

# Stories of Community Mobilization

compiled by  
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for the Project on Community  
Mobilization Against HIV/AIDS-  
Related Stigma and Discrimination



CANADIAN | RÉSEAU  
HIV•AIDS | JURIDIQUE  
L E G A L | CANADIEN  
NETWORK | VIH•SIDA

in collaboration with

AIDS New Brunswick  
Canadian Aboriginal AIDS Network  
Canadian Rainbow Health Coalition  
GAP-VIES  
Vancouver Area Network of Drug Users  
Voices of Positive Women

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## Introduction

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The Canadian HIV/AIDS Legal Network, in collaboration with six Canadian community-based organizations, undertook a one-year project in 2003-2004 to help organizations mobilize their communities to take action against HIV/AIDS-related stigma and discrimination. The project was intended for local community organizations working with one or more of the following populations: people living in smaller cities, towns, or rural areas; people of African or Caribbean origin; people who inject drugs; Aboriginal peoples; women; and gay, lesbian, bisexual, and transgendered people (see Appendix A for a list of participants). The partners organizing the project included: AIDS New Brunswick, the Canadian Aboriginal AIDS Network, the Canadian Rainbow Health Coalition, GAP-VIES, the Vancouver Area Network of Drug Users, and Voices of Positive Women. Funding for the project was provided by Health Canada under the Canadian Strategy on HIV/AIDS.

As part of the project, the Legal Network hosted a workshop on January 30-February 1, 2004, in Montréal (Québec). The workshop was an opportunity for participating organizations to work together to develop plans for community mobilization against HIV/AIDS-related stigma and discrimination. The participating organizations decided what issue they each wanted to mobilize their communities to address, and planned how to do this by drawing on each others' experience and insights.

In preparation for the workshop, the Legal Network identified and described some examples or stories of community mobilization. The stories were selected because they were good examples of community mobilization. They do not necessarily focus on HIV/AIDS-related stigma and discrimination. The hope was that elements of the stories would serve as models for the plans developed at the workshop.

The following criteria were developed to define “community mobilization” for the purposes of this project:

- The mobilization involves taking action (preferably including advocacy).
- Many people in the community are involved in the action(s) – i.e., not just a few people in an organization.
- The mobilization involves more than just providing a support service or training to a community – i.e., community members are more than passive recipients.
- The mobilization has achieved something.
- The mobilization is more than a single event (meeting, workshop, etc.).
- The mobilization is driven by the affected community – i.e., it is not simply a response by the affected community to an external request for involvement; or, if the mobilization is not driven by the affected community, there is significant involvement of the affected community.

It should be noted, however, that to be selected as an example the mobilizations were not required to meet all of the criteria. The partners in the project, as well as other organizations, were asked to provide examples of community mobilization. Of the examples submitted, six were selected for inclusion in this paper. More information was then obtained on each of the six initiatives. As well, an effort was made to identify community mobilizations in other countries. As a result of this additional research, a story from India has also been included in this paper.

The seven stories are:

- Improving Relations Between the GLBT Community and the Ottawa Police
- Fighting to Keep Disability Benefits in Ontario
- Addressing Barriers that Put Women in B.C. at Risk
- Building a Sense of Connection, Belonging, and Esteem through the International Two-Spirit Gathering Movement
- Fighting for a Supervised Injection Site in Vancouver
- Building a GLBT Community Organization in Nova Scotia
- Improving Prevention and Human Rights in the Sex Trade in Kolkata, India

The stories are described on the following pages. They are followed by a short section listing some of the common factors that contributed to the success of the mobilizations.

## **Story #1**

### **Improving Relations Between the GLBT Community and the Ottawa Police<sup>1</sup>**

#### **Background**

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Relations between the gay community and the police in the 1970s and 1980s were tenuous. During this period, there was a case involving an alleged male prostitution ring, where the police arrested a number of men and released their names to the media. One man whose name was released jumped to his death from the roof of his apartment building. Ultimately, the case fell apart and only one man was charged. A year later, the police raided the local gay bath house, made a number of arrests, and offered the names of the arrested men to the media (which this time refused to publish them). This was a classic example of over-policing a specific community.

Consequently, gay men tended not to turn to the police when they were victims of violence, for fear of being outed and treated disrespectfully by the police. An early effort in the spring of 1982 by Pink Triangle Services (PTS), a gay and lesbian social services agency in Ottawa, to sensitize the Ottawa Police to Gay, Lesbian Bisexual and Transgendered (GLBT) issues was not successful.

In the Summer of 1989, there was a series of attacks against gay men in Ottawa. Several men were savagely attacked in a park that gay men frequented next to Parliament Hill. One man was thrown to his death from a bridge near the park because he was assumed to be gay. One of the men attacked in the park was robbed of his wallet, but he did not report the incident to the police because he feared questions about what he was doing in the park. The attackers later appeared at the door of his house and attacked the man and his partner, slashing one and stabbing the other with a screw-driver.

#### **Description of the Mobilization**

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The two men attacked in their home ultimately survived, but there was a public outcry in the gay community. A lot of anger was directed at the police because it was felt that they were not being responsive, and that they were not familiar with the issues of the community. The police were not linking the attacks in the park with the attack in the home of the two gay men. Furthermore, the police were not knowledgeable about the dynamics of the gay male community; they did not acknowledge the hate motivation associated with the targeted attacks; and they were not able to understand the vulnerability of gay male victims. This was a classic example of under-policing a specific community.

The public outcry led to a special meeting of Gays of Ottawa (GO), a gay and lesbian community organization. At the meeting, there were differences of opinion between people who favoured a public and activist approach vs. those who wanted to work with the police to resolve the problem. Ultimately, both approaches were used, though the main emphasis was on working with the police.

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<sup>1</sup> Additional information on this story can be obtained from David Pepper at [davidpepper@eudemonia.ca](mailto:davidpepper@eudemonia.ca).

GO Info, a local gay newspaper, carried stories about what had happened. An activist group, the Ottawa-Hull Task Force on Violence, was formed specifically to deal with the issue. Eventually, two courses of community-initiated action were pursued:

- Self-defence courses were offered by and for gay men.
- Community leaders initiated meetings with the Ottawa Police to seek a constructive means of resolving the issue. The first few meetings were not very productive.

Community leaders also solicited support from allies in the general community, including two city councillors.

Several youths were arrested for the murder of the man who was thrown off the bridge. In 1991, the case against them proceeded and they were found guilty. The testimony of the youths clearly proved it was an anti-gay motivated attack. Some activists in the community were frustrated because no real action had been taken by the police in the intervening two years. As a result of a very confrontational interview on a local radio station, a city councillor brought community and police together in a meeting in July 1991. At this meeting, the community tabled a number of demands, which became the focus of all future meetings. There were many such meetings. (See the next section for examples of what was accomplished at these meetings.)

It should be noted that the meetings were very time-consuming and that a lot of work went into attending the meetings and preparing for them.

## **Outcomes**

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As a result of the meetings with the Ottawa Police:

- In 1991, an Ottawa Police Liaison Committee for the Lesbian, Gay, Bisexual and Transgendered Community was formed, with members from the community and the Ottawa Police.
- The Ottawa Police sent a joint police-community delegation to Boston to see the operations of well-known hate crime unit in November 1992.
- Twelve half-day awareness sessions were delivered by PTS to the Ottawa Police. Each session was introduced by the Chief of Police.
- The Ottawa Police and gay community leaders initiated a problem-solving project on the issue of men having sex in parks. This was frequently an area of discussion at the Liaison Committee as early as 1991.
- In January 1993, the Ottawa Police created a Bias Crime Unit, which had three functions: investigation of hate/bias crime, education and intelligence.
- Since 1993, the Ottawa Police have been very open about hiring from the GLBT communities, including advertising and speaking at events. New police officers have been recruited at recent Gay Pride events.
- In the mid-1990s, special education sessions were provided for the police on violence in same-sex relationships.

- The Ottawa Police participated in Gay Pride activities. They significantly increased their participation in 1998 when the rainbow flag was hung for the first time in the lobby of Police Headquarters. This continues to occur every year for the 10-day pride festival.
- The Ottawa Police provided funded positions (for two community workers) and a budget for, among other things, a website on police and GLBT issues.<sup>2</sup>
- In 1998, a concert was organized featuring the combined choirs of gay men and lesbians and the Ottawa Police Chorus.
- GLBT awareness has begun to be incorporated into the general education policepersons receive on minority issues.

GLBT people now feel much safer in their community. They also feel that they have good access to the police, and that the police are there to support them. The Liaison Committee recently celebrated its 10<sup>th</sup> anniversary. It has been widely studied across the country.

### **Factors that Contributed to the Success of the Mobilization**

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- When the incidents happened in 1989, the gay community had well-established organizations that provided a forum for people to discuss the issue and to start to map out an appropriate response.
- The formation of a specific advocacy group (the Ottawa-Hull Task Force on Violence) was a critical element of the response, as was the leadership provided by a few key individuals in the group.
- Use of the media helped to publicize the issue.
- Alliances with specific city councillors helped to bring the community and the police closer together.
- The philosophy of the Ottawa Police was already moving to one of “community policing.”
- There was a critical analysis of the situation, and solutions were sought that would treat systemic issues.
- The mobilization encompassed both public action (particularly the use of the media) with a problem-solving approach. The problem-solving approach was seen (and welcomed) by the police as largely non-confrontational.
- The individual commitment and leadership on both sides – police and community – contributed significantly to the success.
- Police leadership put their money where their mouths were and funded community-based work.

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<sup>2</sup> See [www.ncf.ca/gay/police-gay/](http://www.ncf.ca/gay/police-gay/).

## **Story #2**

### **Fighting to Keep Disability Benefits in Ontario<sup>3</sup>**

#### **Background**

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When the Progressive Conservative government under Mike Harris was first elected in Ontario, it announced that the province intended to rewrite Ontario's social assistance legislation in accordance with the election promises it had made in the "Common Sense Revolution." In 1996, the government initiated a limited number of consultations with disability groups to talk about what a new disability income maintenance scheme might look like. Statements made by government employees during those consultations were alarming to disabled people and their advocates. The primary area of concern was the government's intention to change the threshold definition of "disabled person," so that only the most severely incapacitated individuals would be able to obtain disability benefits. (The plan was that individuals whose disabilities were not "severe" would be moved to the province's workfare program which paid lower benefit levels.)

In 1997, the government introduced a bill in the Ontario Legislature that contained new welfare legislation and the new disability benefits program. Again, advocates were concerned that the definition of "disability" in the bill would prevent many people living with HIV/AIDS from accessing disability benefits.

#### **Description of the Mobilization**

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##### *Phase 1 – Responding to the Initial Government Announcement*

Disabled people and their advocates started discussing how communities should respond. Some of the people living with HIV/AIDS who had attended these consultations approached the HIV & AIDS Legal Clinic (Ontario) [HALCO]. It was decided that HALCO would take the lead in organizing a response within the HIV/AIDS community. HALCO sent out a notice to all of Ontario's HIV primary care physicians and AIDS Service Organizations (ASOs), explaining what was happening and asking interested people to attend a meeting.

The groups and people that responded eventually became known as the HIV/AIDS Community Ad Hoc Committee on the Definition of Disability. The Committee was made up of representatives of AIDS service organizations, advocacy organizations, health care facilities and providers, and organizations of people living with HIV/AIDS. The Community Committee crafted a plain-language position statement that endorsed basic principles about what the definition of "disabled person" should be, what the application process should look like, what kind of appeals system there should be, and how the transition to any new scheme should be handled.

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<sup>3</sup> Additional information on this story can be obtained from Ruth Carey of the HIV and AIDS Legal Clinic (Ontario) at [careyr@lao.on.ca](mailto:careyr@lao.on.ca).

The position statement was sent to every ASO in Ontario, and organizations were asked to endorse it. A list of dozens of endorsing agencies was added at the beginning of the position statement document, which then became a lobbying tool for the Committee. The document was sent to several provincial Ministers, the social assistance critics of the two opposition parties, other disability groups, and all of the community legal clinics in Ontario. HALCO staff wrote an editorial that appeared in a local newspaper criticizing the direction that the government appeared to be taking. The Minister of Community and Social Services responded with a letter to the editor that was published a few days later.

### *Phase 2 – Responding to the Legislation*

The bill became the focus of an even broader community campaign. The Community Committee came together again and crafted a second position paper.<sup>4</sup> The Committee used the same style of writing and layout as it had used in the first paper to ensure that people would recognize its legitimacy. Once again, dozens of organizations endorsed the paper, and it was distributed to Ministers and opposition critics. With funding from another community committee at St. Michael's Hospital in Toronto, the Ad-Hoc Community Committee placed an ad in a local newspaper about the legislation, explaining some of what was in the position statement and how people could respond. HALCO contacted all of the ASOs in Ontario and encouraged them to contact the government standing committee studying the proposed legislation, and to demand province-wide hearings and an opportunity to speak. As a result of the overwhelming response of ASOs to this call for action, province-wide hearings were scheduled and people representing ASOs and people living with HIV/AIDS appeared at almost every hearing to make submissions.

The Community Committee used the second position statement to help prepare presenters for the standing committee appearances. As a result of the intense pressure that this activity created on the Ministry of Community and Social Services, the Committee was offered a private meeting with the senior government bureaucrats who would be in charge of the new program. In addition, the Ontario Advisory Committee on HIV/AIDS (OACHA), which advises the Minister of Health, endorsed the document. Government officials met with OACHA to discuss the proposed new program and the concerns of the HIV/AIDS community.

During both Phase 1 and Phase 2, there was a parallel campaign going on in the wider disability community. Communications were maintained between the two campaigns and materials were shared back and forth. It should be noted that the campaign in the HIV/AIDS community was incredibly labour intensive and required an enormous commitment of staff resources.

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<sup>4</sup> HIV/AIDS Community Ad Hoc Committee on the Definition of Disability. Position Statement. Undated. Available at [www.halco.org/publications/hps1.pdf](http://www.halco.org/publications/hps1.pdf).

## Outcomes

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The results of the initial lobbying activity were that:

- the government was forced to recognize the Community Committee as an important stakeholder in any discussions about changes to the disability support scheme; and
- the government was forced to respond to the Committee's concerns in all subsequent public discussions about the new disability support scheme.

As a result of the meetings that the government held with the Community Committee and with OACHA, the government stated publicly that people living with HIV/AIDS would be considered very favourably under the new program. The government specifically said that people living with HIV/AIDS would automatically be considered to have a substantial impairment. This was a significant concession to the concerns of the HIV/AIDS community.

The standing committee that conducted hearings on the proposed legislation was also influenced by the repeated criticisms advanced by the HIV/AIDS community during the hearing process. The standing committee made revisions to the definition of disability prior to sending the bill back to the legislature.

Since the legislation was passed, HALCO has continued the relationship with government bureaucrats that the Community Committee's activities originally fostered. In April 2003, the government reiterated in an internal memo its statement that anyone infected with HIV would be considered to have a substantial disability and would be eligible for benefits under the legislation.

## Factors that Contributed to the Success of the Mobilization

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- HALCO was in a position to provide the necessary leadership, information, expert legal advice, etc.
- A separate entity (the Community Committee) was established to focus on this specific issue.
- Many organizations in the community were involved, and their endorsement was sought for positions taken by the Community Committee.
- The Community Committee's positions were reasonable and clear.
- A position statement and other materials were developed. These materials were used to prepare people for their presentations to the Standing Committee of the Legislature.
- The Community Committee's positions were widely endorsed by the entire HIV-affected community.
- The strategy was multi-pronged – i.e., it was both public and private, it was province-wide, and it involved opposition parties as well as government officials.
- The strategy was relatively long-term, and relentless.
- The media was used to publicize the positions of the Community Committee.
- The subject matter of disability benefits was politically sensitive; the government clearly felt vulnerable, and was anxious to be perceived as accommodating the disability communities.

## **Story #3**

### **Addressing Barriers that Put Women in B.C. at Risk<sup>5</sup>**

#### **Background**

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The Listen Up! Women's Health Research Project was initiated in 1998 by the Positive Women's Network (PWN) to examine how the social, economic and political determinants of health put women at risk of HIV infection and disease progression. The goal of this action-oriented research project was to help AIDS service organizations, equality and health advocacy groups, and individual women understand and respond to the ways in which these determinants of health affect women's vulnerability to HIV. Women living with, and affected by, HIV/AIDS were involved throughout the project as advisors, peer researchers and participants.

The project was divided into four phases, during which research was undertaken and action plans were developed. During Phase 1, six focus groups were held in the Vancouver area at:

- Positive Outlook (a drop-in space for those living with HIV at Vancouver Native Health);
- British Columbia Persons With AIDS Society;
- Drug and Alcohol Meeting Support for Women;
- Downtown Eastside Women's Centre;
- Storefront Orientation Services; and
- a small community just outside the lower mainland of Vancouver.

The focus groups ranged in size between four and 18 women. The women were from diverse backgrounds. They included women who were HIV positive; women who slept with women or who were bisexual; women who had a mental illness or a dual diagnosis; Aboriginal women; current or former substance users; and Spanish-speaking immigrants and refugees. The women discussed how income, power in intimate relationships, and relationships with health care providers and institutions affect women's risk of HIV infection and illness progression. The women also identified two other social barriers to their health: (a) discrimination experienced with health care providers and other institutions; and (b) problems with AIDS services and AIDS service organizations.

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<sup>5</sup> Additional information on this story can be obtained from Marcie Summers of the Positive Women's Network at [marcies@pwn.bc.ca](mailto:marcies@pwn.bc.ca). A summary of the research project is available at [www.pwn.bc.ca/documents/listenup/Listen\\_Up\\_summary.pdf](http://www.pwn.bc.ca/documents/listenup/Listen_Up_summary.pdf).

## Description of the Mobilization

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During Phase 2, the project moved from a purely research focus to one that involved both research and action planning. One of the objectives of this phase was to use a community-based peer research model to learn what women wanted to see done to reduce or eliminate some of the barriers identified in Phase 1.

Nine women were recruited as peer researchers. They participated in a two-week training program on community-based research methods. In November 1999, the women completed a series of 44 one-on-one interviews and focus groups involving women with backgrounds that were even more diverse than those of the women involved in the Phase 1 research. Some of the additional diversity was provided by caregivers, families and friends of HIV positive persons, and professionals. The peer researchers and the project coordinator then collated and analyzed the findings, and produced a comprehensive list of recommendations for action. The recommendations were divided into the following categories: poverty, power in intimate relationships, relationships with health care providers and institutions, discrimination, AIDS-specific issues, and other issues. Examples of the recommendations included in the section on poverty were as follows:

- Levels of provincial income assistance should be increased.
- A women's advocate position should be created to help women access certain benefits.
- Programs should be developed at the community level to help women living in poverty receive entrepreneurial loans.
- Community-based organizations should develop high-profile public awareness campaigns on the day-to-day realities of people living in poverty.

In the final two phases of the project (Phases 3 and 4), the research findings and recommendations were shared with women in diverse communities in both the lower mainland and rural B.C. Various methods were employed to share the information, including the following:

- journal and media articles;
- media interviews;
- preparation and distribution of a report;
- preparation and distribution of brochures and handbills;
- community presentations and workshops;
- presentations to organizations;
- presentations at conferences; and
- a public forum.

A Working Group was established to manage the process. It consisted of six women, some of whom were involved in Phases 1 and 2, and some of whom were new. A presentation on the research findings and the recommendations was prepared. The Working Group members were trained in presentation skills. The sessions where the information was presented were designed to

be two-way – i.e., in addition to listening to the presentations, participants shared their knowledge with the presenters. An HIV/AIDS education component was included in the presentations because many of the communities the project worked with had little knowledge of HIV and AIDS. Over 30 presentations were made. Co-presenters from different communities participated in some of the presentations. For example:

- In the African and Vietnamese communities, project personnel were greatly assisted by service providers who had been trained to present basic HIV information in their own language. These women also provided simultaneous translation of the findings and recommendations of the project.
- Educators from Healing Our Spirit Aboriginal HIV/AIDS Society journeyed with project personnel to rural B.C. They presented to both Aboriginal and non-Aboriginal groups.
- One member of the Working Group prepared a presentation in French for a group of Francophone women at La Boussole Community Centre in Vancouver.

During Phases 3 and 4, a concerted effort was made to reach women in rural B.C. This outreach included both liaison with individuals and presentations to conferences and communities in Chetwynd and two nearby reserves; Chilliwack; Kamloops; Prince George; Vancouver Island; and Williams Lake and area, including two reserves and a nearby treatment centre.

During the presentations and community meetings, advocacy strategies and the implementation of HIV action plans were discussed. A B.C.-wide action plan was developed and will be disseminated to the province's six regional health authorities.

In the course of this project, PWN learned that truly representative community consultation and mobilization is a slow and complex process.

## **Outcomes**

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Unfortunately, funding for the project ended before the action plans could be implemented in a systematic way. It is possible that some of the action plans will be implemented locally; because the project has ended, it has not been possible to monitor this.

However, a précis of the Listen Up! Project research and recommendations was included as an addendum to provincial government information packages to all Transition Houses in B.C. As well, women involved in the project have participated in already existing advocacy initiatives (such as the End Legislated Poverty campaign, and the campaign to lobby the B.C. government to improve disability benefits). Furthermore, as a result of participating in this process, many of the women involved over the years have experienced profound personal growth and are now much more involved as active PWN members, and are taking ownership of the issues.

## **Factors that Contributed to the Success of the Mobilization**

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- The project was implemented by and for HIV positive women.
- The project made a concerted effort to reach women in rural areas.
- The information sessions were designed to be two-way – i.e., not only to present the research findings, but also to elicit information from the participants.
- People from specific marginalized and vulnerable communities participated as presenters and interpreters in the information sessions.
- The media was used to publicize the findings of the research and the recommendations.
- Training was provided to help women make presentations.
- Giving back information to women who have shared it with researchers helped to empower the women.

## **Story #4**

### **Building a Sense of Connection, Belonging, and Esteem through the International Two-Spirit Gathering Movement**

#### **Background**

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International Two-Spirit Gatherings began in 1988 with a gathering of Canadian Aboriginal and Native American gays and lesbians in Minneapolis, Minnesota. (The term “Two-Spirit” was adopted around 1990) Since then, there have been gatherings every year except 2000. Many of the gatherings, including the last three, have been held in Canada: the 13<sup>th</sup> annual gathering in 2001 in British Columbia, the 14<sup>th</sup> annual gathering in 2002 in Alberta, and the 15<sup>th</sup> annual gathering in Ontario in 2003.

Two-Spirit Aboriginal people struggle with the legacy of genocide and colonization – residential schools and their intergenerational effects, violence, addictions, poverty, and loss of language and culture. Two-Spirit people also face homophobia and transphobia from the dominant non-Aboriginal culture and from their own communities. Many Two-Spirit people are displaced from their home communities and culture; others are forced to lead secretive lives. All these factors contribute to low self-worth, mental and emotional health issues, addictions as coping mechanisms, and high-risk activities.

The gatherings provide a safe space for people to recover or affirm their cultural and social identity as Two-Spirit Aboriginal people. The gatherings also provide many opportunities for peer-to-peer sharing and support.

The gatherings are alcohol- and drug-free events.

#### **Description of the Mobilization**

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The gatherings are hosted by local or regional Aboriginal Two-Spirit groups, and are organized by a planning committee created specifically for the gathering. For example, the 14<sup>th</sup> annual gathering was sponsored by Nechi Training, Research and Health Promotions Institute in Alberta, which drew together a planning committee of 12 people from throughout Alberta.<sup>6</sup> Similarly, the 15<sup>th</sup> annual gathering was sponsored by 2-Spirited People of the 1<sup>st</sup> Nations in Ontario, with the support of a planning committee of 16 people.<sup>7</sup>

The gatherings take their own approach and format. They usually involve traditional Aboriginal ceremonies, workshops, and recreational activities. Traditional ceremonies include the Traditional Welcome, the Sacred Fire, sweat lodges, talking and healing circles, the pipe ceremony, a memorial ceremony, and other ceremonies. These ceremonies give participants a

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<sup>6</sup> Return to the Spirit: Building Health Attitudes in Families and Communities. 14<sup>th</sup> Annual Two-Spirit Peoples Gathering, Morley, Alberta, August 2002. Final Report.

<sup>7</sup> Transforming Generations. 15<sup>th</sup> Annual Two-Spirit Gathering, Geneva Park – Mnjikaning, Ontario, 20-25 July 2003. Final Report.

sense of community and worth, and help to overcome feelings of social, cultural, and emotional isolation. They help people to heal from their personal legacies of genocide, colonization, and homophobia.

Workshops or similar events allow participants to discuss and learn about specific issues. For example, the 15<sup>th</sup> annual gathering included events focusing on spiritual and creative dimensions of people's being, traditional roles of Two-Spirit people, dealing with life's stresses, harm reduction, issues of gender, healthy sexuality, supporting Aboriginal people in prison, and addressing homophobia in Aboriginal communities.

## Outcomes

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In their evaluations of the gatherings, participants speak about how the gatherings have given them a sense of belonging, worth, confidence, health, and celebration. Comments from participants of the 13<sup>th</sup> annual gathering are illustrative.<sup>8</sup>

- I think it's great to have our people together in this kind of setting as it is not always accepted. So, to have acceptance with our orientation and culture all in one is a good thing. As well, the young people being re-introduced to our Elders is very important.
- I have witnessed so much growth and confidence building in my brothers and sisters, possibly even breathing new life into them and myself.
- My life is truly the better for it. I cannot express how important this has been. I loved it. Thank you. Thank you.
- I think the gathering increases my own sense of self-worth which makes me feel more prone to take the precautions to preserve my health.
- I feel more balanced, a healthy sense of acceptance and belonging.
- The better I know myself, the better I feel and the more I care for myself.
- Connectedness – to belong is important, to be valued is important.
- This gathering was a wonderful experience – the love and open giving, sharing, the feeling that one is not alone. The ability to experience ceremonies and learn new things.
- Being comfortable with myself and accepting me for who I am. My first and not last experience. It was fabulous.
- I know who I am and am able to make healthy choices.
- A much needed celebration in my life.

The gatherings have also led to further activities. For example, the 14<sup>th</sup> annual gathering recommended that there be a national forum on HIV/AIDS and health that brings together not only Two-Spirit peoples but also Aboriginal and non-Aboriginal families, community members, and service providers. This led to the planning and hosting of the 1<sup>st</sup> Canadian Forum on Two-Spirit Peoples, HIV/AIDS, and Health in 2003. The 14<sup>th</sup> gathering also recommended that a national Two-Spirit organization be developed to address social and health issues for Two-Spirit

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<sup>8</sup> K Naucklaus, M Cook. Report on the 13<sup>th</sup> Annual International Two-Spirit Gathering. 10 September 2001.

peoples. This recommendation came to fruition in November 2003, when the members of 2-Spirited People of the First Nations passed a resolution that it becomes a national organization.

### **Factors that Contributed to the Success of the Mobilization**

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- The gatherings are community-driven, organized by and for Two-Spirit peoples.
- The gatherings are safe spaces where people can speak equally, from the heart, about their experiences.
- The gatherings are sometimes the first, or one of the few, places where participants are among Two-Spirit people like themselves.
- Funding from government agencies pays for scholarships for people to attend the gatherings.
- The host organization provides the financial and administrative systems required to organize the event and manage the finances.
- The gatherings draw people from nations and tribes across Canada and the United States, and also draw some international participants.

## Story #5

### Fighting for a Supervised Injection Site in Vancouver<sup>9</sup>

#### Background

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In response to the epidemics of HIV, hepatitis C and overdose deaths in the Downtown Eastside of Vancouver, a group of individuals gathered in 1997 to form a user-run organization, known eventually as the Vancouver Area Network of Drug Users (VANDU). The founders felt that little had been done in response to the health emergency, and that the voice of users had not been heard. With over 1,000 members and 800 peer volunteers, VANDU is now recognized as one of the strongest user organizations in the world.

VANDU combines the values of liberation theology with the methods of popular education. Through community consultations and board-directed activity, VANDU identifies and responds to gaps in support for people who use illicit drugs. Among the group's priorities is promoting low-threshold harm reduction for all users – in Canada and abroad. In the last few years, working with a number of allies, VANDU became a pivotal organization in the fight to establish a supervised injection site (SIS) in the Downtown Eastside.

#### Description of the Mobilization

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*Many of the actions described in this section relate to the full spectrum of issues that VANDU deals with, not just the drive to establish an SIS. This is because many VANDU actions dealt with multiple issues.*

VANDU's earliest work involved setting up drug use discussion groups. The very first discussion group took place right in the heart of the open drug scene in Oppenheimer Park. The organizers asked users to voice their concerns and needs. The first questions were simple and included: "What are the issues facing drug users?" and "What would most help you now?" The facilitators then documented the concerns raised on flip chart paper. The organizers continued to place notices about the meetings throughout the neighbourhood, and within a couple of months hundreds of users were attending these meetings to plan user-based actions.

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<sup>9</sup> Some of the information in this story was taken verbatim from the remarks made by Thomas Kerr and Libby Davis on the occasion of the presentation of the 2002 Canadian Award for Action on HIV/AIDS and Human Rights. See *Ten Years of Action for Health and Human Rights: Presentations Made on the Occasion of the Canadian HIV/AIDS Legal Network Annual General Meeting and Skills Building Workshops*. Available at [www.aidslaw.ca/Maincontent/events/agm2002/proceedings.pdf](http://www.aidslaw.ca/Maincontent/events/agm2002/proceedings.pdf). Additional information on this story can be obtained from Ann Livingston of VANDU at [annlive@direct.ca](mailto:annlive@direct.ca).

These community meetings were held every two weeks. Popular education techniques were used. For example, questions like the following were posed and answered:

- What are your issues?
- Why do they exist and persist?
- What actions should we be taking?
- What will this involve?

The bi-weekly meetings continued over the years. As a result of these meetings, drug users learned the facts about the number of overdoses, HIV rates, and the accompanying epidemics (e.g., tuberculosis, hepatitis C, hepatitis B, syphilis). They also learned about public health initiatives implemented elsewhere, initiatives such as SISs, heroin prescription, low-threshold methadone maintenance, and proper housing for users. It was from these meetings that the call came for the establishment of an SIS in the Downtown Eastside.

VANDU members began to attend public meetings, city council meetings and conferences to push for measures to respond to their needs. VANDU also invited politicians, public health officials, members of the health and police boards, epidemiologists and others to its meetings. As well, VANDU members began to speak at meetings of social work students, medical students, police officers, church associations and human rights organizations. VANDU members also gave numerous media interviews, including participating on open line radio shows.

VANDU performed a critical public education function by bringing hundreds of policy makers, health-care professionals, researchers, and others face-to-face with the harsh realities of the Downtown Eastside. Through public presentations and back alley tours, VANDU actively countered the stereotypes that perpetuate the disabling stigmatization of people who inject drugs.

A number of allied organizations were formed involving non-users who wanted to support the demands of VANDU. These organizations included:

- From Grief to Action, a parents group;
- the Harm Reduction Action Society (HRAS), made up of nurses, physicians, researchers, outreach workers, and AIDS service workers; and
- the PIVOT Legal Society, made up of lawyers, law students, and sex trade workers.

Drug users were also members of HRAS and PIVOT.

When VANDU began to work with parents in a very middle-class neighbourhood on the West side of Vancouver whose kids were dying of overdoses, they formed an incredibly powerful force that was able to begin to change political and legal agendas.

The following are examples of actions that were taken to push for solutions to the needs of drug users in general, or for the establishment of an SIS in particular:

- In March 2000, over 3,000 people attended a conference on Keeping the Door Open: Health, Addiction and Social Justice. Participants included drug users, their friends and families, health and social service providers, public policy makers, health authorities, researchers and the general public. At the closing plenary, participants expressed frustration with government inaction and the escalating rates of HIV, hepatitis C and overdose deaths in the community.
- In July 2000, VANDU, along with other agencies, blocked traffic at the corner of Main and Hastings streets (in the heart of the Downtown Eastside), and then organized a demonstration in Oppenheimer Park. Two thousand wooden crosses were erected to commemorate drug-related deaths that had occurred during the past ten years. VANDU followed the demonstration with a media conference.
- In May 2001, VANDU organized an information picket outside the Carnegie Community Centre to protest the fact that the Centre was turning away users of illicit drugs whom they considered to be too addicted or too sick.
- In December 2001, on World AIDS Day, VANDU and HRAS members constructed a small model SIS inside a church, and held tours for neighbours, politicians and the media.
- VANDU participated on several national task forces looking at drug use issues, including the Federal-Provincial-Territorial Committee on Injection Drug Use.
- VANDU members opened unsanctioned SISs in 2000 and 2003, thus creating pressure on governments and local health authorities to proceed with the establishment of a sanctioned SIS.
- Two founding members of VANDU ran for Vancouver City Council in 1999. They were successful in getting two parties (the Green Party and the Coalition of Progressive Electors) to embrace harm reduction as a policy. They also succeeded in getting all candidates to discuss injection drug use issues.
- VANDU members participated in registering potential voters for the city council elections (in the process, registering more people than the officials whose job it was to register potential voters).
- During the city council election campaign, VANDU organized a meeting of its members that was attended by a number of candidates.
- In April 2003, VANDU and the Housing Action Committee organized a demonstration at City Hall to protest against a decision to assign additional police to the Downtown Eastside. (Residents had been promised that no additional police would be assigned until the SIS opened.)

## Factors that Contributed to the Success of the Mobilization

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- VANDU used education effectively to empower drug users. This was very much a grassroots effort.
- Specific organizations were established to allow allies to participate in an organized way in efforts to address the issues raised by drug users.
- Through the media interviews and public appearances, VANDU succeeded in giving a human face to the suffering of what was a very marginalized (and therefore very ignored) community. This helped to educate the general public.
- Through user empowerment, organizing and mobilization, VANDU forced researchers, bureaucrats, politicians and policy makers to acknowledge the ongoing harms experienced within the injection drug use community, and to change their point of view about how to respond to drug use.
- VANDU was successful in making allies of people who previously were not doing much to address the needs of injection drug users, including some local AIDS organizations. This was one of the first instances of Downtown Eastside organizations and West End AIDS organizations working together in partnership. These and other alliances were critical to the success of the campaign for an SIS.
- Members of VANDU used the electoral process to draw attention to their issues and to obtain commitments from political parties.
- The process that led to the establishment of the SIS in the Downtown Eastside involved just about every form of community mobilization, from radical activism to high level advocacy.
- The Canadian HIV/AIDS Legal Network was able to offer support. This included providing the legal, ethical, and policy rationale for SISs in its report, *Establishing Safe Injection Facilities in Canada: Legal and Ethical Issues*.

## **Story #6**

### **Building a GLBT Community Organization in Nova Scotia<sup>10</sup>**

#### **Background**

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Truro is a town in Nova Scotia with a population of approximately 12,500 people. There has been an organization for the support of people with HIV/AIDS in the region since 1996. The current name of the organization, now based in Truro, is the Northern AIDS Connection Society.

Many gay, lesbian, bisexual, and transgendered (GLBT) people in the region do not feel that it is safe for them to be “out.” Few people with HIV/AIDS in the region are public about their status. Albert (Al) McNutt, one of the leaders of the Northern AIDS Connection Society, is one of the few people whom the public knows to be gay and HIV positive.

In recent years, the Northern AIDS Connection Society has been partnering with the Colchester Sexual Assault Centre to work with GLBT people. Three groups were started: one for youth, one for adults, and one for parents, families, and friends of GLBT people (P-FLAG).

At the beginning, the groups received help and support from several sources. Vida Woodworth, the Executive Director of the Colchester Sexual Assault Centre, was very supportive and provided space for groups to meet. The Rev. Eldon Hay, President of P-FLAG Canada,<sup>11</sup> came down from New Brunswick to help start the P-FLAG group. Inspiration for the youth group came from a workshop that Bill Ryan led in New Brunswick as part of the Safe Spaces Project.<sup>12</sup> Bill Ryan, an adjunct professor at the McGill University School of Social Work, is National Manager of the Safe Spaces Project. The work of the youth group involved speaking with students, starting a straight-gay alliance, and getting teachers to identify themselves as “GLBT-friendly.”

Al McNutt was involved in all of the groups, particularly in the adult support group.

#### **Description of the Mobilization**

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After awhile, attendance at the adult support group, called Truro Pride, started dwindling. People said that the group was not meeting their needs, and that it wasn't helping them to develop social or intimate friendships with other GLBT people. Al put it to them that what they needed to do was to take some ownership of what they wanted and to work to achieve it.

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<sup>10</sup> Additional information on this story can be obtained from Albert McNutt at [t\\_o\\_p2000@hotmail.com](mailto:t_o_p2000@hotmail.com).

<sup>11</sup> For information about P-FLAG Canada, see [www.pflag.ca/](http://www.pflag.ca/).

<sup>12</sup> For information about the Safe Spaces Project, see [www.artsweb.mcgill.ca/programs/cafs/community.htm](http://www.artsweb.mcgill.ca/programs/cafs/community.htm)

The group talked about what they wanted. They decided that they wanted to have GLBT dances. Then they talked about what it would take to make the dances happen: location, music, advertising, funds.

For a location, someone proposed the local Lions Club. Al agreed to be the one to approach the Lions Club, since it was safer for him to do this. For advertising, different members agreed to design a poster and approach local businesses for permission to put up the poster. For music, someone agreed to approach the disc jockey at a local straight bar. The organizers did some preparatory work with the guys who tended the bar at the Lions Club, so that they wouldn't be surprised by GLBT culture.

Ninety-two people showed up at the first dance in May 2002. About the same number came to the second dance in September 2003, but the people were different. A third dance took place in November 2003.

## **Outcomes**

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The dances have had many ripple effects in the personal and public lives of GLBT people in the region:

- Several GLBT people have become more socially involved, are dating, seeing friends, etc.
- Two men from New Glasgow have become more publicly active. First they joined the board of the Northern AIDS Connection Society. Then they spoke to the congregation of their church about homophobia issues and about HIV/AIDS. (One of the men is HIV positive, and the other is HIV negative.) Next they wrote an article for a local newspaper. People in the town have stopped them in the street to express appreciation for their work and courage. In November 2003, they were awarded the YM-YWCA Peace Medal.
- Members of Truro Pride and of the Northern AIDS Connection Society are becoming more active in the organizations. They are speaking up, giving their views, and taking initiative. They have begun thinking about what other activities they could sponsor. So far, they are working on a retreat on same-sex marriage and its implications for people on disability pensions. (They see a need to collaborate in this with the Nova Scotia Rainbow Action Project.) And they have established networks for people interested in different kinds of social or recreational activities for GLBT people.
- The bank manager at the branch where Truro Pride has its account has let it be known to the group that he is very open to their work and happy to have their business.

## **Factors that Contributed to the Success of the Mobilization**

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- Individuals and networks in the area provided inspiration and support in the early stages of the work.
- Members of the group took ownership of what was needed to break through the isolation they experienced as GLBT people, and together they did the work to make the dances a reality.

- The group benefited from the leadership of some individuals, and from the fact that some people were in a position to act publicly as GLBT or HIV-positive people.
- The first thing the group did was something that met the personal and social needs of members of the community.
- The approach that people took in planning the dances has continued to be the approach in planning other activities: a self-starting, collaborative effort.
- The dances were self-financing and revenue-generating. The revenues have made it possible for the group to plan other activities.
- As people become more active, there were organizations where they could contribute: Truro Pride, Northern AIDS Connection Society, the Colchester Sexual Assault Centre, the Nova Scotia Agricultural College, the local churches, etc.
- People who have become more public about being GLBT or HIV-positive have discovered that there are many supportive or accepting people in the community around them.

## Story #7

### Improving Prevention and Human Rights in the Sex Trade in Kolkata, India<sup>13</sup>

#### Background

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Sonagachi is the largest red-light district in Kolkata, India. The Sonagachi AIDS Project was started in 1992 as a government operational research project spearheaded by Dr. Smarajit Jana, an epidemiologist. Then, Dr. Jana met representatives of sex work projects from around the world at an international AIDS conference. He came back from the conference emphasizing the need to use community organizing as a model. Now, the Project is run by sex workers themselves.

Following the initial research, an outreach program was implemented with the objective of controlling the spread of STDs and HIV among sex workers and their partners and clients. The program had three principal components: (a) providing health services; (b) disseminating information, education and communication (IEC) messages regarding prevention of STD and HIV transmission; and (c) promoting condom use. Twelve sex workers from the locality were employed as peer educators. These women informed their “sisters” about STDs, urged them to get blood tests every three months, and distributed condoms. Soon, hundreds of women were refusing unprotected sex, even when clients offered to pay more.

The Project adopted a series of guiding principles, including the following:

- The sex workers were accepted for what they were. There was no attempt to “rescue” or “rehabilitate” them.
- The sex workers’ capabilities as human beings and workers were recognized and respected.
- The sex workers were not treated as passive “beneficiaries” without any choice or agency, but rather as *change agents*.
- The sex workers were regarded as complete persons with a range of emotional and material needs, and not merely in terms of their sexual behaviour.
- The needs and interests of the sex workers were given prime importance in designing and carrying out the Project’s activities.
- The Project strongly emphasized the genuine representation and active participation of the sex workers at every level.

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<sup>13</sup> The information in this section was taken from a draft of a document being prepared by the Coalition of Asia Pacific Regional Networks on HIV/AIDS (the Seven Sisters). The draft was entitled, *People Who Matter: The involvement of affected communities in responding to HIV/AIDS*. Seven Sisters can be contacted through Susan Chong of the Asia Pacific Council of AIDS Service Organizations at [apcaso@pd.jaring.my](mailto:apcaso@pd.jaring.my).

## Description of the Mobilization

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The Project adopted the following approaches in its interventions with the sex workers:

- Activities that directly addressed the needs articulated by sex workers were undertaken, even if they were not necessarily in the original plan. These activities included general literacy training and legal literacy training for the sex workers; and immunization and other support services for the children of the sex workers.
- The contribution of the sex workers to the Project and their role as members of the labour force were highlighted at local, national and international fora, thereby making them more visible as legitimate citizens, and improving their self-esteem.
- Steps were taken to address all forms of stigma and discriminatory practices against sex workers, within the sex trade (such as police harassment, violence, and oppression by madams); and outside the sex trade (such as exclusion of the children of sex workers from mainstream education, and social stigma).

On-the-job training increased the capacity of sex workers, increased their self-esteem, and empowered them socially, economically and politically. The Project helped the sex workers to form their own credit society and social marketing agency. It also helped them to organize to fight for their rights.

The Sonagachi AIDS Project also carried out extensive advocacy campaigns and individual lobbying with policy makers and opinion builders at all levels to persuade them of the legitimacy of the Project's approach, and to convince them that sex workers were entitled to equal rights concerning health and life. The Project targeted local opinion makers, elected representatives, ministers, political party officials, human rights organizations, women's groups, trade unions, bureaucrats, intellectuals, other NGOs, and bilateral and multilateral donor agencies. As a result, the Project gained public recognition and wide acceptance, which gave it enough credibility to challenge some of the fundamental structural constraints that marginalize sex workers and increase their vulnerability.

In 1997, the women of the Project organized the Durbar Mahila Samawaya Committee (DMSC), Asia's first union of sex workers. With 60,000 male and female members in West Bengal, the DMSC worked for the decriminalisation of prostitution, for equal worker's rights, and for the right to negotiate working conditions. Today, 430 peer educators spread awareness throughout Bengal, and 36 brothel-based medical clinics regularly treat sex workers. Among other things, the DMSC has established a school for sex workers' children, a money-lending co-op, and a cultural group that spreads AIDS awareness through music, dance, and street theatre.

On the local level, the work of the Project has inspired others, such as a City Counseling Center in downtown Kolkata which provides medical and psychological consultation, as well as cheap antiretroviral drugs, and which started one of India's first support networks for people living with HIV/AIDS, the Kolkata Network of HIV Positive People.

## **Outcomes**

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Only about nine percent of the 6,000 sex workers in the district served by the Project are HIV positive. In comparison, rates of infection among Mumbai (formerly Bombay) sex workers were as high as 70% in 1997. While in 1992 a government survey revealed that only 1.7 percent of 450 sex workers surveyed were using condoms, by 1994 the figure had jumped to 69.3%.

Stigma and discrimination against sex workers has been reduced. Their economic situation was improved.

## **Factors that Contributed to the Success of the Mobilization**

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- The use of a peer education approach helped to build self-esteem among the sex workers.
- The initial involvement of the sex workers as full partners in the Project, and the subsequent decision to have the sex workers take control of the Project, has contributed significantly to the success of the Project.
- Training was undertaken in literacy and legal literacy.
- Support services were provided for the children of sex workers.
- Public fora were used to highlight the contributions of sex workers to the Project.
- The use of a needs-driven approach ensured that the Project responded to the issues that sex workers were concerned about.
- The use of a flexible approach helped to ensure that the Project could be adapted to the changing needs and circumstances of the sex workers.
- Specific measures were taken to create a supporting environment.
- A broad-based advocacy campaign was used to achieve social change.

## **Summary of Common Success Factors**

No two stories presented in this paper are exactly alike. For one thing, each mobilization responded to a different problem. For another, the dynamics in each community are different. Nevertheless, it is possible to identify factors that contributed to the success of the mobilizations that were present in most or all of the stories. The following is a list of these common factors:

- Existing organizations, with good roots in the community, were able to take up an issue when it first arose, and to provide leadership in the response.
- Separate entities – organizations, committees or projects – were established specifically to deal with the issue at hand.
- Members of the community who got involved in the mobilization took ownership of the issue(s).
- Specific individuals within the community took a leadership role.
- The concerns of the community were identified and clearly articulated. The positions taken by the people doing the advocacy work were widely endorsed by the community.
- The issues were critically analyzed, the solutions were identified, and actions were carefully planned.
- Multiple approaches were used, often combining public demonstrations and protests with attempts to problem-solve with the “other side.”
- Leadership was demonstrated on “both sides.”
- Alliances were formed with sympathetic organizations and individuals.
- Efforts were made to build the capacity of individuals and organizations participating in the mobilization.
- Written materials were produced and widely disseminated.
- Many people in the community were involved in the response.
- The media was used effectively to publicize the issue and educate the public.
- The mobilizations were planned for the long term, and the campaigns were relentless.
- The mobilizations involved considerable advocacy work.