS Knowledge, Attitudes, Behaviours and Risk Level of Northwestern American Indians." American Journal of Public Health, 80(7):875-877.

Hankins, C. (1990). "Women: and HIV infection and AIDS in Canada: Should we worry?" Canadian Medical Association Journal, 143(11):1171-1173.

Hankins, C. A., C. Laberge, N. LaPointe, M.T. Lai Tung, L. Racine and M. O'Shaughnessy (1990). "HIV Infection among Quebec Women Giving Birth to Live Infants," Canadian Medical Association Journal, 143(9):885-893.

Hankins, C. S. Gendron, M. Handley, F. Rouah, and M. O'Shaughnessy (1991). "HIV-infection among incarcerated men - Quebec." Canada Diseases Weekly Report, 17(43):233-235.

Hanna, D. (1990). "Native Services Set to Combat AIDS", The Vancouver Sun, May 4, 1990:C6.

Haraldsdottir, S. (1990). Processes Affecting the Spread of HIV Infection in Iceland. Geographical Monographs No. 20, Toronto: York University.

Harding, S. (1987). Feminism and Methodology. Bloomington: Indiana Press.

Harding R., S.D. Helgersen and T. Damron, "Hepatitis B and injecting drug use among American Indians - Montana, 1989-1990," Mortality and Mortality Weekly Report, 41(1):13-14.

Haugeneder, R. (1990). "Officials Fear an AIDS Epidemic," Windspeaker, July 20, 1990:7.

Health and Welfare Canada (1992). Surveillance Update: AIDS in Canada, January 1992. Ottawa: Health and Welfare Canada.

----- (1988). Health Status of Canadian Indians and Inuit - 1987. Ottawa: Health and Welfare Canada.

Hedley M. (1986). "Community based research: the dilemma of contract." Canadian Journal of Native Studies, VI(1):91-103.

Heymann, D.L., J. Chin and J. Mann (1990). "A Global Overview of AIDS" in N. Alexander, H.L. Gabelnick, J.M. Speiler, op. cit.:1-8.

HIV/AIDS Division (1992). Quarterly Surveillance Update: AIDS in Canada. July 1992. Ottawa: Laboratory Centre for Disease Control.

Honey, E. "AIDS and the Inner City: Critical Issues." Social Casework, June 1988:365-370.

Imrie, Robert and R. Warren (1988). "Health promotion survey in the Northwest Territories," Canadian Journal of Public Health, 79:16-21.

Indian Health Service (1991). Trends in Indian Health. Washington D.C.: United States Department of Health and Human Services.

International Development Research Centre (1988). Doing Participatory Research in IDRC. Working Group Paper. Unpublished.

Jackson, P. (1989). "Geography, race and racism" in New Models in Geography, Vol.2. eds. R. Peet and N. Thrift, London: Unwin Hyman:176-194.

Jeres, J.A., G.D. Kelly, S.W. Dooley Jr., G.M. Cauthen and D.E. Snider Jr. (1992). "Tuberculosis morbidity in the United States: Final data 1990." Mortality and Morbidity Weekly Report, 41(5):86.

Johannes, P. and R.C. Leach (1988). "The Indian Health Service AIDS Prevention Program." The IHS Primary Care Provider, 13(6):53-57.

Johnson, A.M. and M. Laga (1990). "Heterosexual Transmission of HIV," in eds. N.J. Alexander, H.L. Gabelnick and J.M. Speiler op. cit.:9-24.

Joint National Committee for Aboriginal AIDS Education and Prevention (JNC) (1990a). Findings Document. Ottawa: Health and Welfare Canada :Ottawa.

----- (1990b). Recommendations for a National Strategy on Aboriginal AIDS Education and Prevention. Ottawa: Health and Welfare Canada.

----- (1990c). Aboriginal Prison Populations. Internal Document.

Joseph, A.E. and D.R. Phillips (1984). Accessibility and Utilization: Geographical perspectives in health care delivery. New York: Harper and Row.

Kaplan, H. B. (1991). "Social Psychology of the Immune System: a conceptual framework and review of the literature," Social Science and Medicine, 33(8):909-923.

Kewayosh, A.A. (1991). "Diabetes in the Canadian Aboriginal Population" First Nations Health News, Summer 1991:3.

King, A., J.L. Radford and W.K. Warren (1988). Canada Youth and AIDS Study. Ottawa: Health and Welfare Canada.

Kirby, A. (1990). "And the Bandwagon Drove on: Geographers and the AIDS Pandemic." Focus, 40(1):10-14.

Kirby, S.L. and K. McKenna (1989). Experience Research Social Change: Methods from the Margins. Toronto: Garamond Press.

Knight, Janet. Personal communication, August 1992.

Koybashi, A. and S. Mackenzie (1989). "Introduction: humanism and historical materialism in contemporary geography." in Remaking Human Geography eds. A.Koybashi and S.Mackenzie. Boston: Unwin Hyman:1-14.

Kramer, J.M. and G.R. Weller (1989) North American Native Health: A Comparison Between Canada and the United States. Lakehead Centre for Northern Studies Research Report No. 6. Thunder Bay: Lakehead University.

Kue Young, D.E., editor (1988). Health Care Issues in the Canadian North. Edmonton: Boreal Institute for Northern Studies.

Kue Young, T. and R.I. Casson (1988). "The Decline and Persistence of Tuberculosis in a Canadian Indian Population: Implications for Control", Canadian Journal of Public Health.79:302-305.

Lang, N.G. (1990). "Sex, Politics and Guilt: A study of Homophobia and the AIDS Phenomenon, in Feldman, D. (ed.) op. cit.

LaRoque, R. and J.Bourget, "Needle Sharing and Exchange", Presentation at the First Quebec Native AIDS Conference, April 8 1992.

Lee, B. (1991). "Living with AIDS: Towards Effective and Compassionate Health Care Policy." in Perspectives on AIDS: Ethical and Social Issues. eds. C. Overall and W.P. Zion, Toronto: Oxford University Press.

Lewis, G., J. Finlay and R. Widdus (1991). "AIDS Programmes in Transition," World Health Forum 12(3):297-301.

Lockhart, A., and D. McCaskill (1986). "Towards an integrated, community based partnership model of Native development and training: a case study in process." Canadian Journal of Native Studies, VI(1):159-172.

Loytonen, M. (1991). "The Spatial Diffusion of Human Immunodeficiency Virus Type 1 in Finland, 1982-1987." Annals of the Association of American Geographers, 81(1):127-151.

Maguire, P. (1987). Doing Participatory Research: A Feminist Approach, Boston: University of Massachusetts.

Manthorne, J., editor (1990). Canadian Women and AIDS: Beyond the Statistics. Montreal: Les Editions Communiqu'Elles.

Masse, R., H. LaPierre, H. Rousseau J. Lefebvre and R.S. Remis (1991). "Chlamydia Trachomatis cervical infection: prevalence and determinants among women presenting for routine gynaecological examination," Canadian Medical Association Journal, 145(8):953-961.

McDonald, R.J. (1991). "Canada's off-reserve Aboriginal population," Canadian Social Trends, Winter 1991, 23:1-7.

McNamee J.E. and D.R. Offord (1990). "Prevention of Suicide", Canadian Medical Association Journal, 142(11):1223-1230.

Medicine, B. (1988). "Aboriginal Views of Health", in Inner City Health: the Needs of Urban Natives, Proceedings of the Ninth Symposium on the Prevention of Handicapping Conditions:46-50.

Metler, R., G.A. Conway, and J. Stehr-Green (1991). "AIDS Surveillance among American Indians and Alaskan Natives." American Journal of Public Health, 81(11):1469-1471.

Molgaard, C.A., C. Nakamura, M. Hovell and J.P. Elder (1988). "Assessing alcoholism as a Risk Factor for AIDS." Social Science and Medicine, 27(11):1147-152.

Montagnier L. (1991). "Taking a positive line on HIV and AIDS." Guardian Weekly, December 15, 1991:16.

Morse, J.M., D.E. Young and L.Swartz (1991). "Cree Indian healing practices and Western health care: a comparative analysis." Social Science and Medicine, 32(12):1361-1366.

Mortality and Morbidity Weekly Report (MMWR) (1992). "Infant Mortality - United States 1989." 41(5):81-85.

----- (1991a). "Primary and Secondary Syphilis - United States, 1981-1990.", 40(19):314-321.

----- (1991b). "HIV infection prevention messages for injecting drug users: Sources of information and use of mass media - Baltimore, 1989." 40(28):465-489.

----- (1991c). "Drug Use and Sexual Behaviours among the Sex Partners of Injection Drug Users - United States, 1988-1990." 1991c, Vol 40(49): 855-860.

Muir, M.A. (1991). The Environmental Contexts of AIDS. New York: Praeger.

Myers, T. (1992). "First Nations and University research near completion," Canadian AIDS News, V(3)6.

Myers, T., D. Locker, K. Orr and E. Jackson (1991). Mens Survey'90. AIDS: Knowledge, Attitudes, Behaviours. A Study of Gay and Bisexual Men in Toronto. Toronto: AIDS Committee of Toronto.

National Task Force on Suicide in Canada (1987). Suicide in Canada. Ottawa: Ministry of National Health and Welfare.

National Association of Friendship Centres (1992). HIV/IDU Prevention Program, February Report. Personal Communication.

National Centre for Health Statistics (1991). Health United States 1990. Hyattsville: United States Public Health Service.

National Council of Welfare (1991). Welfare Incomes 1990. Ottawa: National Council of Welfare.

Newman, J.L. (1990). "On the Transmission of AIDS in Africa." Annals of the Association of American Geographers, 80(2):300-301.

O'Brien, D., and J. Page. (1990). "The role of empowerment in Social Work Degree programs for Indigenous Native people: a critique of one school's experience." Canadian Journal of Native Studies (1990). Vol X, no 1:1-13.

Office of Minority Health (1990). Closing the Gap: AIDS/HIV Infection and Minorities. Washington D.C.: Department of Health and Human Services.

Ontario Native Women's Association (1989). A Proposal for Change to Aboriginal Family Violence. Ontario Native Women's Association: Thunder Bay.

Ornstein, M. (1989). AIDS in Canada: Knowledge, Behaviour and Attitudes of Adults. Toronto: University of Toronto Press.

Ostrow, D., editor (1990). Behavioural Aspects of AIDS. New York: Plenus Medical.

Packard, R.M., P. Epstein (1991). "Epidemiologists, social scientists and the structure of medical research in Africa." Social Science and Medicine, 33(7):771-794.

Padian, N. (1990). "Heterosexual Transmission: Infectivity and Risks." in N.J. Alexander, H.L. Gabelnick, J.M. Speiler (eds.) op. cit.:25-34.

Pagliaro, A.M. and L.A. Pagliaro, (1992) "Sentenced to death? HIV infection and AIDS in prisons - Current and future concerns." Canadian Journal of Criminology, 34:201-214.

Pagliaro, A. M., L.A. Pagliaro, P.C. Thauberger, D.S. Hewitt and J.R. Reddon (1992). Knowledge, Behaviours, and Self-Perception of Risk in Relation to HIV Infection and AIDS: Indigenous Peoples Studies. Paper submitted to Healing Our Spirit Worldwide Conference, July 8-9, 1992.

Panos Dossier (1990). The Third Epidemic: Repercussions of the Fear of AIDS. London: Panos.

Patron, E. J. (1991). "Native Americans with AIDS Struggle with Bureaucratic Red Tape and Little Access to Care." The Advocate, August 27, 1991:58-60.

Personal Narratives Group, editors (1989). Interpreting Women's Lives: Feminist Theory and Personal Narratives. Indiana University Press: Bloomington.

Peterman, T. A. (1990). "Facilitators of HIV Transmission During Sexual Contact." in N.J. Alexander, H. Gabelnick, J.M. Speiler op. cit.:55-68.

Peters, E. (1984). Native Households in Winnipeg: Strategies of Co-residence and Financial Support. Institute of Urban Studies Research and Working Papers No. 5. Winnipeg: University of Winnipeg.

Pickering, J. and C. James (1991). Attitudes and Knowledge of James Bay Cree with Respect to the Prevention of Sexually Transmitted Diseases and Teenage Pregnancies. Montreal: The Montreal General Hospital, Department of Community Health.

Platier, R. (1991). "Suicide Increase Troubles Natives," Globe and Mail, June 31, 1991:A1-A2.

Postl, B., M. Moffat and P. Sarsfield (1987). "Epidemiology and Interventions for Native Canadians." Canadian Journal of Public Health, 78:219-220.

Potterat, J., R. Rothenberg, D. Woodhorse, J. Muth, C. Pratts, J. Fogle (1985). "Gonorrhoea as a social disease." Sexually Transmitted Disease, 12:25-32.

Proceedings of the First Nations Health Transfer Forum. Convened by the Union of Ontario Indians and the Assembly of First Nations, November 28-30, 1990. Ottawa: Assembly of First Nations.

Procyk, R. (1992). "Swampy Cree AIDS project makes great gains." Canadian AIDS News, V(3):10.

Radford, J., D. Weatherbee and F. Mathews (1991). Young People Living with HIV. Toronto: Central Toronto Youth Services.

Radford, J.L., A. King and W.K. Warren (1989). Street Youth and AIDS. Ottawa: Health and Welfare Canada

Rees, W. (1986). "The Genesis and structure of the "Dene Gondie" study: what the people say about the Norman Wells Project." Canadian Journal of Native Studies, VI(1):141-157.

Rekart, M. (1992), British Columbia Centre for Disease Control. Personal communication, June 6, 1992.

Ricketts, Maura Dr., HIV/AIDS Division, Laboratory Centre for Disease Control. Personal communication, August 1991; July, 1992.

Roberts, E. (1988). "Health Care Providers: the solution or the problem?" in (ed.) D.E. Young op. cit.:31-40.

Rounds, K.A. (1988). "Responding to AIDS: Rural Community Strategies" Social Casework, June 1988:360-365.

Rowell, R. M. (1991). Warning Signs: Intravenous Drug Abuse Among American Indians/Alaskan Natives, 1991, Oakland: The Haworth Press.

Sabatier, R. (1989). AIDS and The Third World. Philadelphia: New Society Publishers.

----- (1988). Blaming Others: prejudice, race and worldwide AIDS. Philadelphia: New Society Publishers.

Sarsfield, P. (1988). "Health Issues in Northern Canada." in Health Care Issues in the Canadian North, David E. Young (ed.). Edmonton: Boreal Institute for Northern Studies.

Schechter, M.T., P.J. Ballem, N.A. Buskard, T.N. Le, M. Thompson, S.A. Marion, and M.V. O'Shaughnessy (1990). "An anonymous seroprevalence survey of HIV infection among pregnant women in British Columbia and the Yukon Territory." Canadian Medical Association Journal, 143(11):1188-1192.

Schoepf, B.G. (1990). "Ethical, Methodological and Political Issues of AIDS Research in Central Africa." Social Science and Medicine, 33(7):749-763).

Schwager, S.J., C. Castillo-Chavez, H.W. Hethcote (1989). "Epidemic Models, Empirical Studies, and Uncertainty." in (ed.) C. Castillo-Chavez, op. cit.:2-35.

Sekla, M.B., G. Hammond, W. Stackiw, G. Eibisch, and R. Tate (1991). "Manitoba HIV Seroprevalence Study." Canada Diseases Weekly Report, 17(33):179-184.

Shah, C. P. and C.S. Farkas (1985). "The health of Indians in Canadian cities: a challenge to the health care system." Canadian Medical Association Journal, 133:859-863.

Shah, C.P. (1988) "A National Overview of the Health for Native People Living in Canadian Cities." in Inner City Health: the Needs of Urban Natives. Proceedings of the Ninth Symposium on the Prevention of Handicapping Conditions:2-45.

Shannon, G.W. and G.F. Pyle (1989). "The Origin and Diffusion of AIDS: A View from Medical Geography." Annals of the Association of American Geographers, 79(1):1-24.

Shannon, G.W. and G.F. Pyle, and R.L. Bashur (1991). The Geography of AIDS: origins and course of an epidemic. Guilford Press: New York, 1991.

Shkilnyk, A.M. (1985). A Poison Stronger Than Love. Newhaven: Yale University Press.

Siegel, K., F.P. Mesagno, J-Y. Chen and G. Christ (1989). "Factors distinguishing homosexual males practicing risky and safer sex." Social Science and Medicine, 28(6):561-569.

Siggner, A.J. (1989). "The Inuit." Canadian Social Trends, Winter 1989, 15:8-10.

Slutkin, G. J. Leowski, J. Mann, editors (1988). "The effects of the AIDS epidemic on the tuberculosis problem and tuberculosis programmes," in (ed.) A.F.Fleming The Global Impact of AIDS:21-25

Smith, G.W. and E. Mitchell (1990). Getting "Hooked Up": An organisational study of the social-service delivery/access connection for people with HIV/AIDS, A Research Proposal. Unpublished.

Statistical Data Technical Working Group (SDTWG) (1991). Statistical Profile of Native Mental Health, Background Report #1 to Medical Services Branch Steering Committee on Native Mental Health. Ottawa: Medical Services Branch.

Statistics Canada (1991). Highlights of the Statistics Canada Presentation to the Royal Commission on Aboriginal Peoples. October 1991, Ottawa: Statistics Canada.

Steering Committee for First Nations and Inuit Mental Health (1991). Agenda for First Nations and Inuit Mental Health. Ottawa: Medical Services Branch.

Sutherland, Don Dr., Director, HIV/AIDS Division, Laboratory Centre for Disease Control. Personal communication, August 1992.

Tasaka, M. (1992). "New AIDS workplace program to serve Native people." Canadian AIDS News, 5(3):3.

Taylor, M. (1991). "Drug use in street kids is staggering." Toronto Star, August 4, 1991:B2.

Thouez, J-P. (1987). Organisation spatiale des systemes de soins. Montreal: Les Presses de l'Universite de Montreal.

Thouez, J-P., P. Foggin and A. Rannou (1990). "Correlates of Health-Care Use: Inuit and Cree of Northern Quebec." Social Science and Medicine, 30(1):25-34.

Toomey, K.E, A.G. Oberschelp and J.R. Greenspan (1989). "Sexually Transmitted Diseases and Native Americans: Trends in Reported Gonorrhoea and Syphilis Morbidity, 1984-88." Public Health Reports, 104(6):566-572.

Valverde, C. (1992). "James Bay Cree see 18-month turnaround in community support." Canadian AIDS News, 5(3):9.

Waldram, J.B. (1990). "Physician Utilization and Urban Native People in Saskatoon, Canada", Social Science and Medicine, 30(5):579-589.

Wallace, R. (1991a). "Social Disintegration and the Spread of AIDS: Thresholds for Propagation along 'Sociogeographic' Networks." Social Science and Medicine, 33(10):1155-1162.

----- (1991b). "Travelling Waves of HIV Infection on a Low Dimensional 'Socio-Geographic' Network." Social Science and Medicine, 32(7):847-852.

----- (1990). "Urban Desertification, Public Health and Public Order: 'Planned Shrinkage', Violent Death, Substance Abuse and AIDS in the Bronx." Social Science and Medicine, 31(7):801-813.

Watts, S.J. and R. Okello (1990). "Medical Geography and AIDS." Annals of the Association of American Geographers, 80(2):301-303.

Weller G.F. and P. Manga (1988). "The Feasibility of developing and integrated health care delivery system in the North: The case of Northwestern Ontario." in Health Care Issues in the Canadian North, David E. Young (ed.), Edmonton: Boreal Institute for Northern Studies.

Willms, S.M., M.V. Hayes and J.D. Hulchanski (1991). Choice, Voice and Dignity: Housing Issues and Options for Persons with HIV infection in Canada, A National Study. Vancouver: UBC Centre for Human Settlements.

Wood, W.B. (1988). "AIDS north and south: Diffusion patterns of a global epidemic and a research agenda for geographers." Professional Geographer, 40:266-279.

Worth, D. (1990). "Minority Women and AIDS: Culture, Race and Gender." in ed. Feldman, D. op. cit.: 111-135.

Wortman, J. (1992). "AIDS awareness grows among Aboriginal people", Canadian AIDS News, 1992, 5(3):5.

Young, D.E., editor (1988). Health Care Issues in the Canadian North. Edmonton: Boreal Institute for Northern Studies.

APPENDIX 1

GLOSSARY

ABORIGINAL: refers to Canadians of Aboriginal descent ie., Status and non-Status Indians, Metis, and Inuit peoples. In this study it is used interchangeably with Native peoples and Indigenous peoples

AIDS (acquired immunodeficiency syndrome): a syndrome which impairs the bodies ability to fight infection. Immunosuppression weakens the bodies resistance to a variety of infections, viruses and malignancies called opportunistic infections.

ANONYMOUS TESTING: when blood is taken to be tested for the presence of HIV antibodies, the sample is identified only by a number. The testing institution has no record of the identity of the individual being tested. It is believed that anonymous testing increases the number of people coming forward to be tested.

ASYMPTOMATIC: infection without symptoms. A person with HIV may not show symptoms of infection.

AZT (Zidovudine): was the first antiretroviral agent to be licensed for the treatment of HIV. It is believed to slow progression in people with asymptomatic or mildly symptomatic HIV and prolong survival in people with more severe infection. It can cause severe side effects in some people. Its long term effectiveness has been questioned. It is only effective for limited periods of time so it may be taken for a period (usually a year), and rotated with other drugs eg. ddI.

BAND: a body of Status/Registered Indian people recognised by the government for whose benefit use land and money have been set aside and held by the government.

BILL C-31: (and 1985 amendments to the Indian Act), Bill C-31 was passed in 1985 to expand the definition of who could apply for status. It was designed to amend (some) of the discriminatory aspects of the Indian Act, particularly those discriminating against women. It has had a significant impact, increasing the 'official' population.

CHLAMYDIA (Chlamydia trachomatis): one of the most common sexually transmitted diseases particularly among young adults and adolescents. It causes urethral infections, inflammation of the cervix. Long term consequences of undetected chlamydia may be pelvic inflammatory disease, ectopic pregnancies and infertility.

CLINICAL TRIALS: drug trials that use people to test the efficiency, safety and appropriate dose levels of a drug. They follow laboratory and animal testing. There has been some discussion that clinical trials of some drugs have tended to exclude

women, minorities and drug users.

COFACTOR: a condition, agent or activity which may increase a persons vulnerability to HIV infection or stimulate the development of AIDS.

CONFIDENTIAL TESTING: when blood is taken for testing it is identified by the individuals name. Incidence where confidentiality has not been respected and an unwillingness of some individuals to identify themselves has discredited this method of testing - see anonymous testing.

DEPARTMENT OF INDIAN AFFAIRS AND NORTHERN DEVELOPMENT (DIAND): the Department that administers the duties, powers and functions that fall under the Indian Act.

EXPOSURE CATEGORY: or transmission category. The way the virus passes from one person to another eg., homosexual/bisexual contact, injection drug use, heterosexual sex.

HEPATITIS B (HBV): is transmitted most commonly and efficiently through percutaneous, sexual and perinatal exposures. It is primarily a sexually transmitted disease. Can cause death. Notifiable in Canada since 1969 - surveillance case definitions changed greatly between 1980-1989.

HIGH RISK BEHAVIOUR: activities which increase the possibility of HIV being transmitted eg., unprotected penetrative or oral sex or needle sharing.

HIV (human immunodeficiency virus): a retrovirus which is thought to be the sole or major cause of AIDS.

HIV POSITIVE: when a persons blood has tested positive for HIV antibodies.

HIV TESTING: most tests do not directly test for HIV, but for the existence of HIV antibodies. HIV antibodies may not exist in sufficient numbers to be tested for between 3- 6 months after infection. Elisa and Western Blot are the most common tests used.

IMMUNE SYSTEM: the bodies system of fighting disease producing agents and other toxic foreign substances. Specific antibodies are produced to attack the invading agent.

IMMUNOSUPPRESSION: weakening of the immune system and its ability to respond to infection. It is associated with HIV, and some anti-viral and anti-cancer treatments. A persons immune system is thought to become less efficient or suppressed when it has to fight many infections simultaneously.

INDIAN ACT: Federal legislation first passed in 1876 which, with amendments, defines who the government will recognise as Indian, Inuit or Metis. People who fall outside the scope of the Act are not recognised as being Aboriginal by the Federal government which takes no responsibility for them.

INUIT: Native people who have traditionally lived north of the tree line in Northern Canada (NWT, Labrador, and Quebec).

MANDATORY TESTING: testing a person for infection without their consent and/or without their knowledge.

METIS: the term Metis has different meanings for different people. It may refer to people of Aboriginal ancestry who descend from the Metis community of Western Canada. It may also be used to refer to anyone of mixed descent who identifies themselves as Metis.

NON-STATUS INDIANS: people of Aboriginal descent who do not meet the criteria for registration under the Indian Act and who are usually excluded from official data and studies.

OPPORTUNISTIC INFECTIONS: infections which develop in people who are immunosuppressed, but which are not normally found in people who have healthy immune systems. Opportunistic infections associated with AIDS include PCP, CMV, MAI, and toxoplasmosis. Pelvic inflammatory disease, HPV, chronic vaginitis, chlamydia and endocarditis are common opportunistic infections affecting women with AIDS.

REPORTED AIDS CASES: Doctors are responsible for reporting AIDS cases. When a case is diagnosed they complete a standard Case Report Form which is sent to the local Medical Officer for Health who then forwards them to the provincial Ministry of Health or AIDS coordinator who then sends them to the Laboratory for Disease control. There is no requirement to report native AIDS cases to Medical Services

REPORTING LAG: the time taken for a case to be diagnosed and then reported - in Canada this may range from six months to a year and a half. It occurs because of the time taken for reports to move through the system and because of the time it takes doctors to make a final AIDS diagnosis

RESERVE: land set aside for the use and benefit of a Band, the legal title is held by the crown. It is subject to the terms of the Indian Act.

SK FACTOR: anything that influences a persons chances of getting a disease

SAFER SEX: sexual activities which attempt to reduce the risk of HIV transmission, eg. using condoms, dental dams, avoiding penetration etc.

SEROCONVERSION: the development of antibodies to an antigen, eg HIV antibodies.

SEROPOSITIVE: when antibodies to an antigen have been found in the blood, the test is positive. eg. HIV+

SEXUALLY TRANSMITTED DISEASE (STD): a disease which is transmitted through the exchange of bodily fluids. This may include kissing, or vaginal, anal or oral sexual intercourse. Common STDs include chlamydia, gonorrhoea, syphilis, hepatitis B, herpes, chancroid trichomas and other gonococcal diseases and HIV. HIV cannot be transmitted by kissing.

STATUS INDIAN: refers to Registered or Status Indian people as defined by the Indian Act. DIAND holds a list of all Registered Indians. The majority of available data, particularly official data, applies only to Status Indians. Inuit people may also be included in official data.

SYPHILIS: an STD which is transmissible by kissing, oral or penetrative unprotected sexual intercourse. It can be serious if left untreated causing paralysis, dementia and death. It is strongly associated with HIV infection. More controversially some scientists argue that syphilis is a cofactor in the development of AIDS, even more controversially some, like have linked AIDS to a mutation of syphilis, not HIV.

T-CELLS: lymphocytes (white blood cells) which control the immune system. HIV encodes itself onto the structure of the T-cells destroying the immune system in the process. It is believed that HIV when activated causes an overproduction of T-8 cells (suppressors) and inhibits the production of T-4 cells (helpers), causing immunosuppression.

UNDER-REPORTING: It is estimated that 15 to 25 % of AIDS cases are not reported. Some of the reasons are: the disease is not diagnosed; patients or their families may ask the doctor not to report them as having AIDS; doctors may not have diagnosed AIDS as the cause of death; overworked doctors may not fill in the reporting form.

WESTERN BLOT: a blood test indicating the presence of HIV anti-bodies. It is usually used to confirm positive ELISA tests.

APPENDIX 2REPORTED CASES OF AIDS IN CANADA - JULY 19921. ALL CASES

		<u>Alive</u>	<u>Deaths</u>	<u>Known Total</u>
<u>Adults:</u>	Males	2303	3842	6144
	Females	123	221	344
	Subtotal	2425	4063	6488
<u>Children:</u>	Males	13	23	36
	Females	10	26	36
	Subtotal	23	49	72
TOTAL		2448	4112	6560

2. ADULT CASES BY RISK FACTOR

<u>Risk Factors</u>	<u>All Cases (%)</u>	<u>Males (%)</u>	<u>Females (%)</u>
Homosexual/bisexual activity	5087 (78)	5087 (83)	-----
Injection drug use	125 (2)	91 (2)	34 (10)
Both of the above	229 (4)	229 (4)	-----
Recipient of blood	145 (2)	81 (1)	58 (17)
Recipient of blood products	138 (2)	127 (2)	11 (3)
Heterosexual activity*			
a) origin in pattern-II country	263 (4)	166 (3)	97 (28)
b) sexual contact with person at risk	259 (4)	143 (2)	116 (34)
No identified risk factors	242 (4)	214 (4)	27 (8)
TOTAL	6488	6144	344

3. GEOGRAPHIC DISTRIBUTION

<u>Province*</u>	<u>Male</u>	<u>Female</u>	<u>Total (%)</u>	<u>Deaths</u>	Known
British Columbia	1189	23	1212 (18)	752	
Alberta	401	18	419 (6)	144	
Saskatchewan	54	3	57 (1)	38	
Manitoba	71	3	74 (1)	49	
Ontario	2504	96	2600 (40)	1937	
Quebec	1796	219	2015 (31)	1090	
New Brunswick	45	6	51 (<1)	19	
Nova Scotia	89	8	97 (1)	62	
P.E.I.	4	0	4 (<1)	4	
Newfoundland	22	4	26 (<1)	1	
N.W.T.	3	0	3 (<1)	0	
Yukon	2	0	2 (<1)	1	

*Cases are attributed to the province where onset of illness occurred.

Source: HIV/AIDS Division (1992). Quarterly Surveillance Update: AIDS in Canada.
July 1992. Ottawa: Laboratory Centre for Disease Control.

APPENDIX 3

REPORTED AIDS CASES IN THE ABORIGINAL POPULATION OF CANADA - JULY 1992

This data is unreliable and unrepresentative of risk (as outlined in the main text), and should be read with caution (Sutherland, personal communication, July 1992).

1. ALL CASES

Males:	47
Females:	6
<hr/>	
Total:	53

2. REPORTED CASES BY ETHNICITY

	<u>Number</u>	<u>(%)</u>
Aboriginal people	53	<1
Caucasian	3,079	47
Other	375	6
Unknown	3,053	46

3. RISK FACTORS

<u>Risk factor</u>	<u>Male</u>	<u>Female</u>	<u>All</u>
Homosexual/bisexual activity	38	-	38
Injection drug use	1	2	3
Both of the above	6	-	6
Recipient of blood transfusion or blood product	1	1	2
Heterosexual	1	2	3
Perinatal	-	1	1

4. REPORTED CASES BY YEAR, 1988-1992

<u>1988</u>	<u>1989</u>	<u>1990</u>	<u>1991</u>	<u>1992*</u>
3	6	7	23	53

*Reported cases by July 1992, all other years run January to December.

Source: Sutherland, personal communication, July 1992.

APPENDIX 4**REPORTED CASES OF AIDS IN THE UNITED STATES****1. AIDS CASES BY EXPOSURE CATEGORY, AND RACE/ETHNICITY*,
REPORTED THROUGH NOVEMBER 1991, UNITED STATES**

	White** No. (%)	Black** No. (%)	Hispanic No. (%)	American Indian Alaska Native No. (%)
Men who have sex with men	82,065 (76)	20,149 (35)	13,032 (40)	172 (55)
Injecting drug use (IDU)	9,103 (8)	22,493 (39)	12,968 (40)	57 (18)
Men who have sex with men and IDU	7,463 (7)	3,521 (6)	1,887 (6)	41 (13)
Hemophilia/ coagulation disorder	1,381 (1)	131 (0)	136 (0)	8 (3)
Heterosexual contact	2,455 (2)	6,904 (12)	2,162 (7)	13 (4)
Blood transfusion, blood components, or tissue	2,975 (1)	758 (1)	471 (1)	6 (2)
Other/ Undetermined	2,616 (2)	3,021 (5)	1,682 (5)	16 (5)
Total	108,058	56,977	32,356	313

* data for Asian/Pacific Islander people not shown

** not Hispanic

**2. ADULT/ADOLESCENT AIDS CASES BY EXPOSURE CATEGORY, AND SEX
REPORTED THROUGH NOVEMBER 1991**

Exposure category	Males No. (%)	Females No. (%)	Total No. (%)
Men who have sex with men	116,609 (65)	-	116,609 (58)
Injecting drug use	34,309 (19)	10,482 (51)	44,791 (22)
Men who have sex with men and inject drugs	12,953 (7)	-	12,953 (6)
Hemophilia/coagulation disorder	1,641 (1)	39 (0)	1,680 (1)
Heterosexual contact	4,558 (3)	7,051 (34)	11,069 (6)
Blood transfusion, blood components	2,650 (2)	1,656 (8)	4,306 (2)
Other/undetermined	5,958 (3)	1,511 (7)	7,469 (4)
Total	178,678	20,739	199,417

Source: Centre for Disease Control (1991). HIV/AIDS Surveillance U.S. cases
reported through November 1991. Atlanta: CDC.

APPENDIX 5

**QUESTIONNAIRE, LETTER OF INTRODUCTION, CONSENT FORM,
LETTER TO DISTRIBUTING ORGANISATIONS,
AND LETTER TO HEALTH CENTRES**

QUESTIONNAIRE

Code No:

If you would rather talk to me than fill this out, call me COLLECT on (613) 234 2514 and we can talk on the phone or arrange to meet.

This should take about 20 minutes to fill out. You do not have to answer every question if you don't want to. For some questions you may want to tick more than one answer. If you have anything to say about the questionnaire or want to add anything of your own, please write on the back.

Not much is known about people who are living with HIV and AIDS. By understanding who you are, and what problems you have getting what you need may mean that in future services can be provided better. The questions which are about you and where you live will help build a picture which may help to target education and prevention programmes, and to predict how much HIV will spread in Aboriginal communities.

ABOUT YOU

male ____ female ____ age ____

Are you "Registered" under the Indian Act? yes ____ no ____

Are you married or do you live with a partner? yes ____ no ____

Do you have children? yes ____ no ____

When did you test positive for HIV? _____

WHERE DO YOU LIVE

Do you live on reserve ____ off-reserve ____ both ____

How long have you lived in the community where you live? _____

Why do you live where you live? - to be near family ____

to be near friends ____

to be near work ____

to be near medical services ____

to be near husband/wife, ____

partner/lover ____

other reasons _____

Have you moved since testing positive? yes ____ no ____

- if yes, Why? _____

Would you rather live somewhere else? yes ____ no ____

- if yes, Where? _____

Why? _____

Did you move in the last	1 - 6 months	_____
	6m - 1 year	_____
	1 - 2 years	_____
	2 - 5 years	_____
	over 5 years	_____
	never moved	_____

If you live in a city - do you live in the "inner city"	_____
the suburbs	_____
somewhere in between	_____

Roughly how big is the community you live in?	
	rural area _____
	100 - 1,000 people _____
	1,000 - 5,000 people _____
	5,000 - 10,000 people _____
	10,000 - 100,000 people _____
	100,000 - 300,000 people _____
	over 300,000 people _____

HOUSING

Where do you usually sleep?	no fixed address	_____
	shelter	_____
	rooming house	_____
	house or apartment by yourself	_____
	house or apartment with friends	_____
	house or apartment with family	_____
	house or apartment with husband/wife	_____
	partner/lover	_____
other	_____	_____

Do you share a room with someone who
isn't your lover/partner, husband or wife?

yes ___ no ___

Which rooms do you share?

bedroom	___	with friends or family?	___	strangers?	___
bathroom	___	"	"	"	___
kitchen	___	"	"	"	___
living room	___	"	"	"	___

How many people live where you live? _____

How many rooms does your home have ? _____

Do you have - central heating?

yes ___ no ___

What floor do you live on? _____

Is there an elevator?

yes ___ no ___

WORK AND INCOME

Do you have a paid job?

yes ___ no ___

do work for yourself?

Do you get unemployment benefits?

welfare?

disability allowances?

Has your job changed since you tested positive?

if yes,

How? _____

If you changed jobs or became unemployed did it have anything to do with your
testing positive or the state of your health? _____

How much is your total income -

under \$500 per month ___

\$500 - 1000 per month ___

\$1000 - 3000 per month ___

over \$3000 per month ___

Do you have enough money to:

buy the food you need?	yes	___	no	___
buy any medicine you need?		___		___
pay your rent		___		___
pay hydro/heating bills		___		___
buy winter clothes/shoes		___		___

How many people do you support on your income? _____

Is lack of money a constant worry for you? _____

SUPPORT AND SERVICES

Because everybody has different needs which change, and because people get different services and support, it is difficult to find out what, and where you need things from a questionnaire. I hope some of these questions will help, but it would be good to talk to you so that you can tell me yourself what you need to maintain your health.

	Yes	No	Need more
Do you get enough support from			
- family?	1	2	3
- friends?	1	2	3
Do you use agencies like Friendship Centres and AIDS Organisations for help?	1	2	3

What kinds of organisations do you go to for support and services?

You may be using all kinds of services - or none. Please fill out the following two questions (which are the same), by putting in the two most important services you USE (if you use two):

eg. medical treatment (which could be provided by a Doctor, hospital, community health centre), housing, home care services, counselling, child care, housing emotional support:

1) What kind of service? _____

Who provides it? _____

How often do you use it?

once a week _____ every two weeks _____ once a month _____ other _____

How often would you like to use it?

once a week _____ every two weeks _____ once a month _____ other _____

Is the service you get? good _____ bad _____ could be better _____

Do have problems getting to it or using it? yes _____ no _____

If yes, why?

my health makes it difficult to get there _____

it costs too much to travel _____

its too far to go _____

it costs too much _____

I don't feel comfortable there _____

Other reasons _____

2) REPEATED QUESTION 1

Please fill out the following two questions (which are the same), by putting in the two services you feel you NEED most but DON'T GET eg. medical treatment,(which could be provided by a doctor, hospital, community health centre), housing, home care services, counselling, child care, housing, emotional support:

3) What kind of service? _____

How often would you like to be able to use it?

once a week ____ every two weeks ____ once a month ____ other ____

Why can't you get what you need?

my health makes it difficult to get there ____

it costs too much to travel ____

its too far to go ____

it costs too much ____

I don't know where to go to get it ____

its not available ____

I don't feel comfortable there ____

Other _____

4) REPEATED QUESTION 3

What other services and/or support do you think you need? _____

Are they available where you live? yes ____ no ____ don't know ____

If there is anything else that you would like to say about HIV or AIDS and how it has affected you and your life, or if you want to say more about your needs and how they are being met, please use this page. You can also use this space if you have any comments to make about the questionnaire.

Thankyou for filling out the questionnaire. Please return it with the letter of consent in the stamped addressed envelope.

If you would like to talk to me, and/or if you would like to see the results of the study when I have finished it, so that you can comment on what I have said, please give me an address or phone number where you can be contacted. This will be kept separately from the information you give me so that you are completely anonymous.

Sally Peberdy

Address and telephone number

LETTER OF INTRODUCTION TO PARTICIPANTS

I am doing a study to find out what services and support Aboriginal people who are living with HIV and AIDS need. I would like to know where you need services and who you want them provided by.

I will be giving the results of the study to the Joint National Committee for Aboriginal AIDS Education and Prevention. The Committee is made up of representatives from national Aboriginal Organisations including the Assembly of First Nations, the Native Council of Canada, the National Association of Friendship Centres and the Indian and Inuit Nurses Association. The Committee helped me to decide what I should study. I will be referring everything I do to them.

I am a graduate student at Carleton University.

QUESTIONNAIRE AND INTERVIEWS

I would like you to fill in a questionnaire. I am asking organisations who may be providing services and support to people who have tested positive for HIV to distribute the questionnaire. It asks questions about you, your living conditions, your income, and the services and support you receive. I would be grateful if you could fill it out.

If you do not want to fill out the questionnaire, or if you want to talk to me after filling it out, please call me COLLECT so that I can talk to you on the phone or arrange a meeting. My number is at the end of this letter.

Questionnaires can only provide basic information. They do not let you speak for yourself. If I can talk to you, you can tell me what you need in your own words. My number is at the end of this letter.

The questionnaire should take about 20 minutes to fill out. An interview would take as long as you wanted it to - probably about an half an hour to an hour.

PURPOSE OF THE STUDY

Services for people living with AIDS and HIV have been designed for non-Native people. Aboriginal people may have different problems and needs, and may want services to be provided differently. People need all kinds of services, like money, housing, emotional support, medical treatment, help in the house, child care etc. This study will hopefully provide information about people living with HIV and AIDS, their circumstances, and identify where services need to be provided and who should be providing them.

It is important that you have the opportunity to say not only, what kind of services you are using, but what kind of services you need, where you want them, and who you think should be providing them.

The study is in two parts. The first looks at the AIDS epidemic in Canada, and how it is affecting and will affect Aboriginal communities. The second looks at how the needs of aboriginal people living with HIV and AIDS are being met.

CONFIDENTIALITY

You can be assured that all the information you give me will be kept confidential. I do not need to know your name or address. The questionnaires will be seen only by myself and the Joint National Committee. It will not be possible to identify you when the results are written up.

If for any reason you give me a name and address (they don't have to be yours), they will be kept separately from the rest of the information. They will not be able to be linked to surveys or records of interviews. They will be destroyed at the end of the study. Unless you wish otherwise, the results of the questionnaires will be put together so that you cannot be identified from the information you have given about yourself.

RIGHT TO REPLY

If you decide to take part, I would like you to see what I have concluded from the information I get from the questionnaires and interviews. If you disagree with my conclusions, your disagreements will be included in the final copy. This should help to ensure that you are not misrepresented in any way. Please give a number or address so that I can send what I have written to you.

WITHDRAWING

Please can you sign the consent form if you want to take part.

You can withdraw from the study at any time, even after signing the consent form. Any information that you have already given me will be destroyed.

GENERAL INFORMATION

When you have filled in the questionnaire and letter of consent, please send them back to me in the stamped addressed envelope provided.

If you want to talk to me please call me collect, or send me your phone number or address so that we can arrange a time to talk. If I am not able to answer when you call, please leave your first name and phone number on my answering machine, and I will call you back.

If you have any questions about the study, you can contact me by calling collect at (613) 234 2514.

Thankyou for your time.

INFORMED CONSENT AGREEMENT

**PLEASE SIGN THIS AND RETURN IT WITH THE QUESTIONNAIRE IN
THE STAMPED ADDRESSED ENVELOPE**

I have read the information about the study, and have had an opportunity to ask questions to help me understand what my participation will involve. My signature below indicates that the study and procedures have been explained to me in terms I can understand.

I agree to participate in the study.

I understand that I can withdraw from the study at any time, and that any information that I may have already given will be destroyed.

I will allow the information that I give to be shared with the Joint National Committee for Aboriginal AIDS Education and Prevention on the condition that my confidentiality is preserved.

Signature of participant

Date

Signature of researcher
Sally Peberdy

Date

LETTER TO DISTRIBUTING ORGANISATIONS (see Appendix 6)

Thankyou for agreeing to distribute the enclosed questionnaires. Please could you pass them with the letter of introduction, the consent form and the stamped addressed envelope, to any aboriginal person living with AIDS or HIV that you are providing services or support to. They can then decide if they want to participate.

I would like them to fill in the questionnaire which will provide information about who has tested positive, their living conditions, income and the services and support that they receive. If someone does not want to fill out the questionnaire, has problems reading or writing, or does not like the questions on the questionnaire but would still like to take part they can call me COLLECT, and I can then talk to them over the phone. I would like to talk to as many people as possible, as questionnaires do not allow people to speak for themselves.

As I explained on the phone, the purpose of the study is to find out what services and support are needed by aboriginal people living with HIV and AIDS, where they want resources, and who they want them to be provided by. The study will be given to the Joint National Committee for Aboriginal Education and Prevention. I am referring everything I do to them for their comments and approval.

The study, which will also form part of my work as a Graduate Student at Carleton University in Ottawa, is in two parts. The first part looks at the AIDS epidemic in Canada, and how it is affecting and may affect aboriginal communities in the future. The second part looks at how the needs of Aboriginal people living with AIDS and HIV are being met. It is hoped that the study will provide information about who is living with AIDS and HIV and their circumstances, which may help in identifying gaps in service provision and to target education and prevention programs.

All information given will be kept confidential. I do not need to know anyone's name or address. The questionnaires will be seen only by myself and will be given to the Joint National Committee when the study is finished. I will aggregate the data so it will not be possible to identify an individual when the results are written up. If people provide a name and an address where they can be contacted so that they can participate in the interviews and/or see the results, it will be coded and kept separately from the rest of the information, and destroyed as soon as it is no longer needed. Participants can withdraw from the study at any time.

If participants are interested, they can comment on the results when I have written them up. Their comments will be incorporated into the final copy.

If you have any questions, please do not hesitate to contact me.

Yours etc.

LETTER TO HEALTH CENTRES (see Appendix 7)

Dear

I would be grateful if you could help me. I am doing a study to find out what services and support are needed by aboriginal people living with HIV and AIDS, where they want resources, and who they want them to be provided by.

I will be giving the results of the study to the Joint National Committee for Aboriginal AIDS Education and Prevention. The Committee is made up of representatives from all national aboriginal organisations, including the Assembly of First Nations, the Native Council of Canada, The National Association of Friendship Centres, and the Native Nurses Association. The Committee helped me decide what I should study. I am referring everything I do to them for their comments. The study will also form part of my work as a graduate student at Carleton University.

I am gathering the information by asking people with HIV and AIDS to either talk to me, or fill out a questionnaire. I am asking organisations which may be providing services and support to aboriginal people living with AIDS and HIV to distribute the questionnaire and give my phone number to any people that they are providing support or services to.

The study is in two parts. The first part looks at the AIDS epidemic in Canada, and how it is affecting and will affect aboriginal communities. The second part looks at how the needs of aboriginal people living with HIV and AIDS are being met. Services for people living with HIV and AIDS have mainly been designed for non-aboriginal people, and therefore may not meet the needs of aboriginal people living with AIDS and HIV. The study should provide information about who is living with AIDS and HIV, their circumstances, and identify gaps in service provision.

Please could you pass my phone number to anyone that you are providing services to, and ask them to call me COLLECT if they want to take part. If the person does not want to talk to me directly, but would like to take part, please contact me and I will send you a copy of the questionnaire to give to them.

I will be asking people questions about themselves, their housing, their income, and the services and support that they receive. I would like to talk to as many people as possible so that they can tell me what services they use, and would like to be able use in their own words.

All information given will be kept confidential. I do not need to know anyone's name or address. The questionnaires will be seen only by myself and will be given to the Joint National Committee when the study is finished. I will aggregate the data so it will not be possible to identify an individual when the results are written up. If people provide a name, address or phone number where they can be contacted, it will be coded and kept separately from the rest of the information, and destroyed as soon as it is no longer needed.

Participants can withdraw from the study at any time. If participants are interested, they can comment on the results when I have written them up. Their comments will be incorporated into the final copy.

If you have any questions or comments about the study, please do not hesitate to contact me.

Yours etc.

APPENDIX 6**BRITISH COLUMBIA**

AIDS Vancouver Island
304-733 Johnson Street
Victoria, BC
V8W 3C7

Vancouver PWA Society
1447 Hornby Street
Vancouver BC V6Z 1W8

AIDS Vancouver
1272 Richards Street
Vancouver BC
V6B 3G2

Nu-Chah-Nulth Health Board
P.O.Box 1280
Port Alberni, V9Y 7M2

ALBERTA

AIDS Network of Edmonton Society
2nd Floor
10704 108th Street
Edmonton, T5H 3A3

AIDS Calgary Awareness Assoc.
1000-1021 10th Avenue, S.W. Calgary
Alberta T3R 0B7

Feather of Hope Aboriginal AIDS
Prevention Society
2nd Floor
10704 108th Street
Edmonton, T5H 3A3

AIDS: A positive co-ordinated
response society of Jasper
P.O.Box 1090
Jasper T0E 1E0

South Peace AIDS Council
P.O.Box 902
Grande Prairie, Alb T8V 3Y1

Lethbridge AIDS Connection Society
421, 515 - 7 Street South
Lethbridge, T1J 2G6

Health Unit
Box 727
Fort McLeod, T0L 0Z0

Central Alberta AIDS Network Society
4935 51 Street
Red Deer, T4N 2A8

SASKATCHEWAN

AIDS Saskatoon
P.O.Box ???
Saskatoon S7K 4E3

AIDS Regina
P.O.Box 432
Regina, S4P 3A2

MANITOBA

Manitoba Aboriginal AIDS Task Force
 Apartment 18
 212 Langside
 Winnipeg, R3C 1Z7

Village Clinic
 688 Corydon Avenue
 Winnipeg, R3M 0X7

ONTARIO

Anishnawabe Health Centre
 225 Queen Street East
 Toronto, M5A 1S4

AIDS Committee of London
 301 - 343 Richmond Street
 London N6A 3C2

Two Spirited Peoples of
 the First Nations
 476 Parliament Street
 Suite 202
 Toronto, M4X 1P2

AIDS Committee of Cambridge
 Kitchener/Waterloo and Area
 13-1601 River Road East
 Kitchener N2A 3Y4

Native Child and Family Services of
 Toronto
 22 Collet Street, Suite 101
 Toronto, M5G 1K2

AIDS Committee of Guelph and
 Wellington County
 202-73 Delhi Street
 Guelph N1E 6L9

Street Outreach Services of Toronto
 622 Yonge Street
 2nd floor
 Toronto, M4Y 1Z8

AIDS Committee of Niagara
 541 Glenridge Avenue
 St Catharines, L2R 6S5

Youth Link Inner City
 151 Gerard Street E
 Toronto, M6H 3B7

AIDS Committee of Windsor
 P.O.Box 7186
 Windsor N9C 3Z1

AIDS Committee of Toronto
 202-464 Yonge Street
 Toronto M4Y 1W9

Hamilton AIDS Network for
 Dialogue and Support
 900-143 James Street South
 Hamilton, L8P 3A1

Toronto PWA Foundation
 201B-464 Yonge Street
 Toronto M4Y 1W9

AIDS Committee of Durham Region
 22 Simcoe Street N
 Oshawa, L1G 4R8

Casey House Hospice Inc.
 9 Huntley Street
 Toronto, M4Y 2K8

Kingston AIDS Project
 P.O.Box 120
 Kingston, K7L 4V6

AIDS Committee of Thunder Bay
P.O.Box 3586
Thunder bay, P7B 6E2

AIDS Committee of Sudbury/
Comite du sida de Sudbury
23 Durham Street
Sudbury, P3C 5E2

Peterborough AIDS Resource Network
P.O.Box 1582
Peterborough, K9J 7H7

AIDS Committee of Ottawa/
Comite du SIDA d'Ottawa
201-267 Dalhousie Street
Ottawa, K1N 7E3

QUEBEC

Comite sida aide Montreal (C-SAM)
3600 Hotel-de-Ville
Montreal, H2X 3B6

Chez Ma Cousine
3809 Laval
Montreal, H2W 2H

Centre Pierre Henault Inc.
1732 rue Orleans
Montreal, H1W 3r3

Mouvement d'information,
d'education et d'entraide dans
la lutte contre le sida (MIENS)
c.p. 723
Chicoutimi, G7H 5E1

Bureau local d'intervention
traitant du sida (BLITS)
59, Monfette Local 110
Victoriaville, G6P 1J8

Mouvement d'information et
d'entraide dans la lutte contra la sida a
Quebec (MIELS Quebec)
575 ouest, boulevard St-Cyrille
Quebec, G1S 1S6

Bureau regiona' d'action sida (BRAS)
811 boul. St-Rene ouest
Piece 700
Gatineau, J8R 2S4

SIDA/AIDS Information & Ressources
Quebec Sud-Ouest
C.P. 10
St-Chrysostome, J0S 1R0

NEW BRUNSWICK

SIDA Nouveau-Brunswick/
AIDS New Brunswick
65 Brunswick Street
Fredericton, E3B 1G5

SIDA-AIDS Moncton
100 Arden Street, Suite 427
Professional Arts Building
Moncton, E1C 4B7

AIDS St John
116 Coburg Street
St John, E2L 3K1

NOVA SCOTIA

AIDS Nova Scotia
5224 Blowers Street
Suite 206
Halifax, B3J 1J7

Nova Scotial PWA Coalition
P.O.Box 1374
Postal Station North
Halifax, B3K 5H7

P.E.I.

AIDS P.E.I.
P.O.Box 2762
Charlottetown, C1A 8C4

NEWFOUNDLAND AND LABRADOR

Newfoundland and Labrador AIDS
Committee
P.O.Box 626
Station "C"
St John's, A1C 5k8

NORTH WEST TERRITORIES

NWT AIDS Program
Department of Health
Government of the N.W.T.
P.O.Box 1320
Yellowknife X1A 2L6

YUKON

Yukon AIDS Program
Skookum Jim Friendship Centre
3159 3rd Avenue
Whitehorse, R3B 2K3

APPENDIX 7**BRITISH COLUMBIA**

Adolescents Street Unit
575 Drake Street
Vancouver
British Columbia V6B 4K8

Anaham Reserve Health Services
Box 88
Alexis Creek
British Columbia V0L 1A0

Gitwinksihlkw Health Centre
Box 1
Gitwinksihlkw
British Columbia V0J 1A0

Health Services
Kincolith Indian Band
Kincolith
British Columbia V0V 1B0

Kakawis Family Development Centre
Meares Island
Box 17
Tofino
British Columbia V0R 2Z0

Lakalzap Health Clinic
Greenville
British Columbia V0J 1X0

Mount Currie Health Centre
Box 165
Mount Currie
British Columbia V0N 2K0

Nanaimo Indian Health Centre
1145 Totem Road
Nanaimo
British Columbia V9R 1H1

Nimkish Health Centre
Box 290
Alert Bay
British Columbia V0N 1A0

Nisga'a Valley Health Centre
New Aiyansh
British Columbia V0J 1A0

Nisga'a Social Services Society
327 Adanac Street
Vancouver
British Columbia V5K 2P4

Okanagan Self-help Project
Okanagan Indian Band
RR 7, Comp 20, Site 18
Vernon
British Columbia V1T 7Z3

Urban Native Youth Association
2929 Commercial Drive
Vancouver
British Columbia V5N 4C8

Vancouver Native Health Society
200-73 Water Street
Vancouver
British Columbia V6B 1A1

ALBERTA

Alexis-Stoney Tribe Health Centre
Box 7
Glenevis
Alberta T0E 0X0

Atikameg Health Centre
Atikameg
Alberta T0G 0C0

Battlefords Indian Health Centre
Box 250
North Battleford
Saskatchewan S9A 2Y1

Beardys and Okemasis Health
Box 96
Duck Lake
Saskatchewan S0K 1J0

Beaver Lake Health Centre
Box 90
Lac La Biche
Alberta T0A 2C0

Blood Indian Hospital
Box 490
Cardston
Alberta T0K 0K0

Calling Lake Health Centre
Calling Lake
Alberta T0L 1Y0

Chipewyan Lake Health Centre
Chipewyan
Alberta T0G 0V0

Cold Lake Health Centre
Box 1109
Cold Lake
Alberta T0A 0V0

Goodfish Lake Health Centre
Goodfish Lake
Alberta T0A 1R0

Heart Lake Health Centre
Box 1950
Lac La Biche
Alberta T0A 2C0

Hobbema Indian Health Services
Box 100
Hobbema
Alberta T0C 1N0

Horse Lake Health Centre
Box 128
Hythe
Alberta T0H 0C0

Janvier Health Centre
Chard
Alberta T0A 0S0

Jean D'Or Health Centre
Box 124
Fort Vermillion
Alberta T0H 1N0

Kehewin Health Centre
Box 550
Bonnyville
Alberta T0A 0L0

Little Buffalo Health Station
Box 2038
Peace River
Alberta T0H 0L0

Meander River Health Station
c/o High Level Health Unit
Bag 400
High Level

Driftpile Health Centre
Driftpile
Alberta TOG 0V0

Duncan Health Centre
Box 125
Brownvale
Alberta T0H 0L0

Eden Valley Health Centre
Box 178
Black Diamond
Alberta T0L 0H0

Enoch Health Centre
Box 2
Site 2, RR 1
Winterburn
Alberta T0E 2N0

Fort McKay Health Centre
Fort McKay
Alberta T0P 1C0

Frog Lake Health Centre
General Delivery
Frog Lake
Alberta T0A 1M0

Garden River Health Centre
Bag 7000
Garden River
Alberta T0H 1N0

Alberta T0H 1Z0

Nunee Health Board
Cree Indian Band
Box 366
Fort Chipewyan
Alberta T0P 1B0

Paul Band Health Station
Box 89
Duffield
Alberta T0A 0N0

Peerless Health Centre
Peerless
Alberta T0G 2N0

Peigan Health Centre
Box 56
Brocket
Alberta T0K 0H0

Rocky Mountain House Health Centre
Box 9997
Rocky Mountain House
Alberta T0M 1T0

Saddle Lake Health Centre
Box 86
Saddle Lake
Alberta T0A 3T0

Sarcee (Tswwtina) Health Centre
Box 51
3700 Anderson Road
Calgary
Alberta T2N 1N0

SASKATCHEWAN

Cowessess Health Centre
Box 607
Broadview
Saskatchewan S0G 0K0

Thunderchild Health Station
Box 398
Turtleford
Saskatchewan S0M 2Y0

Standoff Health Centre
Box 229
Standoff
Alberta T0L 1Y0

Stoney Health Centre
Box 8
Morley
Alberta T0L 1N0

Tall Cree Health Station
Box 68
Fort Vermillion
Alberta T0H 1N5.

William Charles Health Centre
William Charles Band
General Delivery
Montreal Lake
Saskatchewan S0J 1Y0

Moose Woods Health Station
Box 149, RR 5
Saskatoon
Saskatchewan S7K 3J8

MANITOBA

Dakota Ojibway Tribal Council
Health Coordinator
Crescent Road W
Box 1599
Portage La Prairie
Manitoba R1N 3P1

First Nations Confederacy Health
Coordinator
Joyce Cochrane
203-286 Smith Street
Winnipeg
Manitoba R3C 1K4

Interlake Reserve Tribal Council Health
Coordinator
Eleanor Shorting
Box 580
Ashern
Manitoba R0C 0E0

Island Lake Tribal Council Health Services
Advisor
400-338 Broadway
Winnipeg
Manitoba R3C 0T3

Norway House Health and Social Services
Box 218
Norway House
Manitoba R0B 1B0

Otineka Health Centre
The Pas First Nation
Box 297
The Pas
Manitoba R9A 1K3

Peguis Health Centre
Box 238
Hodgson
Manitoba R0C 1N0

Sagkeeng First Nations Health Centre
Box 70
Pine Falls
Manitoba R0E 1M0

Sandy Bay Health Centre
General Delivery
Sandy Bay First Nation
Marius
Manitoba R0H 0T0

Keewatin Tribal Council Health Liason
Director
102-83 Churchill Drive
Thompson
Manitoba R8N 0L6

Long Plain Health Centre
General Delivery
Edwin
Manitoba R0H 0G0

Manitoba Keewatinowi Okimakanak Health
Liason Director
23 Station Road
Thompson
Manitoba R8N 0N6

Mathias Colomb First Nation
Health Authority
Nursing Station
Pukatawagan
Manitoba R0B 1G0

Native Services
Health Sciences Centre
CH407-840 Sherbrooke Street
Winnipeg
Manitoba R3A 1M4

Short Bear Health Centre
General Delivery
Edwin
Manitoba R0H 0G0

Swampy Cree Tribal Council Health
Advisor
Box 150
The Pas
Manitoba R9A 1K3

Valley River Medical Clinic
Valley River Reserve
Shortdale
Manitoba R0L 1W0

West Region Tribal Council Health
Coordinator
21, 4th Avenue
Dauphin
Manitoba R7N 1H9

QUEBEC

Centre de Sante
Marie-Paule Sioui-Vincent
255 Place Chef Michel Laveau
Village des Hurons
Wendake
Quebec G0A 4V0

Centre de Soins de Point-Bleue
Centre Mashteuiasht
403, Amishk
Pointe-Bleue
Quebec G0W 2H0

Health and Social Services
River Desert Band
Box 309
Maniwaki
Quebec J9E 3C9

Hospital de L'Ungava
Box 149
Kuujjuaq
Quebec J0M 1C0

Clinique de Mingan
Comte Duplessis
Quebec G0G 2A0

Clinique de Maliotenam
115 rue Montagnais
Box 547
Sept-Iles
Quebec G4R 4K7

Conseil Attikamek-Montagnais
80 boul. Bastien
Village Huron
Quebec G0A 4V0

Cree Health Board of James Bay
Chisasibi
James Bay
Quebec J0M 1E0

Innu Takuaikan Uashat-Maliotenam
1089 Dequen
C.F. 8000
Sept-Iles
Quebec G4R 4L9

Kateri Memorial Hospital Centre
Box 10
Kahnawake
Quebec J0L 1B0

Poste/Soins Infirmiers de Romaine
Cte. Duplessis
La Romaine
Quebec G0G 2E0

Reserve Indienne de Natashquan
Cte. Duplessis
Pointe-Parent
Quebec G0G 2E0

ONTARIO

Brant County District Health Unit
225 St Paul Avenue
Brantford
Ontario N3R 5Z3

Community Health Unit
Health Director
North Shore Tribal Council
76 BailPark Road
Cutler
Ontario P0P 1B0

Community (Public) Health Program
Cheifs Wood Road
Ohsweken
Ontario N0A 1M0

Rama Reserve Health Centre
101 Collegiate Drive
Orillia
Ontario L3V 3R9

Tyendinaga Health Centre
Mohawks of the Bay of Quinte
RR 1
Deseronto
Ontario K0K 1X0

West Bay Health Centre
West Bay
Ontario P0P 1G0

Whitefish River Health Centre
Birch Island
Ontario P0P 1A0

Kettle and Stony Point Health Centre
Box 670
Forest
Ontario N0N 1J0

Wikwemikong Community Health Centre
Post Office
Wikwemikong
Ontario P0P 2J0

Lawrence Commanda Health Centre
RR 1
Sturgeon Falls
Ontario P0H 2B0

NEWFOUNDLAND AND LABRADOR

Amelia Joe Medical Clinic
Conne River
Bay d'Espoir
Newfoundland A1C 6E7

NORTHWEST TERRITORIES

Baffin Regional Health Board
Bag 200
Iqaluit
N.W.T. X0A 0H0

Keewatin Regional Health Board
Box 298
Rankin Inlet
N.W.T. X0C 0G0

Fort Smith Health Centre
Box 1080
Fort Smith
N.W.T. X0E 0P0

Kitikmeot Regional Health Board
c/o G.N.W.T. Bag Service
Cambridge Bay
N.W.T. X0E 0C0

Inuvik Regional Health Board
Bag Service #2
Inuvik
N.W.T. X0E 0T0

Mackenzie Regional Health Service
Box 520
Yellowknife
N.W.T. X1A 2N4

APPENDIX 5

QUESTIONNAIRE RESULTS

Of the 248 questionnaires sent out 10 were returned. This questionnaire presents collated answers. Numbers will not necessarily add up to ten, as all questions were not answered by all respondents.

ABOUT YOU

male 9 **female** 1

ages 28, 36, 41, 31, 28, 21, 27, 31, 24.

Are you "Registered" under the Indian Act? yes 4 no 6

Are you married or do you live with a partner? 2 8

Do you have children?	<u>2</u>	<u>8</u>
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When did you test positive for HIV? 1985 [3], 1988 [2], 1989 [2], 1990 [2].

WHERE DO YOU LIVE

Do you live on reserve 1 off-reserve 8 both

How long have you lived in the community where you live? 11 years; 8 years; 7 years; 4 years; off and on the last 3 years; 2 years; 1 year; 14 months; 2 months.

Why do you live where you live? - to be near family	<u>2</u>
to be near friends	<u>4</u>
to be near work	<u>2</u>
to be near medical services	<u>2</u>
to be near husband/wife,	
partner/lover	<u>0</u>
other reasons	<u>6</u>

"Other reasons" given were:

"Support, ease of living, travel etc."

"To be in the gay community"

"Close to downtown"

"To be able to live the way I want (alternative lifestyle)."

"Volunteer work with AIDS organisation."

Have you moved since testing positive?

yes 7 no 3

- if yes, Why?

"I needed to move closer to family and support and away from influences that would hinder my health."

"Not initially. I stayed away from my reserve for four years before I moved home."

"I moved home, or closer to home from where I have been tested at (Vancouver)."

"Just like to move around."

"More work being done in Vancouver for natives."

"Allergic to pets. Causes asthma."

Would you rather live somewhere else?

yes 5 no 5

- if yes, Where and Why?

"In the country on acreage or similar - for peace of mind, access to fresh air, and possibly a garden for food."

"On my home reserve - to be with my people." (lives where he lives to be near the gay community).

"Vancouver - for more support."

"Banff, Alberta - for the sun."

Did you move in the last	1 - 6 months	<u>5</u>
	6m - 1 year	<u>3</u>
	1 - 2 years	<u>-</u>
	2 - 5 years	<u>3</u>
	over 5 years	<u>1</u>
	never moved	<u>-</u>

One respondent said - "I was in Montreal, Vancouver, Calgary, Edmonton and back and forth to my reserve."

If you live in a city - do you live in the	"inner city"	<u>8</u>
	the suburbs	<u>1</u>
	somewhere in between	<u>-</u>

Roughly how big is the community you live in?	rural area	<u>1</u>
	100 - 1,000 people	<u>-</u>
	1,000 -5,000 people	<u>1</u>
	5,000 - 10,000 people	<u>-</u>
	10,000 - 100,000 people	<u>-</u>
	100,000 - 300,000 people	<u>2</u>
	over 300,000 people	<u>6</u>

HOUSING

Where do you usually sleep?	no fixed address	<u>-</u>
	shelter	<u>-</u>
	rooming house	<u>1</u>
	*house or apartment by yourself	<u>3</u>
	house or apartment with friends	<u>4</u>
	house or apartment with family	<u>1</u>
	house or apartment with husband/wife	
	partner/lover	<u>1</u>

*one person indicated living in a house and 2 specified living in an apartment.

Do you share a room with someone who isn't your lover/partner, husband or wife?	yes	<u>3</u>	no	<u>2</u>
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Which rooms do you share?

bedroom	<u>3</u>	with friends or family?	<u>3</u>	strangers?	<u>-</u>
bathroom	<u>5</u>	" "	<u>4</u>	"	<u>1</u>
kitchen	<u>6</u>	" "	<u>5</u>	"	<u>1</u>
living room	<u>6</u>	" "	<u>6</u>	"	<u>1</u>

How many people live where you live? 4; 15; 1 [4]; 2 [3].

How many rooms does your home have? 2 [3]; 4 [3]; 25; 1. - answers to this question are difficult to interpret because it is ambiguous. Different people may have counted different rooms.

Do you have central heating? yes 9 no 1

What floor do you live on? 2nd [3]; basement; main; 14th; third.

Is there an elevator? yes 3 no 5

WORK AND INCOME

Do you have a paid job? yes - no 10
do you work for yourself? 3 -

Do you get unemployment benefits? yes - no 10
welfare? 6 1
disability allowances? 4 4

Has your job changed since you tested positive? 4 3
if yes, How?

"Became unemployed"

"I am a spokesperson for the prevention of AIDS. I never dreamed of doing this before I tested positive."

"I can no longer work for psychiatric reasons."

"Became HIV/AIDS frontline community worker."

If you changed jobs or became unemployed did it have anything to do with your testing positive or the state of your health? Yes - 4.

How much is your total income -	under \$500 per month	<u>1</u>
	\$500 - 1000 per month	<u>8</u>
	\$1000 - 3000 per month	<u>1</u>
	over \$3000 per month	<u>-</u>

Do you have enough money to:

buy the food you need?	yes	<u>3</u> *	no	<u>6</u>
buy any medicine you need?		<u>4</u>		<u>3</u>
pay your rent?		<u>6</u>		<u>2</u>
pay hydro/heating bills?		<u>4</u>		<u>6</u>
buy winter clothes/shoes		<u>2</u>		<u>8</u>

* one person answered "most of the time."

How many people do you support on your income? Only one respondent was supporting another person on their income.

Is lack of money a constant worry for you? Every respondent except one answered YES. The remaining person said "SOMETIMES" and was also the only person with an income over \$1000.

SUPPORT AND SERVICES

	Yes	No	Need more
Do you get enough support from			
- family?	3	5	2
- friends?	4	2	4
Do you use agencies like Friendship Centres and AIDS organisations for help?	7	3	0

What kinds of organisations do you go to for support and services? Vancouver PWA Support;/ Toronto PWA Foundation; Two Spirited People of the First Nations; AIDS Committee of Toronto;/ AIDS Saskatoon; PLWA Saskatoon; /AIDS service organisations; government social services;/ PWA Office; AIDS Vancouver; food banks;/ AIDS Committee of Toronto; /my sisters; and praying, I'm a Roman Catholic;/ AIDS Vancouver Island (support groups); and personally through friends and family;/ AIDS Committee of Toronto; Anishnawbe Health;/ Manitoba Aboriginal AIDS Task Force; Health Science Centre support groups.

You may be using all kinds of services - or none. Please fill out the following two questions (which are the same), by putting in the two most important services you USE (if you use two):

The answers to these two questions have been put together.

What kind of service? - Who provides it?

Support group - Health Science Centre
 Medical treatment and support - Anishnawbe Health
 Housing - MSSH
 Medical treatment - Doctor
 Complementary health care and current information - PWA
 counselling and support - AIDS Saskatoon
 support - AIDS Saskatoon
 medical treatment - doctor
 housing subsidy - provincial government
 AIDS Information - AIDS Vancouver
 Complementary Health Fund - Vancouver PWA
 Support - PLWA Saskatoon
 Support group - Manitoba Aboriginal AIDS Task Force
 Medical Treatment - University Hospital
 Medical Treatment - MSSH.

How often do you use it?

once a week 3 every two weeks 2 once a month 4 other 4

How often would you like to use it

once a week 1 every two weeks 4 once a month 4 other 3

Is the service you get? good 7 bad - could be better 7

Do you have problems getting to it or using it? yes 6 no 6
If yes, why?

my health makes it difficult to get there 2
 it costs too much to travel 4
 its too far to go 2
 it costs too much 4
 I don't feel comfortable there 2

Other reasons:

"Walking distance is a bit too far when feeling fatigue and have no money."

"The doctor has a large practice and is sometimes hard to see."

Please fill out the following two questions (which are the same) by putting in the two services you feel you NEED most but DON'T GET.

What kind of service? Money for home and food - special diet; counselling; counselling/mental health; emotional support; home care; housing; housing; nutritional advice.

How often would you like to be able to use it?

once a week 2 every two weeks 1 once a month - other -

Why can't you get what you need?

my health makes it difficult to get there	<u>2</u>
it costs too much to travel	<u>2</u>
it's too far to go	<u>2</u>
it costs too much	<u>6</u>
I don't know where to go to get it	<u>3</u>
it's not available	<u>3</u>
I don't feel comfortable there	<u>1</u>

Other: One respondent who said they needed more counselling noted "My own schedule sometimes limits my time and willingness to share."

One respondent with housing problems noted that they needed affordable housing for independent living with leeway for sickness.

What other services and/or support do you think you need? Are they available where you live?

"Extra money for foods, special bills etc. \$575 per month does squat." - more money not available.

"Emotional support - I'm not gay and therefore not comfortable with existing support groups. I'm native and therefore not comfortable with non-natives. I'm alone." - doesn't know if they are available.

"Family support, I think my family need some kind of support, and they need it to be able to help me by supporting me." - said yes and don't know to are they available.

"Services need to come to the home - if you have one. More housing subsidies."

"Drop-in street youth services." - not available.

"First Nations cultural events and sweat lodge healing circle." - doesn't know if they are available.

If there is anything else that you would like to say about HIV or AIDS and how it has affected your life, or if you want to say more about your needs and how they are being met, please use this page. You can also use this space if you have any comments to make about the questionnaire.

"I feel the issue on the questionnaire form is trying to meet the need to fill the gaps. However some of the agencies need ought be confronted and addressed on the executive spending of the money donated for PWA's. And to meet the needs that are in question. I have a lot of friends who have come and gone, who haven't had the opportunity to fill out the questions on this questionnaire. It would be gratefully appreciated if someone somewhere could make the difference."

"Don't really need any services at present because I've been coping with the virus quite okay. I've had it now for just about eight years and I'm maintaining my health. I'm taking AZT for a second time. But I'll be going off it soon."

"I do not want to die young. I want to grow old like my parents. I wish bureaucracy (politics) would speed up the research to find an AIDS cure and not take 10-15 years till one vaccine is found. They should not have to restrict volunteers (it should be up to us), for research."

"Being HIV positive has definitely changed my life... At first it was devastating. Then I learned to use it as a powerful tool. The more I turned back to my native ways, the more I got in tune with myself..."

I would love to see more native cultural practice on urban areas."

"Don't let it get to your head."

"I get out of life what I put in. I have to be the one who seeks out help, it won't come to me."

"I feel that culturally appropriate services should be made more readily available to gay and lesbian natives. It should also be a safe place for two-spirits to access without fear of racism or homophobia."

APPENDIX 9INTERVIEWS AND DESCRIPTION OF ORGANISATIONSPRIMARY INTERVIEWS

<u>Name</u>	<u>Organisation</u>	<u>City</u>
<u>25/6/92</u>		
Albert McLeod	Manitoba Aboriginal AIDS Task Force	Winnipeg
<u>26/5/92</u>		
Members of the PLWA/HIV support group and, Pauline Wood-Steinman	Manitoba Aboriginal AIDS Task Force also of, Manitoba AIDS Steering Committee	Winnipeg
Anne Katz	Village Clinic	Winnipeg
Laurel Mc Tavish	Street Links	Winnipeg
<u>29/5/92</u>		
Nils Claussen and, Margaret Akan	AIDS Regina also of, Feather of Hope Society - Saskatchewan	Regina
<u>2/6/92</u>		
Donna Reed	AIDS Saskatoon	Saskatoon
Members of	Feather of Hope Society - Saskatchewan	North Battleford
<u>9/6/92</u>		
Alan LaRoque Kennard	Vancouver PWA	Vancouver

10/6/92

Leonard Johnston Frederick Haineault	Healing Our Spirit	Vancouver
Sandy Cooke	Adolescent Street Youth Services	Vancouver
Outreach workers	Street Youth Services	Vancouver

12/6/92

George Poitras	Feather of Hope Aboriginal AIDS Prevention Society - Alberta	Edmonton
Jerome Yellowdirt	Alberta Indian Health Care Commission	Edmonton

7/7/92

Susan Beaver	Two Spirited Peoples of the First Nations	Toronto
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8/7/92

Janice Trudeau	Anishnwabe Health Centre	Toronto
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DESCRIPTION OF ORGANISATIONS

ADOLESCENT STREET SERVICES: Provide integrated services to youth who are Wards of Court. 60% of its clients are Native. Social workers, mental health workers, drug and alcohol counselling, a medical clinic, teachers and a job readiness program are available. It is linked to a street outreach program.

AIDS REGINA: Has a mandate to provide information and education to inform the public about AIDS and HIV, and to provide support and for PLWA/HIV. It provides: an AIDS hotline; referrals and advocacy; emotional and practical support; a health care fund and a speakers bureau and resource library. Margaret Akan (also of Feather of Hope - Saskatchewan) is the Native Outreach Worker organising similar services for the Native community, particularly the establishment of education workshops.

AIDS SASKATOON: A community based AIDS organisation providing advocacy, services and support to PLWA/HIV, and which includes a Native clientele.

ALBERTA INDIAN HEALTH CARE COMMISSION: Its objective is to assist in improving the health conditions of Indians throughout the province. The Commission includes representatives from the three Treaty areas of Alberta. Two urban health workers advocate for and arrange for medical treatment for clientele. Three Community Health Liaison Workers work with Chiefs and Councils in the development of community based health care delivery systems. The Commission is also involved in AIDS education and prevention initiatives.

ANISHNABE HEALTH: Provides all the facilities of a mainstream health center plus other services including counselling; child care; food; a mothers and kids group. It provides access to traditional healer and healing and talking circles are held. The AIDS prevention program includes: education; counselling; distribution of Native specific education materials which are available in Cree, Mohawk and Ojibway as well as English; posters; information kits; condoms and lubricants; bleach kits; and anonymous HIV testing with pre and post test counselling. The needle exchange program has a street parol and provides condoms; information; the needle exchange; as well as food, fruit, coffee and juice.

FEATHER OF HOPE ABORIGINAL AIDS PREVENTION SOCIETY: The society was initiated by Ken Ward in 1990, who was diagnosed as being HIV positive in 1989, to provide: education and prevention services and materials for communities and organisations that are culturally relevant; and to provide support services for PLWA/HIV. It is involved in developing AIDS education and prevention workshops and materials translated into Native languages.

FEATHER OF HOPE SOCIETY INC. - SASKATCHEWAN: Established in 1991 and is in the process of development. It is a group of Aboriginal people and people working with Aboriginal people who have a concern for preventing the spread of HIV and AIDS. The objectives of the organisation are to: provide education and develop teaching and learning methods that are accessible and acceptable to communities; to coordinate special events; to provide a supportive environment to people affected by HIV and AIDS; and to "renew interest in the traditional teachings on rights of passage and family reproductive health.

HEALING OUR SPIRIT: The organisation was established by two Aboriginal men living with HIV and AIDS. It is involved in education prevention and awareness programs and providing support to PLWA/HIV and their families and friends. Their workshop presentation is based on the concept of an HIV/AIDS wheel (Johnston, 1992:7). It provides culturally relevant workshops and includes traditional and western healing practices. There is a "closed circle" for PLWA/HIV and their extended families.

MANITOBA ABORIGINAL AIDS TASK FORCE: Was established by Myra Laramée, a counsellor; Dorland McKay, an aboriginal man living with HIV; and Albert McLeod an AIDS educator to present culturally appropriate AIDS education and prevention information to Aboriginal communities. Members participate in workshops and initiatives in communities. It acts as a liaison between Aboriginal PLWA/HIV and resources that promote education and treatment and facilitates a support group for Native PLWA/HIV.

STREET LINKS: Operates from a van and the STD Clinic of the City of Winnipeg Health Department (once its funding is secured it hopes to develop a street front property). Its goal is to reduce the spread of AIDS and provide information and support to people involved with street life and IDUs. It offers: counselling; condoms; bleach kits; a needle exchange; bad trick list; health information; referral for drug and alcohol treatments; testing, including pre and post test counselling and a street newsletter. A large percentage of its clientele are Native.

TWO SPIRITED PEOPLES OF THE FIRST NATIONS: The goal or "vision statement" of the organisation to attempt to create a positive self-identity and self-image and creating a positive image within the native and lesbian and gay community and to strengthen relationships with traditional culture. Developing culturally specific and gay positive materials emphasising non-written materials. It provides: education and prevention services; a talking circle; counselling - including drug and alcohol abuse counselling; and advocacy.

VANCOUVER PWA: An organisation established by PLWA/HIV to service themselves. It provides: medical services; access to complementary therapies; financial support -including some housing subsidies; advocacy; practical support; and it has a Native support group.

VILLAGE CLINIC: A health centre with a large gay clientele. It has a holistic approach to health providing for physical health needs; testing - including pre and post test counselling; mental health services; advocacy; practical support; access to complementary therapies; and AIDS education and prevention. It has a mandate for the prevention, education, care and treatment of HIV infection.

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