Community Mobilization Against HIV/AIDS-Related Stigma and Discrimination

Workshop Report

31 January – 1 February 2004

Prepared by
Theodore de Bruyn

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

CANADIAN | RÉSEAU
HIV·AIDS | JURIDIQUE
LEGAL | 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

March 2004

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Background

Research in Canada[1] and internationally[2] has demonstrated that people living with HIV/AIDS and people affected by HIV/AIDS continue to experience stigma and discrimination. This contributes to the spread of the epidemic and to the hardship it brings. Stigma and discrimination isolate people living with HIV/AIDS and people affected by HIV/AIDS, discourage them from seeking HIV testing, discourage them from seeking health care, contribute to the personal and social circumstances that increase the risk of infection with HIV and other diseases, and create personal anxieties and social risks in disclosing HIV status.

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[1] T de Bruyn. *HIV/AIDS and Discrimination: A Discussion Paper*. Montréal: Canadian HIV/AIDS Legal Network/Canadian AIDS Society, 1998; C Olivier. HIV-related discrimination in New Brunswick increasing. *Canadian HIV/AIDS Policy & Law Newsletter* 2000; 5(2/3) : 52; J Leech. Survey reveals human rights abuses in Alberta. *Canadian HIV/AIDS Policy & Law Newsletter* 2003; 8(1): 24; S Matiation. *Discrimination, HIV/AIDS and Aboriginal People: A Discussion Paper*. 2nd edition. Montréal: Canadian HIV/AIDS Legal Network, 1999; D Schneider et al. Attitudes and beliefs towards HIV and AIDS among Aboriginal peoples living in British Columbia. Healing Our Spirit Research Papers, no date (available via www.healingourspirit.org); Alliance for South Asian AIDS Prevention. *Discrimination and HIV/AIDS in South Asian Communities: Legal, Ethical and Human Rights Challenges. An Ethnocultural Perspective.* Toronto: Alliance for South Asian AIDS Prevention, 1999; W Lau et al. *Legal, Ethical and Human Rights Issues Facing East and Southeast Asian-Canadians in Accessing HIV/AIDS Services in Canada.* Toronto: Asian Community AIDS Services, 1999; B Ryan and M Chervin. *Framing Gay Men's Health in a Population Health Discourse*. Ottawa: Canadian HIV/AIDS Clearinghouse, and Saskatoon: Gay & Lesbian Health Services of Saskatoon, 2000; National Reference Group. *Valuing Gay Men's Lives: Reinvigorating HIV Prevention in the Context of Our Health and Wellness*. Ottawa: Canadian HIV/AIDS Clearinghouse, and Saskatoon: Gay & Lesbian Health Services of Saskatoon, no date; S Kellington et al. *Listen Up! Women are Talking About.... The social determinants of women's risk for HIV infection and illness in lower mainland British Columbia.* Vancouver: Positive Women's Network, 1999; S Kellington et al. *Listen Up! Women are Talking About..... .Examining community-based strategies and solutions to address the social determinants of women's risk for HIV infection and illness progression in Lower Mainland British Columbia.* Vancouver: Positive Women's Network, 2000; HIV Endemic Task Force. Complete Report of the Community Forum "For Us, By Us, About Us": An Opportunity for African and Caribbean Communities to Address the Issue of HIV/AIDS Related Stigma and Denial. November 2001; HIV Endemic Task Force. Summary Report of the Community Forum "For Us, By Us, About Us": An Opportunity for African and Caribbean Communities to Address the Issue of HIV/AIDS Related Stigma and Denial. November 2001; Ekos Research Associates. HIV/AIDS – An Attitudinal Survey. Final Report. 24 June 2003, at 47-54. (An executive summary of the Ekos report is available at www.hc-sc.gc.ca/hppb/hiv_aids/pdf/execsum_e.pdf.)

[2] For a list of recent international studies, see T de Bruyn. HIV/AIDS-related stigma and discrimination – the epidemic continues. *Canadian HIV/AIDS Policy & Law Review* 2002; 7(1): 8-13 at 8 (available at www.aidslaw.ca/Maincontent/otherdocs/Newsletter/vol7no12002/stigmaanddiscrimination.htm); for an overview of findings around the world, see A Malcolm et al. HIV-related stigmatization and discrimination: its forms and contexts. *Critical Public Health* 1998; 8(4): 347-370.

A combination of conditions and actions is required to prevent, reduce, or redress HIV/AIDS-related stigma and discrimination.[3] These include:

- a legal and policy framework (including anti-discrimination provisions) that protects the human rights of people living with HIV/AIDS and people affected by HIV/AIDS;
- legal and community advocates and agencies to act on individual cases of discrimination;
- greater involvement of people living with HIV/AIDS and people affected by HIV/AIDS;
- public education about HIV/AIDS and about stigma and discrimination;
- professional education of health-care workers, educators, and other professionals about HIV/AIDS and about non-stigmatizing and non-discriminatory relations with people living with HIV/AIDS and populations affected by HIV/AIDS;
- workplace policies and education on HIV/AIDS;
- school education about HIV/AIDS, sexuality, alcohol and other drugs;
- strategies to address the determinants of health, including inequities associated with gender, sexuality, ethnic identity, poverty, and other social determinants.

Community mobilization is essential to positive action on HIV/AIDS-related stigma and discrimination,[4] for a number of reasons. Stigmatization is a process of devaluation that creates, and is reinforced by, social inequality. It can result in discriminatory actions against those who are stigmatized, either by acting inappropriately or failing to act appropriately.[5] Through community development and action, people who are stigmatized can identify processes of stigmatization and discrimination as they experience them, resist these processes with the moral and legal support of a framework of human rights, and engage other actors (such as community leaders, municipal authorities, school administrators, professional bodies, legal advocates, etc.) in efforts to change the local environment (through laws, education, policies, campaigns, etc.).

The processes of stigmatization and discrimination, and the ways that they are experienced, vary in different communities and in different populations. Therefore, the involvement of communities and their organizations in the effort to prevent, reduce, or redress stigma and discrimination is crucial. It is at the local level that communities can identify the processes of stigmatization and discrimination that they experience. Collectively, people directly affected by stigmatization and discrimination can acquire a voice in the community, can influence public opinion, and can work with other

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[3] Cf. de Bruyn, supra, note 2 at 11-13; R Parker, P Aggleton. *HIV and AIDS-Related Stigma and Discrimination: A Conceptual Framework and Implications for Action.* Rio de Janeiro: Associação Brasileira Interdisciplinar de AIDS/London: Thomas Coram Research Unit, 2002.

[4] See R Parker et al. *HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action.* New York: Horizons Program and Washington, D.C.: Population Council, 2002, at 13-15 (www.popcouncil.org/pdfs/horizons/sdcncncptlfrmwrk.pdf). For examples of community mobilization, see D Garmaise and T de Bruyn, Stories of Community Mobilization, December 2003, available at www.aidslaw.ca/Maincontent/issues/discrimination/Stories_Community_Mobilization.pdf.

[5] Aggleton and Parker, supra, note 4 at 8-11.

organizations to address their needs. In the process, people who were previously devalued assert or discover their value and their rights as human beings, something which in and of itself works to combat the effects of stigmatization and discrimination.[6]

The Community Mobilization Project

The Canadian HIV/AIDS Legal Network, in collaboration with six Canadian community-based organizations, undertook a one-year project 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.

The project included the following activities:

- the establishment of a committee of project partners to plan the activities of the project;
- the gathering of stories of community mobilization, as a resource for participants in the project;[7]
- the development of materials and a training program for a capacity-building workshop on community-based action on stigma and discrimination;
- the establishment of a dedicated listserv for participants to communicate before and after the workshop;
- a three-day workshop, held 30 January -1 February, 2004,in Montréal;
- a report summarizing the outcomes of the workshop; and
- an independent evaluation of the project.

Listserv Exchanges Before the Workshop

A listserv was set up two months before the workshop for participants to communicate with each other. The moderator of the listserv put forward some questions, one at a time, to animate discussion. Participants replied in English or French. A selection of the responses were translated and included in the materials provided for the workshop.

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[6] See, eg, T Kerr et al. *Responding to an Emergency: Education, Advocacy and Community Care by a Peer-Driven Organization of Drug Users. A Case Study of Vancouver Area Network of Drug Users (VANDU).* Ottawa: Health Canada, 2001, at 29-34.

[7] These are available on the website of the Canadian HIV/AIDS Legal Network at www.aidslaw.ca/Maincontent/issues/discrimination/Stories_Community_Mobilization.pdf

The exchanges on the listserv were as follows:

- *Introduction to the listserv:* Please share a little information about yourself, including your name, the name of your organization, and the work your organization is doing to reduce stigma and discrimination in your community.

- *Round 1: Please describe the things that, in your experience, have worked well to increase acceptance of people living with HIV/AIDS or people affected by HIV/AIDS.* The acceptance could be acceptance by themselves (self-esteem, sense of value, etc.) or acceptance by others. You could draw on insights from your personal or social life as well as insights from your work in an organization. You might find it interesting to ask other people in your organization about this as well.

- *Round 2: What has worked well in your experience of mobilizing a community of people?* Please share the things that, in your experience, have worked well to bring people together and create a sense of solidarity in your community. Have you worked together on a project to meet the community's needs or to increase its acceptance by others? This could be in any area of life, not necessary in formally organized activities, or with respect to HIV/AIDS. You might find it interesting to ask other people in your organization about this as well.

- *Round 3: What do you need to mobilize your community to work to increase the acceptance of people living with HIV/AIDS or people affected by HIV/AIDS?* This could be different types of things: access to a community that is hard to reach because of stigma; support from local organizations; staff and time; a better idea of where to start and what to focus on.

See Appendix B for responses to the three rounds of questions on the listserv.

Workshop Design

The workshop was designed to help participants learn from each other and from the workshop process about:
- ,gmatizing attitudes and behaviour,
- how people change,
- how to create the conditions that facilitate change,
- ways that organizations have taken action to change stigmatizing attitudes and behaviour, and
- steps they might take in their organization or community.

As a result of the workshop, the organizers hoped that participants would leave with:
- greater understanding of stigmatizing attitudes and behaviour,
- greater skill and confidence in creating the conditions that help to facilitate change,
- a strategy to work with their community or organization to identify or take some

specific form of action,
- a plan of the next steps they will take when they return to their community or organization,
- a sense of shared mission and action with a community of change agents, and
- a belief that change is possible.

Workshop Process

The workshop drew on participants' experience and reflection in order to arrive at:
- a greater understanding of stigma, both in ourselves and in others (Day 1);
- a greater understanding of change from stigma to acceptance, in ourselves and in others (Day 2); and
- a plan for change in ourselves and others (Day 3).

The workshop included times for individual reflection and writing, for sharing reflections with a small group, for brainstorming and identifying common themes with a small group, and for sharing of main points with all the participants in the workshop (see Appendix C for a detailed version of the process as it actually unfolded).

The workshop was conducted in English and French, with interpretation provided in plenary sessions by staff and by participants.

Day 1: Understanding Stigma

Participants explored the experience of stigma and discrimination by considering the following questions:
   a) Explore when have you stigmatized an individual or group (personal writing/reflection, then sharing in small group).
   b) Explore when you have felt stigmatized by an individual or group (personal writing/reflection, then sharing in small group).
   c) Explore the positive intentions behind stigmatizing attitudes and behaviours (small group brainstorming/theming).
   d) Explore the common ground between stigmatizers and stigmatized (small group brainstorming/theming).

Participants then reported and reflected on what they discovered in a plenary session.

Day 2: Understanding Change

Participants reflected on their answers to the questions they discussed on the previous day, in order to identify what makes change happen:

> Thinking back on your answers to (a) and (b) yesterday and your discussions, did you change from stigmatizing to accepting an individual or group? Did an individual or group change from stigmatizing to accepting you? How did this happen? If it did not happen, why do think that was the case? How, if at all, do

your reflection on (c) and (d) fit in with the change/no change situations?

From their reflections, participants identified the values, desires, attitudes, and ways of communicating that either made change happen or prevented change from happening. They were asked to summarize what they identified in a plenary session. In preparing their summary, they were asked to focus on those values, desires, attitudes, or ways of communicating that represented their strengths, their opportunities to grow, their biggest challenges, or their biggest needs.

Participants then described the action or projects that they were working on or thinking about in their communities. Based on these descriptions, participants were organized into pairs. Drawing on the reflections about what makes change happen, they worked in pairs to identify:
- one goal for reducing stigma against, and increasing acceptance of, their population within their community;
- one obstacle to achieving this goal.

Participants wrote up their goal and obstacle on a flip chart and posted these for everyone to review in a plenary session.

Day 3: Planning for Change

Working in the same pairs as the previous day, participants began by reviewing two stories of community mobilization: "Fighting for a Supervised Injection Site in Vancouver" and "Building a GLBT Community Organization in Nova Scotia."[8] They were asked to identify:
- what were key elements in mobilizing communities in these stories;
- what opportunities these stories or these key elements suggested in their own situation.

Then participants identified, in a process of personal reflection, one factor (relating to values, ways of communicating, desires, or attitudes) that, in their opinion, was the most important in facilitating change toward greater acceptance.

Participants returned to their pairs to brainstorm the next steps that they might take to achieve the goal and to overcome the obstacle they identified on the previous day. Then, bearing in mind the factors that facilitate change, they selected one next step and described how they would achieve this next step. Participants wrote this up on flip charts for everyone to review in a plenary session.

At the end of the workshop, all the participants presented their plans (see Appendix D to read participants' activities), which included:
- one goal for reducing stigma against, and increasing acceptance of, their population within their community;
- one obstacle to achieving this goal;

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[8] See supra n. 7.

- a next step toward achieving the goal or overcoming the obstacle;
- a description of how they would take this next step.

The workshop concluded with a description of the remaining events in the project and a questionnaire evaluating the workshop.

Workshop Concepts

Several concepts were introduced during the workshop, or emerged from the workshop. They had to do with processes of reflection and planning, and with processes of community mobilization and action against stigma. These were presented in graphic form, and are summarized below.

The Process of Reflection or Brainstorming

The process of reflection or brainstorming, both individually and in groups, leads first of all to more ideas or awareness. This is a process of expansion that often includes diverse or conflicting ideas or awareness. It can sometimes feel a little overwhelming. But then one begins to select from among the ideas or awareness and work toward a focus. This is a process of convergence that provides the basis for the next step in planning an action.

Expressing
Ideas

Expanding Ideas

Focussing Ideas

Next Step
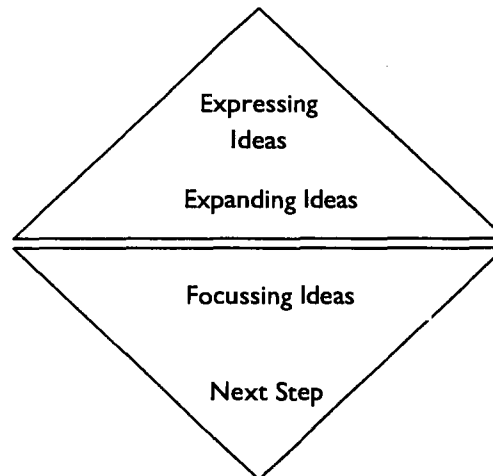
Circles of Influence

When mobilizing communities, it is important to be aware of the circles of influence one has. Change often starts with oneself, then with people or organizations that are close by, and only later with people or organizations that are the targets of advocacy. It helps to ask, "Who do I or we have the best chance to influence?"
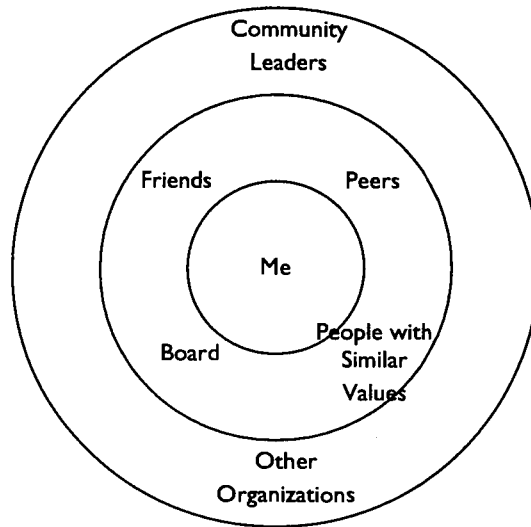
Relations between Stigmatizers and Stigmatized

People who stigmatize and the people they stigmatize often occupy common ground. Sometimes this can be a common physical or geographical space – an office, a neighbourhood, an identifiable community, etc. Sometimes it can be a common set of desires or intentions – the desire for safety, the desire to protect oneself, the desire to protect certain values. Often the first step toward change is for people who are stigmatized to come together, recognize their common experience, and mobilize together against stigma and discrimination. But then a further step is necessary to change the stigmatizers, sometimes by challenging them, sometimes by finding common ground with them that they recognize and that helps them to change.

Common ground

Stigmatized

A space for challenge, and a space for commonality

Stigmatizers

Common desires
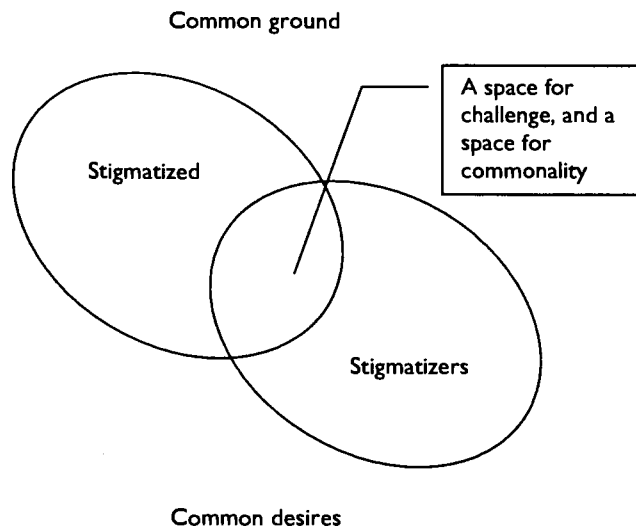
Moving from Here to There: Planning for Change

There are several steps to planning for change. It involves identifying:
- the situation one is in now;
- what one wants to achieve (a goal);
- the obstacles that make it harder to achieve this goal (barriers);
- the action needed to overcome the obstacles; and
- the resources or strengths one has with regard to factors that facilitate change.

Where we are

Where we want to be

Resources and strengths

After the Workshop

In the two months left in the project, participants were asked to act on their plans with their organizations or other collaborators, and to report back to the listserv on what happened and what they learned in doing so.

During those two months, staff at the Canadian HIV/AIDS Legal Network agreed to provide the following support:
- send out a document with the plans of all the participants;
- facilitate exchanges among participants on the listserv;
- prepare a report on the workshop;
- send out a question to the listserv six weeks after the workshop to ask participants what happened with their plans and what they learned;
- send out a final evaluation of the project by 15 March 2004.

The evaluation of the workshop will be included in the evaluation of the project as a whole.

APPENDIX A

LIST OF PARTICIPANTS

NAME	ORGANISATION	E-MAIL
Babcock, Joseph	HIV/AIDS Regional Services	josephbdesigns@hotmail.com
Betteridge, Glenn	Canadian HIV/AIDS Legal Network	gbetteridge@aidslaw.ca
Conway, Tracey	Voices of Positive Women, Canadian HIV Trials Network	tconway@vianet.ca
de Bruyn, Theo	Canadian HIV/AIDS Legal Network	tdebruyn@aidslaw.ca
Flaro, Haley	AIDS New Brunswick/SIDA Nouveau-Brunswick	sidaids@nbnet.nb.ca
Fortin, Marielle	MAINS Bas St-Laurent (Mouvement d'aide et d'information sida du Bas St-Laurent)	mainsbsl@globetrotter.net
Gibson, Barbara	AIDS PEI	bgibson@aidspei.com
Howard, Terry	British Columbia Persons with AIDS (BCPWA) Society	terryh@bcpwa.org
Lavoie, René	COCQ-Sida	rlavoie@cocqsida.com
Livingston, Ann	Vancouver Area Network of Drug Users (VANDU)	annlive@direct.ca
Luly, Marie-Hélène	GAP-VIES	boobool18@yahoo.com
Manning, Liz	Nine Circles Community Health Centre	lmanning@ninecircles.ca
Oliver, Jim	AIDS Vancouver Island	jim.oliver@avi.org
Scanlon, Kyle	Trans Programs, 519 Community Centre	MealTran@the519.org
Simard, Hélène	MIENS (Mouvement d'information, d'éducation et d'entraide dans la lutte contre le sida)	lemiens@cybernaute.com
Summers, Penny	AIDS Calgary	psummers@aidscalgary.org
Taylor, Cynthia	Facilitator	cynthiataylor@iprimus.ca
Teffera, Hiwot	People to People Aid Organization	p2p@p2pcanada.org
Thompson, David	AIDS Community Care Montréal/Canadian Network for Vaccines and Immunotherapeutics	dthompson@aidslaw.ca
Wright, Elana	Canadian HIV/AIDS Legal Network	ewright@aidslaw.ca

LISTSERV EXCHANGES

8 December 2003 – First Question :

> *What has worked well to increase acceptance of people living with HIV/AIDS?*

From: "Terry Howard" <terryh@bcpwa.org>
Date: Thu Dec 11, 2003, 5:51 pm
Subject: Increasing acceptance

Hi All:

In my experience the most effective means of increasing acceptance has been through discussing the consequences of stigma and discrimination to whomever will stand still long enough to listen.

In my work in the prison system I'm told often of the physical consequences to inmates who disclose their HIV status, either voluntarily (self-disclosure) or by being "outed". Part of my educational program delivered in BC prisons has a "personal impact" statement where an HIV positive person describes to Corrections staff and guards what their daily life is like. This portion of the presentation has always received very positive comments like "I had no idea..." or "I'm certainly much more compassionate now than before the presentation".

Delivering educational services directly to inmate populations that are at high risk of infection usually begins with some heckling, but the mood quickly changes when the facts and figures are presented. The approaches are entirely different, but the message is the same.

Living as 48 year old HIV positive gay man, I have been on the receiving end of numerous "gay-bashing" incidents, usually containing the assumption that I must be HIV positive and I must be gay, followed by numerous suggestions of what should be done with me. Rather than live in fear of these assaults, I have found that "telling" my colleagues, friends, family, and work associates of my experience has lead to unforeseen allies and action taken on my behalf (and others, of course) to deal with this kind of ignorance as well. I believe that this kind of "rallying" by our peers is a great way to increase acceptance and help to raise the issue into the light.

Terry Howard, Prison Outreach Coordinator
BC Persons with AIDS Society

From: "Tracey" <tconway@vianet.ca>
Date: Tue Dec 16, 2003, 7:42 pm
Subject: things that work

Hi All:

There are a number of things which I feel have worked in reducing stigma and discrimination especially as it relates to HIV. One of the most important things I believe is education. Ignorance perpetuates false assumptions about HIV/AIDS and individuals infected/affected by this illness. By educating the public, health care professionals and individuals social services with accurate, relevant and up to date information we can begin to dispel some of the misperceptions as well as address relevant concerns of our communities.

Along with this I believe that having positive role models willing to be public and do media is essential to breaking down stigma and discrimination barriers. Many individuals living with HIV are discriminated in other areas of their life. Homosexual individuals often face discrimination related to their sexuality, IDUs for lifestyle choices, immigrants face many difficult in coming to a new country and being "different" and women are often systemically discriminated across the board be it for health care, jobs, equal pay for equal work and societal expectations. Having a positive role model willing to take a stance and relate personal experience helps to put a face to the illness and touch people on a more basic level.

Finally, I believe that support from peers and providing an opportunity to find support and acceptance within than HIV community can assist individuals in becoming more accepting of an HIV diagnosis, let them know they are not alone and look at similarities we share rather than differences. Once you can accept your status you can move forward, and while doing this we often end up empowering others.

Tracey Conway

From: "Penny Summers" <psummers@aidscalgary.org>
Date: Thu Jan 8, 2004, 10:56 am
Subject: RE: [stigma] Increasing acceptance of people living with and affected by HIV/AIDS

Stigma Group:

I have found that if I can engage people into a conversation and provide information and education about HIV/AIDS it is easier to go deeper into putting a face to the Virus. As part of my responsibilities I go out to Addictions Centres, Remand Centre, Provincial Jail, and First Nations Communities. My first thought is to get people comfortable to talk about Risky Behaviours and health issues. Once I have established that link and trust we can move forward and start addressing HIV/AIDS with the proper lingo. Once we have had a chance to open the floor to questions & answers and sharing thoughts I move into introducing my co-facilitator whom is

usually positive. It is a win/win situation as the group can meet someone who is living with and see that they are OK to be with in the same room. The next important issue here is giving power to the person living with to speak about the Virus in a non-threatening environment. By the end of the session everyone is hugging and a dialogue has begun between those who are living with and those who are not. I tend to get a lot of follow up calls after the sessions looking for support to go and get tested and those who have been tested looking for support after the results. It works well.

16 December 2003 – Second Question:

> ### What has worked well in your experience of mobilizing a community of people?

From : "Marie-Hélène" Luly <boobool18@yahoo.com>
Date : Fri Dec 19, 2003, 4 :03 pm
Subject: Effective strategies for community mobilization

As part of its training, education, and information activities, GAP-VIES has developed some effective community mobilization strategies. After numerous projects, the organization has gleaned the most effective strategies:

1) First of all, invitation by mail, and by email for some, which enables the maintenance of close contact with clients, to keep them up to date on services offered and organized activities, and to encourage them to participate;
2) Individual follow-up by phone, although time-consuming, is even more efficient, allowing community workers the opportunity to use their powers of persuasion to encourage clients to participate actively, while keeping track of the client's health;
3) Childcare services respond to clients' needs; this way they feel confident, and can commit to take part in the activities;
4) To increase community involvement in an activity, offering a meal to clients is in very good taste, and offers a family atmosphere and closer relationships;
5) Community media are very useful for community mobilization, since it reaches a large number and large variety of people;
6) Offering a monetary compensation, particularly for research activities, mobilizes people;
7) Keeping activities and services free helps and encourages more people to participate;
8) Reassuring a group of stigmatized people, by guaranteeing full respect and full confidentiality, nourishes regular community participation;
9) Using stimuli to mobilize, for example: target certain people as spokespeople or ambassadors of a noble cause like the fight against HIV-related stigma, in order to have a greater community impact.

These strategies can be used simultaneously as well as separately, according to context and participating group. The most important thing is to take each individual into consideration, and more particularly their cultural and ethnic identity.

Marie-Hélène Luly
GAP-VIES

From: "Tracey" <tconway@vianet.ca>
Date: Wed Jan 14, 2004, 2:26 pm
Subject: mobilizing a community

The only example within the HIV community that I have first hand knowledge is the Peer Mentor Program at Voices of Positive Women.

The process of developing the Peer Network began in 1996-1997 with a focus group set up to identify the needs of the women in Ontario and strategies to address the inequities. The group consisted of Voices members (meaning that those who participated were HIV positive women from the province of Ontario.) I believe that including individuals from the community you are trying to address is essential to the success of any program especially. The people who are actually "living it" can sometimes vocalize concerns in a way that is very different that professionals. Also providing a non-threatening environment can raise new issues and allow participants to speak more freely.

After the initial consultation process was complete a proposal was sent out to ACAP in order to secure the funds for a staff person to develop the program. A part of the Peer Network Coordinator's position was to asses why women were not accessing services at ASOs and how to decrease the barriers. Funding was secured in 1999 for a 4 year position. At the end of that year a peer network advisory committee. Again this committee consisted of women living with HIV many who had been doing the work of mentors without the formal title. Much work was done on expectations for the mentors, questionnaires were developed and a peer mentor training manual was developed. In April of 2002 the first peer mentor training took place in Toronto and 10 women from across Ontario were trained to be mentors within their local communities.

Over the years many faces have changed but there have remained those older mentors (I guess that would be me) and new voices to ensure that the history is not lost but also to grow and change with the diversity of our members. I honestly believe that one of the reasons for the success of the program is the inclusion of women from the community and the acceptance that we all have something to offer. However we did need to have buy in from the government as well as pharma companies who recognize the program as a unique and essential service.

Tracey

From: "Terry Howard" <terryh@bcpwa.org>
Date: Thu Jan 15, 2004, 2:24 pm
Subject: What do we need to mobilize?

What do we need to mobilize our fight against stigma and discrimination?

Working within and around the Corrections system in BC my first and biggest need
is for COOPERATION. It becomes increasingly frustrating when, excellent work, wonderful
materials, the appropriate people all become redundant due to the fact that often we can't get IN!!
The tiniest amount of cooperation on the part of an Institution or Correctional Centre to let us do
our work would do wonders to mobilize the infected community inside the walls. Inmates
become apathetic about self-help or working to change any existing stigma or discrimination
when faced with a steady dose of "Sorry,
we can't get in...." The reasons for this are numerous and warrant greater discussion (which I hope
to be able to do in person) but the day that Corrections staff, both Federal and Provincial come to
terms with the idea that cooperation with AIDS Service Organizations is not a security risk or a
power tool to be used against inmates, then we will affect enormous change to stigma and
discrimination.

Terry Howard
Prison Outreach Coordinator
BC Persons with AIDS Society

5 January 2004 – Third Question:

> **What do you need to mobilize your community to work to increase the acceptance of people with HIV/AIDS or people affected by HIV/AIDS?**

From: "Marie-Hélène" Luly <boobool18@yahoo.com>
Date: Wed Jan 14, 2004, 10:36 pm
Subject: Third question

In the Haitian and African communities, social taboos, myths, and prejudice represent enormous
obstacles to the prevention of HIV transmission and care of PLWHA. As well, they are the main
causes of discrimination and stigmatization of PLWHAs.

For effective community mobilization, in order to accept PLWHAs and people affected, several
conditions become necessary.

In effect, we must have:

- A greater involvement of PLWHA on committees, in events, and in decision-making. The lack of their involvement shows the fear of negative reactions from their social integration.
- A larger number of volunteers actively committed to the fight against AIDS, in order to reach a larger portion of the target population.
- The support of more local organizations and more respected organizations, which would enlarge our field of action, and would reach their clientele for information sessions, for example, or even for training workshops.
- Greater financial support from the Canadian government in order to be able to afford to promote activities to the media (which is very expensive).
- More staff and material to do surveys which would identify essential points for concentrating our work and to respond to the real needs of PLWHAs and their loved ones.

The myths, prejudices, and taboos are expressed in all aspects of daily life. To fight them, actions and activities must be done regularly. And strong community mobilization is absolutely essential in these circumstances. This will then respond to the diversity of the needs of different community and institutional contexts committed to the fight against AIDS.

Marie-Hélène LULY
GAP-VIES

From: "Haley Flaro AIDS NB/SIDA N.-B." <sidaids@nbnet.nb.ca>
Date: Wed Jan 7, 2004, 8:22 am
Subject: Third question

Good question.

- Campaigns (and the resources to develop and implement them) that educate the general public and policy makers about acceptance and tolerance (which from a counselling perspective can be just as harmful as ignorance) vs. recognizing differences, valuing differences and celebrating diversity.

- Better use of media. Media is a powerful tool that can enhance our work and perpetuate inequalities at the same time. Our Board is working on a media package for media in New Brunswick that highlights critical issues in NB, including stigma and discrimination, and includes a section on terminology and the power of words (e.g., PLWHIV/AIDS versus AIDS victim, gay/lesbian vs. homosexual).

- Partnerships and involvement with provincial Human Rights stakeholders and other groups and organizations dealing with the same issues. We are behind the times when it comes to campaigns that focus on recognizing differences and celebrating diversity. Some of the US

campaigns are phenomenal. Our vision has been to implement a "Day in my shoes" campaign but it's been a long time gaining resources, including partners....and we are trying to move beyond the traditional poster to newspaper, television campaigns. We have secured persons willing to be profiled (e.g., female injection drug user living with Hep C, gay youth, older person living with HIV).

- While there are dignitaries that have become powerful advocates for these issues, we have yet to identify visible Canadian role models (celebrities if you wish) that speak out on these issues from a Canadian perspective. It has been a challenge locally too.

From: "Kyle S" <mealtran@the519.org>
Date: Tue Jan 6, 2004, 4:20 pm
Subject: Third question

Well....off the top of my head, we need:

- access to more skills for our community members that would enable them to do the work - many of the women in my community who are interested in doing this work are not "skilled" officially in social services - we need to do some serious capacity building

- more organizations that are willing to do what it takes to be inclusive of trans issues, to take our community seriously and to listen to our feedback

- more trans people who are HIV positive who are willing to use services that have previously been less than accessible because places won't GET accessible unless they're pushed

- more materials geared towards trans people, or that is specifically inclusive of trans people's bodies and identities

- LESS focus on research telling us how "high risk" trans sex workers are and MORE research about how to support trans people who are HIV positive, how it will impact their hormone replacement therapy, etc

Kyle Scanlon
Trans Programmes Coordinator
519 Church Street Community Centre

From: "Tracey" <tconway@vianet.ca>
Date: Wed Jan 14, 2004, 2:10 pm
Subject: what I need

I honestly think that one of the biggest things I need right now is money. I am very fortunate that through my volunteer work in the field of HIV/AIDS I have me numerous contacts and resources at the local, provincial and national levels. My educational background has enabled me to put together workshops, PowerPoint presentations and write articles relevant to numerous communities within the movement. Unfortunately, I am on a disability pension and have very limited financial resources. It would be helpful to have costs such as printing and local transportation covered so that I could do more presentations to organizations in the community who could be potential community partners, to identify how I could help or refer them to other organizations that are more appropriate.

Tracey

WORKSHOP PROCESS IN DETAIL

Day 1:   Friday, 30 January 2003

Understanding Stigma – In Ourselves and Others

9:00   Welcome and warm-up.
Introduction exercise.

10:00 Purpose of and process for workshop.
What do we hope for? How will we get there?
Review schedule for today.
How will we know if we got there?

10:20 Break

10:40 Our experience of stigma
(a) Exploring when have you stigmatized an individual or group (personal
writing/reflection, then sharing in small group).
(b) Exploring when you have felt stigmatized by an individual or group (personal
writing/reflection, then sharing in small group).
(c) Exploring the positive intentions behind stigmatizing attitudes and behaviours
(small group brainstorming/theming).
(d) Exploring the common ground between stigmatizers and stigmatized (small
group brainstorming/theming).

12:30 Lunch

1:45   Large group sharing of morning's output, especially (c) and (d).
Large group reflection: surprises, new perceptions, troubling points.

3:00   Break

3:15   Large group sharing and reflection (continued).

4:00   Review of day/Check back.
Review schedule for tomorrow.

4:30   Adjourn.

Day 2:   Saturday, 31 January 2003
From Stigma to Acceptance: Understanding Change In Ourselves and Others

9:00   Welcome and Check-in.
(How are we doing, what movement on/reflections from yesterday)

9:15   Review of what we are doing today.

9:20   How do we change – or not?!
Personal reflection/small group sharing/theming:
Thinking back on your answers to (a) and (b) yesterday and your discussions, did you change from stigmatizing to accepting an individual or group? Did an individual or group change from stigmatizing to accepting you? How did this happen? If it did not happen, why do think that was the case? How, if at all, do your reflection on (c) and (d) fit in with the change/no change situations?

10:20   Break

10:40   Large group sharing when small groups are ready.

11:45   Turning toward action: tell others about the activities you are working on or planning.

12:15   Review of what we are going to do this afternoon, working in pairs according to the actions we are planning.

12:30   Lunch

2:00   Personal reflection on the values, desires, attitudes, and ways of communicating that either make change happen or prevent change from happening.

2:20   Drawing on the reflections about what makes change happen, work in your pairs to identify: (a) one goal for reducing stigma against, and increasing acceptance of, your population within your community; and (b) one obstacle to achieving this goal. Write up this goal and obstacle on a flip chart.

3:45   Post your flip chart for everyone to read, and read other people's flip charts.

4:00   Review of day/Check back.
Review of tomorrow's schedule.

4:30   Adjourn

Day 3:   **Sunday, I February 2003**

        Planning for Change In Ourselves and Others

9:00   Welcome and Check-in.
(How are we doing, what movement on/reflections from yesterday).

9:15   Review of what we are doing today.

9:20   Reflect in pairs on stories of community mobilization ("Fighting for a Supervised Injection Site in Vancouver" and "Building a GLBT Community Organization in Nova Scotia"): What were key elements in mobilizing communities in these stories? Does this suggest any opportunities in this situation?

10:20 Break

11:00 Personal reflection: Among the factors which we have identified that facilitate change towards greater acceptance (values, ways of communicating, desires, attitudes), which one, in your opinion, is the most important?

11:30 Working in pairs, plan your next step: First, brainstorm about possible next steps. Then, out of the next steps you brainstormed, pick one and think about how you might do it in light of the factor you identified (what you might do and how you might do it). Write this up on a flip chart.

12:00 Post the flip charts of your plan (goal, obstacle, next step) in main room.

12:30 Lunch

1:45   Thank-you.

2:00   Flip chart fair: Walk around and look at other people's plans.

2:30   Large group closing session.
Remaining activities in Phase I of the project.
Evaluation of the workshop.
Closing remarks.

3:00   Adjourn.

PARTICIPANTS' ACTIVITIES
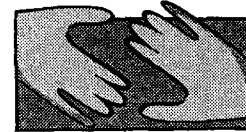
KYLE SCANLON

- To ensure that Toronto AIDS organizations take responsibility to provide relevant services addressing HIV, ensuring that trans lives (sex work, mental health, homelessness, and addictions) are recognized and encouraged.

PENNY SUMMERS

- To create a gathering place that is trans-friendly (i.e., Drop-In Centre).

JOSEPH BABCOCK

- To use stories (in the form of art, poetry, journaling, drawing, painting, etc.) to add a human element to HIV/AIDS

TERRY HOWARD

- To recruit and train inmate peer educators in each (8) institution in BC to provide HIV awareness and harm reduction tools for other inmates, both pre and post infection.

RENÉ LAVOIE

- To hold AIDS Service Organizations (ASOs) accountable to truly involving people living with HIV/AIDS in their organizations.

JIM OLIVER

- To increase involvement and feeling of ownership of gay men in prevention programs

HALEY FLARO

- To enhance the general public's understanding of the impact of stigma and discrimination using a website and personal stories.

TRACEY CONWAY

- To increase access to health care (specialized doctors, counsellors) with a solid knowledge base in her Northern Ontario city.

BARBARA GIBSON

- To enhance the general public's understanding of harm reduction.

DAVID THOMPSON & LIZ MANNING

- To increase access to services for refugees who are HIV positive.

ANN LIVINGSTON

- To have heroin prescription trials up and running with public support by May 1, 2004.

MARIE-HÉLÈNE LULY & HIWOT TEFFERA

- To reduce stigma through education.

HÉLÈNE SIMARD

- To educate the population about people living with HIV/AIDS

MARIELLE FORTIN

- To educate the general public about HIV and the realities of people living with HIV/AIDS.

For more information about an activity, please contact the participant by email (see Appendix A: Participants' List).