

Winter 2008 Edition

Why CAAN does so much research!

by Kevin Barlow, Chief Executive Officer

Since I became Executive Director about 4.5 years ago, working with Randy Jackson, our Director of Research and Programs, we began to pursue research grants and opportunities. The result has been that we have learned a great deal about this process and also about our community needs.

We have developed and refined tools that help keep Aboriginal people in control of our own research agenda. We have placed a lot of emphasis on capacity-building, such as through our Research Technical Assistants and the Wise Practices Conference where close to 70 APHAs were involved.

Even our National Research Advisory Committee (NRAC) fulfills a capacity-building role, as well as an accountability role. As individuals learn about all the different research we are doing, they also get a stronger sense of the processes we take to get a study started up and completed.

Much of the research is pursued at the direction of CAAN membership, such as through resolutions at the AGM or through advisory and steering committees, as well as at Board direction.

Some is identified from current studies we do, that identifies new areas we want to look at. CAAN strongly believes that we need to do research, by and for the Aboriginal population so that we understand what is really happening in our communities.

In the early days of the epidemic, we didn't have the hard numbers yet we all knew something was happening. Now, we have stronger evidence to help determine what course of action we should take.

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Note: CAAN is currently undergoing an organizational restructuring exercise authorized by the 2007/2008 Board of Directors. As a result one of the changes to CAANs structure is the role of the Executive Director has been changed to that of a Chief Executive Officer.

Research helps develop better policies and also can help make stronger programs so that we begin to turn the epidemic around.

If CAAN wasn’t doing the research, then someone would need to. The advantage of CAAN doing it is we understand better what HIV/AIDS is and how to analyze the data. We also want to find improved ways of getting this new knowledge out to our communities.

We believe that by focusing on creating and maintaining a strong evidence base, that we will continue to lead the way for our communities. In the past four years, a vast majority of resolutions have been acted upon. Each year, my reports have shown that between 80 to 90% of resolutions are in progress or complete.

This is because we have research underway looking at many different issues. Other funding opportunities are not that plentiful. The Non-Reserve Fund, Specific Populations Fund, First Nations & Inuit Health Branch, and the National Voluntary Sector Fund where we get our main operations covered, are four of the areas where we access resources. CIHR and some other research funding bodies, as well as private funding has also allowed us to host events like our recent Aboriginal Women’s Gathering, a Youth Forum and others.

These all help us to keep in contact with our membership and to respond to the needs that are raised. We look forward to seeing you all at the next Annual General Meeting here in Ottawa, June 17-20, 2008.

Kevin Barlow
Chief Executive Officer

Aboriginal women, HIV/AIDS and CAAN

-by Doris Peltier, CAAN Board of Directors Member At-Large
Chair CAAN VOW (Voice of Women)

As many of you may have already heard, CAAN hosted its first inaugural Aboriginal Women's Gathering February 17 – 19, 2008 in Toronto, ON. I am so thrilled to report the event went extremely well.

One of my roles with CAAN has been to act as chair for CAAN VOW (Voice of Women), an external committee which helped to guide the organization of this event.

On behalf of the CAAN VOW committee, I would like to thank the Ontario Aboriginal HIV/AIDS Strategy (OAHAS) and the Two Spirited People of the First Nations for your partnership and commitment in organizing this event. I would also like to thank the CAAN staff for all of their hard work, it is much appreciated.

This Gathering was so necessary because as we all know, the face of AIDS has changed over the last few years, and women and youth account for many of the new numbers.

For those of us that have to live with HIV on a daily basis, I believe it is fair to say that we would not want our children, sisters, mothers, aunts and grandmothers to be touched by this epidemic in such a huge way, as is the case now.

The Gathering gave those of us who are living with and affected by HIV the opportunity to come together, listen to each other and support each other.

I saw some new faces in attendance at this gathering, and it was very exciting to see and meet new people.

It was also nice to meet with old friends and acquaintances that are helping to do the work and meeting the challenges head on.

I was amazed to see a transformation in the women who were participating over those three days. Given the high rates of HIV infection among Aboriginal women in our communities it was so important that we were able to come together to discuss issues specific to us as Aboriginal women living with and affected by HIV.

The transformation was quite remarkable to see; the women that left to return to their communities were empowered after having this opportunity to share with each other, especially for those who shared their lived experiences as women living with HIV.

Leading up to this gathering, I decided through the CAAN social marketing campaign to reduce HIV/AIDS related stigma and discrimination that I would go public with my status as an HIV positive Aboriginal woman. Since this campaign is engaging leaders on a national level to join us in this fight to address Aboriginal HIV and AIDS at all levels I hope to contribute in whatever way I can to try to engage our leadership.

Whenever I have the opportunity to speak to any of our leaders, both elected and non-elected, I tell them about this campaign and share with them some of the new statistics and how the face of AIDS has changed for our nations. I believe in this campaign, and I believe it will achieve a greater participation from our leadership.

Another initiative, where I represent CAAN to help increase awareness of Aboriginal women and HIV/AIDS is the Status Report on Women and Girls which is a Public Health Agency of Canada (PHAC) working group to help prepare a mainstream report/snapshot of HIV/AIDS for all of Canada. Additionally, PHAC is also working on a Status Report on Aboriginal People and HIV and AIDS.

Is Valentine's Day all about love?

Editorial by Trevor Stratton,
CAAN APHA Advocate

It's hard to avoid this time of year, when most stores are pushing every kind of Valentine's Day gift from the \$1.99 discount card to fur coats and fancy ties. Did you notice the day after Christmas that Rudolf and Frosty were replaced with chocolates, edible underwear and heart shaped candies at almost every store's check out stand?

For Aboriginal people living with HIV/AIDS this time of year can also be a time of reflection. While some of us have life partners and caring relationships with our lovers others have been single for a very long time. Sex and Relationships can be a difficult issue for APHAs, especially for those who have given up on romance, love and sex because it is too complicated. As the CAAN APHA Advocate, I hear the stories of APHAs who have all but given up on romance, as if they no longer are able or willing to hold onto any hope.

Attraction is a complex thing especially when you're positive. I've noticed that there are so many different kinds of couples. Recently, a number of my friends who are HIV positive have entered into relationships after previously saying that they probably would never find a partner. Two of my friends who are both HIV positive found each other and I thought that was so sweet. Their attraction and commitment to each other inspires me to let others know about it.

There are also couples where one partner is HIV positive and the other is HIV negative, the technical term used to describe this is sero-discordant. More commonly used however and the term I prefer is "magnetic couples".

I have had magnetic relationships and they can be difficult. In fact, I was married for 10 years to an HIV negative woman. She is still HIV negative because we used a condom every time.

Sometimes sex in a Sero-discordant/magnetic relationship can feel like there is a third person in the bedroom. It has to do with the safer sex negotiation. We are no longer talking about the idea of protecting yourself/your partner against HIV transmission; we're talking about the fact of it. HIV is in the room.

The stigma is because we are positive we are not supposed to have sex. The reality is as human beings we are entitled to love.

As an APHA, I hope the campaign will remind our leaders that HIV/AIDS is a serious concern for all of us, HIV positive and HIV negative alike.

As individuals, when we find the courage to share our love, there are great rewards and the potential to grow stronger. Together, we can reduce our risk along the way.

This Valentine's Day, please remember Aboriginal people living with HIV/AIDS because life isn't always a box of chocolates.

CAAN Media Room

OTTAWA, February 12, 2008

This Valentine's Day show you care... about Aboriginal People Living with HIV/AIDS

**CAAN Challenges Leaders to
Reduce HIV/AIDS Stigma and
Discrimination**

-by Colleen Patterson,
CAAN Senior Communications Officer

OTTAWA, February 12, 2008 – Kevin Barlow, Executive Director for the Canadian Aboriginal AIDS Network (CAAN), today announced the launch of a Valentine's Day initiative that challenges Leaders to show they care about Aboriginal People Living with HIV/AIDS (APHA) by reducing HIV/AIDS related Stigma and Discrimination.

"During this special time of year when most show appreciation for their loved ones, we are reminded that many Aboriginal People living with HIV/AIDS do not have this opportunity," says Kevin Barlow, Executive Director of the Canadian Aboriginal AIDS Network. "Many APHAs simply face too many barriers and choose to be single because of the fear, stigma and discrimination that come with HIV/AIDS".

Barlow goes on to challenge, "this Valentine's Day, we seek both action and commitment from Aboriginal leaders and our communities to help stop stigma and discrimination."

"Valentine's Day can be a difficult time for Aboriginal people living with HIV/AIDS," says Trevor Stratton, APHA Advocate for the Canadian Aboriginal AIDS Network. "Today we are supposed to express our love but many APHAs have given up on romance, love and sex because it is too complicated."

"The stigma is because we are positive we are not supposed to have sex. The reality is as human beings we are entitled to love," asserts Stratton. "As an APHA, I hope this campaign will remind our leaders that HIV/AIDS is a serious concern for all of us, HIV positive and HIV negative alike."

Valentine's Day is the first initiative of the "Fostering Community Leadership to Reduce HIV/AIDS Stigma and Discrimination" national campaign that will seek to increase awareness and knowledge. This campaign scheduled to launch next month will set out to increase support from and endorsement by Aboriginal leaders and officials for prevention, care and treatment programs intended for our communities.

"Not only must all of our leaders acknowledge HIV/AIDS is an epidemic but they must address the stigma and discrimination that is fuelling it," says Doris Peltier, a board member with the Canadian Aboriginal AIDS

CAAN Media Room...continued

Network. "Our leaders must take action to build healthy communities."

Now is an ideal time to engage your community about HIV/AIDS and how to reduce the HIV related stigma and discrimination too often associated with this virus. Beginning on Valentine's Day (February 14th) and extending to December 2008, CAAN would like to remind individuals, communities and leaders that because HIV/AIDS does not discriminate it affects everyone.

The Canadian Aboriginal AIDS Network represents a coalition of hundreds of Aboriginal organizations and individuals committed to providing leadership, support and advocacy for all Aboriginal people living with and affected by HIV/AIDS, and those most at risk to infection, regardless of where they reside.

For more information:

Colleen Patterson,
Senior Communications Officer

Canadian Aboriginal AIDS Network
1.613.567.1817 ex 115 or email
colleenp@caan.ca
Or visit www.caan.ca/endstigma

Campaign Backgrounder

Aboriginal people living in Canada represent 3.8% of the country's total population but represent more than three times that number in prevalent HIV infections. Aboriginal people are the most vulnerable population in Canada to test positive for HIV. Statistics from the Public Health Agency of Canada (PHAC) indicate that Aboriginal people now represent 27.3% of positive HIV test reports in 2006. This is a 4.1% increase from 2005.

In partnership with the Federal Initiative to Address HIV/AIDS in Canada, the Canadian Aboriginal AIDS Network (CAAN) has developed and distributed Valentines to First Nations, Métis and Inuit community leaders to raise awareness about HIV/AIDS related stigma and discrimination.

Reducing HIV/AIDS related stigma and discrimination is seen as an appropriate first step towards creating an environment that is conducive to engaging Aboriginal people, communities and leadership in the real work to; (1) prevent further infections, (2) provide support for testing and diagnosis, and (3) care and treatment of Aboriginal People living with HIV/AIDS (APHA).

By launching its biggest and longest running social marketing campaign ever...

CAAN hopes to increase support from and endorsement by Aboriginal leaders and officials for prevention, care and treatment programs intended for our communities.

CAAN will provide leaders with resources and promotional materials related to this campaign to help raise levels of awareness and knowledge of Aboriginal HIV/AIDS related stigma and discrimination.

In November 2008, leaders across the country will be asked to “sign on the line” to let their community know there are committed to reducing HIV/AIDS related stigma and discrimination.

Through this leadership commitments initiative, our vision is to get 5000 signatures by next year, to show we are standing together to turn the page, and end stigma.

CAAN acknowledges that Aboriginal political and health leaders (at the community, provincial, regional and national levels) are crucial to creating environments free of stigma and discrimination. Although many leaders have already stepped forward to face the real challenges associated with HIV/AIDS, a long-term commitment is required to engage, foster and expand messaging to those political and health leaders where HIV/AIDS endorsement is lacking.

Trauma, Addictions and HIV must be ‘Treated Together’

-by Colleen Patterson,
CAAN Senior Communications Officer

OTTAWA, February 7, 2008 – HIV/AIDS continues to be a serious health concern for all Aboriginal communities, but the rise in HIV rates among Aboriginal peoples is most apparent in Canada’s inner cities where an increasing proportion of Aboriginal people now live.

“Research being conducted by the Canadian Aboriginal AIDS Network has revealed that many Aboriginal people are dealing with some very difficult pasts, including for some, physical and sexual abuse from residential schools”, says Kevin Barlow, Executive Director for the Canadian Aboriginal AIDS Network.

Two recent studies by CAAN (Addressing Homophobia in Relation to HIV/AIDS in Aboriginal Communities and Canadian Aboriginal Peoples Living with HIV/AIDS Care, Treatment and Support Issues) showed 16% of participants in each study had attended a residential school and an overwhelming majority, 90%+ had a parent or grandparent who had attended.

Barlow asserts, “These deep childhood wounds do not go away in four or five therapy sessions. They often are lifelong wounds that pose very significant challenges for Aboriginal people coming from difficult pasts”.

CAAN Media Room...continued

“Many Aboriginal people do not have access to adequate care, treatment and support services,” says Ken Clement, President of CAAN. “Colonization, loss of land, territory, and culture, and the impact of the residential school experience must be considered in correlation with the social determinants of health.”

Clement explains, “Not considering these important factors directly impacts the health and well-being of Aboriginal communities. The current situation continues to perpetuate the HIV/AIDS epidemic among Aboriginal people in Canada.”

Preliminary data indicates that half of Aboriginal People Living with HIV/AIDS (APHA) who participated in CAANs Cultural Competence study said; addictions are a major factor in living with HIV/AIDS: intensified use of drugs and alcohol was an initial coping strategy when diagnosed, or; addictions were dealt with soon after diagnosis in order to begin anti-retroviral treatment, or; getting “cleaned up” was more important than dealing with HIV.

Service providers who inform, encourage and support APHAs’ choices are viewed as “culturally competent”. Programs that integrate addiction treatment with HIV/AIDS care are viewed as “wise practice” models by participants in this research.

Another key finding of CAANs Cultural Competence research study is that for many APHAs, adherence to HIV/AIDS drug regimes is a “journey” involving choices between health priorities.

Programs that integrate treatment of addictions and HIV and that encourage and support APHAs choices are also presented as “wise practices” in culturally competent care.

The Canadian Aboriginal AIDS Network represents a coalition of hundreds of Aboriginal organizations and individuals committed to providing leadership, support and advocacy for all Aboriginal people living with and affected by HIV/AIDS, and those most at risk to infection, regardless of where they reside.

What’s Happening?

Healing Our Spirit BC Aboriginal HIV/AIDS Society 12th Annual BC Aboriginal HIV/AIDS Conference

Co-hosted with Carrier Sekani Tribal Bands,
Carrier Sekani Family Services Prince George,
Northern Aboriginal HIV/AIDS Task Force,
Positive Living North
April 28-30, 2008 at the Coast Inn of the North,
Prince George, British Columbia
<http://www.healingourspirit.org/conference.htm>

CAAN RESEARCH DEPARTMENT

What's Happening?

Sexual Health and Community-based Research

-by Renee Masching, Research Technical Assistant

At first glance it might be hard to image what Sexual Health and Community-based research have in common. I wondered if any of the participants at the Labrador Sexual Health Conference (recently hosted from January 29 – 31 in Happy Valley-Goose Bay) struggled with this question before they arrived.

Fortunately, I was invited to attend this Conference and was eager to find out what the participants had to say!

Conference participants were mostly, but not exclusively, women, who had travelled from all over Labrador to attend. This forum provided an opportunity to discuss the variety of challenges facing Labrador as industry expands by leaps and bounds and health services do not.

Research can play a very important role in this context and can help to advocate for new policies, to ground recommendations in the wisdom of many research project participants rather than the sole voices of workers in the field.

The conference structure effectively demonstrated the connection between Sexual Health and Community-based research through 3 keynote presentations.

Two of the Keynote presenters discussed healthy sexuality by:

- Offering definitions of sex, gender, and sexuality,
- Describing insights regarding the development of healthy relationships,
- Explaining factors that can influence developing strong, positive relationships,
- Exploring various expressions of healthy and sometimes unhealthy sexuality.

The presenters were both well educated and dynamic in the delivery of their materials.

As the third keynote speaker, I have to admit I was a little bit intimidated to follow such well delivered presentations. Let's face it, the third topic which was a discussion about research, on the surface may appear to be less 'stimulating' than the first two presentations, but the possibilities of research can be interesting too.

One of the most important and exciting things that research can do, is bring attention to an issue and create an evidence base to guide decision making. We know that knowledge is power, and therefore, those who produce knowledge also build a power base to work from.

What is the link between Sexual Health and Community-based Research?

Community-based research is - research that is conceived of, directed by and relevant to the people involved in the research process.

- We use research all the time to inform our understanding of the sexual needs and desires of human beings.
- We use research to help to describe the range of what is healthy and what is unhealthy.
- We use research to support statements about specific populations, differences between the sexes and to describe the variety of gender identities that are 'recognized' today.

As Aboriginal peoples and organizations, the potential for research to help to breathe life into our programs and policies is enormous. For too long we have been told by others about ourselves and this includes being told about our sexuality. By learning about research and engaging in research we position ourselves to lead rather than follow.

We tell our stories, in our ways with our words.

For more information on the community-based research projects CAAN is involved in please visit www.caan.ca or contact Randy at randyj@caan.ca or Renee at reneem@caan.ca.

Aboriginal People Living with HIV: The Influence of Stigma on Access to Health Services

-by Randy Jackson and Judy Mill

This article summarizes findings from a Canadian Institutes of Health Research funded study that explored the impact of stigma on access to health services for persons living with HIV. The purpose of this research was to develop an intervention for the provision of health services to persons living with HIV that addressed the impact of stigma and improved access to appropriate health care. The objectives were to explore the practices in health care organizations that persons living with HIV perceived to be stigmatizing; develop an improved design for health service delivery to eliminate stigmatizing practices; and describe the process required to reorient health services to incorporate this improved service design. This article focuses on Aboriginal participants accessing HIV care.

A participatory action research design, using interviews, focus groups, and document reviews guided the study. Thirty-three individuals living with HIV (of which self-identified as 16 Aboriginal) were recruited from hospitals, HIV/AIDS service organizations, and community health clinics in Ottawa and Edmonton. They were interviewed about their experiences using health services. In addition, 20 interviews and 2 focus groups with health providers explored their experiences providing care to people living with HIV and their perspectives on ways to improve health care for this group. A community advisory committee in both cities guided the research.

Key findings suggest that Aboriginal people living with HIV encounter a wide range of stigmatizing practices when using health services. Most experienced a layering of stigma (e.g., as Aboriginal people, as people living with HIV, as sexual minorities, as poor individuals, as injection drug users, etc.). As one individual shared, “I went the one day [to the hospital] but they tried to kick me out; they thought I was just a drunk off the street.” Interestingly, health care providers also acknowledged many of their clients as being vulnerable to stigma for reasons other than HIV status, including mental illness, addictions, homosexuality, poverty, homelessness, having lice or abscesses, being unreliable, disruptive and/or violent, being deaf, or a sex trade worker.

Stigmatizing practices were also encountered with respect to building design, service scheduling, and interactions with staff and other clients. Another individual said, he felt stigmatized when he perceived that he might be being judged by a health care provider on the basis of his appearance. He recalled: “They treated me pretty good, really. Except for when they made out an accident report from up there that [I] reeked of alcohol and they thought I had an alcoholic seizure. [Well,] I never had a drink of alcohol in years.” Health care providers acknowledged that when they had assumptions or judgments towards clients this would inevitably impact the quality of health care services.

Problems were also encountered negotiating the health care system, including accessing traditional cultural health systems. One health care provider mentioned stigmatizing experi-

ences could also be compounded by historical experiences that lead to a generalized mistrust of a largely non-Aboriginal healthcare system. Health care providers at times seemed aware of this and attempted to be sensitive to client’s cultural backgrounds. As one community development worker shared: “I realize this is not a Native organization, but I really do appreciate the fact that at least they try to incorporate a part of community development geared towards Aboriginal people and Aboriginal communities. So I think that’s a step forward.”

Culture appeared to be one way APHAs mitigated stigma and therefore positively influenced coping strategies. As a service provider commented “to make a place that is safe – particularly when they have a past history,” it is necessary to support cultural identity. Similarly, one APHA commented: “[I’ve used] the women’s healing circle or just [to] talk about our problems. ... In our language – it helps!

Stigma continues to influence decisions and access to appropriate health services for Aboriginal people living with HIV. Service can be improved to address stigma at a number of key points. For example, it is necessary to acknowledge that layering of stigma is common and that services can address this. Services can also be improved to reduce other forms of barriers, including, for example, “camouflaging service” in other health services to reduce stigma associated with providing solely HIV related services. Finally, it is important to recognize that culture is an important factor in providing care. To improve cultural competence it may be necessary to hire Aboriginal staff and to provide referrals to traditional supports, such as Elders.