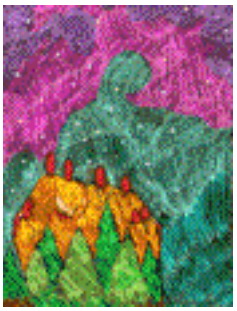
Vol.15, Summer 2000

National Indian & Inuit Community Health Representatives Organization

IN TOUCH



BREAKING DOWN THE BARRIERS - ADDRESSING THE EMERGING EPIDEMIC

IN THIS ISSUE: THE BATTLE AGAINST HIV/AIDS

This issue of In Touch is built around the National HIV/AIDS Leadership Conference: Breaking Down the Barriers - Addressing the Emerging Epidemic, which took place in Regina from March 14-16.

The conference began with a warning that Aboriginal people are now the highest risk group in Canada for contracting HIV/AIDS. Over the three-day period, conference delegates looked at specific Aboriginal risk groups, Aboriginal women and HIV/AIDS, the current battle against the disease and harm reduction programs.

At the end, they made a call for complete community mobilization to prevent the current epidemic from becoming pandemic. To point the way, the delegates made a series of wide-ranging recommendations, which we haveincluded on p.15-17.

The Assembly of First Nations (AFN) will be using these recommendations to develop a Plan of Action on HIV/AIDS. ”It is time we took on this battle,” said AFN Health Director Allen Deleary at the opening of the conference. ”It is one we simply cannot afford to lose.”

NATIONAL HIV/AIDS LEADERSHIP FORUM

Breaking Down the Barriers
- Addressing the Emerging Epidemic

The National Leadership Conference on HIV/AIDS, held in Regina on March 14-16 marks a new starting point in the battle against disease in Aboriginal communities. Co-hosted by the Assembly of First Nations (AFN) and the Federation of Saskatchewan Indian Nations (FSIN), the conference brought together Aboriginal leaders, healthcare workers and professionals, and government representatives to work on a new national Plan of Action. The delegates called for First Nations control of research, more lobbying for treatment and prevention funding, a more active role for community leadership in the HIV/AIDS fight and a greater role for traditional healing in AIDS treatment. They also called for a greater focus on youth and injection drug users to prevent the behaviors that are putting them, and their communities, at risk.

HIV/AIDS Epidemic Feared

The sense of urgency at the conference behind the new plan came from alarming new statistics on the nature and extent of the disease in Aboriginal populations. Dr. Donald Sutherland, Director of the HIV/AIDS Bureau at the Laboratory Centre for Disease Control, told the delegates that although Aboriginal people make up only 5 per cent of the population in Canada, they now represent 16 per cent of the new cases of HIV.

Aboriginal people infected with HIV/AIDS also tend to be much younger than the HIV cases in the general Canadian population, and they are more likely to be infected through injection drug use. There is also a much higher percentage of Aboriginal women infected than the Canadian average, with women making up 45 per cent of the new Aboriginal HIV cases.

Costs to Communities

Along with the enormous cost to individuals and families, the Assembly of First Nations' (AFN) Health Director, Allen Deleary, spoke about the financial burden the disease is placing on communities. The costs for supporting someone with HIV are estimated to be over $50,000 per year, and Deleary said that these costs have to be taken into account by communities negotiating health transfer agreements. "If the current numbers continue to increase, or if five or ten people with AIDS return home from the city," Deleary warned, "communities could face financial disaster."

Lindsay Cyr, the Health Director at the FSIN, said that one of the biggest problems is that Aboriginal communities do not have solid information to draw on, and without that information it is difficult to design effective programs. "First Nations people have certain rights," he said. "Treaties have the Medicine Chest clause which guarantees that medicines will be made available. But in the history of the Medicine Chest, we have not been in control of its contents. We have to get control now. Part of this is to have our own information systems in place. If we don't have control of the data, we cannot control our programs."

MORE RESOURCES NEEDED

A number of CHRs and other frontline workers made a plea to the political leadership for more support. They said they were given almost no resources for public education or for care of people with AIDS in their communities, and that they often had to scrounge for the basics in HIV/AIDS prevention materials. Kathleen Brant, of the Thayendanega Health Centre, told the delegates that she receives only $2000 a year for HIV/AIDS education, care and treatment. “This simply isn’t enough to do what has to be done,” she said. Allen Deleary told the delegates that the AFN would be lobbying for considerably more funding and human resources to meet the heavy burden of the disease. ”We also have to make sure that it is multi-year funding,”he said, “because HIV/AIDS is a long-term problem and requires long-term solutions.”

CHANGES FROM WITHIN

Deleary also said that many of the solutions would have to come from within. He said it was vitally important to get more First Nations involvement in planning, implementing and evaluating programs. “But we also have to look at strengthening the family and opening up a dialogue in our communities on healthy sexuality.”

One issue that was addressed by a number of delegates was the problem of homophobia in some Aboriginal communities. The conference was told that part of the reason that the average life expectancy of Aboriginal people with AIDS is only half that of non-Aboriginal people with AIDS, is that they waited much longer before seeking testing and treatment.

As Arlo Yuzicappi-Fayant, the past president of the Canadian Aboriginal AIDS Network (CAAN) put it, many of the young men who are infected “would rather go without treatment and die than admit they were gay.”

Carl Orr, an AIDS Educator with the Union of Ontario Indians, said the disease is still a controversial issue at the community level. “They are waiting for the Chiefs and Councils to take the next step in addressing the issue,” Orr said. “Five minutes from a Chief carries more weight than a whole national strategy in motivating people at the community level.”

COMMUNITY MOBILIZATION

Many of the HIV/AIDS activists said that it was time for complete community mobilization in the HIV/AIDS battle, and suggested that even community members who have been incarcerated should be enlisted in the fight. “Many First Nations youth look up to the men whose involvement in risky behaviors landed them in prison,” Allen Deleary said. “If you can enlist these men in the fight against AIDS, they can be powerful voices in instructing the young about the dangers of the disease and how to protect themselves from it.” Delegates were also reminded that many young Aboriginal people, women and men, are dying from AIDS in prisons, and these people also need care, compassion and support.

Conference delegates also called for more traditional healing and ceremonies to be included in treatment. Examples were given of countries like Peru where traditional healers and medical doctors work side by side in government clinics. The AFN was asked to lobby for an equal role for traditional healers; healthcare workers were urged to use more Aboriginal languages in HIV/AIDS health promotion materials.

Healthy childhood development was seen as crucial to combating the disease in the long term, and it was suggested that Head Start and other youth programs should be linked to HIV/AIDS education programs. ”We need to educate the young and foster self-esteem in 7 to12 year olds,” Allen Deleary said. “That is missing at the community level. We have to build safe environments. We have to legislate safe communities - promote non-violence, self-esteem and reduced risk-taking, and not tolerate drug dealers and bootlegging. We have to get down to basics- and keep youth out of the environments where they might be at risk: the streets and prisons.”

TRACKING THE DISEASE

Latest LCDC Statistics Raise Fears of Aboriginal HIV/AIDS Epidemic

Dr. Donald Sutherland, Director of the HIV/AIDSBureau at the Labratory Centre for Disease Control, paintsa sombre and disturbing picture of HIV/AIDS in Aboriginal communities.

Among Aboriginal gays, or two-spirit men, the disease rates are dropping slightly, presumably because of safer sexual practices. But the disease is growing to dangerous levels in Aboriginal injection drug users (IDUs), and through them in the heterosexual population.

In fact, of the Aboriginal people who tested positive for HIV since 1998, when ethnicity information was first included in HIV data collection, 62 per cent were injection drug users, as opposed to 33.3 per cent in the non-Aboriginal population. Aboriginal women are also becoming infected at the rate of twice non-Aboriginal women, and twice as many new Aboriginal cases occurred in the under 30 age group than in the non-Aboriginal population. The following is a summary of the current statistics on HIV/AIDS in the Aboriginal population.

HIV AND AIDS SURVEILLANCE DATA

By the end of 1996, there had been an estimated 50,000-54,000 HIV infections in Canada since the onset of the epidemic. But the characteristics of the epidemic have changed over time. Most notably is the shift from men who have sex with men (MSM) to injection drug users (IDU). This has led to emerging HIV epidemics among heterosexuals and women, and this trend is felt most strongly in Aboriginal populations.

Predictors for Sero-Conversion

Low income
Low education
Involvement in sex trade
Injecting with others
STDs
Irregular condom use with non-regular partners
Determinants of HIV-related Risk Behaviour
Use of alcohol and other drugs
Depression
Low socio-economic status
Homophobia
Social isolation
Low self-esteem
Belief that trust, love and intimacy provide protection against disease
Belief that one can visually identify those who are infected
Family dynamics and the influence of peers, particularly for younger participants

HIV Surveillance data: Comparisons of positive HIV test reports among Aboriginal persons and non-Aboriginal persons in Canada, 1998-1999

	ABORIGINAL (N = 179)	NON-ABORIGINAL(N=689)
GENDER		
Male	52.5%	79.1%
Female	45.8%	20.3%
AGE (years)		
Under 30	39.1%	20.6%
30-39	40.8%	42.2%
40+	21.2%	37.1%
EXPOSURE CATAGORIES		
Men having sex with men	11.1%	30.0%
IDU	62.0%	33.3%
Heterosexual	15.6%	24.5%

Bureau of HIV/AIDS, STD and TB. LCDC. March 2000

The statistics show that the incidence of HIV/AIDS is now reaching epidemic proportions among Aboriginal women, and has been accompanied by a corresponding increase in perinatal transmission. This was shown in two recent studies, one in British Columbia, the other in Northern Alberta. In the British Columbia study at the Oak Tree Clinic, 36 per cent of children born to mothers with HIV/AIDS were Aboriginal. In Northern Alberta HIV clinics, 42 per cent of all infected women were Aboriginal; and 91 per cent of those delivering HIV-infected children in Northern Alberta and the Northwest Territories during 1996-98 were Aboriginal.

OVER-REPRESENTATION OF ABORIGINAL PERSONS IN HIGH-RISK POPULATIONS

SOURCE	ABORIGINAL %
IDU studies (Calgary, Edmonton, Winnipeg, Vancouver, Ontario)	11%-75%
Men who have sex with men studies (Vancouver, Winnipeg)	8%-17%
Studies among inmates	14% in federal penetentiaries; up to 40% of provincial penetentiaries
Sexually Transmitted Diseases reported rates	2-11 times the national average

Bureau of HIV/AIDS, STD and TB. LCDC. March 2000

ABORIGINAL PEOPLE AT HIGH RISK

Dr. Sutherland underlined that a great danger for future transmission of the disease is that Aboriginal people remain highly over-represented in all of the main risk categories for HIV/AIDS. In fact, he compared the pattern of HIV/AIDS cases among Aboriginal people to the one he saw while working in Uganda, where AIDS is a full-blown epidemic. ”In Africa it is the poor and the marginalized people who are now the most affected by AIDS,” he said, “and those are also determinants of HIV for Aboriginal people in Canada.”

HIV/AIDS ON THE FRONTLINES

HEALTHCARE WORKERS ASK FOR LEADERSHIP SUPPORT IN HIV/AIDS BATTLE

Confronting the Aboriginal HIV/AIDS epidemic at the community level often means scrounging for resources, working with indifferent Chiefs and Councils, and trying to allay deep-seated community fears. That was the view expressed at the AFN's National Leadership Conference on HIV/AIDS held in Regina last March, as CHRs and other community health workers spoke bluntly about their experiences on the frontlines in the HIV/AIDS battle. Arlo Yuzicappi-Fayant, the past president of the Canadian Aboriginal AIDS Network (CAAN), said that AIDS service organizations are plagued by lack of staff and daunted by the challenges HIV/AIDS poses Aboriginal people. She explained that an HIV/AIDS worker has to know about the history of the disease, its symptoms, current research, palliative care, women with AIDS, children with AIDS, pre- and post-test counseling, safe sex, IDU and AIDS, needle-sharing and harm reduction, family violence and self-esteem, healthy sexuality, racism, homophobia, privacy and AIDS, AIDS in prison, clinical trials and case management. "CHRs, already stressed by having to deal with the diabetes epidemic in their communities, are wondering how they can handle AIDS as well," she said.

FEW RESOURCES AVAILABLE

Kathleen Brant, a CHR from the Thayendanega Health Centre, said that when she was told she would be the AIDS educator, she knew nothing about the disease. After reading everything she could find on the subject, she advertised an HIV/AIDS workshop. She had her first indication of what was ahead when only one community member showed up. She had more success at a later workshop when she convinced someone with HIV to speak, and the community members were surprised when he pointed out that he was receiving almost no support in his personal battle against the disease.

In a community with a combined on- and off-reserve population of 6,000, Brant receives only $2000 a year for HIV/AIDS awareness programs and for special care for people with AIDS. So she has to scramble to make ends meet. She gave examples of outright bartering for services, as well as using a neighbourhood kid as a resource to help her put together an HIV/AIDS pamphlet for 12 to15-year-olds. To get up-to-date materials on HIV/AIDS, she often tells other Aboriginal offices they need them when it was really she who needed them and couldn't afford to purchase them on her small AIDS Awareness budget.

CAREGIVING

Harm reduction on the frontlines, Brant explained, is not only condoms and needles, it is getting a warm coat for someone who is wasting away. It is buying fresh fruit for someone with HIV who has to take care of his/her diet. Frontline workers also have to look after the dying. And for this, they end up using personal time - even to go to the funerals of AIDS victims. "There is a big emotional toll in taking care of people with AIDS," she said, "that is impossible to quantify."Caring for AIDS patients is also made more difficult because of community fears. Brant said that one First Nations community in Southwestern Ontario paid a community member afflicted with AIDS to leave. He took the money and left, but committed suicide a short time later. "It's vital that the rights of these individuals be protected," she said.

ADDRESSING COMMUNITY FEARS

Carl Orr, an AIDS Educator with the Union of Ontario Indians, agreed that in some communities, people with AIDS "are treated like biblical lepers." He added that many of those communities claim traditional or Christian values, but he said he sometimes wondered "where the values of care and compassion go, when these communities are faced with a band member with HIV/AIDS."

Orr also knew of a community where a person with AIDS was evicted. After this occurred, health workers from that community were asked to evaluate the social and personal habits of other band members and guess how many others in that community might be HIV positive. The healthcare workers guessed maybe six or eight. "Those six to eight people will never come forward to seek health care on HIV," Orr said. "because now they know if they seek care, they too will be discriminated against, or simply evicted."

Patti Yuzicappi-Buffalo of the Saskatoon Tribal Council said that homophobia remains a major problem, and part of that stems from the fact that First Nations people have often forgotten their traditions. "Among the Dakota," she said, "we always had two-spirit men who took on the women's role. Traditionally, they were seen as sacred people, often with special powers. It is important to look at our history and take the shame away. As it stands today, two-spirit people leave the community and never come back because people aren't accepting of them. We have to deal with the denial and the shame."

In the majority of the 43 Ontario communities he is accountable to, Orr said, there is someone with AIDS walking around the community untreated and receiving little or no support. Healthcare workers and people with AIDS are waiting for the Chiefs and Council to take the next step," he said.

He gave as a positive example Beausoleil (Christian Island), where the band council took the matter into their own hands and passed a resolution to ensure that AIDS patients and their families would not be discriminated against. The resolution stated: "The Chief and Council recognizes the rights of Band members infected with HIV/AIDS to pursue activities such as attending school, attaining employment, occupying a residence and other rights and privileges granted to them as Band and community members."

Other Ontario First Nations that have passed similar resolutions include: Dokis, Sheshegwaning, Mississauga and Sarnia. Several more have their HIV/AIDS protocols in final draft form ready for endorsement from Chief and Council. Recently, The Union of Ontario Indians has also passed a Resolution encouraging First Nations health staff in all communities to begin drafting community planning documents (protocols) for HIV/AIDS.

"In all of these cases, the political leadership recognized that taking care of community members with HIV/AIDS is simply part of the responsibility to take care of all community members," Orr said.

Another challenge for CHRs and other community health workers is the issue of preserving confidentiality for HIV/AIDS patients. One CHR said she had been pressured to reveal to the band council who is HIV positive, but she refused and periodically destroys sensitive files. The rest are in her computer under password. Ways must be found, the delegates agreed, for the political leadership to get the information they need in planning for health expenditures without jeopardizing the confidentiality of individual band members who do not want their HIV status known.

GOVERNMENT PROGAMS INADEQUATE

In the area of community-based AIDS treatment, some hope was held out for the new Medical Services Branch (MSB) home care program offering more options for palliative care. But there were also serious complaints about the NIHB drug program for HIV/AIDS patients because of the red tape required to get even the most rudimentary medications. Often initial drug requests are refused and it takes repeated attempts to get what is needed. Important items for AIDS patients, like vitamin supplements and special skin creams, were often left off the NIHB list entirely.

AFN Health Director, Allen Deleary, agreed that the NIHB red tape was “horrendous” and promised to make that and other community workers’ concerns part of the Assembly’s HIV/AIDS Plan of Action.

There was also a large degree of support and sympathy for CHRs and other healthcare workers from the Chiefs present at the Regina conference. Chief Harry Cook said “the leadership needs to be told of its shortcomings. We need to understand the problems you face. Continue to be brave. Say what you have to say. We need to support our frontline workers.”

HIGH RISK GROUPS

The first fact that any HIV/AIDS prevention worker hasto confront is the variety of ways HIV/AIDS is now entering their communities. Today, high-risk populations include injection drug users, men having sex with men, and people having unprotected heterosexual activity. With the high percentage of women becoming infected, perinatal transmission, where infants are infected at birth or through breastfeeding from HIV-positive mothers, is also becoming a growing concern.

By far the largest group of new Aboriginal infections are from injection drug users. HIV/AIDS workers are looking at the expansion of harm reduction programs such as needle exchanges. Part of the problem with delivering these programs to Aboriginal people is their high mobility, with many moving back and forth between their communities and urban centres. The idea of expanding needle exchange programs into the communities has been suggested, but HIV/AIDS activists said that this meets strong resistance from community leaders who fear they will be seen to be sanctioning drug use.

Many HIV/AIDS workers feel that the only long-term solution is to treat the root causes of injection drug use. They refer to the “post-colonial stress syndrome,” which continues to drive many young First Nations people to self-abusive behaviours, including alcohol and drug use and suicide. In the prevention of the disease among the young, HIV/AIDS workers say that it is imperative to address the underlying emotional and self-esteem issues.

A COMMUNITY APPROACH

The call at “Breaking Down the Barriers - Addressing the Emerging Epidemic” was to begin HIV/AIDS education and awareness programs with the young and involve all elements of the community. Carl Orr of the Union of Ontario Indians said that for the very young, you could begin to teach about HIV/AIDS without mentioning the disease, or even sex. He suggested Elders could explain to children that if they cut themselves when they were skinning a fox, they could get any illness that the fox had. “And from there they cantalk about the exchange of fluids in a more general way. ”But the direct approach was preferred for older children with the HIV/AIDS workers calling for a broad-based community education campaign. “We have to get to the children in the second or third grade,” Orr said. “Age 7 to 12 are the most formative years and this is the critical group to equip with information. We know that children as young as 14 are already having babies in some communities.”

Teaching tools like Let’s Rap About AIDS were recommended as starting points. Among other things, this game teaches kids about needles and condoms, and how they should go to find an adult if they see one. It was also suggested that children be brought into community HIV/AIDS awareness campaigns, like the Annual AIDS Walk.

As part of the community mobilization, and to encourage open, honest dialogue, band councils and daycares were encouraged to develop HIV/AIDS policies and protocols. In programs for young people in the 12 and up age group, it was thought essential that the young people themselves be brought in to help design the programs and to take a leadership role in running them.Two other crucial elements in HIV/AIDS awareness and prevention programs were parental and school involvement.Jake Linklater, the executive director of the Canadian Aboriginal AIDS Network (CAAN), pointed out that the schools were often the weak link because of jurisdictional problems with provincial governments. But cooperation from the schools was viewed as essential, and healthcare workers called on the political leadership to help them break the political logjam.

Carl Orr said that child abuse was also an issue, and that one way to prevent HIV/AIDS was to ensure you have a safe community. Kids who grow up in an abusive home, or a home with violent or addicted parents, are at high risk for developing the behaviors- injection drug use, unprotected sexual activity, and behaviors leading to incarceration - that greatly increase the risk of contracting HIV/AIDS.

WORKING WITH THE INCARCERATED

A special focus at the conference was also placed on the role of Aboriginal prisoners. People in prisons are 10 times more likely to have HIV/AIDS than the general population and Aboriginal people are incarcerated at a much higher rate than other people in Canada. As one participant pointed out, unless the incarcerated people are given prevention and awareness programs, they will bring the virus home.

Health workers described the current HIV/AIDS awareness programs in prisons as inadequate. Most of them are peer education programs, which didn't seem to be working on HIV/AIDS issues. They suggested enlisting Elders into making prison visits to promote healthy lifestyles and to give spiritual support. Teaching prisoners, and all young people, their national language would also help to root them more firmly into their culture and its traditional values.

Communities were encouraged to look into early release programs that would allow them to bring some band members home from prison so they could intervene in positive ways. The returning prisoners, if they responded well, could become important role models for the young, particularly for young men who tend to look up to those who have been incarcerated and are far more likely to heed a warning from a man who has experienced street life, than from a social worker or health professional.

TWO-SPIRIT PEOPLE

Art Zoccole of the Red Road AIDS Network reminded the conference about the need to work to address discrimination against two-spirit men. His own connection to HIV/AIDS, he said, came in 1982 when a friend died from the disease. In 1989, he started an association of two-spirit Aboriginal men in Toronto. "Two-spirit people generally migrate to urban areas," he said, "with only a few very courageous individuals staying home. When most two-spirit were infected, they were living away from the community. They had no one to tell. They couldn't tell their families they were gay, let alone that they had HIV and AIDS." He added that now even straight men who contract AIDS as injection drug users are afraid to admit it because people will think they are gay.

"We need to talk about these things all of the time," he said. "We have to go to every venue we can to talk about HIV/AIDS - to get it into the open. People are waiting for communities to take on the AIDS issue. And the moment they do, people are going to start to return home. They are waiting."

ABORIGINAL WOMEN

One of the most startling elements of the new statistics on HIV infections is the number of Aboriginal women who are becoming infected. In the general Canadian population, only 20 per cent of the new infections are among women. In the Aboriginal population, more than 45 per cent of the new infections are among women, and most of these are young injection drug users, who are often forced to work as prostitutes to support their drug habit. Arlo Yuzicappi-Fayant described the risk factors for infection among women as low education, unemployment, substance abuse, injection drug use, and unprotected sex. But she also said that when working with women at risk, it was important not to be judgemental about their lives. "The most essential first step is that women get help with their self-esteem," she said.

A large number of women also get HIV from sex with their husbands, lovers or boyfriends, or from sharing needles with their partner as injection drug users - unaware that their partner has been sharing needles or having unprotected sex with others. In heterosexual activity they sometimes assume they don't need condoms because they trust their partners. "This often leaves them not knowing they are infected because they haven't been engaging in risky behavior. So they are diagnosed only when they have full-blown AIDS, and therefore they have a very short survival rate," Yuzicappi-Fayant said.

Part of the problem for young women, Yuzicappi-Fayant added, was that they did not understand their own historical roles as highly respected members of their Nations. It was suggested that community women's groups and health agencies target information workshops at women, particularly at young women, to give them a better sense of pride in their heritage.

CHILDREN WITH AIDS

The youngest victims of HIV/AIDS are those who receive the virus at birth, or shortly after, through breastfeeding. Testing for young women becomes particularly important because a caesarean section birth, with no breastfeeding, can dramatically cut down the rate of transmission of the disease to the children of HIV-positive mothers.When the virus is transmitted perinatally, the symptoms of AIDS for young children are similar to those of adults, although many of these children die before reaching adolescence. During their life, children with HIV/AIDS often face discrimination within the community with parents pulling kids out of schools and daycares because they don't want them near children with HIV. The conference delegates urged communities to pass resolutions guaranteeing the rights of all children, as well as adults with HIV/AIDS, to all community services. Ultimately, the message HIV/AIDS workers had about the disease was a stark one: from birth until death, everyone is vulnerable. Getting that message out, and changing the behaviours that result in transmission of the virus, has become a matter of life and death for growing numbers of Aboriginal people, families and communities.

HIV/AIDS CONFERENCE RECOMMENDATIONS

These recommendations came from the summary session, as well as from individual workshops, at the March 14-16 National Aboriginal HIV/AIDS Leadership Conference: Breaking Down the Barriers - Addressing the Emerging Epidemic.

HEALTH PROMOTION FOR CHILDREN, YOUTH AND WOMEN MUST BE SUPPORTED AND FUNDED

Recent studies show that the HIV virus is attacking Aboriginal women in alarming numbers, and through perinatal infection, Aboriginal children. It is imperative that Aboriginal women be given the information and tools they need to prevent the infection. It is also essential that children and youths be instructed about the disease, and about the behaviors that will put them at risk.

ADDRESS JURISDICTIONAL PROBLEMS BETWEEN PROVINCIAL AND FEDERAL GOVERNMENTS

Aboriginal healthcare professionals and workers have urged that in tracking and treating HIV/AIDS the approach be coordinated between the community and urban centres. But jurisdictional issues between the provincial and federal governments must be addressed to ensure that coordinated services can be provided to the affected individuals.

MORE FUNDING AND MORE HUMAN RESOURCES

Aboriginals now have the highest rate of HIV/AIDS in the country, and current government funding does not reflect this. Our healthcare workers find themselves having to beg and borrow resources simply to run a local HIV/AIDS health promotion and prevention program. Funding is urgently needed for programs targeted at Aboriginal youth, women, prisoners and two-spirit people.

PROGRAMS MUST RECEIVE MULTI-YEAR FUNDING

Aboriginal healthcare workers and professionals point out that the current single-year funding means staff have to be laid off and programs left in limbo while funding is sought. To be sustainable and to retain trained staff and reap the benefits of their HIV/AIDS programs over the longer term, the program funding must also be long-term.

SUPPORT PRINCIPLES OF OWNERSHIP, CONTROL AND ACCESS IN RESEARCH AND DATA COLLECTION.

Before we can act, we must have the information and we must be in control of it. We need to ensure that Aboriginal people have the information they require to build the programs needed to address the HIV/AIDS crisis. We need to build up our own expertise to ensure the highest quality and consistency of the data produced.

SUPPORT RESEARCH PARTICULAR TO STDS AND RISK BEHAVIOR

HIV/AIDS is a difficult disease to track because of its long incubation period and unless people are tested, there is no way of knowing the exact extent of the problem. Gathering information on STDs and high-risk behaviors is the best way to estimate the extent of the problem we are facing today and, equally important, the threat posed in the future.

LEADERS MUST SHOW LEADERSHIP ON THE HIV/AIDS ISSUE

Aboriginal healthcare workers and professionals are strongly urging Chiefs and Councils to show courage and commitment in the face of the HIV/AIDS crisis. As one Ontario activist put it, ”Five minutes of attention from the Chief carries more weight that a whole national strategy in motivating people at the community level.” Healthcare workers ask that Chiefs, members of Council and other community leaders wear the red ribbon, attend HIV/AIDS information sessions and take part in activities like the annual AIDS walk.

RECOGNIZE THAT PEOPLE, SUCH AS PRISONERS, CAN BE NEGATIVE OR POSITIVE ROLE MODELS. GET THEM ONSIDE.

Many Aboriginal youth look up to the men whose involvement in risky behaviors landed them in prison. If you can enlist these men in the fight against AIDS, they can be powerful voices in warning the young about the dangers of the disease, and informing them about how they can protect themselves from it.

INCREASE THE ROLE OF TRADITIONAL HEALING

Traditional healers and medical doctors must have equal accessin the treatment of the disease. In Latin American clinics, traditional healers work side by side with medical doctors and this should be promoted in Canada (which could require development of occupational standards or potential self-regulation by healers). Opportunities for integration of ceremonies, alternative medicine and western medical forms of treatment must be provided.

USE ABORIGINAL LANGUAGES IN HEALTH PROMOTION MATERIALS

Aboriginal languages and traditions must continue to be revived in all areas of healthcare and daily life. This is important not only for the Elders, who may not understand English or French, but also for the young. One of the great risk factors of HIV/AIDS is low self-esteem and nothing helps more in regaining self-esteem than for cultures and individuals to retain their language.

EDUCATION ABOUT THE HISTORICAL ROLE OF TWO-SPIRIT PEOPLE IN YOUR NATION

Healthcare workers and professionals dealing with HIV/AIDS point to a real problem of discrimination against gay or two-spirit people, who often avoid testing and treatment because they fear their sexual orientation will become known. The delay in seeking treatment is given as one of the reasons Aboriginal people diagnosed with AIDS live only 50 per cent as long as non-Native people diagnosed with the disease. As one HIV/AIDS worker put it, “Some young men would rather die than let anyone know they are gay.” The solution is to educate people about the traditionally respected role two-spirit people played in most communities, and to therefore remove the shame that has become associated with the lifestyle.

ENSURE INFORMATION IS ACCESSIBLE

In any popular medical education program, it is important to make it understandable to people. We must communicate information to the people in ways they can understand it.

MORE ABORIGINALS PEOPLE INVOLVED IN PLANNING, DEVELOPMENT AND EVALUATION OF SERVICES AND PROGRAMS

Aboriginal people with HIV/AIDS have different needs from others with HIV. They have shorter survival times after diagnosis and this means different palliative care, etc. The pattern of the disease is also distinctly different among Aboriginal people, with the main source of transmission now intravenous drug use. As one healthcare worker put it, in Aboriginal people, the basic risk is caused by “post-colonial stress syndrome and its symptoms of low self-esteem, denial and abuse.”Only Aboriginal people, who understand what underlies destructive behaviors like intravenous drug use that transmit HIV/AIDS, can hope to design the programs and services needed to attack the disease at its source. We have to confront this crisis with our own culture-based service delivery practices and open-door services.

PROMOTE HEALTHY CHILD DEVELOPMENT

The under-15 age group is the largest part of the Aboriginal population. We must focus on street-proofing them by teaching them about risks and how to protect themselves. Healthy child development is crucial in developing resilience against the behaviours that lead to HIV/AIDS. We have to link programs such as Early Childhood Education and Head Start to HIV/AIDS awareness programs. We must foster self-esteem, particularly in the 7 to 12-year-old age group, which tends to be neglected - they need safe playgrounds, recreation facilities and injury prevention programs to ensure they grow up healthy and strong, physically, mentally and spiritually.

PROMOTE AWARENESS ABOUT SERVICES AVAILABLE

Time after time, Aboriginal healthcare workers said that they had no resources even to publicize to the community what services were available. We have to get them the resources they need to inform people of where and how they can get help. The work done by non-Aboriginal organizations in this area doesn't reach our peoples, because non-aboriginal AIDS service organizations tend to be ignorant of our cultural history and the diversity of Aboriginals.

PROVIDE A SAFE ENVIRONMENT FOR COMMUNITY MEMBERS WITH HIV/AIDS WHO WANT TO COME HOME

Many of the Aboriginal people with HIV/AIDS are living in urban centres. We have to make sure we are ready to accept their return. To ensure their welcome, band councils can pass resolutions explicitly recognizing the rights of HIV/AIDS-affected people to pursue activities such as attending school, attaining employment, occupying a residence and other rights and privileges granted to them as band and community members. As part of the preparation for dealing with the disease, communities must also be aware of the costs of the HIV/AIDS drugs when they are arranging Health Transfer Agreements. These drugs can run as high as $5,000 a month per person and because of the nature of the disease, communities will have to look at these costs not only for the next year or two, but for ten or fifteen years into the future.

SUPPORT HEALTH WORKERS ON CONFIDENTIALITY AND PRIVACY ISSUES

Health workers have a very difficult task in dealing with HIV/AIDS. They are sometimes caught between a band council's wish to know details of HIV status in the community, and their need to protect the privacy of the infected community member. Bands should put in place confidentiality and safety considerations to protect the person with HIV/AIDS, as well as healthcare workers and professionals.

LEGISLATE SAFE COMMUNITIES

Safe, healthy and happy children will be at a far lower risk of HIV/AIDS infection than troubled youths. Within families, encourage training in anger management and promote self-esteem among the young to reduce risk-taking behavior. Undertake crime prevention activities and do not tolerate bootleggers and drug dealers in the community. Keep our youth from ending up in the environments where they will be most at risk: the streets and the prisons.

CANADIAN ABORIGINAL AIDS NETWORK (CAAN) STUDIES ON INJECTION DRUG USERS

ABORIGINAL HIV/AIDS AND INJECTION DRUG USE

Due to colonization, poverty, and racism, Aboriginal people are over-represented among Canadians who use injection drugs. An unfortunate aspect of injection drug use is that the use of needles places people at an increased risk of HIV infection

Aboriginal injection drug users (IDUs) are the fastest growing group of new HIV cases in Canada.

According to our survey, as many as 79 per cent of Aboriginal IDUs visit their Reserve with some frequency. While on their reserve, they may share needles or have unprotected sex with community members.

Very few Reserves in Canada have condom distribution and/or needle exchange programs to reduce the risk of HIV transmission between people in the community. Education about HIV/AIDS remains low on many Reserves.

If the prevalence of HIV increases among Aboriginal people, a major HIV epidemic will occur where the virus is primarily spread by sex between Native men and women.

According to our survey, as many as 87 per cent of Aboriginal IDUs have been incarcerated, often for drug-related crimes.

Drug use within the penal system is a fact of life, but there is no program for providing clean needles in prison. Thus while in prison, Aboriginal IDUs are unable to protect themselves against HIV infection.

Although Aboriginal IDUs interact with three communities (the streets, the reserve and prison), only urban agencies have developed programs to reduce HIV transmission by injection drug use and sex.

The transmission of HIV through injection drug use (IDU) has reached crisis proportions in Canada. A recent study of Aboriginal people in Vancouver revealed that they make up a disproportionate number (27 per cent) of the city's IDU population, and are more likely than non-Native IDUs to become infected with HIV. As many as 87 per cent of Aboriginal IDUs spend time in prison where there is a high prevalence of HIV, but prison officials do not give inmates all the necessary means to protect themselves against infection.

Because as many as 79 per cent of Aboriginal IDUs also visit their communities where they may have sex and share needles, the issue of HIV and Aboriginal IDUs is not limited to urban streets, but is also a community problem.

There are three Aboriginal communities involved in the issue of HIV and injection drug use: the urban Aboriginal street population, the Reserve population and Aboriginal people in Canadian prisons. All three communities need to act. Failure to react to the issue of Aboriginal IDU and HIV may lead to the spread of HIV throughout our community.

As the HIV epidemic evolves from being a virus affecting only the gay community, we the Aboriginal people, are the next group of people in Canada most vulnerable to a general HIV epidemic. The Harm Reduction approach is a pragmatic, non-judgmental approach to drug use which focuses upon reducing the harm caused by drugs. The four mainstays of the Harm Reduction model are: needle exchange programs, condom distribution, methadone maintenance treatment and counseling. The implementation of a Harm Reduction program does not necessarily mean you condone drug use, but rather, offer a pragmatic solution to stopping the spread of HIV.

In order to better understand and communicate the issues and needs of Aboriginal IDUs, the Canadian Aboriginal AIDS Network (CAAN) has conducted a survey among 126 Aboriginal IDUs in various Canadian cities and prisons. The survey identifies the social and economic profile of Aboriginal IDUs, their needs and the barriers which prevent them from accessing social and health services.

The CAAN survey of Aboriginal IDUs revealed a group of Aboriginal people who are severely economically depressed, with low levels of formal education and who live in unstable housing or on the streets. Many have ended up on the streets partly as a result of abuse and neglect during their childhood. The majority (87 per cent) have spent time in jail and 71 per cent of the women are involved in prostitution. According to all the means by which we can predict HIV infection, these people are at great risk of acquiring HIV. The respondents indicate that they do not want to contract HIV, and where Harm Reduction services are made available, most have changed their risk behaviors in order to reduce their chance of HIV infection.

Over two-thirds of the respondents have tried to stop using injection drugs. Those who quit and remain HIV negative will have a chance to take up new roles in the Aboriginal community. Better services and information will also help to reduce the chances of Aboriginal youth deciding to start injecting drugs. HIV/AIDS information will educate community members about the risks of HIV infection through unprotected sex.

TWO SUCCESSFUL HARM REDUCTION EXAMPLES FROM SASKATCHEWAN

In Saskatchewan, the Beardy's and Sandy Lake First Nations have established bi-weekly outreach HIV and STD testing clinics. The clinics are not part of the Band or Tribal Council's operations. They are staffed by employees of the provincial Prince Albert Health District (PAHD) and funded by the Government of Saskatchewan.

Each First Nation is about an hour's drive from the city of Prince Albert where the PAHD has a central health centre. In 1996, the Community Health Nurse and Community Health Representative at Sandy Lake wrote to the PAHD and inquired about establishing an HIV clinic with the First Nation. A PAHD nurse explains that the Government of Saskatchewan was pleased to allow the linkage and no jurisdictional debates over funding occurred.

For the first year the nurses conducted an HIV and STD educational campaign at Sandy Lake by attending sessions to which they were invited. These interactions developed trust between the community and the nurses. In the second year, a confidential bi-weekly outreach clinic was started. It provides anonymous HIV testing as well as testing for chlamydia, gonorrhea, syphilis, herpes and hepatitis B and C. The clinic also provides counseling, condoms and referrals to other services.

There have been no concerns in the community that the clinic is encouraging sex and members of the community recently staged a theater presentation on HIV and AIDS.

The biggest barrier to be overcome by the clinic was the concern about confidentiality. Reserves are close-knit communities where the CHR or clinic secretary is often a relative or friend. Accessing services for stigmatized programs such as HIV testing is unimaginable for some people on reserve. Confidentiality has not been a barrier to the operation of the clinic at Sandy Lake for three reasons. First, the clinic is staffed by an outsider and the testing records are not kept on site. Second, the clinic is connected to the school where it can be discreetly accessed by students (the office itself is private). Third, the nurse and outreach workers have gained credibility and trust in the community. Indeed, community cooperation between reserve staff, the CHR and the nurses has been very good. One report stated, “Crucial to the success of the program, is trust in the individuals providing the service along with strong community commitment, cooperation and ownership.”

A similar bi-weekly clinic began at the Beardy’s First Nation last June 1997. In this community a popular teacher was living with HIV and helped to raise awareness about the disease in the community. As one person put it, the community “was ready” for an outreach clinic and HIV testing program. The community recently secured funding from Medical Services Branch, Health Canada, to conduct a needle exchange program.

Again, the program in this community is successful because of the increased awareness about HIV, the building of trust between the provincial nurses and the community, and the alleviation of confidentiality concerns through the use of outsiders, private offices and off-site record keeping. The program is also successful because of the generous funding of the Government of Saskatchewan and the Prince Albert Health District, which have not chosen to create jurisdictional arguments against funding the programs and staff.

RECOMMENDATIONS

After the study, it was recommended that the three main components of an Aboriginal community Harm Reduction program be condom distribution, needle exchange and methadone maintenance treatment. It was highly recommended that abstinence not be the focus of these programs. Culture is important and should be part of the program and this needs to be determined at the local level. It is recommended that the issues of confidentiality be overcome where necessary, by the use of outside nurses and off-site record keeping.

The program must be: non-judgmental, pragmatic, flexible and recognize the IDUs’ ability to make their own informed decisions. Speakers who have been through street life and IDU will be important in selling the program to each community.

ABORIGINAL WOMAN FEATURED AT NATIONAL AIDS CONFERENCE

CANADIAN WOMEN SHOCKED BY RATE OF DISEASE IN ABORIGINAL WOMEN

Aboriginal women and HIV/AIDS were high on the agenda of the first National Conference on Women and HIV/AIDS held in Toronto on May 25-28. “The reason for this,” said NIICHRO representative Marilyn Wright, ”was not only because our women are suffering high rates of the disease, but because we are getting organized to a remarkable degree.”

The conference, which was co-hosted by the Canadian AIDS Society, two AIDS treatment organizations and the Canadian Aboriginal AIDS Network, brought together 500 women from communities across Canada to share theirknowledge and their experiences in combating the disturbing rise of HIV/AIDS among women in Canada.

As part of NIICHRO’s contribution, Marilyn Wright screened the video Keepers of the Faith: Aboriginal Women and HIV/AIDS. The response, she said, was immediate and often emotional. Many, like a guest delegate from South Africa, were deeply moved by it, and by the participation in the workshop of one of the HIV positive women who had been featured in the video. “Since the screening,” Marilyn Wright said, “I have had many enquiries about the video as a teaching tool.”

“The ideais to take into account the WHOLE WOMAN”

Other workshops featuring Aboriginal women and HIV/AIDS included Anishinaabe Mino-Ayaawin Inc. - First Nations Model on HIV and the Immune System (Donna Everette); Canadian Policy, Aboriginal Women and HIV/AIDS (Arlo Yuzicapi Fayant); Women Prisoners and HIV/AIDS (Patti Tait); and Aboriginal Women, Substance Abuse and HIV/AIDS. Among the main conference themes were the exclusion of women from basic and clinical scientific HIV/AIDS research, the discrimination faced by women living with the disease, and the serious lack of resources for HIV/AIDS services and programs directed at women. In its approach to these themes, the conference was organized around four broad principles: public policy; prevention; legal and ethical; and support and treatment. In all, there were 73 workshops and plenary sessions, with presenters ranging from members of the medical professions and sex-trade workers to healthcare service providers and women with HIV/AIDS.

The only negative that Wright found in the conference was that it was impossible to sit in on all of the workshops. But as a forum for sharing information and networking with others involved in HIV/AIDS care and awareness, she said it was invaluable.

”We are often isolated in small groups,” she said. “No one knows what others are doing. This conference gave us all an amazing sense about what is possible.”Unlike other such events, the women’s conference tried to broaden the approach to the disease by holding workshops on self-care, some with playful themes. Among the self-care workshop subjects were Massage, Yoga, and even one called Sex Toys 101. “The idea,” Wright said, “is to take into account the whole woman. Even in the face of HIV/AIDS, we are still wives, mothers, grandmothers, girlfriends and aunties. In treating the disease, we have to address the whole person.”

Conference organizers are putting together a list of recommendations that came from the workshops and plenary sessions, and they will use these recommendations in the design of follow-up activities.

RESOURCE MATERIAL ON HIV/AIDS

The following are printed and video resources on HIV/AIDS that are available at:

Health Canada’s First Nations and Inuit Health Program (FNIHP)
Resource Centre, Health Programs Support Division
20th Floor, Jeanne Mance Building, P.L. 1920A
Ottawa, ON K1A 0L3
Fax: (613) 954-8107
PSPNI@hc-sc.gc.ca
www.hc-sc.gc.ca/msb/fnihp/ref e.htm

PRINTED MATERIAL

AS - 1 Guidelines for the Delivery of HIV/AIDS Programs and Services by Medical Services Branch - This document provides information and guidelines that make up a policy framework including: education and prevention; HIV testing, counselling and risk assessment; and care, treatment and support for people living with HIV or AIDS. March 1995. English/French.

AS - 2 National Inuit HIV/AIDS and STDs Training Workshop - May 3-5, 1995, Iqaluit, Nunavut: Final Report - Workshop organized by Pauktuutit, Inuit Women’s Association, to identify issues and to propose possible solutions. English/French.

AS - 4 HIV/AIDS And Its Impact on Aboriginal Women in Canada - Aboriginal Nurses Association report. March 1996. English/French.

AS - 5 Indigenous Peoples' Gathering - Satellite Conference - XIth International Conference on AIDS. July 1996. English/French.

AS - 6 Healing Our Nations - Proceedings of the 4th Canadian Aboriginal Conference on HIV/AIDS and related issues. November 1996. English/ French.

AS - 7 Indigenous Traditional Medicine and HIV/AIDS: A Literature Review - An examination of the historical beliefs of the First Nations, their approach to healing and how this might be used to develop culturally relevant HIV/AIDS training and education. August 1996. English/French.

AS - 8 First Nations HIV/TB Training Kit - Designed to address ways in which community health educators can assist in the prevention, care and treatment of HIV/TB and Dual Infection within First Nations communities. April 1997. English/French.

AS - 9 Interjurisdictional Co-ordination on HIV/AIDS and Aboriginal Populations: Issues and Approaches - This paper provides a starting point for the discussion of mechanisms that could improve information sharing and co-ordination within current jurisdictional mandates and structures. January 1995. English/French.

AS - 10 Joining the Circle: An Aboriginal Harm Reduction Model- This package is designed to help CHRs and other Aboriginal health programmers learn more about Aboriginal injection drug use and develop a Harm Reduction program for their community. 1998.

AS - 11 Coping with HIV/AIDS in Aboriginal Communities- This resource manual was developed by NIICHRO to provide an outline for conducting AIDS 101 workshops. March 1998. English/French.

AS - 12 Research on HIV/AIDS in Aboriginal People - A Background Paper - HIV/AIDS burden of illness among Aboriginal peoples in Canada; determinants and risk factors; interventions; and research methods and ethics. Aboriginal people throughout Canada provided feedback on the content of this paper. English/French.

AS - 15 HIV/AIDS Resource Guide- This guide was developed by the Assembly of First Nations Health Secretariat in order to meet the needs of First Nations individuals living with the HIV/AIDS virus, their families and their communities. March 1997. English/French.

AS - 16 11th ANNUAL - International Two-Spirit Gathering- This report is about a gathering of Aboriginal People held at the Dr. Jessie Saulteaux Resource Centre. This is a project sponsored by the Manitoba Aboriginal AIDS Task Force. December 1998.

VIDEOS

ASV - 1 HIV/AIDS - Presentation from the Aboriginal Nurses Association's First National Teaching Conference "Keeping Our Children Safe." 1997.

WEBSITES

http://www.caan.ca
Canadian Aboriginal AIDS Network
http://cfeweb.hivnet.ubc.ca/CfE.html
British Columbia Centre for Excellence in HIV/AIDS
http://www.cpha.ca
CPHA National AIDS Clearinghouse
http://www.cdnaids.ca
Canadian AIDS Society
http://www.canfar.com
Canadian Foundation for AIDS Research
http://www.hivnet.ubc.ca/ctn.html
Canadian HIV Trials Network
http://www.catie.ca
Community AIDS Treatment Information Exchange
http://www.hc-sc.gc.ca/hpb/lcdc/bah/epi/epi_e.html
Health Canada Bureau of HIV/AIDS and STDs
http://www.aidslaw.ca
Canadian HIV/AIDS Legal Network
http://pan.ca
Pacific AIDS Network
http://www.healingourspirit.org
Healing Our Spirit
http://persweb.direct.ca/vnhs/index.html
Vancouver Native Health Society
http://www.fnsummit.org
First Nations Chiefs' Health Committee