

# Dynamics of the 1999 AIDS Walk in the 31 First Nations Communities: The community within the community approach.

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## **Visioning Through Community Partnerships**

The overall Atlantic First Nations community consists of 31 distinct Maliseet and Mi'kmaq Nations with populations ranging from 60 to almost 3,000. HIV/AIDS has found its way into several Atlantic First Nation communities. It can probably be assumed that all of these communities, at one time or another, will have members who are affected by this disease.

The response to HIV/AIDS in Atlantic Canada began in 1991 when the Nova Scotia Mi'kmaq AIDS Task Force, founded by T'uma Young and Elizabeth Paul, became concerned about HIV/AIDS and the effect it could have on our communities. The two founders asked others throughout the region to share in teaching our people about the virus. In 1993, the Atlantic First Nations AIDS Task Force (AFNATF) was formed, and First Nations communities across Nova Scotia, New Brunswick, Prince Edward Island and Newfoundland joined in the effort to inform our Native communities about HIV and AIDS.

The Atlantic First Nations AIDS Task Force operates using a community-based model. As a coalition of the 31 First Nations communities in the Atlantic region, the AFNATF is sustained through the support of each community. Support is renewed on an annual basis by the Chiefs and by the Atlantic Policy Congress, which meets as a regional body on a quarterly basis. Based in Halifax, Nova Scotia, the AFNATF is governed by a board of directors from across the region.

Directors represent each community from tribal councils. Drug and alcohol treatment directors are also represented, and there are directors who are themselves living with HIV. This coalition is unique in Canada because of its reserve-based mandate, which also extends to the off-reserve population, under the direction of chiefs and councils. The AFNATF educates and supports Native persons who are HIV positive or who have AIDS, whether they live on or off reserve.

One of the major goals of the Atlantic First Nations Task Force was to encourage our communities to participate in the 1999 AIDS Walk. This paper reflects the experiences and processes undertaken to organize AIDS Walk Canada in communities across the Atlantic region.

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AIDS Walk Canada is a nationally co-ordinated event, which takes place during the last weekend of September each year. The AIDS Walk has taken place in Canada for 5 consecutive years. In 1999, it was estimated that over 55,000 walkers took part and raised over two million dollars across Canada.

The Walk has two purposes. First, it is an event which increases awareness of HIV/AIDS by drawing public attention to the issue. Second, it is designed to raise funds for HIV/AIDS work, to provide financial assistance to AIDS service organizations, and to help persons living with HIV/AIDS to achieve a better quality of life. In the AFNATF, the money raised is directed towards maintaining the office, staff development and a support fund which helps First Nations individuals with HIV/AIDS.

The AFNATF has been involved in AIDS Walk Canada for several years to varying degrees. Despite insufficient funding and limited staff resources, the AFNATF undertook the 1998 Walk with enthusiasm and hopes for new funding. Participation in the walk involved the immediate staff (four to six people) and several communities in the Atlantic region. That year, our office had faxed out the call for walkers, and two First Nation communities answered our request. We were ecstatic! The combined efforts of our office and the two communities raised over \$1800.00. This was a triumph. Never before had we raised so much money.

It was then decided that we should attempt to involve all 31 Atlantic First Nation communities in the 1999 AIDS Canada Walk. Although we were concerned as a staff about the logistics of co-ordinating 31 Walks at 31 different sites, we decided to "go for it."

We had a vision. As our vision for a Walk in each community grew, we began to identify the resources necessary to make this event happen. We understood that in order to make money we would have to take a risk and invest money in the people, travel and supplies necessary to make the Walk a success.

Motivating communities would involve more than just a fax or a phone call. This goal proved to be a challenge because of the stigma associated with HIV/AIDS within many First Nation communities. The challenge for us was to convince community members that they could advocate for AIDS education by participating in the walk, without being stigmatized by an association with HIV or AIDS.

The AFNATF has worked extensively with the Atlantic First Nation communities over the years to address the stigma associated with HIV/AIDS. From the beginning, it has been an uphill battle; people were

reluctant even to attend workshops on the topic. The mistaken belief that "HIV/AIDS will not affect us" has been the obstacle.

This hurdle was overcome by "reaching around the problem" and using the concept of a "community within a community" as our guide.

### **The Community within A Community... A New Understanding**

The "community within a community" concept was developed during the Sustaining First Nations AIDS Programming Project. In our preparations for training sessions with community-based agencies within First Nation communities, we had assumed that all First Nation communities have similar structures and values; but we were wrong. For example, some communities and agencies smudge before undertaking a specific task and some do not. There is no consistency from community to community, or agency to agency. Thus, not only do communities differ from each other, but individual agencies within communities may also have unique values and practices. As such, these agencies form "a community within a community".

All First Nation communities contain several of these "micro communities". **Diagram I** illustrates how this concept can be applied.

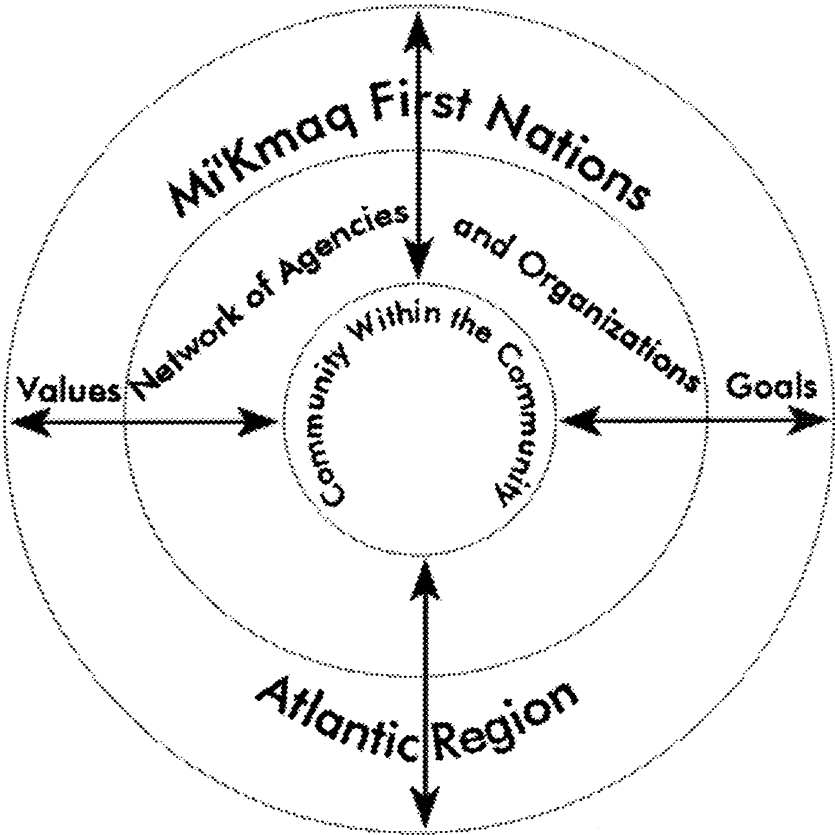
We decided to apply the "community within a community" perspective in trying to organize the AIDS Walk. Within most First Nation communities there are several persons that will support a cause and become fully involved. It was our goal to find these individuals and begin to network with them. Through networking with these community leaders, we would begin to break through the abovementioned barriers to organizing around the HIV/AIDS issue in First Nation communities.

In order to acquire the human resources necessary to do this networking, funding was obtained from the human resources development offices of both the province of Nova Scotia and the federal government to hire two summer students to coordinate the walk.

Time was also a factor. Since the funding was a bit late, some of the deadlines for AIDS Walk Canada had passed. Communities had to be notified, and it was decided that initial contact with communities was to be done by telephone.

The most obvious community contacts regarding HIV/AIDS issues would be the community health representative (CHR) or the community health nurse (CHN). Although it seems obvious that a CHR or CHN would be at the forefront of issues such as HIV/AIDS, it does not hold true in every community. In most communities, CHRs and CHNs are dealing with multiple issues and do not have the time or energy to dedicate to yet another task. Understanding this reality, we nonetheless actively sought the help of the CHRs and CHNs to identify other community leaders.

**Diagram 1: Community Within the Community Relationships  
AIDS Walk 1999**



The Healing Our Nations organization provides services to Mi'kmaq and Maliseet First Nations. The Diagram represents the Community within the Community relationships specific to Mi'kmaq First Nations.

Throughout the months of May and June 1999, we developed our community contacts -- people who were willing to undertake the co-ordination of the Walk in their community. Once we had identified the leaders, we were challenged to empower their communities to participate in the 1999 AIDS Walk.

To begin with, community leaders had to develop trust in the co-ordinators. This task could have been a problem because First Nations people are weary of being told what to do and when to do it by people from outside their communities, a result of years of oppression by various governing bodies. Thus, the co-ordinators had to analyze each community to decide whom to approach.

Another obstacle the co-ordinators identified as a potential problem was that one of the co-ordinators was not of Native descent. Traditionally, the First Nation communities in Atlantic Canada have "adopted" non-Native persons in their communities. More recently, however, communities have opposed non-Native people working in our communities. The AFNATF office has a policy to hire Native people first; however, over the years, we have also "adopted" several non-Native people into our professional family.

The non-Native co-ordinator was accepted as an equal in the AFNATF office. Before leaving on the tour, she was briefed on the history of our communities and the potential problems. Through her studies, experiences and work on the AFNATF, she had developed a very respectful understanding of the issues she might face and knew that she had the full support of the staff in the office.

Fortunately, the non-Native co-ordinator also won the support of the communities through her concerned and caring attitude. The non-Native issue was quickly set aside, and the co-ordinators discovered that each community accepted them with open arms. With trust and credibility established, the co-ordinators found themselves better able to communicate their message. As Bill Lee (1997:61) states, "The organizer is becoming more visible, not as a leader, but as someone who cares about people and the issues and who appears confident that the citizens can work together and produce something of good quality."

Finding the "right person for the job" to co-ordinate the walk in each community proved to be difficult. Many times the designated person would be reluctant to take on the organization once they realized the scope of the task. This pattern proved to be another challenge because each time someone refused, another potential organizer had to be identified, and the entire process of explaining the dynamics of the Walk had to be repeated. For this aspect of the job, personal contact with potential organizers was essential.

### **Logistical Co-ordination**

The AFNATF co-ordinators began an AIDS Walk tour which ~~involved~~ visits to the 31 First Nations communities in Atlantic Canada. The tour was developed based on the notion that personal contact, putting a face

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to the voice, and the “community within a community” approach would develop trust between the AFNATF co-ordinators and the communities. The tour covered all of Atlantic Canada (excluding Newfoundland, since contacts there had been made previously).

Time once again proved to be a challenge. The summer student grants began in late May. By the time the co-ordinators were hired and trained, it was middle of June. Traditionally, July and August are both months that band offices close for vacations. Nonetheless, after many phone calls and faxes, the tour was set for the last two weeks of July. The tour was modified to visit 25 of the 31 communities. Teleconferences with the remaining communities were set up.

The tour began in the province of New Brunswick. The co-ordinators planned a loop of the province to visit each community on the schedule. Time frames proved to be challenging because of the distance between each community. The driving time from one community to the next was approximately one to two hours with an average of 100 to 200 kilometers between. Some days the co-ordinators found themselves arriving with literally minutes to spare before a scheduled meeting.

Credibility for the AFNATF and the co-ordinators had to be established within each community. The AFNATF had done groundwork over the years. This groundwork included workshops such as AIDS 101, Family Based Support Model and Best Practices on Child Sexual Abuse. In previous years, the AFNATF had also contacted the communities regarding the AIDS Walk for that particular year.

Another facet of this under-taking was the issue of “quality vs. quantity.” Involving the 31 First Nations communities was in itself a monumental task, but were the coordinators able to provide quality in the form of committed workers in each community and a realistic plan for achieving the goals?

The answer to this question was yes. This quality was accomplished by taking the time to explain each facet of the Walk in person and giving the contact individuals ample time to question any aspect they found perplexing. A detailed but flexible work plan was provided for the months leading up to the AIDS Walk for each community. The contact persons also had access to the co-ordinators on the AFNATF toll-free line any time.

The co-ordinators had set a goal for 300 registered walkers and \$7000.00 to be raised from all of the communities in Atlantic Canada. This estimate averaged out to approximately \$225.00 from each community, a seemingly realistic goal. To track the progress of the Walk, two thermometer scales were posted in the lobby of our office, and on a daily basis, new communities and more walkers were registered.

## **Reflections and Implications**

After the Walk was concluded, the co-ordinators found that their efforts had been rewarded by an overwhelmingly positive response to the project. Although not all communities participated, the goal of \$7,000.00 had been surpassed. The Walk raised over \$18,000.00.

As we reflected on the event, we found that the “community within a community” approach had indeed been a useful model to apply to the Walk. This experience showed us that targeting the various “communities within communities” was the key to success when introducing a new concept -- in this case, the AIDS Walk.

The 1999 AIDS Walk was by far the largest community driven event that the Atlantic First Nations AIDS Task Force had ever undertaken. The 1999 AIDS Walk was a financial success, raising over \$18,000.00 in the Atlantic First Nations communities. One community alone raised over \$3,000.00 alone. As well, a prize consisting of a trip for two to anywhere in North America was won by one of the participants.

The AFNATF will continue to work on breaking down the barriers to the understanding of HIV/AIDS, and educating Native communities. Someone once said that “assumption was the mother of all mix-ups”, but the AFNATF was blessed in making correct assumptions about the potential of the “community within a community” strategy. Organizing the AIDS Walk 1999 has provided the AFNATF with a model and experience which has proven more useful than countless hours of classroom learning.

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