

AIDS CALGARY

**Evaluation of the Human Rights
Equality Project (Phase II)**

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Prepared for:

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Table of Contents

1. Executive Summary/Recommendations	3
2. Introduction	5
3. Project Summary Statement	5
4. Project Objectives & Projected Outcomes	6
5. Project Statistics & Summaries	7
6. Contribution to the UNGASS Declaration of Commitment on HIV/AIDS Objectives	18
7. Participant Feedback	19
8. AIDS Calgary Staff Feedback	21
9. Community Partners Feedback	25
10. Recommendations	28
11. Appendix - Interview Guides	29

1. Executive Summary/Recommendations

Based on the findings of the evaluation of the Equality Project, it is the opinion of CMS that AIDS Calgary quite successfully met the project objectives and projected outcomes, identified in their original proposal to the Alberta Human Rights Multiculturalism, Citizenship and Education Fund. Participants, community partners and staff all felt that the project provided significant benefits to people living with HIV/AIDS. Participants realized many direct benefits such as obtaining housing, resolving employment issues, and overall were empowered and uplifted to know they had rights in regards to their HIV status. A local lawyer that has many clients living with HIV/AIDS pointed out that the research from the project made a significant impact on his ability to represent his clients in court. He admitted that he simply would not (and had not in the past) taken the time to do the necessary research to defend his clients (as most are Legal Aid clients). Many partners, including The Canadian HIV/AIDS Legal Network, considered this project an excellent model of how to develop a human rights program and maintain a good working relationship with the local Human Rights Commission. The AIDS Calgary worker responsible for disseminating fact sheets at AIDS Calgary's offices noted that the human rights material was of more interest to clients than any of the other HIV materials.

Of course as excellent as everyone believed the project to be, the fact that the project is innovative and just getting off the ground, means that there is still much work to be done. The following recommendations represent findings based on input from participants, community partners, employees and project documentation.

1. The project should become an ongoing program, supporting one full time position at AIDS Calgary. To date, participants received the most benefit through consultations with the human rights worker (as opposed to reading fact sheets). The support staff at AIDS Calgary does not have the time to stay up to date and focused on human rights issues. Although having some awareness of the issues, staff do not have the depth of information someone dedicated to the position has. There is also a need for further research in order to fully develop the program, as well as stay up to date on precedent setting cases. Additionally the program will require someone dedicated to the dissemination of the information.
2. More dissemination of information and education should occur. Some participants although receiving one-on-one counseling from the human rights worker had not seen or read the fact sheets. At least two partners interviewed also had not seen the fact sheets. Fact sheets could be re-written to be more user friendly, however it is the opinion of CMS that the priority should be focused more on reaching more people than re-writing materials. More training/workshops should occur with all groups including AIDS Calgary staff. Building the capacity of service providers is also important. A detailed dissemination strategy should be developed and implemented that targets not only participants and partner organizations but the public as well. Informing employers, landlords and the general public as to the rights of people living with HIV/AIDS would go a long way to addressing systemic discrimination.

3. AIDS Calgary should package their Equality Project in a manner that allows other provinces in the country (and potentially other places in the world) to replicate the development of a human rights project.

4. Further research should be considered in the following areas;
 - Health & dental services
 - Housing
 - Employers
 - Justice system
 - Social workers
 - Injection drug users
 - Aboriginals
 - Women
 - Transgender

5. The program should consider developing a legal network, to provide information as to what people could do, beyond going to the human rights commission.

6. The development of further fact sheets should address literacy issues with the client base, should be more user friendly and ideally developed by professional graphic designers.

2. Introduction

CMS Management Consulting was commissioned by AIDS Calgary to conduct an independent evaluation of Phase II of the Human Rights Equality Project.

CMS relied on two major sources of information to conduct the evaluation. One was a binder of information developed by the human rights worker, which detailed all of the work that was completed on the project, from the initial needs assessment conducted in phase I, to all of the materials & workshops produced by the end of phase II. The second source of information came from conducting primary, qualitative, confidential interviews with 5-6 individuals from each of participant, staff and community partner groups. The interviews were conducted one-on-one, via telephone or face-face.

CMS was also asked to evaluate the degree to which the Human Rights Equality Project was meeting the UNGASS Declaration of Commitment on HIV/AIDS -objectives related to human rights.

Additionally CMS reviewed AIDS Calgary's organizational reports and proposals for funding.

Much of the feedback from respondents interviewed is left in an anecdotal format.

Following are the results of the evaluation.

3. Project Summary Statement

AIDS Calgary's Equality Project (Phase I & II) is a community-based initiative that focuses on identifying and addressing human rights issues facing people living with, at risk for and affected by HIV/AIDS in the Calgary region. Based on the results of the project's community-based research process, AIDS Calgary has developed a series of educational resources on human rights and HIV/AIDS. Additional information and one-on-one assistance is made available through AIDS Calgary's human rights work. Phase II of the project focused primarily on the dissemination of the information and resources created during Phase I of the project.

4. Project Objectives & Projected Outcomes

The Equality Project identified a series of objectives and outcomes. The outcomes were intended to provide guidance for the planning, evaluation and continuous improvement of the project. Specified outcomes include a focus on both short-term and long-term results.

Evidence related to measuring progress toward successful achievement of the identified outcomes will be documented throughout the report and is categorized according to participant feedback, employee feedback, community partner feedback, program statistics and organizational reports. Program objectives and projected outcomes are as follows:

Table 1

Objectives	Expected Outcomes
1. To implement a meaningful dissemination strategy that will reach the greatest number of individuals (target population) to educate them about HIV discrimination	AIDS Calgary’s Human Rights Project has a comprehensive strategy in place to create awareness for those receiving information and they are better equipped to deal with matters of discrimination as they relate to HIV/AIDS
2. To develop a pilot that will monitor the volume and effectiveness of materials distributed through ongoing contact with target population, training of project partners and AIDS Calgary staff/volunteers	Disseminated materials are monitored for their effectiveness; the target population is well connected to information available; project partners as well as AIDS Calgary staff/volunteers are familiar with the HIV related discrimination and its consequences for service users
3. To continue research of the target population as well as appropriate resources in order to keep information up to date	Human Rights Project has relevant information and resources available to administer the project
4. To establish and maintain partners within the community such as <i>pro bono</i> lawyers, and other relevant service providers	Project partners and AIDS Calgary staff/volunteers have access to materials developed in phase one of the project and are aware of and ready to respond to requests relating to individual and systemic HIV discrimination
5. To conduct an external evaluation of the Human Rights Project at AIDS Calgary upon completion of Phase Two	External evaluation is completed and AIDS Calgary/Alberta Human Rights and Citizenship Commission are equipped with the knowledge to proceed with subsequent phases of this project; sustainability can be determined.

5. Project Statistics & Summaries

The following section details all of AIDS Calgary's deliverables on Phase I and II of the Human Rights Equality Project, within the following categories;

- 1) Resources produced
- 2) Dissemination figures
- 3) Service user contact
- 4) Presentations to service users
- 5) Training for ACAA staff & volunteers
- 6) Partnership training via presentations
- 7) Partnership training one-on-one
- 8) Anecdotal evidence
- 9) Additional research
- 10) Committee work

1) Resources Produced Phase II:

- **Fact Sheet Series (Finalized):**
 - Stigma, Discrimination and HIV/AIDS
 - A Rights-Based Approach to HIV/AIDS
 - Human Rights and HIV/AIDS
 - Disclosure and HIV/AIDS
 - Employment and HIV/AIDS
 - Housing and HIV/AIDS
 - HIV/AIDS and Accessing Services
 - Filing a Human Rights Complaint
- **Complaints Form: A Tool for Service Providers and People Experiencing Discrimination** (includes Community Resources Section)
- **Press Release:** Human Rights and HIV/AIDS: International Human Rights Day also hits close to home, December 2003.
- **Articles:**
 - The Equality Project, *Ellipse Newsletter*, November 2003
 - It's About Equality, *Positive Post*, January 2004
 - AIDS Calgary Addresses Human Rights Violations of People Living with HIV/AIDS, *The Anti-Racist Voice*, Winter 2004
- **Workshops:** (Note: There is no single workshop manual. Although several of these workshops have the same name and similar content, each workshop was tailored to the specific audience. All workshop participants were given a print out of the workshop presentation, copies of the fact sheets, the complaints form, and other resources as relevant):
 - *A Human Rights Approach to HIV/AIDS: Learning from the Experience of AIDS Calgary*. Co-Presented by Jessica Leech (AIDS Calgary) and

Theo de Bruyn (Canadian HIV/AIDS Legal Network). 4th Canadian HIV/AIDS Skills Building Symposium.

- *Tools for Equality*. 5th Annual Alberta Harm Reduction Conference.
 - *Equality for IDUs: A Discussion*. 5th Annual Alberta Harm Reduction Conference.
 - *Human Rights and HIV/AIDS*. Presented to staff at AIDS Calgary.
 - *Human Rights Fact Sheets and Complaint Form*. Presented to staff at AIDS Calgary.
 - *Human Rights and HIV/AIDS*. Presented to an HIV peer support group.
 - *Human Rights and HIV/AIDS*. Presented to the Alberta Community Council on HIV/AIDS (ACCH) Member Organizations.
 - *Human Rights and HIV/AIDS*. Presented to the Alberta Human Rights Commission.
 - *Human Rights and HIV/AIDS*. Presented to the Youth ROAR (Reach Out Against Racism) Group.
 - *Human Rights and HIV/AIDS*. Presented to an HIV peer support group.
 - *The Equality Project: Translating Research into Human Rights Programming*. Presented by Eric Berndt at Translating Science into Health, Canadian Association of HIV Research Conference in Montreal, Quebec.
 - *Incorporating Human Rights into your Career*. Presented to youth at a career fair sponsored by the Youth ROAR group.
 - *HIV/AIDS: What you need to know*. Presented to Daycare/ After School Care Workers.
 - *Human Rights and HIV/AIDS*. Presented to Staff at AIDS Calgary.
 - *Human Rights and HIV/AIDS*. Presented to an HIV/AIDS peer support group
- **Tracking Tools**
 - Human Rights Tracking Form (to track human rights client contacts)
 - Human Rights Resource Tracking Form (to track resources distributed)
 - Meeting Notes Form (to keep a record of human rights client contacts to be placed in client's AIDS Calgary Support Services file in order to keep the Support Team up to date on a client's status)
 - **Draft Bill of Rights for People Living with HIV/AIDS**
 - Will be passed to the community to finalize and take ownership.
 - A draft developed with the HIV community, which has been transferred solely to the community for further development and completion.
 - **Legal Resource:** Includes summary of Calgary legal services for low-income people, detailed information on each service, and collected pamphlets.

2) Resource dissemination (including #, who received, method)

Dissemination Strategy: Although AIDS Calgary did not create a written dissemination strategy, the following gives an overview of how the resources were disseminated.

- **Methods:** direct service (one on one), workshops, resource tables, e-mail, website, staff meetings, staff mailboxes, pamphlet rack, fax, mail outs.

- **Target Audiences:** Service users, service providers, staff, practicum students, AIDS Calgary members, volunteers, general public, media contacts, misc. (includes employees, employers, landlords, etc.- as required during direct service or by other ACAA staff for workshops in community).
- **Tracking:** Materials distributed have been tracked using tracking forms.
- **Evaluation of Distribution:** No formal evaluation of resource distribution has been done to date. Workshops were evaluated at the end of each workshop.

DRAFT FACT SHEET DISSEMINATION

Resource Disseminated	# Disseminated	Venue	Audience	Method
Draft Fact Sheets	20 sets	Alberta Community Council on HIV/AIDS	Service providers/ Service users	Workshop and Resource Table
Draft Fact Sheets	13 sets	Alberta Human Rights Commission	Service providers/ funder	Workshop
Draft Fact Sheets	20 sets	AIDS Calgary	ACAA staff and practicum students	Staff meeting, mail boxes.
Total Sets	53			
Total Individual Fact Sheets (= # of sets x 8 sheets/set)	424			

FACT SHEET DISSEMINATION

Resource Disseminated	# Disseminated	Venue	Audience	Method
Fact Sheets	50 sets	Canadian Skills Building Symposium (National Conference)	Service providers/ service users/ international service providers	Workshop, and AIDS Calgary Resource Table
Fact Sheets (November)	20 Sets	AIDS Calgary	ACAA Staff, practicum students	Workshop and staff meeting
Fact Sheets	20 sets	Alberta Human Rights Day Celebration at University of Calgary	Service providers, Students, general public	Resource table
Fact Sheets	9 sets	Youth ROAR	General Public	Workshop

		Meeting	(Youth/ students, 1 service provider)	
Fact Sheets	6 sets	AIDS Calgary	ACAA staff, practicum students	Workshop
Fact Sheets	12 sets (approx.)	Alberta Community Council on HIV/AIDS	Service providers, service users	Resource Table
Fact Sheets	15 sets	HIV Support Group	Service users	Workshop
Fact sheets	70 sets (approx.)	Alberta Harm Reduction Conference (Provincial Conference)	Service providers, Service users	Workshop, Resource Table
Fact Sheets (February)	20 Sets	AIDS Calgary	ACAA Staff, practicum students	Staff meeting
Fact Sheets (May)	8 Sets	AIDS Calgary	ACAA Staff	Staff Workshop
Fact Sheets	10 sets	HIV Support Group	Service Users	Workshop
Fact Sheets	8 sets	Daycare	Daycare Workers	Workshop
Fact Sheets	5 Sets	HIV Support Group	Service Users	Workshop
Fact Sheets	50 Sets	Canadian Association of HIV Research Conference	Researchers	Workshop
Fact Sheets: #1 Stigma #2 Rights #3 Human #4 Disclosure #5 Employ #6 Housing #7 Services #8 Complaint	9 copies 8 copies 8 copies 27 copies 11 copies 8 copies 11 copies 8 copies	AIDS Calgary	Service Users, service providers	Pamphlet Rack in service user area (tracked March-June 2004)
Accessing Services Fact Sheet	12 Copies	Community Partner, Sexual orientation and suicide workshop	Service providers	Resource table
Stigma, Employment and Services Fact	20 copies of each (40 copies total)	Palliser Hotel	Employees of hotel	Workshop

Sheets				
Disclosure Fact Sheet	8 Copies	HIV Support Group	Service Users	Requested by group member
Assorted Fact Sheets	[Not Tracked]	Direct Service at AIDS Calgary	Service users	Direct Service
Total Fact Sheets Distributed Individually	150 copies			
Total Fact Sheets Distributed as Sets	303 sets			
Total Fact Sheets Distributed (= individual sheets + # of sets x 8 sheets/ set)	2574 copies			

COMPLAINTS FORM DISSEMINATION

Resource Disseminated	# Disseminated	Venue	Audience	Method
Complaints Form and Community Resources	70 copies	Canadian Skills Building Symposium	Service providers/ service users	Workshop, and AIDS Calgary Resource Table
Complaints Form and Community Resources	30 copies	Alberta Human Rights Day Celebration at University of Calgary	Service providers, Students, general public	Resource table
Complaints Form and Community Resources	9 copies	Youth ROAR Meeting	General public (Youth/ students, 1 service provider)	Workshop
Complaints Form and Community Resources	6 copies	AIDS Calgary	ACAA staff, practicum students	Workshop
Complaints Form and Community Resources	20 copies	AIDS Calgary	ACAA Staff, practicum students	Staff meeting
Complaints Form and Community Resources	10 copies	Alberta Community Council on HIV/AIDS	Service providers, service users	Resource Table
Complaints Form	15 copies	Heterosexual	Service users	Workshop

and Community Resources		Peer Support Group		
Complaints Form and Community Resources	60 copies	Alberta Harm Reduction Conference	Service providers, Service users	Workshop, Resource Table
Complaints Form and Community Resources (May)	8 Copies	AIDS Calgary	ACAA Staff	Staff Workshop
Complaints Form and Community Resources	10 Copies	HIV Support Group	Service Users	Workshop
Complaints Form and Community Resources	8 Copies	Daycare	Daycare Workers	Workshop
Complaints Form and Community Resources	5 Copies	HIV Support Group	Service Users	Workshop
Fact Sheets	50 Copies	Canadian Association of HIV Research Conference	Researchers	Workshop
Complaints Form and Community Resources	3 copies	AIDS Calgary	Service Users, service providers	Pamphlet Rack in service user area
Total Copies	304			

OTHER RESOURCE DISSEMINATION

Resource Disseminated	# Disseminated	Venue	Audience	Method
Press Release	na	Na	Media Contacts in print, TV and radio, General public	Fax, e-mail, and posted on website.
Article: The Equality Project	18000	Ellipse Newsletter	General public, AIDS Calgary members, volunteers, service providers	1000 Mailout to ACAA members, volunteers, service providers and booths at community events, 8000 Outlooks magazine 9000 FFWD magazine
Article: It's About Equality	Unknown	Positive Post	Service Users	e-mailed, mailed
Article: AIDS Calgary Addresses Human Rights Violations of People Living with HIV/AIDS	Unknown	The Anti-Racist Voice	General Public, Community Partners, Newcomer Community	E-mailed
Workshop Notes [power point]	236 copies	Assorted Venues	Assorted Audiences	Workshops, Resource Tables

WEBSITE DISSEMINATION

- Program Description: <http://www.aidsalgary.org/programs/communityDevelopment.shtml>
- Questionnaire Summary: <http://www.aidsalgary.org/programs/humanRightsQuestion.shtml>
- Fact Sheets, Complaints Form, Community Resources: <http://www.aidsalgary.org/news/briefingDocuments.shtml>
- News Release: <http://www.aidsalgary.org/news/newsReleases.shtml>

EMAIL DISSEMINATION

- PDF Versions of the Fact Sheets have been e-mailed to service users and service providers by request. [no formal tracking of this has been done].

3) Service User Contacts (direct/ targeted education) – both formal and informal

- **Formal Service User Contacts with Human Rights Worker January 1 2004-June 30 2004** (Tracking of these contacts began in January 2004):
 - **Number of Service Users: 19**
 - **Number of “First Contacts” on a particular issue** (i.e. some service users contacted Human Rights worker at several times, but each time were dealing with a new issue): **22**
 - **Total Number of Service User Contacts: 41**
 - **Number of Service Provider Contacts regarding Service User issues** (this includes service providers contacting the human rights worker to ask questions regarding a service user and the human rights worker contacting other service providers to do follow up regarding a service user): **34**
 - **Total Number of Direct Service Contacts: 75**
 - **Range of issues:** employment (10), confidentiality/disclosure/criminal law (3), access to services (4), insurance (2), general discrimination (2), justice system (1), housing (2), education system (1), interpersonal harassment (2).
 - **Range of Who Contacted AIDS Calgary:** Registered clients (8), Family member of PHA (2), Non-client PHA (1), Service Provider (3), employer (1), Other (4). [note: “other” includes members of the general public and referrals made by community partners].
- **Informal Contacts with Human Rights Worker:** Aids Calgary did not track informal contacts. However, the Human Rights Worker works onsite and speaks informally with service users on a daily basis and attends Friday lunches every second Friday. Also, during and after workshops, service users often ask questions and request information regarding human rights issues.
- **Formal Contacts with AIDS Calgary Support Services Team:** Between October 1, 2003 and April 15, 2004 Support Services had 694 clients access services and, of those, 19 clients accessed services related to Human Rights issues.

PRESENTATIONS: In total, 217 people attended workshops presented through the Equality Project. Based on how participants were counted, it is impossible to determine the exact number of service users versus service providers who attended. Due to the need for confidentiality, AIDS Calgary does not ask workshop participants to identify whether they are service users or service providers. However, as many people voluntarily disclose this information during the workshop, and as conferences recruit both of these groups for participation, AIDS Calgary does know that the conference workshop audiences are made up of people from these two groups.

4) Presentation to service users:

- *A Human Rights Approach to HIV/AIDS: Learning from the Experience of AIDS Calgary.* Co-Presented by Jessica Leech (AIDS Calgary) and Theo de Bruyn (Canadian HIV/AIDS Legal Network). 4th Canadian HIV/AIDS Skills Building Symposium. [25 participants, service users and service providers].
- *Tools for Equality.* 5th Annual Alberta Harm Reduction Conference. [25 participants, service users and service providers].
- *Equality for IDUs: A Discussion.* 5th Annual Alberta Harm Reduction Conference. [10 participants, service users and service providers].
- *Human Rights and HIV/AIDS.* Presented to the Alberta Community Council on HIV/AIDS (ACCH). [20 participants, service users and service providers].
- *Human Rights and HIV/AIDS.* Presented to an HIV Peer Support Group. [3 participants, service users].
- *Human Rights and HIV/AIDS.* Presented the HIV Peer Support Group. [5 participants, service users].
- *Human Rights and HIV/AIDS.* Presented to an HIV/AIDS peer support group [3 participants, service users].

5) Training for ACAA staff and volunteers:

- *Human Rights and HIV/AIDS.* Presented to staff at AIDS Calgary. [7 participants, staff and practicum students].
- *Human Rights Fact Sheets and Complaint Form.* Presented to staff at AIDS Calgary. [6 participants, staff and practicum students].
- *Update on Criminal Law and HIV/AIDS.* Presented to staff at AIDS Calgary during staff meeting. [15 participants, staff and practicum students]
- *Human Rights and HIV/AIDS.* Presented to Staff at AIDS Calgary. [8 participants, staff].
- *One on one:* The Human Rights Worker works one-on-one with staff, by request, to provide information and assistance regarding human rights issues. Also, the Human Rights Worker works in conjunction with the Support Team when service users request human rights related information and assistance.

6) **Partnership training via presentation (including # of workshops, # of participants in the workshops, community sectors):**

- *A Human Rights Approach to HIV/AIDS: Learning from the Experience of AIDS Calgary.* Co-Presented by Jessica Leech (AIDS Calgary) and Theo de Bruyn (Canadian HIV/AIDS Legal Network). 4th Canadian HIV/AIDS Skills Building Symposium. [25 participants, service users and service providers].
- *Tools for Equality.* 5th Annual Alberta Harm Reduction Conference. [25 participants, service users and service providers].
- *Equality for IDUs: A Discussion.* 5th Annual Alberta Harm Reduction Conference. [10 participants, service users and service providers].
- *Human Rights and HIV/AIDS.* Presented to the Alberta Community Council on HIV/AIDS (ACCH) Member Organizations. [20 participants, service users and service providers].
- *Human Rights and HIV/AIDS.* Presented to the Alberta Human Rights Commission. [13 participants, service providers].
- *Human Rights and HIV/AIDS.* Presented to the Youth ROAR (Reach Out Against Racism) Group. [9 participants, youth, students, 1 service provider].
- *The Equality Project: Translating Research into Human Rights Programming.* Presented by Eric Berndt at Translating Science into Health, Canadian Association of HIV Research Conference in Montreal, Quebec. [40 participants, HIV Researchers].
- *Incorporating Human Rights into your Career.* Presented to youth at a career fair sponsored by the Youth ROAR group. [10 participants, youth, students, service providers].
- *HIV/AIDS: What you need to know.* Presented to Daycare/ After School Care Workers. [18 participants, service providers].

A Note on Community Sectors: broadly speaking, workshop participants were from the HIV/AIDS sector, the Human Rights sector and the Youth sector.

7) **Partnership training one-on-one**

- To date, this training has been informal. When service providers contact the Human Rights Worker the Worker provides information and assistance as requested. This often includes the targeted dissemination of specific resources (i.e. a relevant fact sheet). This information has not typically been tracked.

8) **Anecdotal evidence**

- **Anecdotes:**
 - Paraphrased quote from an informal discussion between a service user and the Human Rights Worker:
“I have a good support network here [at AIDS Calgary]...No really, when I lost my job a few times my self esteem was really low. So it helped to know that I have rights even though I’m a low life AIDS victim. That’s not how I see myself, anymore.”

- Statement made by focus group participant:
“I probably have never really thought about the fact that I have human rights issues, that I have been discriminated against, and that I have just kind of choked it back and that’s kind of the way life is, and not really realized that no, I don’t have to take that, there is resources.”
- When asked: “Is there any other information about human rights that you’d like to have?”, one focus group participant stated that he wanted access to a human rights worker, as he put it, “We want you!”
- Paraphrased quote from a participant at the end of a workshop with an HIV Peer Support Group: “It was really empowering to hear that I have rights just because I am human.”
- **Complaints Filed:** The Equality Project has assisted three human rights complaints including one appeal of a human rights complaint.
 - One complaint was resolved during Conciliation. The complainant received a favorable settlement.
 - One complaint was not resolved during Conciliation. This complaint has moved forward to Investigation and is still in process.
 - One complaint is still in the appeals process.

Sectors identified for future education regarding systemic discrimination:ⁱ

- Health and Dental Services
- Housing
- Employers
- Justice System
- Social Workers

9) Additional Research Conducted:

- Focus Group: AISH Service User Consultation [15 participants, service users]
- Focus Group: A Bill of Rights for People Living with HIV/AIDS [7 participants, service users]

10) Committee Work:

- **AISH Public Policy Table** A Capacity Building initiative piloted by the United Way to build the capacity of community based organizations to work for policy change. This initiative gathered disability groups to focus on making recommendations to revise Assured Income for the Severely Handicapped policies.
- **Committee on Race Relations and Cross Cultural Understanding** [A committee of community workers in the diversity sector. This group is responsible for the celebrations of International Human Rights Day and the International Day for the Elimination of Racial Discrimination.

6. Contribution to the UNGASS Declaration of Commitment on HIV/AIDS Objectives

As per paragraph 58 in the UNGASS Declaration, Canada has made a commitment to:

"By 2003, enact, strengthen or enforce as appropriate legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and vulnerable groups; in particular to ensure their access to, inter alia education, inheritance, employment, health care, social and health services, prevention, support, treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social exclusion connected with the epidemic;"

While Canada has enacted human rights legislation, and interpreted it in a way that it includes people living with HIV/AIDS under the umbrella of physical disability, enforcement of this legislation remains inadequate. In most cases, it is up to the individual who experiences discrimination to 1) know their rights, 2) recognize that they have been discriminated against, 3) have knowledge of the complaints mechanisms available for redress, and 4) be willing/ able to lodge a complaint. These mechanisms for enforcement present many barriers for people living with HIV/AIDS and vulnerable populations. In order to access their basic rights, people must first have access to basic human rights information, rights-based education, and knowledgeable service providers to advocate and support self-advocacy. Given the nature of HIV/AIDS related stigma and the corresponding need for confidentiality, national and community based AIDS serving organizations have a key role to play in eliminating discrimination by bridging the enforcement gap through supporting such education and advocacy. The role of education and advocacy is not just the promotion of human rights, but also an integral part of ensuring the adequate enforcement of human rights legislation (particularly for vulnerable populations who might not otherwise have access to the information and resources they need).

AIDS Calgary's Equality Project has made significant contributions to meeting the UNGASS Declaration of Commitment on HIV/AIDS objectives, by helping people living with HIV/AIDS to;

- be aware of their rights,
- recognize that they have been discriminated against,
- gain knowledge of the complaints mechanisms, and
- be willing to lodge a complaint.

Ultimately the project has contributed to the UNGASS Declaration of Commitment on HIV/AIDS objectives by;

- eliminating discrimination to some extent,
- encouraging the full enjoyment of all human rights and fundamental freedoms of people living with HIV/AIDS and vulnerable groups,
- aiding in access to education, employment, health care, social and health services, prevention, support, treatment, information and legal protection, while respecting privacy and confidentiality, and
- developing strategies to combat stigma and social exclusion connected with the epidemic.

7. Participant Feedback

Overall Impressions

Participants overall impressions of the equality project were; excellent, extremely helpful and a very important project. All specifically mentioned the human rights worker as extremely helpful. Most also commented on how important it is to keep the program going. Although the work done to date has been excellent, most felt there was much more work to be done.

Key Learning

All of the participants interviewed said that the impact of the project on them was considerable, primarily because they realized they had rights they didn't know they had and could do something about the discrimination they were experiencing.

All participants mentioned "disclosure" as the key learning area. As well the project taught them how to research, what complaints were feasible to pursue, and how to file a complaint. Rights related to housing & employment were identified as key learning areas.

"My boss put out an email throughout the organization saying I was gay. I lost my job and became suicidal. As a result of learning I had rights and there was something I could do about it, I filed a complaint, received compensation and put my life back together."

Outcomes & Benefits

Following are a list of the outcomes/benefits participants identified resulting from the Equality Project;

- Received money that was owed to me from employer
- Gained self-respect back
- Received a letter of recommendation from employer that otherwise they were not willing to provide
- Didn't commit suicide, I'm still looking for a job though.
- Helped in getting housing. And through human rights commission ended up getting compensation. Empowered me to go after the people that were discriminating against me.
- Understanding my rights - much more informed
- Understanding my rights around disclosure
- Education around disclosure and employment issues.
- Helped in relationship with employer.

Improvements

When asked what improvements could be made to the project, participants commented on what an excellent job the human rights worker did and how there was nothing that could be improved upon. The suggestions that were made included;

- More people with the kind of compassion [the human rights worker] has.
- Get the word out more to people that the program exists.
- Educate and provide counseling to the families of people with HIV/AIDS, to reduce the discriminating done by our own families.
- Educate the public and employers and everyone that is doing the discriminating.
- Develop strategies for getting labor standards to do their job. Alberta & Nova Scotia do everything for the employer.

The areas of further research suggested included disclosure with dentists and privacy with employers. One participant stated that job application forms of large organizations still ask medical questions, and this is in violation of human rights.

Impressions of Materials & Training

Two of the five participants interviewed did not see the printed materials. Three did see them, thought they were well done and were particularly interested in the disclosure piece. One participant passed all of the fact sheets on to his peer support group.

8. AIDS Calgary Staff Feedback

Key Learning

AIDS Calgary staff were asked to identify the key things they learned as a result of the Equality Project. Following are their comments;

- Disclosure - the fact that people don't have to disclose. Human rights issues surrounding employment and housing.
- Really learning what the rights of people living with HIV/AIDS are.
- What the issues are around human rights and HIV, and how those rights transfer to other areas of the country. Discrimination is alive and well in this community. People are living with HIV and didn't know what their basic human rights were.
- That clients are not aware of their rights; particularly around disclosure, employment & housing.
- All of the information that [the human rights worker] has put into the handouts has been hugely informative and has been transferred within the organization to other support workers and their training materials.
- People living with HIV are not aware of their rights and not aware of the process of ensuring their rights are protected. And that the discrimination they face covers a gamete that I wasn't aware of.

Key Benefits

When staff were asked to identify the key benefits arising as a result of the Equality Project, they said;

- That the human rights research was completed.
- Information sheets.
- People living with HIV getting educated, educating their peers and having someone to talk to about human rights.
- Capacity building of people living with HIV/AIDS in relation to human rights.
- Has benefited people living with HIV in terms of helping them understand that they do have rights and helped them to proceed through the complaints process.
- Empowering people living with HIV and their family members.
- The human rights worker provided non-judgmental support to clients. Clients always reported meetings with the worker as a healing experience.
- The initial needs assessment in Phase I, made people living with HIV feel valued, and was described as a healing experience.
- Raised the awareness for clients as to where their rights were being violated, and how to address standing up for their rights. Also showed them that it's not as daunting as they first thought.

Limitations

AIDS Calgary staff were asked what they thought were the limitations to the project being more effective. Following are their responses;

- Support staff doesn't have the time to take on the human rights role of conducting research – more staff would have helped.
- Insufficient funding is available to keep the project going. Therefore the project is not receiving the attention it needs. There should be more funding to educate community partners.
- Volume of work has been very high.
- Human rights worker wasn't physically close enough to participant area.
- Human Rights worker could be part-time human rights and part-time support (because they usually connect with the person).
- Limited knowledge of human rights within service providers including AIDS Calgary. Staff are educated academically and don't have a rights-based approach. There is a lack of resources to teach staff this new approach. And as a result support staff would refer participants to the human rights worker, rather than try to help clients on their own.
- Not enough human rights workers.
- Frequent cycling out of that position (human rights worker). Would like a long-term person in that position.
- Without a fulltime human rights position, we will not stay up on the latest legislation and precedents, and will not be providing a service that is well informed.
- The process of filing a complaint is too daunting for those that are ill. Many people in focus groups choose not to go through the process.
- Resources have been limited
- Travel to attend conferences has been limited
- Materials - budget for fact sheets should be higher.
- Energy of service providers (staff and partners). Its a steep learning curve to learn the human rights material.
- Practicality of clients complaining to human rights, due to disclosure & energy. Because there are so many stigmas around HIV, many won't address human rights issues.

Improvements

Staff was asked what improvements or changes could be made to insure the continuous improvement of the Equality Project. The following represents their feedback;

- Staff – dedicated funding for at least one person, educating the community – being more proactive. Specifically educating organizations that have contact with people living with HIV.
- There needs to be recognition of systemic human rights issues, or educate people that are discriminating.
- Educate corporations and landlords.
- Website with information on human rights.
- Newsletter should always mention human rights issues.
- The government human rights process should be more user friendly.
- Funding for phase III, and move from a project to a program (something AIDS Calgary does on a regular basis).

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- Human Rights should be taught at medical and nursing facilities.
 - Have a legal clinic.
 - Create a kit to replicate the project. Begin to advocate for a funding base for it.
 - Expand this project to other provinces.
 - Project should be on going, become a program vs. a project. There should be someone working human rights full-time on an on-going basis.
 - More workshops to the client base, partner agencies and staff
 - Private space for the human rights worker.
 - More marketing.
 - More manpower.
 - Stronger partnerships with legal bodies – a legal clinic, to provide information as to what people living with HIV can do beyond going to the commission.
 - So far the project has been focused on targeting the discrimination. Whereas little has been done to target the discriminators. Improvements should be made in informing this group.
 - Do more work with people who were under-represented in original focus groups; aboriginals, women, and injection drug users. Develop fact sheets for each of these groups.
 - More dissemination of information. More workshops with service users and providers/ partners.
 - Building the capacity of other providers to do this work (staff and community partners). Getting the information incorporated in the human rights materials.
 - Have at least a full-time position for a human rights worker.
 - A budget to cover nutritious food so that we could invite service users to come out to workshops where they would also receive a meal. Obviously, this would be an incentive for them to participate, but it also just makes sense that you are able to offer people something when they show up for a three-hour workshop in the evening. I find food is central to community building and even more appropriate for folks who may not have enough resources to eat nutritiously a lot of the time.

Further Research & Education

Staff were asked if there were any other areas of research or further education that should be addressed by the Equality Project;

- Stay on top of precedent setting cases.
- Study to look at historical human rights complaints.
- Human rights person to have a presence with the HIV Legal Network.
- Partner with international human rights organizations.
- Systematic issues
- Injection drug users
- Endemic populations living here, i.e. Africa.
- Healthcare – accessing services and discrimination.
- Determine how to access people at risk from other cultures that have barriers to understanding and fighting for their rights i.e. female circumcision & first nations
- Health and Dental Services
- Housing
- Employers

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- Justice System
 - Social Workers
 - Develop information package on how to implement a human rights project.

Training and Materials

Staff were asked their impression of the training materials and asked to identify suggestions for improvements;

- Excellent – although there are often literacy issues with clients.
- Require more graphic design capability.
- The human rights series of publications seemed to be of most interest to clients, more popular than any other HIV/AIDS materials. The most popular of the human rights series is the housing one.
- Very good. Support staff may require more training. In the past training was only at an introductory level, therefore more is needed. Consumers and staff are hungry for more.
- The training material is very useful for care providers. Regarding improvements: they need to be user-friendlier for clients.

How the Program Could Better Meet Staffs' Requirements?

Many of the AIDS Calgary staff interviewed thought they could use more training on human rights. As they pointed out, the depth of specific information that was researched and developed takes much time to learn. Although many thought that a full time human rights worker on staff on a regular basis would help address this issue.

9. Community Partner Feedback

Impact of the Equality Project

Partners of AIDS Calgary were asked what impact, if any, the Equality Project had on their organization. Following are their responses;

- We were able to refer three patients that had potential human rights issues
- Has definitely made an impact. Referred many people to [the human rights worker]. It gave our organization more credibility and validity, in providing this service/information.
- Basic fact sheets were helpful. These educational tools were useful in court. They provided information that frankly I wouldn't have researched on my own. (Lawyer) There are huge discrimination problems by the courts themselves, so the fact sheets and past precedents were very useful.
- Made information available around advocacy issues.
- Identified the ways HIV solicits a lot of discrimination.
- The work from this project is very important, providing tools to address discrimination.
- Project gave legs to principles and rights.
- Helped us understand what's involved in establishing and implementing an human rights project.
- The resources produced were very useful to us.
- A very important service.

Key Learning

Partners were asked to identify any learning that occurred as a result of the Equality Project. Following are their responses;

- Learned much about human rights through a workshop.
- The procedure on how to file a human rights complaint.
- Provided information on human rights, which never had before.
- [The human rights worker] told him (lawyer) his client was being discriminated against in court and worked with the lawyer to ensure the client wasn't further discriminated against (in court).
- Passed along the fact sheets to many people.
- Learned how to go about communicating rights to public, employees, service users and providers.
- How much work is involved – very long process.
- That an organization like AIDS Calgary can have a good relationship with a human rights organization.

Key Benefits

Community partners were asked to identify the key benefits resulting from the project:

- The ability to refer clients to experts on the subject matter.
- Dissemination through fact sheets and trade shows, health fairs.
- Referrals – even people that weren't necessarily HIV+ had human rights claims, for which the fact sheets helped.
- Many organizations have incorporated this projects information into their own material.
- A neutral source is important when dealing with discrimination issues.
- We have a great model of a Human Rights program. Has not happened in Canada before. Traditionally, organizations have not had the resources to support HIV victims.
- This program is a premier example of an AIDS program incorporating human rights into their work.

Limitations

Partners were asked what they believed were the limitations, if any, to the project being more effective;

- The fact that it ended.
- None. Just hope that the funding comes through to continue the program.
- None
- No limitations in relation to the organization and staff (AIDS Calgary). An extraordinary amount of work went into the project.
- The equality project was run as a project - not an ongoing program. This undermined the sustainability of the project.

Improvements

Partners were asked what improvements or changes could be made to insure the continuous improvement of the Equality Project;

- Long-term sustainable program - having the program there and a credible resource to send people to is very important.
- Website – stand alone related to human rights. Giving the equality project its own website, would give it more impact. As it is, the human rights information gets lost in all of AIDS Calgary's stuff.
- Advertising this new initiative – poster campaign, website.
- Expanding to the general public so that everyone can be educated as to human rights. Particularly landlords and employers.
- Don't have any copies of the fact sheets, we ran out.
- Sustained funding over time.
- To use it as a pilot project, as a model of a human rights project that could be reproduced.
- Provide materials
- Individual that understands HIV human rights issues to refer people to.

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- Continuity of program.
 - Expand the model to target the general public, so they can be educated as to what their rights and responsibilities are in dealing with people living with HIV.
 - More presentations in the community

Training & Materials Provided

Partners were asked their impressions of the training and materials provided by the project;

- I've met with [the human rights worker] once, but haven't seen fact sheets.
- Haven't seen any.
- Great. Easy to read. A lot of text, someone with lower literacy could have trouble.
- Excellent
- Superb
- [The human rights worker] is an excellent educator. Workshop participants were very engaged.

Research and Further Education

Partners were asked if there were any other areas of research or further education that should be addressed by the Equality Project;

- Employment
- Group benefit plans - because HIV causes rates to go up, and HIV is on the rise – we should understand what the implications would be.
- Disclosure and dissemination around dentists.
- Justice system – police, crown attorneys & judges all stereotype and discriminate
- Development of a legal network to support people dealing with discrimination in the courts.
- Educate more service users & service providers.
- More specific information needed for gay and lesbian issues such as “transgender”.
- No. I think [the human rights worker] did a really good job of laying down a solid foundation.
- Project was fairly comprehensive

10. Recommendations

The following recommendations represent findings based on input from participants, community partners, employees and project documentation.

1. The project should become an ongoing program, supporting one full time position at AIDS Calgary. To date, participants received the most benefit through consultations with the human rights worker (as opposed to reading fact sheets). The support staff at AIDS Calgary does not have the time to stay up to date and focused on human rights issues. Although having some awareness of the issues, staff do not have the depth of information someone dedicated to the position has. There is also a need for further research in order to fully develop the program, as well as stay up to date on precedent setting cases. Additionally the program will require someone dedicated to the dissemination of the information.
2. More dissemination of information and education should occur. Some participants although receiving one-on-one counseling from the human rights worker had not seen or read the fact sheets. At least two partners interviewed also had not seen the fact sheets. Fact sheets could be re-written to be more user friendly, however it is the opinion of CMS that the priority should be focused more on reaching more people than re-writing materials. More training/workshops should occur with all groups including AIDS Calgary staff. Building the capacity of service providers is also important. A detailed dissemination strategy should be developed and implemented that targets not only participants and partner organizations but the public as well. Informing employers, landlords and the general public as to the rights of people living with HIV/AIDS would go a long way to addressing systemic discrimination.
3. AIDS Calgary should package their Equality Project in a manner that allows other provinces in the country (and potentially other places in the world) to replicate the development of a human rights project.
4. Further research should be considered in the following areas;
 - Health & dental services
 - Housing
 - Employers
 - Justice system
 - Social workers
 - Injection drug users
 - Aboriginals
 - Women
 - Transgender
5. The program should consider developing a legal network, to provide information as to what people could do, beyond going to the human rights commission.
6. The development of further fact sheets should address literacy issues with the client base, should be more user friendly and ideally developed by professional graphic designers.

11. Appendix – Interview Guides