RESEARCH REPORT

Housing, Long Term Care Facilities and Services for Homeless and Low-Income Urban Aboriginal Peoples Living with HIV/AIDS: Issues Identification Paper

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Housing, Long Term Care Facilities and Services for Homeless and Low-Income Urban Aboriginal Peoples Living with HIV/AIDS: Issues Identification Paper

Final Report
Submitted to
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Canada Mortgage and Housing Corporation

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For Sweetgrass Consulting

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Executive Summary

The objectives of this research study of limited scope were: a) to examine housing issues and residential facilities and services available to homeless and low-income Aboriginal people with HIV/AIDS in urban centres, and gaps in services; b) to identify appropriate services for homeless and low-income urban Aboriginal people with HIV/AIDS.

This research report is a synthesis of secondary research; a review of the existing literature, and primary research conducted utilizing survey questionnaires with 29 respondents that included a range of Aboriginal and non-Aboriginal service providers as well as Aboriginal people living with HIV/AIDS in Vancouver, Edmonton, Regina, Winnipeg, Toronto, Ottawa, Montreal and Halifax. Two of these respondents spoke to the specific issues affecting Aboriginal people with HIV/AIDS in the Far North (Inuit) and Labrador. In addition, three (3) Native American HIV/AIDS organizations in New York, in Minneapolis-St. Paul and in Oakland were contacted for relevant information regarding housing options and culturally appropriate models of long-term care for Native Americans living with HIV/AIDS.

The profile of Aboriginal people with HIV/AIDS in urban centres that emerged from this limited research study indicates they are a heterogeneous low-income population whose housing and care needs may differ. At the same time, a majority of this population is living on the "hem of life" in unstable housing conditions and in destabilizing lifestyles. Additional supports, services and transitional housing are required to meet their housing and care needs which differ from those of Aboriginal people with HIV/AIDS in a stable lifestyle. There is also a need to ensure that the specific housing and care needs of Aboriginal families living with HIV/AIDS, particularly those of single-parent, female-headed families, are met.

Service providers and Aboriginal people with HIV/AIDS (PHAs) identified a number of important gaps in housing, long-term residential care facilities and services for homeless and low-income Aboriginal people living with HIV/AIDS in urban centres.

Under-utilization of mainstream HIV/AIDS long-term care and related services by Aboriginal people living with HIV/AIDS

Aboriginal people living with HIV/AIDS tend to under-utilize mainstream hospices, long-term residential care facilities and other HIV/AIDS related services and supports including home care. Discrimination as Aboriginal people, cultural barriers, linguistic barriers and gender barriers in addition to a bureaucratic and culturally-alienating process are the main reasons why Aboriginal people with HIV/AIDS under-utilize mainstream services, social housing, hospices and other HIV/AIDS related services.

Limited Housing Options for Aboriginal people living with HIV/AIDS

There is limited access to supportive housing for low-income Aboriginal PHAs in Native Urban Housing Programs is limited. Native Urban Housing Corporations are not mandated or necessarily equipped to accept Aboriginal people living with HIV/AIDS, particularly those with addiction and mental health problems: many who tend to be homeless. The situation is further complicated by the long waiting lists for the current stock of social housing and the lack of funding for increasing the number of new units. Many Aboriginal people living with HIV/AIDS are reluctant to disclose their seropositive status even if this were to facilitate access to housing.

The housing options, including transitional housing and units in Native Urban Housing Programs, for homeless Aboriginal people living with HIV/AIDS particularly those with substance abuse, alcohol abuse and/or mental health problems, are particularly limited. Many respondents indicated that homeless Aboriginal people need additional support and services such as life skills training and on-going supports and services including access to Elders and culturally-appropriate counselling, currently not universally available to assist them in preparing for and maintaining stable housing and a stable lifestyle. In addition, meeting their basic needs for shelter, food, health care and clothing is also essential.

Finally, not all Aboriginal people living with HIV/AIDS are aware of the housing options available to them. They need more information and assistance in the procurement of social housing.

Limited Aboriginal-Specific long-term care facilities, supports and services

There are no Aboriginal-specific culturally appropriate hospice/long-term residential care facilities or supportive housing facility, despite advocacy efforts by Aboriginal organizations for almost a decade.

Access to culturally-appropriate and competent healing and health services, particularly for counselling and palliative care, such as access to Elders, sweat lodges, traditional medicines, traditional food and ceremonies is limited for many Aboriginal people with HIV and AIDS in inner-cities.

Some Aboriginal families choose to care for their loved ones living with HIV/AIDS. There is insufficient funding and access to respite care for Aboriginal families who care for family members living with HIV/AIDS at home.

The need for culturally appropriate services for Aboriginal people living with HIV/AIDS

Appropriate services for Aboriginal people with HIV/AIDS in urban centres necessarily include a cultural component, as respondents in this study have made clear. Guiding principles for the development of culturally-appropriate services (provided by

Aboriginal people for Aboriginal people) and cultural enhancement of mainstream services include:

- Consultation with key First Nations, Inuit and Métis stakeholders as well as people with HIV/AIDS
- Aboriginal driven (staff and participation in decision-making)
- Affirm cultural values, spirituality, traditions and practices
- Respect for diversity. The cultural component varies in accordance with the specific composition of the Aboriginal groups for whom the service is designed or the Aboriginal clients who use them.

Culturally Appropriate Services

- The setting up of long-term care facility/facilities for Aboriginal people with HIV/AIDS staffed with Aboriginal health workers and resources. Services offered might also include the provision of a culturally-appropriate continuum of care that would comprise home care for Aboriginal people with HIV/AIDS living on their own and outreach for homeless Aboriginal people with HIV/AIDS in a destabilizing lifestyle. Such facilities should be able to accommodate family members for an indefinite period.
- Implementing a continuum of care, where currently not available, that includes culturally appropriate healing, health and support services such as counselling and palliative care for Aboriginal people living with HIV/AIDS in inner-cities.
- Ensuring access to culturally-appropriate and competent healing and health services that includes access to Elders, sweat lodges, ceremonies, traditional medicines, traditional food and traditional healing practices.
- Increasing the number of culturally-appropriate and supportive low-income housing units for Aboriginal people with HIV/AIDS in Native Urban Housing Programs and providing education for staff on Aboriginal HIV/AIDS issues.
- Increasing the number of social housing units for Aboriginal people with HIV/AIDS and ensuring better access for seropositive Aboriginal women with children.
- Addressing the specific needs of homeless Aboriginal people with HIV/AIDS by providing transitional housing (emergency, short-term and long-term), life skills training and on-going support services (counselling, access to Elders, family support) to assist them in preparing for and maintaining stable housing and lifestyle.
- Ensuring better access to information on available housing/long-term care options and providing more assistance to Aboriginal people with HIV/AIDS in procuring space.
- Increasing financial and other supports for low-income single people and families with HIV/AIDS specifically female-headed single-parent families.

Cultural-Enhancement of Mainstream Services

- Providing cross-cultural and anti-racism education and training for non-Aboriginal staff.
- Increasing the number of Aboriginal staff (home care, outreach, counselling, nurses)
- Enhancing Aboriginal participation in decision-making

- Providing linguistic and cultural interpreters
- Accompanying Aboriginal clients to mainstream services
- Providing access to Elders, ceremonies and traditional healing practices
- Providing culturally-appropriate counselling and supports
- Ensuring enhanced access to mainstream hospices, social housing and respite care through better access to information and assistance in the procurement of space.

Improving the housing and long-term care options for a heterogeneous urban First Nations, Inuit and Métis population living with HIV/AIDS, taking gender into account, are all the more critical since the majority of Aboriginal PHAs can not return home to their communities. Barriers include the lack of services as well as the stigmas around AIDS and the associated stigmas related to injection drug use and sex work, in addition to gender-based discrimination that affects women and Two-Spirited men. Accommodating the diverse housing and care needs of a heterogeneous urban First Nations, Inuit and Métis people living with HIV and AIDS entails a multi-faceted strategy tailored to the local context to ensure that they may live positively.

Résumé

Cette recherche dont la portée est limitée avait pour objectifs a) d'examiner les enjeux liés à l'habitation et les installations de logements, de même que les services offerts aux Autochtones sans-abri à faible revenu atteints du VIH/sida dans les centres urbains, ainsi que les failles dans la gamme des services et b) de déterminer les services qu'il conviendrait d'offrir aux Autochtones sans-abri et à faible revenu atteints du VIH/sida en milieu urbain.

Ce rapport de recherche se veut une synthèse des recherches secondaires : une analyse documentaire et des travaux de recherche primaires menés à l'aide d'un questionnaire auquel ont participé 29 répondants, dont une large gamme de fournisseurs des services auprès d'Autochtones et de personnes non autochtones, de même que d'Autochtones atteints du VIH/sida habitant Vancouver, Edmonton, Regina, Winnipeg, Toronto, Ottawa, Montréal et Halifax. Deux des répondants ont abordé les questions particulières ayant des répercussions sur les Autochtones vivant avec le VIH/sida dans le Grand Nord (Inuit) et le Labrador. En outre, trois organismes d'aide autochtones sur le VIH/sida des É.-U., New York, Minneapolis-St. Paul et Oakland, ont été consultés au sujet d'information ayant trait au choix de logement et aux modèles de logement de soins de longue durée adaptés à la culture autochtone pour les Autochtones de États-Unis qui vivent avec le VIH/sida.

Le profil des Autochtones vivant avec le VIH/sida dans des centres urbains qui émerge de ces travaux de recherche limités indique qu'ils forment une population hétérogène à faible revenu dont les besoins en soins et de logement peuvent différer. Parallèlement, une majorité de cette population vit en marge de la société dans des conditions de logement instables et affichent un style de vie déstabilisateur. Il faut des mesures de soutien, des services et des logements d'urgence additionnels qui répondent à leurs besoins en logement et en soins et qui diffèrent de ceux fournis aux Autochtones vivant avec le VIH/sida dans un style de vie stable. Il faut également faire en sorte de répondre aux besoins particuliers en soins et en logement des familles Autochtones vivant avec le VIH/sida, particulièrement les ménages monoparentaux dirigés par une femme.

Les fournisseurs de service et les Autochtones vivant avec le VIH/sida ont dégagé un certain nombre de failles dans le logement, dans les établissements de soins de longue durée et dans les services visant les Autochtones sans-abri et à faible revenu vivant avec le VIH/sida dans les centres urbains.

Sous-utilisation des soins de long durée visant le VIH/sida et les services connexes destinés à la population en général par les Autochtones qui vivent avec le VIH/sida

Les Autochtones vivant avec le VIH/sida se montrent enclin à sous-utiliser les établissements de soins palliatifs, de soins de longue durée et autres services et mesures de soutien, y compris les soins à domicile, destinés à la population en général. La discrimination auprès des Autochtone, les obstacles culturels, les barrières linguistiques et de sexe, en plus des processus bureaucratiques et aliénant au chapitre de la culture sont

autant de raisons qui font que les Autochtones vivant avec le VIH/sida sous-utilisent les services et les établissements susmentionnés.

Options de logement limitées pour les Autochtones qui vivent avec le VIH/sida

Pour les Autochtones à faible revenu vivant avec le VIH/sida, l'accès aux logements en milieu de soutien des programmes pour les Autochtones en milieu urbain est limité. Les sociétés de logements pour Autochtones en milieu urbain n'ont pas le mandat, et ne possèdent pas nécessairement les installations requises pour recevoir des Autochtones vivant avec le VIH/sida, particulièrement ceux qui ont des problèmes mentaux ou sont toxicomanes et qui sont souvent sans-abri. La situation est exacerbée par les longues listes d'attente pour un logement social et le manque de financement pour augmenter le nombre de nouveaux logements. Nombreux sont les Autochtones vivant avec le VIH/sida qui hésitent à dévoiler qu'ils sont séropositifs même si cela leur permettrait d'accéder à un logement.

Les options de logement, y compris le logement d'urgence et ceux des programmes de logement pour Autochtones en milieu urbain, destinés aux Autochtones sans-abri qui vivent avec le VIH/sida, spécialement les toxicomanes et ceux qui abusent de l'alcool ou ont des problèmes de santé mentale, sont particulièrement limitées. De nombreux répondants ont indiqué que les Autochtones sans-abri ont besoin de soutien et de services additionnels, comme une formation en dynamique de la vie, des mesures de soutien et des services continus, y compris l'accès aux Aînés et à des services de consultation adaptés à la culture autochtone, car ces derniers ne sont pas offerts universellement pour les aider à acquérir et à maintenir un logement et un mode de vie stables. Qui plus est, il est impératif de répondre à leurs besoins fondamentaux en matière de logement, d'alimentation, de soins de santé et d'habillement.

Enfin, ce ne sont pas tous les Autochtones qui vivent avec le VIH/sida qui sont conscients des options de logement qui leur sont offertes. Ils ont besoin de plus d'information et d'aide pour se trouver un logement social.

Pénurie d'installations de soins de longue durée, de soutien et de services à l'intention des Autochtones

Il manque actuellement d'établissement de soins palliatifs, de soins de longue durée ou de logement en milieu de soutien adaptés à la culture autochtone, et ce malgré les efforts de sensibilisation déployés à cet effet pour près d'une décennie par les organismes Autochtones.

L'accès à des soins de santé adaptés à la culture autochtone, spécialement en ce qui a trait aux conseils et aux soins palliatifs, tels que l'accès aux Aînés, aux cabanes à suer, aux médecines selon la tradition autochtone, aux aliments et aux cérémonies traditionnelles est limité pour nombre d'Autochtones vivant avec le VIH/sida dans les centres urbains.

Certaines familles autochtones choisissent de soigner eux-mêmes leurs proches vivant avec le VIH/sida. Les fonds sont insuffisants; il en est de même pour l'accès aux soins de relève pour les familles autochtones qui soignent à domicile leurs proches atteints du VIH/sida.

Le besoin en services adaptés à la culture autochtone pour les Autochtones vivant avec le VIH/sida

Des services appropriés destinés aux Autochtones vivant avec le VIH/sida en milieu urbain doivent comprendre une composante culturelle, tout comme les répondants l'on clairement indiqué. Les principes directeurs axés sur l'élaboration de services adaptés à la culture autochtone (services fournis par des Autochtones pour des Autochtones) et les améliorations culturelles apportées aux services destinés à la population en général comprennent :

- Des consultations auprès des intervenants clés des Premières nations, des Inuits et de la Nation des Métis, de même qu'avec les personnes vivant avec le VIH/sida
- Services sous l'impulsion d'Autochtones (personnel et participation à la prise de décision)
- Réaffirmer les valeurs culturelles, la spiritualité, et les traditions et pratiques
- Respect pour la diversité. La composante culturelle varie en fonction de la composition particulière des groupes autochtones auxquels sont destinés les services ou des clients autochtones qui les utilisent.

Services adaptés à la culture autochtone

- La mise en place de services de soins de longue durée destinés aux Autochtones vivant avec le VIH/sida doit comprendre un personnel de la santé et des ressources autochtones. Les services offerts peuvent aussi inclure la fourniture d'un modèle de services de soutien permanent adapté à la culture autochtone qui comprendrait les soins à domicile pour les Autochtones vivant avec le VIH/sida qui mènent une vie autonome et des services d'extension pour les sans-abri Autochtones atteints du VIH/sida qui mènent un mode de vie déstabilisant. De telles installations devraient être en mesure d'accueillir les membres de la famille pour des périodes indéfinies.
- La mise en œuvre d'un modèle de services de soutien permanent, là où il n'est pas offert, et qui comprend des services de santé, de rétablissement et de soutien adaptés à la culture autochtone, comme les soins palliatifs pour les Autochtones vivant avec le VIH/sida dans les noyaux urbains.
- Assurer l'accès à des services de santé et de rétablissement compétents et adaptés à la culture autochtone, dont l'accès aux Aînés, aux cabanes à suer, aux cérémonies, à la médecine traditionnelle autochtone, aux aliments traditionnels et aux pratiques de guérison traditionnelles.
- Augmenter le nombre de logements en milieu de soutien adaptés à la culture autochtone destinés aux Autochtones vivant avec le VIH/sida à faible revenu dans le cadre des programmes de logements pour les autochtones en milieu urbain, et sensibiliser le personnel aux enjeux autochtones en matière de VIH/sida issues.

- Augmenter le nombre de logements sociaux à l'intention des Autochtones vivant avec le VIH/sida et assurer un meilleur accès aux femmes autochtones séropositives qui ont des enfants.
- Traiter des besoins particuliers des Autochtones sans-abri atteints du VIH/sida en leur fournissant des logements d'urgence (d'urgence, à court terme et à long terme), un cours de préparation à la vie quotidienne et des services de soutien continus (conseils, accès aux Aînés, soutien familial) pour les aider à acquérir un logement et un mode de vie stables.
- Améliorer l'accès à l'information portant sur les options de logement et de soins de longue durée et fournir davantage d'aide aux Autochtones vivant avec le VIH/sida à se procurer une place.
- Augmenter les appuis financiers et autres auprès des familles et des personnes seules autochtones à faible revenu vivant avec le VIH/sida, en particulier les familles monoparentales dirigées par une femme.

Améliorations culturelles des services destinés à la population en général

- Sensibiliser et former le personnel non autochtone en matière de culture et de lutte contre le racisme.
- Augmenter le nombre de personnes autochtones au sein du personnel (soins à domicile, interventions directes, conseillers, infirmières)
- Rehausser la participation des Autochtones au processus de prise de décision
- Fournir des interprètes pour les aspects linguistiques et culturels
- Accompagner les clients Autochtones dans les établissements desservant la population en général
- Prévoir l'accès aux services des Aînés, aux cérémonies et aux pratiques de guérison traditionnelles
- Fournir des services-conseils et de soutien adaptés à la culture autochtone
- Améliorer l'accès aux établissements de soins palliatifs, aux logements et aux soins de relève destinés à la population en général par l'entremise d'un meilleur accès à l'information et d'aide à se procurer un espace.

L'amélioration des options de logement et de soins de longue durée d'un population hétérogène urbaine des Premières nations, d'Inuit et de la Nation des Métis vivant avec le VIH/sida, en tenant compte du sexe, sont d'autant plus critiques que la majorité des Autochtones vivant avec le VIH/sida ne peuvent retourner vivre dans leur collectivité. Les obstacles comprennent le manque de services, de même que les stigmates associées au sida, à la toxicomanie et aux travailleuses du sexe, en plus de la discrimination fondée sur le sexe qui affecte les femmes et hommes bi-spirituels. Répondre aux besoins divers en matière de logement et de soins d'une population hétérogène de membres des Premières nation, d'Inuits, et de la Nation des Métis vivant avec le VIH/sida nécessite la mise en œuvre d'une stratégie diversifiée adaptée au contexte local afin de leur assurer une vie harmonieuse.

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1.0 Overview of HIV/AIDS and Aboriginal People in Canada

1.1 Aboriginal People at Risk for HIV: The Legacy of Disadvantage

Vulnerability to HIV often has more to do with "social and environmental factors such as stigma, poverty, discrimination, racism and sexism than with individual behaviour" (Trussler and Marchand:1997:63). Understanding HIV risk and how HIV/AIDS affects Aboriginal peoples in Canada necessarily raises the issues of the unique historical, social and economic factors that have shaped their trajectories and lives. This demands situating the HIV epidemic among Aboriginal peoples within the context of the legacy of disadvantage that resulted from European contact and colonialism which continues to affect the physical, mental-emotional, social and spiritual health of Aboriginal peoples, families and communities. Residential schooling, multigenerational abuse and forced assimilation in tandem with widespread poverty, racism, gender discrimination, loss of culture, values and traditional ways of life have given rise to a disadvantaged health profile and a range of pressing social problems that includes alcoholism, substance abuse, high suicide rates, family violence, violence against women and more recently, HIV/AIDS (Ship and Norton 2001, 2000; RCAP 1996b, 1996c; Imrie and Newhouse 1994).

First Nations and Inuit people have a disadvantaged health status as compared to all other Canadians that includes lower life expectancy and higher rates of physical disorders such as diabetes, infectious and parasitic diseases as well as mental health problems (Ship and Norton 2000; Thoms 1995; RCAP 1996a). As Imrie and Newhouse (1994:5) point out, "there is evidence to suggest that an individual with an already compromised immune system may experience a more rapid expression of illness when infected with HIV." In addition, "As for nearly all disease, there is a causal relationship between socio-economic inequalities and HIV/AIDS. Studies confirm that AIDS patients living in poverty die sooner than their peers who enjoy more stable economic conditions…Living with HIV often accentuates the problem of poverty" (Health Canada:1995:45). First Nations people living with HIV are sicker earlier, with fewer days on antiretroviral therapy, have a shorter life span from diagnosis to death, have more hospital admissions and hospital days per admission and less palliative care, as Goldstone et al's (2000:145) research in Vancouver confirms.

Furthermore, risk factors such as high rates of sexually transmitted disease, alcoholism and substance abuse in tandem with low rates of condom use and high rates of teenage pregnancies continue to increase vulnerability to HIV, particularly among Aboriginal young people who are over-represented in high risk groups – runaways, street youth, sex workers, intravenous drug users and homeless people (Kevin et al. 2003; Ship and Norton 2001; Thoms 1995; Imrie and Newhouse 1994). HIV risk is further compounded by the over-representation of Aboriginal peoples in prisons (Marsden et al.:2000:128). The heightened migration and mobility of First Nations and Inuit people between inner cities and rural, remote and/or reserve communities, bring the risk of HIV to even the remotest communities (Northern Health Research Unit:1998:6).

1.2 HIV/AIDS among Aboriginal Peoples: An Increasing Trend

Current but limited epidemiological data, drawn from Health Canada *HIV/AIDS EPI Updates* (2000; 2001a, 2001b, 2001c) shows that:

- Despite under-reporting and the small number of documented AIDS cases among Aboriginal peoples, the proportion of positive Aboriginal HIV cases continues to increase (estimated at 2,740 cases across Canada by the end of December 1999).
- A high proportion of HIV positive pregnant women who deliver are Aboriginal. One cross-Canada study set the percentage at 19% during the period 1995-1997.
- Aboriginal people make up only 2.8% of the total Canadian population but are over-represented in high risk HIV groups – 41% of male street youth who reported having sex only with men, 14% of federal inmates, with rates of up to 40% in provincial or federal jails in some provinces.
- HIV/AIDS patterns among Aboriginal peoples differ from the patterns found among other Canadians. Young people, injection drug users and women are over-represented among Aboriginal HIV and AIDS cases as compared to non-Aboriginal HIV and AIDS cases.

Aboriginal AIDS Cases

- There were 437 reported Aboriginal AIDS cases as of December 31, 2001,
  - 17 Inuit, 34 Metis, 354 First Nations and 32 Aboriginal unspecified
  - 334 men and 102 women
  - 64.9% of all Aboriginal women with AIDS contracted the disease from injection drug use
- The annual proportion of AIDS cases attributed to Aboriginal people increased from less than 1.0% before 1990 to 10.0% in 1999. Recent estimates of the proportion of Aboriginal AIDS cases adjusted for reporting delay have indicated a decrease from 1999 to 6.2% in 2001, although more data are needed to confirm this. However, Aboriginal people were over-represented in reported AIDS cases in 2001.
- The proportion of females (23.4%) among reported Aboriginal AIDS cases are higher than among non-Aboriginal AIDS cases (8.0%).
- The proportion of people under 30 years of age (24.9%) among reported Aboriginal AIDS cases are higher than among non-Aboriginal AIDS cases (17.2%).
- A higher proportion of Aboriginal AIDS cases (35.5%), particularly among women, are attributed to intravenous drug use than is the case among non-Aboriginal Canadians (6.0%). This has dramatically increased over time from 10.3% prior to 1992, to 29.5% during the period of 1992 to 1995 and to 52.9% during the period of 1997 to 2001.

Aboriginal HIV Cases

- Positive HIV tests from provinces/territories reporting (British Columbia, Yukon, Alberta, Saskatchewan, Manitoba, Prince Edward Island, Newfoundland and Labrador) indicate that Aboriginal persons were over-represented among new HIV diagnosis; 19.3% in 1998, 24.3% in 1999, 22.3% in 2000 and 25.9% in 2001.
- Aboriginal people are over-represented among intravenous drug users who test positive for HIV.

- Aboriginal women accounted for 45.6% of new Aboriginal HIV infections while non-Aboriginal women accounted for 19.8% of new infections among non-Aboriginal Canadians in the period from 1998 to 2001.
- People between the ages of 20 to 29 years accounted for 30.6% of new Aboriginal HIV infections but only 20.4% of new infections among non-Aboriginal Canadians in the period from 1998 to 2001.

Current Aboriginal HIV and AIDS statistics are incomplete as a result of under-reporting of ethnic information, inter-provincial variations in reporting ethnicity, misclassification of ethnic status and delays in reporting. The HIV statistics represent only those people who have been tested and not the actual number of Aboriginal people with HIV. Moreover, HIV reporting does not appear to be mandatory in Ontario and only as of January 2002 is HIV reporting mandatory in Quebec – these provinces combined account for over half of the total HIV/AIDS cases in Canada. Thus, Health Canada's Centre for Infectious Disease Prevention and Control asserts that the proportion of Aboriginal people among estimated HIV prevalent and incident infections at the national level is increasing (Health Canada, *HIV/AIDS among Aboriginal Persons in Canada: A Continuing Concern,* 2002:5).

1.3 Limited Housing Options and Long Term Care Facilities for Aboriginal People Living with HIV/AIDS: Review of the Literature

Health Canada's social determinants of health approach " affirms that physical, social, economic and cultural factors influence health and Canadians' access to and benefits from the health system" (Health Canada:2000:4). Housing is known to influence health outcomes and figures in two of the twelve key determinants of health, identified in the Population Health - Health Determinants approach. "Housing plays an integral role in both health protection and health promotion. For persons with HIV infection both health protection and promotion strategies are needed in order to prevent further transmission of the disease" (Manson Willms et al.:1991a:17). As the BC Ministry of Health and Ministry Responsible for Seniors makes clear (1999/2000:6)

> "Access to safe, affordable housing helps people to live with HIV/AIDS and marginalized people to follow medical and drug treatments. Housing is essential to their long-term stability...But more needs to be done. A continuum of appropriate spaces is required for people with addictions and sex trade workers. Supports are needed to help at risk youth living on the street to have safe, stable housing."

Equally important, "preventing rapid transition from seropositivity to AIDS is dependent upon adopting healthy lifestyle choices that are designed to promote wellness, reduce stress and increase supportive contacts within the community...appropriate housing is essential to effective health promotion" (Manson Willms:1991b:17). Despite the importance of housing as an important determinant of health outcomes, the review of relevant literature revealed few documents or research that directly address the housing and long-term residential care/supports needs of Aboriginal people with HIV/AIDS. The paucity of research on housing, health and HIV/AIDS is a direct consequence of a number of inter-related factors.

Bio-medical research (seroprevalence studies) have tended to dominate the research on HIV/AIDS and Aboriginal peoples "as tracking the epidemic has been the primary focus of past research" (Northern Health Research Unit:1998:28). As a result, social research on HIV/AIDS and Aboriginal peoples is underdeveloped in Canada.

Social research conducted on the needs, experiences and perspectives of people living with HIV/AIDS generally does not address the issue of housing, despite the fact that this is a key determinant of health outcomes (see for example Salter Goldie, et al. 2000, 1997; Kali-Shiva AIDS Services 1998; Vanderhoof 1998). Manson Willms et al. 1990 research remains the definitive (the earliest and most comprehensive) research on housing issues and options for people with HIV/AIDS in Canada. It has been used by advocacy groups in British Columbia (Vancouver) and elsewhere in Canada to set up appropriate housing and hospices for people with HIV/AIDS. Although the researchers interviewed two Aboriginal service providers, this research did not address the specific needs of urban Aboriginal people living with HIV/AIDS.

Aboriginal people, particularly urban Aboriginal people, are invisible in research and policy. This is partly due to the bio-medical model's assumptions underpinning much HIV/AIDS research and care strategies which fail to take into account the importance of the social determinants of health such as culture (see Adrien et al. 1996; Canadian AIDS Society 1996; Canadian Public Health Association 1993), gender (see Amaratunga and Gahagan 2002; Commonwealth Secretariat and Maritime Centre of Excellence for Women's Health 2002; Ship and Norton 2002; 2001) and other social differences and inequalities that affect health, illness and well-being. The Northern Health Research Unit pointed out (1998:25) that

> "research to date has identified discriminatory attitudes and an absence of culture-based models for prevention and care as major barriers...also required is more research on the special needs of Aboriginal people and their families living with HIV/AIDS...and the palliative care needs of Aboriginal people with AIDS both on and off-reserve."

To date, there has been no comprehensive national research on the needs, experiences and perspectives of Aboriginal people in Canada living with HIV/AIDS. In addition, as a result of the complex jurisdictional issues related to status and geographic location (reserve and off-reserve) which affect and differentiate Aboriginal people, urban Aboriginal people are particularly ill-served with respect to HIV/AIDS services in almost all major urban centres.

Despite the importance of housing as a determinant of health outcomes, Thom's (1995) review of the relevant literature on housing for Aboriginal people with HIV/AIDS in Canada remains the sole and most comprehensive work to date, identifying the major issue areas. Thom's major findings (1995:5) are and we quote,

- **The need for culturally-appropriate research**
  "There is no data on the housing needs and choices of Aboriginal people living with HIV/AIDS (APHAs). There is no existing literature that is relevant or can assist in the design and development of Aboriginal PHA housing."

- **The need for culturally-appropriate services and a supportive home**
  "A supportive home for Aboriginal PHAs is urgently needed and is one of the greatest gaps in Aboriginal AIDS services. HIV/AIDS education, prevention and care programs for the Aboriginal community must be holistic, culturally appropriate and delivered by the Aboriginal community."

- **The inappropriateness of current Native housing for Aboriginal PHAs**
  "A large part of the existing stock of Aboriginal housing is inappropriate for people living with HIV/AIDS."

- **Cutbacks to funding and jurisdiction issues**
  "Government funding for Aboriginal housing is complex and plagued with interjurisdictional issues. Great obstacles exist to the provisioning of appropriate and supportive housing for Aboriginal PHAs stemming from Federal termination, significant funding cuts and freezes on Aboriginal Housing programs."

- **Disadvantaged socio-economic status and living conditions of Aboriginal peoples**
  "Aboriginal people experience the lowest levels of employment, income and education in Canada. Aboriginal people experience the worst housing conditions in Canada, have the greatest backlog of housing, and receive greatly inadequate housing subsidies."

What little we do know about Aboriginal people at high risk for HIV and living with HIV/AIDS would seem to confirm this finding (see Kevin et al. 1993 and CAAN's 1998 research of injection drug users in Vancouver, Elliott and Blanchard's 1999 study of injection drug users in Winnipeg and Ship and Norton's 2001 research in Montreal on injection drug users, sex workers, survival sex, substance abuse and alcoholism). These studies reveal a similar demographic, socio-economic and cultural portrait of the living conditions of urban Aboriginal people at high risk for HIV in major urban centres in Canada. They indicate that the overwhelming majority of Aboriginal people who are at high risk for HIV generally live in "unstable housing conditions" and on the hem of life. Monette and Albert's (2001:32) survey of Two-Spirited men across Canada showed that "45 percent of their respondents have lived in poor housing" including with friends, rooming houses, in shelters or a halfway house, if not homeless. A British Columbia-wide study that surveyed Aboriginal participants in an HIV/AIDS drug treatment program, found that in comparison to Non-Aboriginal participants, Aboriginal participants were significantly young, more likely to be female, unemployed, have annual incomes less than $10,000.00, to have never graduated high school and to have no stable housing (Special Working Group on Aboriginal Issues Ministerial Council on HIV/AIDS:2000:41).

A handful of studies have addressed homelessness and related issues affecting urban Aboriginal people in Edmonton (Native Counselling Services of Alberta 2000), in Toronto (Report on the Mayor's Homelessness Action Task Force 1999a; 1999b; 1999c, 1999d; Obonsawin–Irwin Consulting Inc. 1999) and in Montreal (Lamontagne 2001; Native Frienship Centre of Montreal 2001). This literature addresses the multiple dimensions of homelessness and points to the need for a holistic, culturally-specific strategy for urban Aboriginal people in which the development of a greater range of culturally-appropriate social housing with supports is a central issue. However, none of these studies address the specific housing and long-term residential care/services and support needs of low-income (at risk of homelessness) and homeless urban Aboriginal people with HIV/AIDS.

1.4 The Objectives of this Research

Awareness of the growth in HIV and AIDS rates among Aboriginal peoples, their disadvantaged heath status, socio-economic and living conditions in comparison with all other Canadians in tandem with the recognition of housing as a significant and growing unmet need of urban Aboriginal people living with HIV/AIDS provided the impetus for this study. CMHC commissioned this small research study with limited scope. The objectives of this research were as follows:

- To examine the housing issues and residential facilities and services available to homeless and low-income urban Aboriginal people with HIV/AIDS in urban centres (6 selected cities), and gaps in services.
- To identify appropriate services for homeless and low-income urban Aboriginal people with HIV/AIDS.

2.0 Methodology

This research report is a synthesis of secondary research; a review of existing literature, and primary research conducted with Aboriginal and non-Aboriginal service providers in major metropolitan and smaller metropolitan centres in Canada. Majority of the respondents are located in Vancouver, Edmonton, Regina, Winnipeg, Toronto, Ottawa, Montreal and Halifax. These are cities where the majority of urban Aboriginal people reside (RCAP:1996c:604). In addition, two respondents spoke to the specific issues affecting Aboriginal peoples in the Far North (Inuit) and in Labrador. Three Native American AIDS organizations were consulted for relevant information regarding housing options, culturally-appropriate models of long-term care for Native Americans living with HIV/AIDS.

The purpose is to provide an understanding of the specific housing and care needs of low-income and homeless urban Aboriginal people with HIV/AIDS in order to serve as a vehicle for developing culturally-appropriate housing, residential facilities and services for them. Culturally appropriate services for Aboriginal peoples (see Waldram 1994:333 for definition) refer to those Aboriginal specific services that:

- are provided by Aboriginal people for Aboriginal people
- are Aboriginal-driven (staff and participation in decision-making)
- affirm cultural values, spirituality, traditions and practices
- with a cultural component that varies in accordance with the specific composition of the Aboriginal groups for whom the service is designed or the Aboriginal clients who use them.

Ample evidence makes clear that "services made available from mainstream agencies are often not appropriate or effective" (RCAP:1996b:295) in addressing the health and social needs of Aboriginal peoples (Benoit and Carroll 2001; Society of Obstetricians and Gynecologists of Canada 2001; Mayor's Homelessness Action Task Force 1999; RCAP 1996b, 1996c; Shah and Dubeski 1993). For the majority of urban Aboriginal people, "their cultural identity remains the core of their existence. They face major difficulties because of the need to deal with non-Aboriginal agencies and institutions...to the extent that services can embrace their cultural values, these services will be more effective" (Mayor's Homelessness Action Task Force:1999:66)

2.1 Qualitative Research Study

As a consequence of the lack of research on the housing and long-term residential facilities care/support needs of homeless and low-income Aboriginal people with HIV/AIDS, primary research was conducted with a range of Aboriginal and non-Aboriginal HIV/AIDS service providers as well as Aboriginal people with HIV/AIDS. The primary research was largely qualitative, utilizing two different survey questionnaires: one for HIV/AIDS service providers as well as Aboriginal people living with HIV/AIDS (Appendix 2a Survey Questionnaire 1) and one for AIDS residential facilities and Native urban housing programs (Appendix 2b Survey Questionnaire 2).

A standardized survey questionnaire aimed at AIDS service providers and Aboriginal people living with HIV/AIDS was constructed, along with consent form and letter of introduction from Sweetgrass Consulting (Appendix 2a). Survey questions focussed on socio-demographic data on Aboriginal PHAs, housing conditions of Aboriginal PHAs, existing housing and long term residential facilities/supports for Aboriginal PHAs, barriers to the use of these facilities and culturally-appropriate services. A draft version of the survey questionnaire was submitted to Anna Lenk of CMHC, Art Zoccole, executive director of the Canadian Aboriginal AIDS Network (CAAN) and Maria McIntosh of Healing Our Nations in Halifax for feedback pertaining to accessibility, cultural appropriateness, validity and potential bias in the construction of the questions. Consequent upon constructive feedback, some revisions were made to the survey questionnaire. Time and financial constraints did not allow for pre-testing of the survey questionnaires or translation into French.

This survey questionnaire (Appendix 2a) was administered to participants at CAAN's Skills-Building Conference in Montreal, October 16-19, 2002, allowing for a large research sample composed of Aboriginal and non-Aboriginal service providers as well as Aboriginal people living with HIV/AIDS from across Canada. A French translation was not done, in part because the over-whelming majority of service providers and participants to this Conference were Anglophones; a reflection of the breakdown of official languages among Aboriginal peoples in general. However, for those participants who preferred French, a member of the research team was available to conduct a face-to-face or telephone interview in French, should the need have arisen.

Seventy (70) survey questionnaires were distributed to the participants at registration for the Conference. Sweetgrass Consulting was present at the Conference for its duration in order to collect as many questionnaires as possible before participants left the conference in order to ensure a higher response rate than if respondents would have mailed in their completed questionnaires. Fifteen (15) completed questionnaires from 5 Aboriginal AIDS organizations, one (1) non-Aboriginal AIDS organization, two (2) national Aboriginal organizations, one (1) regional Aboriginal health commission, two (2) Aboriginal HIV/AIDS consultants and four (4) Aboriginal PHAs were returned to the researchers. Several participants from the above-mentioned organizations took extra copies of the survey for prospective respondents they felt would be suitable. After the CAAN conference, one (1) Aboriginal PHA, one (1) Aboriginal AIDS organization, one (1) non-Aboriginal AIDS organization and two (2) Aboriginal service providers completed survey questionnaires and returned them to us.

Consequent upon receiving the first round of completed questionnaires, a list of key informants from Urban Native Housing Programs, AIDS hospices and long-term residential care facilities in addition to other Aboriginal health and social services was constructed as a result of feedback from respondents. A second smaller survey questionnaire (see Appendix 2b) was developed and faxed to these key informants from Urban Native Housing Programs, AIDS hospices and long-term residential care facilities for feedback on their target groups, services, policies, procedures for admission and availability of units, after initial contact was made with them by telephone or email. Some of these key informants were interviewed by telephone, utilizing the above-mentioned survey questionnaire while others faxed them back to us. Eight (8) respondents included four (4) Native urban housing societies and four (4) AIDS hospices/transitional housing.

Finally, three (3) interviews were conducted with Native American HIV/AIDS organizations in cities serving large concentrations of urban Native Americans for relevant information regarding housing options, and culturally-appropriate models of long-term care for Native Americans living with HIV/AIDS.

This research study is based on feedback from a total of 32 respondents. This includes five (5) Aboriginal people living with HIV/AIDS (Vancouver, Toronto, Montreal, Halifax), two (2) Aboriginal HIV/AIDS consultants and twenty-five (25) organizations including AIDS organizations (Aboriginal and non-Aboriginal), national Aboriginal organizations, Aboriginal service providers including one regional health commission, AIDS hospices, and Native Housing corporations (twenty-two (22) in Canada and three (3) in the United States).

2.2 The Limitations of the Research

This is not a comprehensive study but one intended to identify the key issues and gaps in housing, long-term residential care facilities and supports /services for homeless and low-income Aboriginal people with HIV/AIDS.

It was difficult to provide anything other than a very superficial profile of low-income and homeless Aboriginal people with HIV/AIDS in the cities presented in this report. Some respondents chose not to answer questions related to the size and composition of the Aboriginal population with HIV/AIDS in their particular city. Feedback from respondents was generally based on their knowledge of their clientele living with HIV/AIDS or their personal experiences. As HIV test reporting is not mandatory in some provinces and a matter of client confidentiality for service providers who do not necessarily collect this type of information, it is almost impossible to provide an accurate estimate of the number of Aboriginal people living with HIV, and to a lesser extent, those with AIDS in Canadian cities. This is further complicated by the fact that many Aboriginal people are extremely reluctant to disclose serospositive status for fear of stigma, ostracism and discrimination.

We had hoped for a higher response rate from the service providers, particularly given the large number of participants at the CAAN conference. However, a sizable number of Aboriginal PHAs, all government employees and Community Health Representatives (primary health care providers located in First Nations and Inuit communities), who made up over half the participants, declined to fill out the survey - with the latter two groups expressing the view that they were not the best placed to respond. In addition, some organizations had more than one participant at the conference and only one person per organization filled out the questionnaire. A few participants at the conference declined to fill out the survey for differing reasons including frustration with the lack of movement in meeting pressing health and social needs of Aboriginal PHAs. In addition, some potential respondents who took surveys with them did not return their completed forms to us as promised. Although some Aboriginal PHAs filled out the survey, the majority of APHA participants at the CAAN conference were unable to do so due to illness, disability or a lack of knowledge about available housing options and long-term care facilities/supports. Nevertheless, it is important to note that not all Aboriginal PHAs know what housing/long-term residential care options are available to them.

Time and financial constraints precluded the possibility of conducting an in-depth study on the housing needs and choices of Aboriginal people living with HIV/AIDS with a wider group of respondents. It is essential that Aboriginal PHAs be a part of any and all initiatives designed to improve their housing and long-term care options, as Thoms (1996:6) has also recommended.

In addition, time and financial constraints did not allow for an in-depth or an extensive survey with and of HIV/AIDS service providers, Aboriginal housing corporations and long-term residential care facilities in all Canadian cities, or in a given city. The research sample of cities selected was based on those service providers who chose to fill out the survey and the service providers they suggested that the research team contact. Not all of the information collected by the research team was utilized for this report. In some cases, the information was insufficient to provide an adequate portrait of the urban Aboriginal population with HIV/AIDS and its housing and long-term residential care facility needs (as was the case with Ottawa). Moreover, this research study does not address the needs of Aboriginal people living with HIV/AIDS in rural and remote communities.

Despite the limitations of this research, it provides a valid indication of the limited housing and long-term care options available to Aboriginal people living with HIV/AIDS in urban centres, specifically regarding the barriers to access of mainstream non-Aboriginal services that they face.

3.0 Housing, Long Term Care Facilities and Supports for Aboriginal People with HIV/AIDS in Selected Canadian Cities

People with HIV/AIDS are concentrated in the major metropolitan areas which have more services (Manson Willms:1991a). It is not surprising that "the majority of Aboriginal persons living with HIV/AIDS (APHAs) early in the epidemic were found in the urban areas of Vancouver, Toronto and Montreal. Typically they had lived away from their communities for years and felt that they could not return home due to AIDSphobia and fears of rejection" (Special Working Group on Aboriginal Issues: Ministerial Council on HIV/AIDS:2000:31). Moreover, "an increase in the HIV/AIDS epidemic has been observed in some Aboriginal communities, particularly those in inner-cities"(Health Canada 2002c:1).

Although the majority of Aboriginal people with HIV/AIDS are probably still in major metropolitan centres, feedback from respondents indicated that the number of APHAs in smaller metropolitan and urban centres is growing. These smaller metropolitan centres generally have fewer services and fewer housing and long-term care facilities for people with HIV/AIDS in general and for Aboriginal people in specific and family members play an important role in housing and providing supports. In Ottawa, for example, Bruce House provides supportive housing for people with HIV/AIDS for Ottawa and is the only supportive HIV housing for eastern Ontario region (from Cornwall to Kingston). In addition, as one respondent told us "Inuit people living with HIV and AIDS in Ottawa (as well as in Montreal) experience additional barriers to the use of services, in part because many do not speak English fluently, although nominally English-speakers and mainstream service providers are largely unfamiliar with Inuit cultures. Moreover, their small numbers in urban areas means that they are even more invisible in housing, services and supports."

In the Far North, the number of HIV/AIDS cases has also been steadily increasing. Access to supportive housing, long-term care facilities and services for Aboriginal people with HIV and AIDS is even more limited, particularly in the Far North for Inuit people living with HIV and AIDS. Some Aboriginal people with HIV and AIDS in Labrador commute from communities on the coast to Happy Valley-Goose Bay for medical services and most live with a family member. Should they desire to relocate to Happy Valley-Goose Bay, there is little in the way of low-income housing and long-term residential care for Aboriginal PHAS.

Therefore, as a result of differences in the concentration of Aboriginal people with HIV/AIDS and the availability of HIV/AIDS and related services, we have distinguished between major metropolitan centres and smaller metropolitan centres in order to present our findings, as the issues are somewhat different.

3.1 Major Metropolitan Centres

3.1.1 Vancouver

The population with Aboriginal ancestry in Vancouver was set at 42,795 people with 58.5% of these people identifying as Aboriginal in 1991 (RCAP:1996b:607). The Aboriginal community is extremely diverse.

Aboriginal People Living with HIV/AIDS

Vancouver is home to the largest concentration of Aboriginal people living with HIV and AIDS in Canada, with a large proportion of people from out of province. Most contracted HIV from injection drug use, particularly seropositive Aboriginal women; a trend noted early on in the 1990's (Manson Willms et al:1991b:283). Vancouver has the most developed AIDS services, housing and supports for Aboriginal PHAs. Yet, what little research there is seems to suggest that the majority of Aboriginal PHAs are living below the poverty line, on the "hem of life" and in unstable housing conditions; with "about 40% on the street and 20% using shelters", according to one respondent. Many are still involved in injection drug use, substance abuse and/or alcoholism in addition to sex work. Only a small percentage of Aboriginal people with HIV and AIDS are accessing Native housing or utilizing hospices, palliative care facilities or living with family, according to another respondent.

Goldstone et al.'s (2000) study of 128 HIV positive patients examined First Nations' use of hospital care in Vancouver from the point at which they were known to be HIV positive until death occurred. The portrait that emerges from this research is a despairing one.

> "There has been a steady increase in the hospitalization of (HIV infected) injection drug users, most commonly for the treatment of septicemia, endocarditis, cellulitis or commonly acquired pneumonia. Many are First Nations persons...Some are responsive to the offer of residential recovery programs and/or methadone maintenance. Others return to injection drug use (usually but not limited to cocaine, heroin or both), alcohol, the sex trade and life on the street or in single occupancy hotels in the downtown Eastside, the urban core. Alcoholism, chronic mental illness, a history of head injury, injection drug use, HIV/AIDS, tuberculosis and extreme poverty co-exists in this community. The gentrification of adjacent neighbourhoods has led to urban decay. The withdrawal of federal support for social housing has compounded the loss of low income housing...Issues of safety, nutrition, shelter, addiction and social chaos dominate the lives of the citizens of this neighbourhood...the majority of HIV infected First Nations persons live in these circumstances. (p.147)

The researchers found that

> "17% of First Nations persons died in a hospital or community palliative environment compared to 29% of non-First Nations persons. The degree of poverty and the fear of institutional care (both hospitals and community based palliative care) experienced by First Nations is illustrated by the fact that 25% of first Nations persons died in a single room occupancy hotel (SRO) compared with <1% of non-First Nations persons. In the authors' experience, this is related to

> residual impact of residential schools and the collective experience of abuse, rejection and abandonment (Goldstone et al.: 2000:149)."

The 1997 Annual Report of the Vancouver Native Health Society paints an equally despairing portrait of the final days of many Aboriginal people in an advanced state of AIDS.

> "The number of deaths is increasing with the largest percentage being Aboriginal. Many of those who have passed away have had violent deaths. It is common for our clients to die alone in a single occupancy Hotel Room with no cooking facilities, inadequate bathroom facilities, no homemaking care and inadequate nursing care due to fears of staff safety. Thus dying a very lonely death in squalor, with terrible nausea, pain, diarrhea, dehydration, and impaired mobility status in rooms infested by cockroaches, bedbugs, lice, scabies and rodents (p.22)."

Housing for Aboriginal People with HIV/AIDS

The BC Aboriginal HIV/AIDS Task Force identified housing issues as central to maintaining the health of Aboriginal people living with HIV. It makes the following recommendations (1999:61),

- To ensure adequate housing for people living with HIV ("adequate" includes heating, electricity, clean drinking water, bathing and toilet facilities, cooking facilities, refrigeration, secure storage of medications, emergency telephone access, not crowded, affordable, near to health care and support services).
- To provide a range of housing options (emergency, short & long stay etc.) to serve specialized needs; the homeless, the mentally ill, persons with substance abuse issues who are still using, abused women, women with children, independently-living youth."

In its discussion of Home-Based Care Services in British Columbia, the BC Aboriginal HIV/AIDS Task Force paper identifies the following limitations (1996:28), "Off-reserve, the lack of a single point access to the system, effective case management and complex referral requirements create barriers to accessing these services."

According to Vancouver Native Health Society, which also provides a Home Health Care Program (1997:22), "The Housing Program offers twenty-five (25) portable housing subsidies provided by the British Columbia House Management Commission (BCHMC) for clients living with HIV/AIDS. The waiting list is very lengthy for the self-contained apartments." Marsden et al. (2000:135) indicated that

> "The housing advocacy program provides ten (10) mobile housing subsidies for HIV positive Aboriginal people in BC, which are provided through BC Housing. This number in no way meets the housing need for Aboriginal people living with HIV/AIDS, and as a result, there is currently a long waiting list for this program. It is a priority to address this need by lobbying for more housing subsidies for Aboriginal people living with HIV/AIDS."

Healing Our Spirit makes referrals for affordable housing for Aboriginal people living with HIV/AIDS to Vancouver Native Housing, Lu'ma Native Housing Society and Kekinow Housing. These Native housing agencies are partners in providing suitable, subsidized housing for Aboriginal people living with HIV/AIDS (as Marsden et al.:2000:135 previously noted). Feedback from the three Native Housing Programs indicated that units are not specifically designated for Aboriginal people with HIV/AIDS, the waiting lists are very long – "several years on the average", accessibility is subject to availability and people must meet the core need income threshold requirements. The number of Aboriginal PHAs accessing these units is not known, in part because they do not necessarily disclose their seropositive status for fear of discrimination. One respondent reiterated the need for "housing geared for Aboriginal people living with HIV/AIDS as good accommodation /shelter is part of their healing."

Housing has been identified as a problem for injection drug users and many housing services have explicit policies to not accept them as Manson Willms et al. noted in 1991 (1991b:283). Therefore seropositive injection drug users remain particularly disadvantaged with respect to obtaining stable, affordable housing. Given the high proportion of Aboriginal injection drug users who are HIV positive, the situation is all the more critical.

The Vancouver Native Health Society (1997:22) makes clear that "there is a dreadful lack of pre-palliative and palliative care beds which leads to these people receiving third world health care. There are people dying without compassion and dignity which is supposed to be afforded to all living in Canada (p.22)." While there are a number of hospice and long-term residential care facilities in Vancouver which Aboriginal people do access, "there is a need for "an increase in supported housing and pre-palliative care as well as palliative care resources" (Vancouver Native Health Society:1997:22). In addition, a number of barriers to the use of the services and facilities were identified by respondents in our study:

- APHAs don't know about them
- APHAs don't feel comfortable because the service is not culturally-appropriate
- APHAs don't feel comfortable because there are few Aboriginal people living there
- Won't accept APHAs with multiple addictions
- Housing can't accommodate women with children
- Housing can not accommodate families
- Waiting list is too long
- The process is too bureaucratic and culturally alienating
- Discrimination (Aboriginal)
- Geared to the needs of single, gay men

Ship and Norton (2000) research explored the needs of First Nations women living with HIV/AIDS from a culturally-appropriate holistic perspective. It did not address housing issues per se but the interviews revealed that most of these single mothers and their children were living below the poverty line in the Downtown Eastside of Vancouver. They recommended that (2000:86). "Access to affordable, comfortable housing, and income supplements for medication, alternative therapies and treatments, food, transportation, home support, daycare and babysitting services would go a long way to improve the quality of positive women's and their children's daily lives."

Moreover, as one Aboriginal person with HIV/AIDS told us "there is a need for a hospice for Aboriginal people with HIV/AIDS. I really think that I would feel comfortable when my time comes that I would be watched over by Aboriginal people who understand my wants and needs."

Culturally Appropriate Housing and Long Term Care Facilities/Services Needs for Homeless and Low-Income Aboriginal people living with HIV/AIDS

The following needs were identified by respondents:

- An Aboriginal-specific hospice
- More culturally-appropriate, non-judgmental social housing in a safe environment with access to services and supports
- More housing options, services and supports for women and children
- Continuum of care for people with addictions and in a cycle of abuse
- More research and funds for the housing needs of Aboriginal people with HIV/AIDS in urban and rural areas
- Better access to pre-palliative and palliative care

3.1.2 Toronto

People with Aboriginal ancestry in Toronto number 40,040 people with 35.5% of this group identifying as Aboriginal in 1991 (RCAP:1996b:607). Ojibwa Nation people make up the majority of the Aboriginal community in Toronto (RCAP:1996b:606). Toronto has at least 44 Aboriginal-specific services (Lamontagne 2001).

Aboriginal People with HIV/AIDS

According to respondents, Two-Spirited men make up the largest proportion of Aboriginal people with HIV/AIDS, although the number of seropositive women is increasing. Most are of First Nations ancestry. At least 30% of the urban Aboriginal population living with HIV/AIDS is under 25 years of age. Most are from communities around the province and there is a very high percentage of Aboriginal people with HIV/AIDS who are highly transient and mobile. The overwhelming majority of Aboriginal people living with HIV/AIDS are living on the hem of life, with incomes under $10,000.00 a year and in unstable housing including on the streets, in shelters, rooming houses, "moving from couch-to-couch and back on the street." A 1995 Ontario-based housing needs assessment of Aboriginal people living with HIV/AIDS conducted by Deschamps and Thoms "found that 70% of the sample community was unemployed, 30% did not have stable housing, 52% lived in unaffordable housing and 58% of the housing units presently occupied by Aboriginal people living with HIV/AIDS were unsuitable for people with the disease" (Monette and Albert:2001:32). Only a small proportion of Aboriginal people with HIV/AIDS utilize the hospices and palliative care facilities.

Housing and Long Term Care Facilities and Services

There are housing units in Toronto designated for people with HIV/AIDS, although there is no Aboriginal-specific supportive housing for Aboriginal people living with HIV/AIDS. Aboriginal people with HIV/AIDS utilize Fife House (82 units in three locations) and MacEwan House, supportive social housing for people with HIV/AIDS.

Fife House has 2 units set aside for Aboriginal women with HIV/AIDS and ensures that these clients maintain contact with the community and the referring Aboriginal AIDS service provider (Reynolds 2001). According to respondents, Two-Spirited men remain particularly disadvantaged with respect to supportive housing but efforts are currently underway between Aboriginal and non-Aboriginal AIDS organizations to improve access for Two-spirited Men. Aboriginal people also use Casey House Hospice (now an AIDS hospice) but little is known about them. It has a limited space – in-house care for 12 residents, provides community outreach (residents who have been discharged), bereavement counselling and respite care and is associated with St. Michael's Hospital.

Although there are a number of Urban Native Housing Programs in Toronto, including Wigwamen, Nishawbe Homes and Gabriel Dumont Non-Profit Homes, their mandates are to provide low-income housing to Aboriginal singles, couples, seniors, disabled people and small families. They also provide support services including healing circles for men and for women and children in family violence situations, among other services. In addition to the long waiting lists, the Native Urban Housing Programs in Toronto were not designed to meet the needs of Aboriginal PHAs, particularly those in an advanced state of AIDS who require an extensive set of supports. Anduyin Housing is the Native Urban Housing Program that will admit Aboriginal PHAs but only a case-by-case basis through referral and mediation of AIDS service workers, according to one respondent.

The Native Men's Residence (Na-Me-Res) is a 36-bed hostel that offers safe accommodation, meals and counselling services for men 16 years of age and over. It provides an impressive array of services and counselling including alcoholics anonymous, addictions counselling, life skills and Men's Healing Circles, in addition to operating a Street Help Program for the homeless as part of the Out of the Cold Program. According to respondents, it too is reluctant to accept Aboriginal PHAs, particularly those with multiple addictions. It accepts Aboriginal PHAs only on a case-by-case basis through referral and mediation of AIDS service workers.

According to Obonsawin–Irwin Consulting (1999), the women's shelters most frequently utilized by Aboriginal women are the Woodgreen Red Door Family Shelter and the Women's Residence. The Out of the Cold Program has a high frequency of Aboriginal admissions at about 10% while The Hostel at 60 Richmond operated by Central Neighbourhood House and Dixon Hall is frequented by Native homeless people (7%). In the absence of any firm data, one can only assume that a certain percentage of Aboriginal people utilizing these services are living with HIV and AIDS.

Respondents indicated that Aboriginal people under-utilize existing mainstream low-income and supportive housing for PHAs as well as HIV/AIDS services (health care, food banks and home visits) for the following reasons

- APHAs don't know about them
- APHAs don't feel comfortable because the service is not culturally-appropriate
- APHAs don't feel comfortable because there are few Aboriginal people living there
- Housing can't accommodate women with children

- Housing can't accommodate families
- Won't accept APHAs with multiple addictions
- Won't accept APHAs with mental-emotional problems
- Waiting list is too long
- The process is too bureaucratic and culturally alienating
- Too many restrictions for low-income and supportive housing
- Need a referral from appropriate agency for access
- Discrimination (Aboriginal)
- Discrimination (HIV/AIDS)
- Geared to the needs of single, white, gay men

Culturally Appropriate Housing and Long Term Care Facilities/Services Needs for Homeless and Low-Income Aboriginal people living with HIV/AIDS

The following needs were identified by respondents:

- Increasing long and short-term supportive housing, as housing is a serious issue
- Ensuring access to Elders, traditional healers, ceremonies and medicines
- Improving accessibility and availability to basic health care

3.1.3 Montreal

The urban Aboriginal population of Montreal numbered 44,000 people (38,635 First Nations, 5,820 Métis and 775 Inuit people according to Lamontagne:2001:2), with 15.2% of people with Aboriginal ancestry identifying as Aboriginal (RCAP:1996b:607). Montreal's urban Aboriginal population is the most culturally and linguistically (Aboriginal languages and two official languages) diverse in Canada. With the exception of Ottawa, it is the only metropolitan area to have a sizable Inuit community. In addition, there are few Aboriginal specific services.

Aboriginal People Living with HIV/AIDS

Most of the Aboriginal people living with HIV/AIDS are of First Nations and Inuit ancestry; with 60% English-speakers in a French-speaking metropolitan centre. Previous research conducted by Ship and Norton (2001a) revealed a grim picture of the situation of Aboriginal people living with HIV/AIDS in Montreal.

> "Service providers' feedback about HIV positive First Nations, Inuit and Metis clients indicated that they are in an unstable and destabilizing lifestyle that includes homelessness/at risk of homelessness, substance abuse, alcoholism, injection drug use, violence and abusive relationships (in some cases, the sex trade). Most are living on fixed incomes that are below the poverty line, with few resources and social supports. Many frequent shelters.
>
> Many Aboriginal people do not seek out care, support and treatment upon HIV diagnosis but rather at a later stage of the disease. As a result, they are usually high need clients with co-infections."

Housing and Long Term Care Facilities and Services

According to our respondents, there is only one Native Urban Housing Program in Quebec, Waskehegan, with its head office in Quebec City and a regional office in Iberville, Quebec. There are units in Montreal but feedback from respondents indicated that English-speaking Aboriginal people find it difficult to access. There is currently no housing specifically designated for Aboriginal people living with HIV/AIDS.

There are several hospices in Montreal including Maison Plein Coeur, Les Hébergements de L'Envol (8 rooms), Maison Amaryllis (8 places), Maison Dehon (6 rooms), Maison D'Hérelle (17 beds - double or single occupancy) and Maison du Parc which also provide a range of supports and services (CPAVIH:2001:88-91). In addition, Les Habitations Jean-Pierre Valiquette offers 17 beds available in 19 supervised apartments including other supports and services (CPAVIH:2001:89). However, as we were told by one Aboriginal PHA, the mandates of the hospices in Montreal have recently undergone a transformation, moving away from long-term and palliative care providers to that of transitional housing for people with HIV/AIDS because seropositive people are living longer and better than before. However, while AIDS deaths have declined overall in Canada (see HIV/AIDS Epi Updates), this does not seem to be the case for Aboriginal people with HIV/AIDS.

Previous research conducted by Ship and Norton (2001a) revealed that Aboriginal people generally do not use the hospices as all the hospices contacted reported no Aboriginal clients at that time and few, if any in the past. Aboriginal women with HIV/AIDS use the emergency shelters such as Le Chaînon. Although Le Chaînon has a long-term care program for clients who want to develop a stable lifestyle which was offered to an HIV positive Aboriginal client who was quite ill, the client declined the offer (Ship and Norton 2001). "Very little is known about the experiences, needs and perspectives of First Nations, Inuit and Metis people in an advanced state of AIDS, except that they are almost invisible in mainstream HIV/AIDS and related services. Too many people die alone in hospitals without friends, family and the necessary spiritual support" (Ship and Norton:2001a:Executive Summary p.2-3).

Ship and Norton's previous research (2001:Executive Summary:3) identified seven major barriers to the use of mainstream HIV/AIDS and related services that included:

- Cultural barriers
- Linguistic barriers
- Structural barriers – the historical relationship of entrenched inequality
- Mistrust of doctors and nurses
- Divergent expectations and experiences around medical services delivery
- Financial barriers/non-insured health benefits or beneficiaries
- APHAs' lack of knowledge about existing services

Culturally Appropriate Housing and Long Term Care Facilities/Services Needs for Homeless and Low-Income Aboriginal people living with HIV/AIDS

Two of the recommendations in Ship and Norton's research study (2002:78) for improving the quality of life for Aboriginal people living with HIV and AIDS focussed on "access to safe and affordable housing" and "ensuring access to current hospices, palliative care, home care and supports." In addition, the following needs were identified by respondents,

- Providing transitional housing for homeless Aboriginal people with HIV/AIDS
- Ensuring access to both Western and Aboriginal health services
- Providing accompaniment to services
- Implementing ongoing support to maintain stable housing and a stabilizing lifestyle
- Setting up culturally-appropriate supportive housing units set aside for Aboriginal people with HIV/AIDS that provides a continuum of care
- Making available an Aboriginal health care worker and home care worker for home care
- Setting up a small, long-term culturally-appropriate care facility with a continuum of care
- Setting up a walk-in clinic for Aboriginal people with HIV/AIDS for access and assistance for services (housing, food banks, and other types of assistance) and one-on-one counselling provided by an Aboriginal staff
- Providing a drop-in or in-patient program for Aboriginal PHAs with addictions problems that is culturally-based
- Assistance with re-integration efforts for Aboriginal PHAs

3.2 Smaller Metropolitan Centres

3.2.1 Winnipeg

The population declaring Aboriginal ancestry numbered 44,970 people with 78.2% identifying as Aboriginal in 1991 (RCAP:1996b:607). Ojibwa Nation people make up the majority of the Aboriginal community in Winnipeg (RCAP:1996b:606).

Aboriginal People with HIV/AIDS

According to one respondent, the Aboriginal population with HIV/AIDS is largely of First Nations backgrounds, with a small proportion of PHAs who are Métis. The majority of Aboriginal people with HIV/AIDS would appear to be Two-spirited men, followed by Aboriginal women, including a sizable proportion of single-parent female-headed families living with HIV/AIDS. Most of the Aboriginal people with HIV/AIDS are between the ages of 26 years to 39 years of age. Approximately 80% of the Aboriginal people living with HIV/AIDS are living on incomes under $15,000.00 yearly. About 75% are from communities around the province and about 80% are long-term residents of the city. About 45% of Aboriginal people with HIV/AIDS are living in unstable housing conditions, including on the streets, in shelters, in rooming houses or rooming with people and not paying rent. Most of the APHAs in stable housing conditions are paying rent on their own apartment. About 10 % commute from a First Nations community to the city and only about 5% are living in a hospice.

Housing and Long Term Care Facilities and Services

Respondents indicated that Artemis Housing Co-op, subsidized housing through a Manitoba government program, has housing units for people living with HIV/AIDS, which Aboriginal people living with the disease access. However, according to respondents, access is problematic and it is under-utilized by Aboriginal PHAs for the following reasons:

- APHAs don't know about them
- APHAs don't feel comfortable because the service is not culturally-appropriate
- APHAs don't feel comfortable because there are few Aboriginal people living there
- Housing can't accommodate women with children
- Housing can't accommodate families
- Won't accept APHAs with multiple addictions
- Won't accept APHAs with mental-emotional problems
- Waiting list is too long
- Discrimination (Aboriginal)
- Geared to the needs of single, gay men

Some Aboriginal women with HIV and AIDS stay at the Native Women's Transition House, although it is not set up as a hospice or facility whose main mandate is to provide care for women with HIV/AIDS. This 2-year program offers the stability, culturally-appropriate counselling, life skills and healing which enables them to then make the transition to a stable lifestyle and stable housing. The Transition House does not accept women who are still on alcohol or doing drugs. The options are extremely limited for seropositive Aboriginal women with acute alcohol and/or substance abuse problems whose only recourse is to shelters and the streets.

According to respondents, House of Hesed offers room and board for end-stage people with AIDS. However, only a small percentage of Aboriginal PHAs use this service or any other long-term residential care facilities.

Culturally Appropriate Housing and Long Term Care Facilities/Services Needs for Homeless and Low-Income Aboriginal people living with HIV/AIDS

The following needs were identified by respondents:

For Low-Income Aboriginal people living with HIV/AIDS

- Setting up a house for seropositive mothers with children
- Providing room and respite care for caregivers
- Setting up communal and culturally-appropriate low-income housing for clients who need support such as shared meals, medical services, social supports, transportation to and from housing throughout the city, and confidentiality

For Homeless Aboriginal people living with HIV/AIDS

- Providing access to laundry facilities and a clothing depot
- Providing home cooked meals and a food bank
- Ensuring access to Elders and sweat lodges

- Ensuring access to clean syringes
- Ensuring access to free legal advice

3.2.2 Edmonton

The population declaring Aboriginal ancestry numbered 42,695 people with 68.5% identifying as Aboriginal in 1991 (RCAP:1996b:607). Cree Nation people make of the majority of the Aboriginal community in Edmonton (RCAP:1996b:606).

Aboriginal People with HIV/AIDS

Little is known about Aboriginal men and women living with HIV and AIDS in Edmonton. Feedback from respondents indicated that they are a very transient group of people, who for the most part are in unstable housing conditions that includes living on the street, in shelters, rooming houses and/or rooming with others and not paying rent. Majority of the Aboriginal PHAs are living on incomes below the poverty line; with an annual income under $10,000.00 per year. Most are from communities around the province, although about 25% are from out-of-province. Men also appear to be more visible than women.

Housing and Long Term Care Facilities and Services

Edmonton has three Aboriginal Housing Corporations: Amisk Housing, Metis Urban Housing Corporation and Canative Housing, all of which have long waiting lists. "Although two are heavily subsidized by CMHC and are Rent-Geared to Income, they still experience problems with arrears and overcrowding. Their policies are geared toward families and single parents who have the ability to maintain a household...the disability registry is over 600" (Native Counselling Services of Alberta:2000:12-13). According to one survey respondent, 4 units are designated for Aboriginal people with HIV/AIDS.

However, long waiting lists, particularly for those in the disability category, coupled with the fact that the housing programs are geared to families and single parents who can maintain a household means that the majority of Aboriginal people living with HIV and AIDS is not simply not going to obtain a unit or are not eligible. Aboriginal PHAs in an advanced state of AIDS who can no longer care for themselves or who require extensive supports and those who are homeless and in a destabilizing lifestyle remain particularly disadvantaged.

There is no hospice in Edmonton for people with AIDS and the major long-term residential facility remains Karos House "which was set up in 1987 by Catholic Social Services to provide support to persons living with HIV or AIDS and can accommodate up to seven people. The program serves the needs of persons with HIV or AIDS at that stage of their illness which does not require hospice care, but requires some degree of care and assistance in daily living" (Manson Wilms et al.:1991b:273). In the initial years of its operation, all residents were male and mostly gay, with a few intravenous drug users (Manson Willms et al.:1991b:274). Aboriginal PHAs do access this service, although how many is not clear nor whether Aboriginal women utilize this service.

Palliative care for people with AIDS appears to be minimal, although Edmonton General Hospital had two palliative care beds available in 1991 with discussion of increasing the number of beds (Manson Willms et al.:1991b:275).

Culturally Appropriate Housing and Long Term Care Facilities/Services Needs for Homeless and Low-Income Aboriginal people living with HIV/AIDS

The following needs were identified by respondents:

- Increasing the number of social housing units (private housing and apartments) for Aboriginal PHAs
- Setting up a hospice

3.2.3 Regina

The population declaring Aboriginal ancestry numbered 12,765 people with 86.3% identifying as Aboriginal in 1991 (RCAP:1996b:607). Cree Nation people make of the majority of the Aboriginal community in Regina (RCAP:1996b:606).

Aboriginal People with HIV/AIDS

Feedback from respondents indicated that the majority of Aboriginal people with HIV/AIDS in Saskatchewan live in Regina. They are of First Nations and Métis ancestry. Half of the HIV/AIDS cases are female. The seropositive Aboriginal population is young (about 50% under the age of 25 years), transient and highly mobile, with only 25% long-term residents of the city and most are from out communities around the province. The overwhelming majority live on the hem of life with either no reportable income or an income below the poverty line. Half live in unstable housing conditions – streets, shelters and/or moving from place to place while the other half is living with a family member. Many of the Aboriginal people with HIV/AIDS in Regina are in a destabilizing life style that includes addictions and mental health problems.

Housing and Long Term Care Facilities and Services

There is little available in terms of housing options and long term care facilities and supports in Regina for Aboriginal people living with HIV/AIDS. The major service provider is Aman House Ministries, which is Christian-based housing for HIV positive people and people at risk for HIV. Aboriginal people do not choose to use this service as they don't feel comfortable because it is not culturally-appropriate and there are few if any Aboriginal people living there. For others, they are still in a state of denial about their seropositive status and are still in a destabilizing lifestyle.

There are no long term care facilities for Aboriginal people with HIV/AIDS. They must use Saskatchewan Health public-funded hospitals for palliative care, private homes if they can afford it, or else they must be cared for by a family member. Aboriginal families remain the largest care providers for Aboriginal people with HIV/AIDS in Regina. Barriers to the use of long-term residential care facilities by Aboriginal people with HIV/AIDS include:

- APHAs don't feel comfortable because the service is not culturally-appropriate.
- Discrimination (Aboriginal)
- Discrimination (HIV/AIDS)

Culturally Appropriate Housing and Long Term Care Facilities/Services Needs for Homeless and Low-Income Aboriginal people living with HIV/AIDS

The following needs were identified by respondents:

- Providing Aboriginal-owned, controlled and accessed social housing and long-term residential care facilities and services for Aboriginal people living with HIV and AIDS.
- Mental health issues need to be addressed and homeless Aboriginal people with HIV/AIDS need counselling.
- Providing financial and other social supports for Aboriginal families choosing to care for their own.

3.2.4 Halifax

The population declaring Aboriginal ancestry numbered 6,710 people with 17.7% identifying as Aboriginal in 1991 (RCAP:1996b:607). The Aboriginal community in Halifax is composed predominately of First Nations people who are for the most part Mi'kmaq (RCAP:1996b:606).

Aboriginal People with HIV/AIDS

Feedback from respondents indicated that the number of Aboriginal people living with HIV/AIDS in the Atlantic region is small and for the most part living in stable housing conditions: renting an apartment, living with a family member or commuting from a First Nations community to Halifax. The families, friends and Aboriginal AIDS workers provide the major part of care and support for Aboriginal people with HIV/AIDS, including palliative care.

Housing and Long Term Care Facilities and Services

According to respondents, there are no housing units designated for people with HIV/AIDS or for Aboriginal people with HIV/AIDS. Whether Aboriginal people living with HIV/AIDS access units at Tawaak Housing, the Native Urban Housing Program, is not known. Two specific barriers to accessing these housing units were identified:

- The waiting list is too long.
- Potential discrimination (HIV/AIDS). Some Aboriginal people with HIV/AIDS might feel obligated to disclose their HIV status in order to get an emergency housing unit in order to avoid the long waiting list. Disclosure of HIV status serves as a deterrent from seeking housing as confidentiality is a key issue for most Aboriginal people with HIV/AIDS.

Respondents indicated that there are no long-term residential care facilities for people with HIV/AIDS, First Nations or otherwise. Several potential barriers to the use of mainstream long term care facilities by Aboriginal people with HIV/AIDS were identified:

- APHAs don't know about them
- APHAs don't feel comfortable because the service is not culturally-appropriate
- APHAs don't feel comfortable because there are few, if any, Aboriginal people living there.

- Long-term residential care facilities can't accommodate women with children.
- The process is too bureaucratic and culturally alienating.
- Discrimination (Aboriginal).
- Geared to the needs of single, gay, white men.

Culturally Appropriate Housing and Long Term Care Facilities/Services Needs for Homeless and Low-Income Aboriginal people living with HIV/AIDS

The following needs were identified by respondents:

- Setting up an Aboriginal specific facility, with culturally-appropriate services and Aboriginal care providers, including access to Elders. Accommodations need to be made available for family to come and stay as many of the Aboriginal people with HIV/AIDS are from remote communities.
- Providing greater financial support for families to secure the care and support needed for Aboriginal people living in First Nations communities.

3.3 Culturally Appropriate Housing for Native Americans with HIV/AIDS: A Case Study

Native Americans with HIV and AIDS living in major metropolitan and urban centres in the USA face similar challenges in meeting their housing needs as their brothers and sisters in Canada. According to the Indian Community House of New York, its HIV/AIDS Unit now provides outreach services to Native Americans in New York City, Buffalo, Syracuse, Rochester and Akwesasne. Its clientele is composed of urban Native Americans as well as Native Americans with HIV/AIDS who come to the cities for medical services in addition to seeking the invisibility and anonymity that cities provide. There are no housing units specifically set aside for Native Americans living with HIV and AIDS in New York City. They are subject to the same low-income housing regulations and options as non-Native Americans. In New York City, Buffalo and Syracuse, the waiting lists are very long and it can take up to two to two and a half years to get low-income housing. The HIV/AIDS Unit would like to see the setting up of a culturally-appropriate housing complex for Native Americans with HIV/AIDS similar to the one established by the Indigenous AIDS Taskforce in Minneapolis.

The Indigenous AIDS Task Force, linked to the Indian Community House in Minneapolis–St. Paul set up a culturally-appropriate Indigenous-owned and Indigenous-controlled culturally-appropriate supportive housing complex for Native Americans living with HIV and AIDS in Minneapolis four years ago. They raised the $2.2 million dollars on their own for this venture which was designed and functions as a co-operative managed by the Indigenous AIDS Taskforce. The supportive housing complex, which is also handicap accessible, comprises 14 units – 4 studio apartments, 4 one-bedroom apartments, 4 two-bedroom apartments, 1 three-bedroom apartment and 1 four-bedroom apartment. The larger apartments are for families living with HIV and AIDS. Families can stay up to two years after their loved one has died of AIDS.

In addition to being Aboriginal-driven, providing accommodation and support for families, an emphasis on co-operative and communal living are crucial components of the culturally-appropriate supportive housing in that it is in keeping with the fundamental cultural values of all Native cultures: the importance and centrality of the family and of the community. Programs and services are premissed on the affirmation of Native traditions, cultural values and spirituality. Traditional health and healing practices are emphasized and available. Residents have access to Elders, healing circles, talking circles, sweat lodges and ceremonies. The co-operative is linked with the Healing Lodge in Toronto as the majority of the residents at the co-operative are Chippewa and they have a strong cultural affinity and links with the Ojibway.

The co-op offers a range of supports and services consistent with supportive housing such as life skills training, including skills in housing and co-op living for residents, many of whom are not used to looking after their own apartments. Also offered are drug and alcohol counselling, community centre, community garden, babysitting services for HIV positive parents when they go to the doctor and an afterschool program.

There are two basic requirements for accessing housing: the individual must be seropositive and must have a Case Management worker. The waiting list for units is long, particularly for the studios and one-bedroom apartments. At this particular moment, there is no waiting list for the four-bedroom apartment.

An evaluation of the model is currently underway. One of the main challenges the co-op is facing is the integration of seropositive substance abusers and alcoholics; many of whom have been unable to make a transition to a healthy stable lifestyle. The co-op is now considering a change in policy regarding the admission of people with serious substance abuse and alcohol problems.

4.0 Conclusion: The Need for Culturally Appropriate Housing, Long Term Care Facilities and Supports for Aboriginal People Living with HIV/AIDS

The profile of Aboriginal people with HIV and AIDS in major metropolitan and smaller metropolitan centres that emerged from this research study indicates that they are a heterogeneous low-income population whose housing and care needs may differ. At the same time, a majority of this population is living on "the hem of life" in unstable housing conditions and in destabilizing lifestyles. Additional supports, services and transitional housing are required to meet their housing and care needs which differ from those of Aboriginal people with HIV/AIDS in a stable lifestyle. There is also a need to ensure that the specific housing and care needs of Aboriginal families living with HIV/AIDS, particularly those of single-parent female-headed families, are met.

Feedback from respondents in this research study reveals that little progress has been made in meeting the housing and long-term care needs of Aboriginal people living with HIV and AIDS since Thoms' 1995 review of the literature on housing issues and options for Aboriginal people living with HIV/AIDS. Service providers and Aboriginal people with HIV/AIDS identified a number of important gaps in housing, long-term care facilities and services for homeless and low-income Aboriginal people living with HIV/AIDS in urban centres.

Under-utilization of mainstream HIV/AIDS long-term care and related services by Aboriginal people living with HIV/AIDS

Aboriginal people living with HIV/AIDS tend to under-utilize mainstream hospices, long-term care facilities and other HIV/AIDS related services and supports including home care. Discrimination as Aboriginal people, cultural barriers, linguistic barriers and gender barriers in addition to a bureaucratic and culturally-alienating process are the main reasons why Aboriginal people with HIV/AIDS under-utilize mainstream services, social and/or supportive housing, hospices and other HIV/AIDS related services.

Limited Housing Options for Aboriginal people living with HIV/AIDS

There is limited access to social and supportive housing units for low-income Aboriginal people living with HIV/AIDS in Native Urban Housing Programs. Native Urban Housing Corporations are not mandated or necessarily equipped to accept Aboriginal people living with HIV/AIDS, particularly those with addiction and mental health problems. The situation is further complicated by the long waiting lists for the current stock of social housing and the lack of funding for increasing the number of new units. Many Aboriginal people living with HIV/AIDS are reluctant to disclose their seropositive status even if this were to facilitate access to housing.

The housing options, including transitional housing and units in Native Urban Housing Programs, for homeless Aboriginal PHAs particularly those with substance abuse, alcohol abuse and/or mental health problems, are particularly limited. Many respondents indicated that homeless Aboriginal people need additional support and services such as life skills training and on-going services and supports including access to Elders and counselling, currently not available to assist them in preparing for and maintaining stable housing and lifestyle. In addition, meeting their basic needs for food, clothing, shelter and healthcare is essential.

Finally, not all Aboriginal people living with HIV/AIDS are aware of the housing options available to them. They need more information and assistance in the procurement of social housing.

Limited Aboriginal-specific long term care facilities, supports and services

There are no Aboriginal-specific, Aboriginal-driven, culturally appropriate hospice/long term care facilities along the lines of the supportive housing facility set up by the Indigenous AIDS Taskforce in Minneapolis, despite the advocacy efforts of Aboriginal organizations for almost a decade.

Access to culturally appropriate and competent healing and health services, particularly for counselling and palliative care, such as Elders, sweat lodges, traditional medicines, traditional food and ceremonies is limited for many Aboriginal people living with HIV and AIDS in inner-cities.

Some Aboriginal families choose to care for their loved ones living with HIV/AIDS. There is insufficient funding and access to respite care for Aboriginal families who care for family members living with HIV/AIDS at home.

The need for culturally appropriate services for Aboriginal people living with HIV/AIDS

Appropriate services for Aboriginal people with HIV/AIDS living in urban centres necessarily include a cultural component. Guiding principles for the development of culturally appropriate (provided by Aboriginal people for Aboriginal people) and culturally enhanced (provided by non-Aboriginal people) services include:

- Consultation with key First Nations, Inuit and Metis stakeholders including people with HIV/AIDS
- Aboriginal driven (staff and participation in decision-making)
- Affirm cultural values, spirituality, traditions and practices
- Respect for diversity. The cultural component varies in accordance with the specific composition of the Aboriginal groups for whom the service is designed or the Aboriginal clients who use them.

Culturally appropriate services would include:

- The setting up of a long term residential care facility in each of the major urban areas in Canada for Aboriginal people with HIV/AIDS, staffed with Aboriginal health workers and resources. Services offered might also include the provision of a continuum of culturally-appropriate care that would comprise home care for Aboriginal people with HIV/AIDS living on their own and outreach for homeless Aboriginal people with HIV/AIDS in a destabilizing lifestyle. Such facilities should be able to accommodate family members for an indefinite period.

- Implementing a continuum of care, where currently not available, that includes culturally appropriate healing, health and support services such as counselling and palliative care for Aboriginal people living with HIV/AIDS in inner-cities.
- Ensuring access to culturally appropriate and competent healing and health services such as Elders, sweat lodges, traditional medicines, traditional food and ceremonies.
- Ensuring better access to information on low-income housing/long term care options and providing more assistance in the procurement of space.
- Increasing the number of culturally appropriate and supportive low-income housing units for Aboriginal people with HIV/AIDS and education for staff at Native housing societies on Aboriginal HIV/AIDS issues.
- Increasing the number of social housing units for Aboriginal people with HIV/AIDS and ensuring better access for seropositive Aboriginal women with children.
- Addressing the specific needs of homeless Aboriginal people with HIV/AIDS by providing transitional housing (emergency, short term and long term), life skills training and on-going support services (counselling, access to Elders, family support) to assist them in preparing for and maintaining stable housing and lifestyle.
- Increasing financial and other supports for low-income single people and families living with HIV/AIDS, specifically female-headed single-parent families

Cultural enhancement of mainstream services would include:

- Cross-cultural and anti-racist education and training for non-Aboriginal staff
- Increasing number of Aboriginal staff (home care, outreach, counselling, nurses)
- Aboriginal participation in decision-making
- Providing linguistic and cultural interpreters
- Accompanying Aboriginal people to mainstream services
- Providing access to Elders, ceremonies and traditional healing practices
- Providing culturally appropriate counselling and supports
- Ensuring enhanced access to mainstream hospice and respite care through better access to information and assistance in the procurement of space.

Improving the housing and long-term care options for a heterogeneous urban First Nations, Inuit and Métis population living with HIV/AIDS is all the more critical since the majority of Aboriginal PHAs can not return home to their communities. Barriers include the lack of available services as well as stigmas around AIDS and associated stigmas related to injection drug use and sex work, in addition to gender-based discrimination that affects women and Two-Spirited men. Accommodating the diverse housing and care needs of a heterogeneous urban First Nations, Inuit and Métis people living with HIV and AIDS entails a multi-faceted strategy tailored to the local context to ensure that they may live positively.

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6.0 Glossary of Terms

Two-Spirited:	"In 1988, contemporary Natives coined the term *Two-Spirit.* It refers to 'a Native American who is of two spirits, both male and female"… "The term 'two-spirited' means Aboriginal people who identify themselves as gay, lesbian, (bisexual, or transgendered)…The term doesn't necessarily have a sexual meaning: some transgendered homosexuals identify themselves as Two-Spirit but not as gay"… Monette, L. and D. Albert (2001). *Voices of Two-Spirited Men: A Survey of Aboriginal Two-Spirited Men across Canada.* Toronto: Two-Spirited People of the First Nations, p.2.
Aboriginal:	Refers to organic political, and cultural entities that stem historically from the original peoples of North America…It includes Indian (First Nation), Inuit and Métis peoples of Canada. RCAP (1996a). Volume 1, *Looking Forward, Looking Back.* Ottawa, Terminology p. xv.
First Nations:	Replaces the term Indian. RCAP (1996a). Volume 1, *Looking Forward, Looking Back.* Ottawa, Terminology p. xv.
Inuit:	Replaces the term Eskimo. RCAP (1996a). Volume 1, *Looking Forward, Looking Back.* Ottawa, Terminology p. xv.
Métis:	Refers to distinct Aboriginal peoples whose early ancestors were of mixed heritage (First Nations, or Inuit in the case of the Labrador Métis, and European) and who associate themselves with a culture that is distinctly Métis, The more specific term Métis Nation is used to refer to Métis people who identify themselves as a nation with historical roots in the Canadian west. RCAP (1996a). Volume 1, *Looking Forward, Looking Back.* Ottawa, Terminology p. xv.

Appendix 1 – Research Sample

Indian Community House HIV/AIDS Unit- New York, New York
Indigenous Peoples Task Force- Minneapolis, Minnesota
National Native American AIDS Prevention Center- Oakland, California
Canadian Aboriginal AIDS Network- Ottawa, Ont.
Pauktuutit- Ottawa, Ont.
Metis National Council- Ottawa, Ont.
Labrador Inuit Health Commission- Happy Valley, Goose Bay Labrador
Healing our Nations-Dartmouth, N.S.
Tawaak Housing- Halifax, N.S.
Native Friendship Centre of Montreal-Montreal, Que.
Bruce House-Ottawa, Ont.
Wabano Health Centre-Ottawa, Ont.
Two-Spirited People of the First Nations-Toronto, Ont.
Ontario First Nations HIV/AIDS Strategy-Toronto, Ont.
Casey House-Toronto, Ont.
McKewan House-Toronto, Ont.
Fife House-Toronto, Ont.
Native Women's Transition House-Winnipeg, Man.
All Nations' Hope AIDS Network-Regina, Sask.
AIDS Program South-Regina, Sask.
AIDS Edmonton- Edmonton, Al.
Healing Our Spirit-Vancouver, B.C.
Lu'ma Native Housing Society- Vancouver, B.C.
Kekinow Native Housing Society- Vancouver, B.C.
Vancouver Native Housing Society- Vancouver, B.C.
5 Aboriginal people with HIV/AIDS
2 HIV/AIDS consultants

Appendix 2a

Survey Questionnaire 1

Housing and Long-Term Residential Care Service Needs for Homeless and Low-Income Aboriginal People Living with HIV/AIDS

Survey Number: ____________

Date: ____________________

Name: ____

Title/Position: ____

Organization: ____

Address: ____

City/Province: ____

Postal Code: ____

Telephone: ____

Fax: ____

Email: ____

Do you know of any documents or research on the housing and /or long-term residential care needs of Aboriginal people with HIV/AIDS that might be useful for this research?

Yes:______ No: ______

Would you be willing to do a short telephone interview, if necessary?

Yes: ______ No: ______

Thank you for taking the time to fill out this survey.

1.0 Organizational Profile

1.1 What type of services to Aboriginal people living with HIV/AIDS does your organization provide? Please list: ______________________________

____

____

____

____

1.2 How large is the Aboriginal population with HIV/AIDS using your service?

Approximate number: ______________________________

Comments: ______________________________________

____

____

2.0 Demographic Profile

2.1 To the best of your knowledge, how large is the Aboriginal population with HIV/AIDS in your city? Approximate number: ____________________

2.2 To the best of your knowledge, what is the gender breakdown of Aboriginal people with HIV/AIDS in your city?

Men ____________ percentage
Two-Spirited ____________ percentage
Women ____________ percentage
Transgender ____________ percentage

Comments: ______________________________________

____

____

2.3 To the best of your knowledge, how many Aboriginal families are living with HIV/AIDS in your city?

Families ______________ approximate number
Single-parent female–headed families _____ percentage
Single-parent male–headed families _____ percentage
Two-parent families _____ percentage

Comments: ____
____
____

2.4 To the best of your knowledge, what is the age range of Aboriginal people with HIV/AIDS in your city?

Under 25 _____________ percentage
26 to 39 years _____________ percentage
40 and over _____________ percentage

Comments: ____
____
____

2.5 How diversified is the Aboriginal population living with HIV/AIDS in your city?

First Nations _____________ percentage
Inuit _____________ percentage
Métis _____________ percentage
Non-Status _____________ percentage
Status _____________ percentage

Comments: ____
____
____

2.6 To the best of your knowledge, what are the income levels of the Aboriginal population living with HIV/AIDS in your city?

No reportable income ____________ percentage
Under $10,000/year ____________ percentage
Between $10,000-$15,000 ____________ percentage
Between $15,000-$20,000 ____________ percentage
Between $20,000-$30,000 ____________ percentage
Over $30,000 ____________ percentage

Comments: ____

____

____

2.7 To the best of your knowledge, what proportion of the Aboriginal population with HIV/AIDS in your city are

From the communities around the province: ____________ percentage
From out-of-province: ____________ percentage

Comments: ____

____

____

2.8 To the best of your knowledge, what proportion of Aboriginal population with HIV/AIDS in your city are

Long-term residents: ____________ percentage
Recent arrivals: ____________ percentage
Transient/highly mobile ____________ percentage

Comments: ____

____

____

2.9 To the best of your knowledge, where do Aboriginal people with HIV/AIDS in your city live? Please place an (X) in front of the appropriate responses and if possible indicate the percentage of Aboriginal people with HIV/AIDS for each housing arrangement.

____ Street: ______________ percentage
____ Shelters: ______________ percentage
____ Rooming House: ______________ percentage
____ Sharing an apartment/not paying rent: ______________ percentage
____ Sharing an apartment/paying rent: ______________ percentage
____ Living in an apartment/paying rent: ______________ percentage
____Living in an hospice: ______________ percentage
____Hospital/palliative care: ______________ percentage
____Living with a family member: ______________ percentage
____Commute from community to city: ______________ percentage

Other arrangements: Please specify____

____
____
____

Comments: ____
____
____

3.0 Housing for Aboriginal People with HIV/AIDS

3.1 Are there housing units specifically designated for people living with HIV/AIDS in your city? Yes: _________ No: _________

If yes, how many units?: _______________________

If yes, please name the housing facilities and describe the type of housing (non-profit or private ownership) as well as the services and supports provided, if any:

____

____

____

____

____

____

3.2 Are there housing units specifically designated for Aboriginal people living with HIV/AIDS in your city? Yes: _________ No: _________

If yes, how many units?: _______________________

If yes, please name the housing facilities and describe the type of housing (non-profit or private ownership) as well as the services and supports provided, if any:

____

____

____

____

____

____

3.3a If there are no housing units specifically designated for Aboriginal people living with HIV/AIDS in your city, please list name and type of housing units (with or without supports) they can access:

____

____

____

____

____

3.3b Do Aboriginal people living with HIV/AIDS (APHAs) access these housing units?

Yes: ______ No: ______

If not, why not: Please indicate your responses by placing an (X) in front of the appropriate responses.

____ APHAs don't know about them.
____ APHAs don't feel comfortable because the service is not culturally-appropriate.
____ APHAs don't feel comfortable because there are few, if any, Aboriginal people living there.
____ APHAs may want the status quo in their lives
____ Housing can't accommodate women with children.
____ Housing can't accommodate families.
____ Waiting list is too long.
____ The process is too bureaucratic and culturally alienating (too many forms etc.).
____ Need a referral from an appropriate agency for access.
____ Won't accept APHAs with multiple addictions.
____ Won't accept APHAs with mental-emotional problems.
____ Discrimination (Aboriginal)
____ Discrimination (HIV/AIDS)
____ Geared to the needs of single, gay men.

Other reasons, please specify: ____

____

____

Comments: ____

____

____

4.0 Long-Term Residential Care Facilities for Aboriginal People with HIV/AIDS

4.1 Are there long-term residential care facilities for people living with HIV/AIDS in your city? Yes: ________ No: ________

If yes, please name the long-term residential care facilities, describe the services and the number of spaces available: ____

____

____

____

____

4.2 Are there long-term residential care facilities specifically designated for Aboriginal people living with HIV/AIDS in your city? Yes: ________ No: ________

If yes, please name the long-term residential care facilities, describe the services and the number of spaces available: ____

____

____

____

____

4.3a If there are no long-term residential care facilities specifically designated for Aboriginal people living with HIV/AIDS in your city, please list name and type of long-term residential care facilities/services they can access: ____________________________

____

____

____

____

____

4.3b Do Aboriginal people living with HIV/AIDS (APHAs) access these long-term residential care facilities in your city?

Yes: ______ No: ______

If not, why not: Please indicate your responses by placing an (X) in front of the appropriate responses.

____ APHAs don't know about them.
____ APHAs don't feel comfortable because the service is not culturally-appropriate.
____ APHAs don't feel comfortable because there are few, if any, Aboriginal people living there.
____ APHAs may want the status quo in their lives
____ Long-term residential care facilities can't accommodate women with children.
____ Long-term residential care facilities can't accommodate families.
____ Waiting list is too long.
____ The process is too bureaucratic and culturally alienating (too many forms etc.).
____ Need a referral from an appropriate agency for access.
____ Won't accept APHAs with multiple addictions.
____ Won't accept APHAs with mental-emotional problems.
____ Discrimination (Aboriginal)
____ Discrimination (HIV/AIDS)
____ Geared to the needs of single, gay men.

Other reasons, please specify: ____

____

____

Comments: ____

____

____

5.0 Culturally-appropriate Housing and Long-term Residential Care Facilities/ Services

5.1 What kinds of culturally-appropriate housing and long-term residential care facilities/services do your low-income APHAclients need? Please explain.

5.2 What kinds of culturally-appropriate housing and long-term residential care facilities/services do your homeless APHA clients need? Please explain.

6.0 Comments/Suggestions:

Consent Form

I, ____, agree to participate in this research study by filling out a survey questionnaire.

I understand that the objective of this research is a housing and long-term residential care services needs assessment for low-income and homeless urban Aboriginal people living with HIV/AIDS. I understand that the research will be used for the purpose of preparing a report for the Canada Mortgage and Housing Corporation (CMHC).

I understand that my anonymity with respect to comments and suggestions will be respected.

____________________________________	____________________
Participant's Signature	Date

Sweetgrass Consulting
P.O. Box 480
Kahnawake Mohawk Territory
Quebec J0L 1B0
Tel: (450) 635-2167
Email: laura121@netcom.ca

October 17, 2002

Dear Colleague,

Sweetgrass Consulting is conducting a research study commissioned by Canada Mortgage and Housing Corporation pertaining to housing and long-term residential care services available to homeless and low-income urban Aboriginal people living with HIV/AIDS. The objective of the research is as follows:

- To examine housing issues and residential facilities and services available to homeless or low income urban Aboriginal people with HIV/AIDS in urban centres, and gaps in services.

We have prepared this survey questionnaire to gather pertinent information that you may have as well as your views on the gaps in services and the specific needs of urban Aboriginal people living with HIV/AIDS. Your participation in this research is crucial.

As the time frame for completion of this research is very short, we would appreciate it very much if you would complete the survey and return it to us before the Conference ends. If you prefer a French version of the survey, Susan Ship will be available to interview you in French.

Thank you in advance for your invaluable assistance and cooperation.

Laura Norton and Susan Judith Ship

Appendix 2b

Survey Questionnaire 2

Housing and Long-Term Residential Care Service Needs for Homeless and Low-Income Aboriginal People Living with HIV/AIDS

Survey Number: ______________

Date: ______________________

Name: ____

Title/Position: ______________________________________

Organization: _______________________________________

Address: ____

City/Province: ______________________________________

Postal Code: ____

Telephone: ____

Fax: ____

Email: ____

1. Who is your target population? ___________________________

____

2. How many units do you manage? ___________________________

3. What services and/or supports do you provide? Please describe: ___________

____

____

____

____

4. How many units are set aside for Aboriginal people living with HIV/AIDS? ________

5. How long is the waiting period to get a unit? _______________________

6. How many people (Aboriginal) with HIV/AIDS are on the waiting list? ___________

7. If you have Aboriginal clients with HIV/AIDS, how do they come to you?__________

____

____

____

8. Is there a referral process? Yes: _______ No: __________

Please describe the process: ____

____

____

____

____

____

9. What is your policy regarding who is eligible for a unit? _______________________

____

____

____

____

10. If there are no units for Aboriginal people with HIV/AIDS, please explain why: ____

____

____

____

____

11. Comments/Suggestions: ____

____

____

____

____

Consent Form

I, ____, agree to participate in this research study by filling out a survey questionnaire.

I understand that the objective of this research is a housing and long-term residential care services needs assessment for low-income and homeless urban Aboriginal people living with HIV/AIDS. I understand that the research will be used for the purpose of preparing a report for the Canada Mortgage and Housing Corporation (CMHC).

I understand that my anonymity with respect to comments and suggestions will be respected.

____ ____________________

Participant's Signature Date

Sweetgrass Consulting
P.O. Box 480
Kahnawake Mohawk Territory
Quebec J0L 1B0
Tel: (450) 635-2167
Email: laura121@netcom.ca

October 17, 2002

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We have prepared this survey questionnaire to gather pertinent information that you may have as well as your views on the gaps in services and the specific needs of urban Aboriginal people living with HIV/AIDS. Your participation in this research is crucial.

Thank you in advance for your invaluable assistance and cooperation.

Laura Norton and Susan Judith Ship