A Community- based Approach to Reducing HIV/AIDS Infection in the Wikwemikong Unceded Indian Reserve

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Introduction

Wikwemikong Unceded Indian Reserve has long been committed to self-determination in the development of local community services. In light of this commitment, we examine in this report the response of this rural Native community to the HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome) epidemic. Over the past years, the Nahndahweh Tchigegamig Health Centre in Wikwemikong has developed a community-based HIV/AIDS Education Program with a strong cultural element. We review programs and interventions which have been implemented through HIV/AIDS Education Program in Wikwemikong and recommend a further course of action which will hopefully lead to a significant reduction in the transmission of HIV/AIDS and sexually transmitted diseases (STDs) in the community.

Background

The Wikwemikong Unceded Indian Reserve No. 26 is located in the Georgian Bay, Lake Huron area and is situated on the eastern part of Manitoulin Island. It is the traditional home of the Odawa, Ojibway and Pottawatomi tribes.

The health centre is located in the main village of Wikwemikong where about half the population lives. The other half of the population lives in rural areas in seven small but distinct satellite communities, which consist of South Bay, Buzwah, Kaboni, Wikwemikongsing, Murray Hill and Rabbit Island and the Point Grondine Reserve on the mainland. As of March 31st, 2000, the total membership of Wikwemikong is 6,383. Approximately 2,743 members live on reserve while another 3,640 members live off reserve.

Self-determination and Health Services in Wikwemikong

The Wikwemikong Band Council passed a resolution in 1968 which expressed the desire to work towards the realization of local self-determination by taking control of all services delivered in the community.

The health transfer initiative proposed by Health and Welfare Canada was seen as a major step in realizing this goal in the health care sector. A band council resolution to pursue health transfer was passed in 1986. At that time, the band noted:

> The complete absence of health promotion and the escalating costs of treatment services note the current health care delivery system. This chance to institute change from treatment to promotion occurs at an opportune time and, is also a chance to influence the health care delivery in the non-Native community (Wikwemikong Unceded Indian Reserve 1989).

Health transfer was seen as an option to shift health program emphasis from a curative orientation to health promotion and illness prevention and to increase the involvement of the community in health programs through participation and consultation:

> Health care needs should be met through community-based programs and facilities, so that the community has ownership and responsibility for its health care. Any health care system that is not delivered by the community does not own the system, but is owned by the agency that develops the system. All community programs and systems must begin with community consultation with the residents of the community (Wikwemikong Unceded Indian Reserve 1989).

In 1986, Wikwemikong developed a proposal to transfer health services. Pre-health transfer activities included the development of a comprehensive community health plan to be overseen by a full-time co-ordinator and an assistant. An assessment of available health services and community needs was conducted. A local Health Steering Committee was formed to guide the process of health transfer. The newly constructed Nandah Weh Chi Gegamik Health Centre opened its doors to the community in the same year. Since then, many new services and structures have been added to the local health care system in a relatively short amount of time.

It is not surprising, that HIV/AIDS was not identified as a community priority during the health pre-transfer community consultation in 1988. It was difficult to estimate the risk of this disease to Native communities at that time. Incidence statistics were not known since the ethnicity of individuals undergoing an HIV test was not recorded prior to

1988 (Maar 1996). By 1990, Health and Welfare Canada identified Native Communities as being particularly at risk for HIV/AIDS infection due to poor health status, higher rates of STDs and reduced access to health care (Canada 1990).

The Wikwemikong health centre responded to the growing epidemic with a first HIV/AIDS awareness presentation to Band employees in July 1991. Soon after the HIV/AIDS awareness presentation, the Community Health Representatives (CHRs), Community Health Nurses and National Native Alcohol and Drug Addictions (NNADAP) workers initiated HIV/AIDS awareness presentations in local schools, at community events and on the community television channel. The health centre also began networking with the Access AIDS office in Sudbury.

In August of 1992, there were 33 Wikwemikong band members known to be HIV positive; five of these people had developed full-blown AIDS. These numbers represented 28 percent of the HIV positive cases in the Sudbury District at that time although Aboriginal people represent only three percent of the total population within this district. It was extremely difficult to determine how many of the infected Band members were living on reserve, but the statistics were alarming. It became evident that established reporting procedures failed to provide a clear picture of the prevalence of HIV/AIDS in Native communities.

Subsequently, HIV/AIDS awareness gained priority in Wikwemikong. The health staff worked towards increasing community awareness of HIV/AIDS through community workshops and other promotional activities. In 1993, the Wikwemikong Chief broadcasted live on the HIV/AIDS status in Wikwemikong on the community channel. A talk show hot-line question-and-answer period was also conducted by the health centre in collaboration with Sudbury Access AIDS.

By February 1994, the statistics remained alarming: the number of band members with full-blown AIDS had increased to 10 people. In August 1994, there were two major HIV/AIDS presentations conducted in the community. Knowing that Native people living with HIV/AIDS (PHAs) have a great impact as HIV/AIDS educators, the health staff invited Native guest speakers living with HIV/AIDS from Wikwemikong and other Native communities to speak. HIV/AIDS education videos were also shown on the local community channel and in the health centre lobby. Educational pamphlets and condoms were made available on an ongoing basis at the health centre and at major community events. HIV/AIDS education and prevention components were incorporated into many health programs including the Family Violence Prevention Program, the Nutrition Program, the School Health Program and the Nursing Program.

By 1995, the statistics had climbed again. There were now 45 Wikwemikong band members known to be HIV/AIDS positive. Then, in

1996, the health centre was no longer able to track the number of community members infected with HIV/AIDS due to anonymous testing legislation and related changes in the reporting procedures. At that time, it was anticipated that the First Nations Health Information System (HIS) designed by Medical Services Branch (MSB) could provide a mechanism to track the incidence of HIV/AIDS on reserve. Yet, the HIS did not prove to be useful in determining the prevalence of HIV/AIDS in the community for many reasons. A major factor is MSBs lack of resource allocation to cover data entry and site management expenses of the system at the community level.

In 1997, Wikwemikong health service providers still did not have a good idea of the prevalence of HIV/AIDS on reserve. Later on that year, a videotaped interview on HIV/AIDS was conducted with an HIV/AIDS Educator from the Union of Ontario Indians and a local Community Health Representative. The interview focused on the effect of HIV/AIDS on Native communities and possible strategies to combat the spread of this disease.

In January 1999, the HIV/AIDS Education Program officially became a distinct health program and an integral component of the health services system in Wikwemikong. The goals of the HIV/AIDS Education Program included the following program priorities:

- the provision of a community-based HIV/AIDS education program, including a healthy sexuality program with emphasis on children and youth, and education for adults at community events.

- the provision of support services for people affected with HIV/AIDS and

- the establishment of base-line data, which will allow the health centre to track the success of the program.

The services have a strong cultural component and clients are able to choose between Traditional and Western health services. A Community Health Representative with specialized training and experience in HIV/AIDS education staffed the position of HIV/AIDS Educator. Under the federal health transfer agreement, the current health care system in Wikwemikong provides enough flexibility for program development and adjustments according to community priorities. Although this flexibility is a positive aspect of the agreement, in terms of the Wikwemikong HIV/AIDS program, this kind of flexibility is only a short-term solution. There is no funding allocation in the health transfer agreement for HIV/AIDS programs.

Redesigning a CHR position to encompass the responsibilities of an HIV/AIDS Educator allows the community to address a current health priority, but it also creates a staff shortage in the CHR program.

Because HIV/AIDS is a relatively new health problem and was not identified during the pre-health transfer needs assessment, no resources were allocated to deal with this health problem at the time of health transfer and at this point in time, an HIV/AIDS education program can only be provided in Wikwemikong by reallocating the already scarce resources. To support the ongoing operation of the HIV/AIDS Education Program, the health centre will require an enhanced funding commitment from Medical Services Branch during the upcoming Wikwemikong health transfer re-negotiations (see also: BC Aboriginal HIV/AIDS Task Force 1999:41).

Local Barriers for the HIV/AIDS Education Program

One of the main priorities of the newly established HIV/AIDS Education Program has been to reduce barriers to effective HIV/AIDS prevention program delivery in the community. A major obstacle to effective program development with which most HIV/AIDS prevention workers are struggling is the deep-rooted denial which often pervades communities regarding HIV/AIDS (Ontario Aboriginal HIV/AIDS Strategy n.d.:23). Seeing as this denial was also an issue in Wikwemikong, the HIV/AIDS Educator felt that is was important to begin with a strategy to increase awareness of HIV/AIDS with the community's leadership and health care workers. An HIV/AIDS education session was held in conjunction with the annual health centre staff retreat in May 1999. This session raised the awareness of HIV/AIDS with local health care providers and increased the support for the program with the community's health board. To raise awareness in the community at large, the program invited a PHA from the community to speak at the local high school at a community event.

An HIV/AIDS protocol for Wikwemikong is currently at the draft stage. This protocol will reaffirm the rights of PHA's in the community, outline pre- and post-test counselling procedures for locally administered HIV tests, and provide guidelines for staff to use universal precautions in the health field.

Healthy sexuality school program

A healthy sexuality program, which incorporates a strong traditional component, has been implemented in the Wikwemikong elementary and secondary school system. The goal of this program is to educate children at an early age about healthy sexuality. The elementary

school education component begins in grade five. The purpose of this program is to raise awareness of healthy sexual development. Traditional teaching are used to teach healthy male and female roles. The good touch/bad touch segment gives children an opportunity to learn and practice assertiveness skills. The HIV/AIDS Educator introduces new topics every six weeks. The high school program is designed to raise awareness about HIV/AIDS and STDs, and it includes sessions designed to increase students' capabilities to talk about and practice safer sex.

Support for People Affected With HIV/AIDS

When support services are provided for people with HIV/AIDS who have returned to their community, it is important to ensure that clients have access to all available services. When working with PHAs, it is particularly important to provide case co-ordination and advocacy not only within the health sector but also across the social services agencies. The housing shortage is a particular concern in Wikwemikong. Living in crowded conditions with family members increases chances for PHAs to contract secondary infections. Counseling services and support for families affected with HIV/AIDS, are provided by HIV/AIDS Educator. Traditional support is available through the traditional medicine program.

Base-line data

Base-line data on health indicators related to sexual health need to be collected in order to measure the impact of HIV/AIDS education in the community. We need to answer questions such as: What are common high risk behaviours in this community? Are high-risk behaviours decreasing in the community due to HIV/AIDS education programs? And, ultimately, is the incidence of HIV/AIDS decreasing in the community? When concrete goals for this program were first established, the HIV/AIDS Educator had a clear sense of what needed to be accomplished. Indicators of success included the reduction of teenage pregnancy rates, the decline of the incidence of STDs in the community and an increase of HIV testing in the community. Compiling base-line data and tracking indicators such as the incidence of STDs and teenage pregnancy rates requires a considerable amount of additional work for program staff, but they comprise the tools which will allow the centre to evaluate the effectiveness of HIV/AIDS Education Program.

Recommendations for On-Reserve HIV/AIDS Program

Close collaboration between community-based HIV/AIDS prevention programs and the existing community health network is required to maximize program impact. For example, inter-program collaboration can lead to pr-natal care, which includes HIV/AIDS screening as part of the routine pre-natal screening. The school health program is an ideal interface for HIV/AIDS prevention education for children and youth. In Wikwemikong, we are planning to add a teen-wellness clinic to the school health program. The clinic will be delivered at the local high school and will benefit from collaboration between the Nursing program and the HIV/AIDS program. Community events sponsored by the NNADAP Program are ideal venues for HIV/AIDS education. In order to reach young to middle-ages men, it is necessary to collaborate with programs outside of the health sector. Combining HIV/AIDS education with sports events is a more effective way of reaching this target group than through health centre sponsored community events.

We found that national and provincial tracking procedures fail to provide an accurate assessment of the prevalence of HIV/AIDS on reserves. Programs rely on prevalence estimates by health care workers, such as CHRs or Community Health Nurses, who are recognized as experts in community health. Many related indicators are easier to track and still provide useful data for HIV/AIDs program evaluations. They include community statistics on the number of teenage pregnancies, the rates of STDs, and the number of HIV tests.

Evaluation of the effectiveness of healthy sexuality education programs in changing attitudes, awareness and behaviours, particularly among youth, is also a very important component of a community-based HIV/AIDS prevention program. This kind of data is very valuable but labour intensive to collect and analyse and may require collaboration with staff with experience in program evaluation.

Funding sources are urgently needed to support the development of community-based HIV/AIDS education programs in First Nations since most federal and provincial funding sources currently target urban centres. Similar to many other reserves, the main source of community health funding in Wikwemikong is provided through a health transfer agreement with Medical Services Branch. As part of health transfer, health program dollars have been essentially capped. Drawing on the sparse health transfer budget can at this point, only support the delivery of the HIV/AIDS education program. However, community-based programs, such as the HIV/AIDS Education Program, require ongoing developmental dollars to provide effective services in First Nations. A training budget to educate and keep staff current on issues related to HIV/AIDS is needed. HIV/AIDS

education program resources need to be tailored to suit local culture and social norms, which requires research and evaluation of resources at the local level. Access to these types of resources can prove beneficial for all community-based programs. An ongoing resource commitment is also required to support long-term community health program planning, development and implementation at the local level.

References

BC Aboriginal HIV/AIDS Task Force 1999 *The Red Road: Pathways to Wholeness.* BC Aboriginal HIV/AIDS Task Force.

Canada *HIV/AIDS: Canada?s Blue Print.* Ottawa: Health and Welfare Canada.

Maar, Marion HIV/AIDS in Aboriginal Communities. *Nexus* 12:53-62.

Ontario Aboriginal HIV/AIDS Strategy n.d. *Ontario Aboriginal HIV/AIDS Strategy.*

Wikwemikong Unceded Indian Reserve 1989 *Comprehensive Community Health Plan.* Unpublished document on file at: Nandah Weh Chigegamig Wikwemikong Health Centre.

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