# The Evaluation of Select Programs of the Canadian HIV/AIDS Legal Network

Final Report

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### **Draft Report**

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### Note:

All acronyms are spelled out in their first usage. For a full list of organizations and their acronyms, please see Appendix B, the Interview List.

### 1.0 Executive Summary

### Methodology

In the past five years, the Canadian HIV/AIDS Legal Network has worked, among other issues, on rapid HIV testing, prisons and HIV/AIDS, and injection drug use and HIV/AIDS. To evaluate its efforts in these areas, the Legal Network retained The Alder Group to conduct an outside assessment of the process used to carry out the programs, the activities and outputs that resulted, and their impact in each area. This report summarizes the evaluation process and presents the findings, determined through:

- a review of written materials provided by the Legal Network, including data on publications distributed to target audiences; lists of participants in workshops or other discussion groups, and evaluations completed by them; written and other formal responses to reports; and media coverage of the issues;
- a review of activities carried out by the Legal Network, including presentations, conferences, meetings and media activities;
- a total of 54 in-depth interviews conducted with individuals from 30 organizations, drawn from a list of 80 groups identified as being implicated by the Network's work. (See appendices for interview guide and list of organizations interviewed.)

The interviews provide a qualitative measure of the views of Legal Network stakeholders and others working in the subject areas. They are representative and should not be interpreted as the conclusive views of all stakeholders or others. Every attempt was made to ensure regional and sector representation; however, only one Quebec organization and few professional associations participated. Attempts to secure interviews with these groups were not as successful as with others.

It should be noted that some information with regard to the distribution of materials was unavailable, as appropriate data collection mechanisms were not in place throughout the period under review.

This evaluation provides conclusions and suggestions for future action in all three program areas. It concludes with suggestions for improvements made by those interviewed, and recommendations from The Alder Group for evaluating future programs.

### General Perceptions of Stakeholders

To determine people's views of the Legal Network in general, 33 people were interviewed from federal and provincial government departments, AIDS, health and community groups, and others, including academia. All participants were either very or somewhat familiar with the Legal Network's

work.

### <u>Publications</u>

When asked to rate the value of the Legal Network publications, where one is not at all effective and five is very effective, both the *Canadian HIV/AIDS Policy and Law Review*, and the final reports were rated as 4 or 5 by over 80% of participants. The information sheets (info sheets) were rated even more highly, with 96% rating them at 4 or 5. Generally participants felt that the publications are extremely thorough, comprehensive and well researched. They were cited as valuable resources and excellent reference materials for policy makers and advocacy groups. Suggested improvements included reducing the length and increasing accessibility, both in language and format. It was felt the info sheets addressed this to some extent.

### Collaboration and Consultation

Most of those interviewed have participated in a Legal Network event or collaborated with it on a project. The vast majority of those had a positive experience, with over three quarters of stakeholders saying that their experience with the Legal Network was collaborative and open, allowing a great deal of opportunity for input. Only one felt there was limited opportunity for input, based on a workshop experience that was lacking in regional representation. A large portion of participants identified the open, inclusive and broad representative nature of the Legal Network's collaboration as one of its successes. They felt there was a genuine effort to seek their opinions and were satisfied with the amount of time given to provide input.

### Overall Effectiveness of the Legal Network

Although some participants expressed concern over the difficulty of measuring the specific impact of the Legal Network, the majority agreed that it has had success at varying degrees and in collaboration with other groups' efforts. Unprompted, 55% of participants immediately responded that the Legal Network was successful; a further 26% of participants felt that the Network's efforts had contributed to their goals at varying degrees; and 19% of participants did not feel they were familiar enough with the work of the Legal Network to comment.

Of those participants who stated that the Legal Network was successful in meeting its goals, 40% felt the Network was "very" successful; 33% felt it was "quite" successful; and 27% felt it was "somewhat" successful. Over 80% of those interviewed felt the Legal Network was most successful in raising awareness, providing information on the issue and stimulating discussion and collaboration in this area. About 70% of participants felt the Network was successful at putting issues on the agenda of policy makers,

changing the practices of those working with people with HIV/AIDS, and increasing the skills and capacity of other organizations.

When asked to describe what the Legal Network did to achieve its success, a large portion of stakeholders agreed that the depth and high quality of its research, combined with the comprehensive and thorough analysis of the issues, were important factors. Participants also considered the Legal Network's broad and inclusive consultation process, its collaborative nature and commitment to the issues, as well as its credibility and integrity, to be key reasons for its success.

### **HIV/AIDS** in Prisons

In the five years since the Legal Network began its efforts to reduce the incidence and impact of HIV/AIDS in prisons, a great deal of activity has taken place by groups inside and outside the prison system.

### Review of Activities and Outputs

The Legal Network has undertaken a variety of activities with respect to HIV/AIDS in prisons. It published two editions of info sheets, printing 2000 copies of its first edition and distributing 1400 copies of its second edition; published over 100 articles on HIV/AIDS and prisons in the Canadian HIV/AIDS Policy and Law Review; produced a section on HIV testing of prisoners in HIV Testing and Confidentiality: Final Report (1998); produced and distributed two domestic and one international edition of HIV/AIDS IN PRISONS: FINAL REPORT; and made presentations at numerous conferences. In addition, the Legal Network maintains an up-to-date web site and has recently started an electronic mailing list of interested parties (list-serv).

The Legal Network made good use of the media to promote this issue. After the press conference announcing the release of its report on *HIV/AIDS* and *Prisons*, the issue was covered in at least 57 media reports. In all the articles reviewed, the key message of the Legal Network's news release was clearly communicated. The relatively high rate of interviews (over one third of the reports) is an indication that the Legal Network had good opportunities to convey its message.

### Review of Impacts

Based on the review of activities, outputs and impacts conducted, the Legal Network has achieved the goals it set out for this project.

Although no firm figure was targeted for the number of reports to be distributed, they did receive wide dissemination to key audiences in Canada and internationally. The evaluation found that the Legal Network's publications are used to prompt or guide policy development in this area,

guide or validate current programs and inform the staff of institutions.

To determine the impact of the Legal Network's efforts in the area of HIV/AIDS in prisons, a total of 21 people were interviewed, including representatives of Correctional Services Canada (CSC), Health Canada, provincial prison systems and health departments, inmate organizations and groups doing work in prisons, and AIDS organizations. According to those interviewed, the Network has met its goal to assist CSC and provincial prison systems in their efforts to:

- reduce HIV transmission in prisons and to staff and the public;
- increase their prevention efforts, by proposing concrete solutions;
- fulfil their legal and ethical obligations toward inmates, staff and the public.

Although there is some disagreement on the type and extent of changes made over the past five years, more than three quarters of the respondents cite the efforts of the Legal Network as a factor leading to changes in the way prisons deal with HIV/AIDS. Further, almost all respondents felt the Network had either "a great deal" or "some" influence in affecting changes. All respondents agreed that the Network was successful in raising awareness, stimulating discussion and collaboration, and providing information on the issue. Three-quarters felt the Network was successful in putting the issue on the agenda of policy makers. Half of all respondents felt the Network had successfully changed the practices of those working with prisoners.

Some of the Network's recommendations regarding HIV/AIDS in prisons have not yet been implemented, nor is it clear whether those that have are in place throughout the prison system. However, the Network continues to direct efforts toward this issue, as evidenced by the fact that more than three quarters of respondents had heard from it on this issue within the last two months. Many cite the Network's tenacity as a key feature to advancing this cause.

### Suggestions for future action

Suggestions were drawn from those interviewed on further action the Network could take. A number suggested it should simply continue with current efforts. A small minority felt the Network should not try to change practices or develop skills, feeling this was outside its mandate. Some concrete suggestions were made regarding actions that would move the issue forward, including efforts directed toward CSC, legal intervention, education and information, and communication.

### Rapid HIV Testing at Point of Care

At the time of this evaluation, rapid testing of HIV at the point of care was being used only in Quebec and in British Columbia, as a pilot test. In some cases, discussions were taking place and this report captures the issues being considered.

The Network identified the study of rapid HIV screening at the point of care as an emerging issue, and set out to provide prompt analysis of the pressing legal, ethical and human rights issues raised. It also aimed to obtain input from the membership and other stakeholders on the issues identified and to prepare and disseminate a short paper. The focus in its final report, Rapid HIV Screening at the Point of Care: Legal and Ethical Questions, is on recommendations for action. In all cases, the recommendations require action by outside groups.

This evaluation attempted to determine the role of the Legal Network in the use or discussion of rapid HIV tests. With so few provinces using the rapid tests, any proposed policies or practices regarding their use were also reviewed.

### **Review of Activities and Outputs**

The Legal Network has undertaken a number of activities in this area. In 2000, it produced and distributed over 800 copies of *Rapid HIV Screening at the Point of Care: Legal and Ethical Questions* and 400 copies of info sheets on the subject; it organized a national workshops with over 50 participants; wrote articles for *The Canadian HIV/AIDS Policy and Law Review*; and made several oral presentations on rapid HIV screening at Canadian and international conferences. The Network has strategically disseminated relevant materials and has been proactive in building and strengthening existing partnerships.

The Legal Network's announcement of its findings on the issues around rapid HIV testing at the point of care was extremely well timed, preceding by one day that of the pharmaceutical company licensed to sell the product. Media coverage, assessed through the clippings provided by the Legal Network, was very good, considering the amount of effort applied. Only a news release was issued, and it resulted in 29 stories. In all the articles reviewed, the key message of the Legal Network's news release was clearly conveyed. In fact, many repeated the first two paragraphs of the Network's news release in their opening sentences. The Legal Network was mentioned in all reports and its principal researchers quoted in the majority of articles.

### Review of Impacts

The impact of the Legal Network's efforts in rapid HIV testing at the point of care was assessed through interviews with 16 people. Among them were representatives from Health Canada, provincial health departments, AIDS organizations, health groups and professional associations.

Most people interviewed were aware of the Network's reports and resources, and slightly more than half had used the materials. Those who used the final report did so to help develop policy; stimulate discussion in the community; help prepare proposals, reports and deliver workshops; assist in advocacy efforts; and as a reference document and tool in teaching and clinical settings.

This evaluation determined that all stakeholders felt the Network responded to this issue quickly and that its analysis was effective. Most of those who provided input felt it was a positive experience, and stated that the Legal Network had succeeded in stimulating open, informed discussion and collaboration on the issue.

In assessing the impact of the Legal Network's efforts, respondents noted that the lack of adoption of the rapid tests made it difficult to determine what changes, if any, had been made. Respondents agreed, however, that the Legal Network had been successful in alerting people to potential concerns and sparking a more detailed analysis of the use of the test kits. The Network is credited with initiating discussions on this issue in some provinces and identifying the need for further investigation. Those who have implemented the tests on a limited basis feel the Network helped to ensure the tests are being used effectively. In British Columbia, where training is currently taking place, the materials used derive their content from publications of the Network.

Again, due to the infrequent use of the rapid test kits, the overall influence of the Legal Network in promoting changes in this area is somewhat unclear, with almost an equal number of respondents feeling they had none, some, considerable or a great deal of influence. It should be noted that this evaluation took place less than one year after the Legal Network released its report on rapid HIV testing at the point of care.

### Suggestions for future action

Participants' recommended actions for the Legal Network included the monitoring of provincial regulatory activities, and of the impact the tests are having on patients where the kits are in use, with communication of the findings. Others felt clarification was required on some clinical practice issues. Several people commented that the Network has done all it can in this area, and it is up to others to continue the effort.

### Injection Drug Use and HIV/AIDS

Since the Legal Network first got involved in injection drug use (IDU) and HIV/AIDS in 1996, it has focused a great deal of effort on this issue. The release of its 1999 report, *Injection Drug Use and HIV/AIDS: Legal and Ethical Issues*, created significant media attention. Recently, a Federal/Provincial/Territorial (F/P/T) report on the issue was released and a response to the Legal Network's paper is expected shortly from the federal Minister of Health. This evaluation reviews actions taken by the Network and views of the impacts that have resulted.

The objectives for this program were to bring together key participants knowledgeable in this issue and to identify the legal and ethical issues related to providing care, treatment and support to drug users with HIV/AIDS, and to reducing the harms of drug use. Priority issues were to be analysed in more detail, and a report written that summarizes the issues and potential solutions. The final report does this, and makes recommendations for action regarding the legal status of drugs; drug use and the provision of health and social services; treatment, including prescription of opiates and controlled substances; research into drug users and HIV/AIDS; information and training about the use and effects of illegal drugs; and needle exchange and methadone maintenance treatment.

In addition to assessing success in achieving the program goals, the evaluation attempts to determine whether action has been taken, or is under discussion, regarding these recommendations.

### Review of Activities and Outputs

The Legal Network has undertaken a variety of activities with respect to IDU and HIV/AIDS. In 1999 and 2000, it published and distributed over 2200 copies of *Injection Drug Use: Legal and Ethical Issues*; produced and distributed over 1700 copies of a series of info sheets on IDU and HIV/AIDS in 2000; written several articles for newspapers, journals and the *Canadian HIV/AIDS Policy and Law Review*; made presentations at national and international events; and organized several workshops. In addition, the Network received 70 letters from various organizations as a result of an invitation to respond to the final report.

The Legal Network's news conference announcing the release of its report, Injection Drug Use and HIV/AIDS: Legal and Ethical Issues, received excellent media attention, with at least 153 reports. Analysis of the coverage shows in-depth and widespread reporting on the Legal Network's report, and the issue of IDU and HIV/AIDS. In all the articles reviewed, the key messages of the Legal Network were clearly conveyed. Some articles took a

broader view of the issue, or focused on the local implications, so the Legal Network was not mentioned; however, the local angle increased pick-up of this national story. From the clippings reviewed, it is clear the Legal Network achieved high quality, extensive coverage of this issue.

### Review of Impacts

The F/P/T report on IDU and the pending federal Health Minister's response to the Legal Network's report are two significant formal responses to the issue of IDU. The recommendations made by the Network are addressed in the F/P/T Committee report.

In addition, 17 people were interviewed to determine their views on the impact of the Network's work. Among those interviewed were representatives from Health Canada, provincial health departments, AIDS organizations, health groups and others. Everyone interviewed was aware of the efforts of the Legal Network in relation to IDU, and had read at least some of its documents. They used them as a resource to inform themselves and others, including health professionals; guide policy and programming; facilitate discussion in the community; and in legal cases.

Over half the respondents provided input to the issue, and slightly more than one-third attended a workshop. All of them indicated that they were "satisfied" or "somewhat satisfied" with the process. Some noted that the process could be improved by addressing the impact of IDU in all regions of Canada, rather than just major centres, and by being more specific when asking for input. All respondents agreed, however, that the Network had succeeded in encouraging open, informed debate on the issue.

The two key areas where respondents suggested the Legal Network has had the greatest impact were in increasing awareness of the health issues around IDU and in focusing attention on the need for a policy response. Few felt the Network has been able to change policies or procedures, to date.

Respondents agreed that a change in approach is noticeable, particularly increased discussion and acceptance of a harm reduction approach. Although those interviewed felt progress is being made, there were mixed views on whether concrete changes have yet been implemented in the community.

Those interviewed made a number of excellent suggestions for future action, including the need to raise public awareness of the issue, perhaps through an advocacy campaign or a high-profile legal case. They also felt there was a greater need to communicate to members on the status of efforts. It was felt greater success could be achieved by focusing efforts on key recommendations, specific to particular regulating bodies or regions. In addition, respondents saw the need for more research.

### **Suggestions for Future Action**

During the interviews, respondents were asked for suggestions on improvements to materials and consultations, and suggestions for future action the Legal Network could take. Specific recommendations are made in each section; overarching ones are presented in Section 7.0. The suggestions presented include improvements to the process used by the Legal Network, in consultation, communication and representation. Further suggestions are made regarding ways that activities, such as workshops, and outputs, including reports, can be improved. Finally, ways of improving the impact of the work of the Legal Network are presented, through more specific recommendations and greater collaboration with members.

The Alder Group concludes its report with recommendations on how the Legal Network can more easily evaluate its programs on an ongoing basis. The recommendations are focused on two areas: (1) setting more specific goals and then following up on them through its publications and workshops, and with close collaboration with its members; and (2) by effectively tracking ongoing activities against specific goals.

The Legal Network has clearly established itself as an important voice in the issue of HIV/AIDS. Its work has been shown, through this evaluation, to be extremely well respected and effective. Closer tracking of outputs and activities, and evaluation of impacts will assist the Network in fine tuning its efforts for even further excellence in its work.

### 2.0 Introduction

The Alder Group was retained to evaluate the efforts of the Canadian HIV/AIDS Legal Network in three areas: prisons and HIV/AIDS, rapid HIV testing and injection drug use and HIV/AIDS. This report summarizes the process and presents the findings of the evaluation. It provides conclusions and suggestions for future action in all three program areas. It concludes with suggestions for improvements made by those interviewed, and recommendations from The Alder Group for evaluating future programs, for the Network's consideration.

In evaluating the programs, the following were reviewed:

- 1. the process used throughout the program,
- 2. the activities carried out,
- 3. the outputs which resulted,
- 4. the impact of the programs.

### 2.1 Methodology

The evaluation was carried out according to an agreed-upon framework (see Figure 1). Its main thrust was to determine the impact of the programs, through an assessment of the Network's success in achieving stated goals. The following steps were carried out in completing the evaluation:

- 1. A review of written materials, including:
  - documents distributed regarding each issue,
  - recipients of materials (AIDS groups, Parliamentarians, media, government policy makers, etc.),
  - participants in workshops or other discussion groups,
  - written and other formal responses to reports,
  - media coverage of issues.

It should be noted that some information with regard to the distribution of materials was unavailable, as appropriate data collection mechanisms were not in place throughout the period under review, both at the Legal Network and at the AIDS Clearinghouse, which also distributed materials.

- 2. A review of activities carried out by the Legal Network, including presentations, conferences, meetings and media activities.
- 3. Interviews were conducted:

Representation: 54 in-depth interviews were conducted with 33 people from 30 organizations identified as being implicated by the Network's work. Each interview conducted about a specific program was counted as "one"; so in cases where people were familiar with two or all three of the program areas, interviews on each area were conducted and counted separately. In cases

where two or three people from the same organization participated in the interview, it was counted as only one interview.

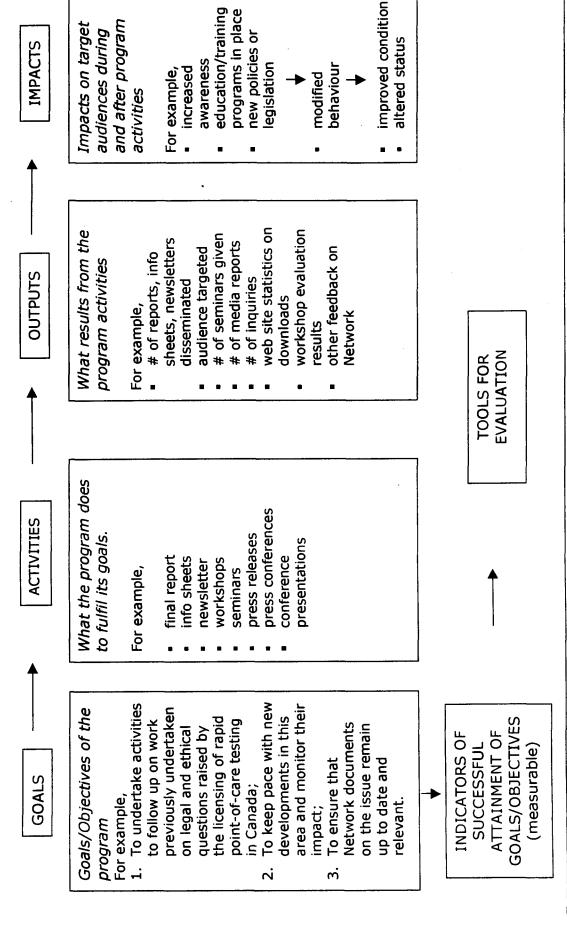
The organizations to be interviewed were drawn from a master list of 80 non-governmental organizations, government departments, associations and individuals familiar with the work of the Legal Network. The list was begun with input from the Legal Network and augmented by The Alder Group with names of respondents to reports, attendees at workshops and people suggested by a contact in a government department or organization.

A fax or e-mail notification was sent to the groups by the Legal Network to make them aware of the evaluation. The Alder Group followed up with e-mail and phone calls to schedule interviews. One e-mail and up to three follow-up phone calls were made before discarding a candidate. Every attempt was made to ensure regional representation and a representative sample of federal and provincial government departments, AIDS groups, community organizations and professional groups for each program area. This was not achieved in all cases. Only one Quebec organization and few professional associations participated. The master list did have good representation from these groups; however, attempts to secure interviews were not successful.

<u>Process:</u> The interviews were structured such that interviewees were invited to give their views on the question posed, then prompted with elements of the issue, to elicit further comments. The interview guides are attached (Appendix A).

The interviews provide a qualitative measure of the views of Legal Network stakeholders and others working in the subject areas. They are representative and should not be interpreted as the conclusive views of all stakeholders or others. In addition, the impacts presented are based on their views alone, and not on empirical evidence of HIV/AIDS incidence, prevention and other hard measures that would indicate success in the fight against the disease.

# The Evaluation Framework 2.2



# PROCESS MEASURES (as an ongoing process)

- How decisions were made to take specific actions/activities How goals were set
   How decisions were

Involvement of others
 How activities were carried out

### 3.0 General Perceptions of Stakeholders

To determine people's views of the Legal Network in general, 33 people were interviewed. Among them were:

- 6 from federal government departments,
- 8 from provincial government departments,
- 7 from community, health or inmate organizations,
- 7 from AIDS organizations,
- 5 from other groups (professional associations, academia, human rights groups, etc.)

### 3.1 Information and Publications

When stakeholders were asked about their familiarity with the work of the Legal Network, approximately half of the participants reported that they were very familiar (17 of 33) with the Legal Network's work and the remainder was somewhat familiar (14 of 33) with its work.

A large portion of the stakeholders interviewed receive information from the Legal Network regularly (12) or periodically (17).

The Legal Network web site has been used by over half of the participants (19) interviewed. The amount of usage varies evenly between regular visits, periodic usage and those who view the site infrequently. There was a consensus that the web site is extremely well organized and an excellent resource. Participants use the web site for such purposes as searching for documents and information (4), referring people (3), downloading documents (3), reference materials (3), viewing new information (when prompted by the Legal Network) (2), identifying emerging issues (2), and links (1).

The majority of participants in the evaluation were familiar with all Legal Network publications.

When asked to rate the value of Legal Network publications in terms of effectiveness in their work on a scale from one to five (where one is not at all effective and five is very effective), participants selected the following:

Canadian HIV/AIDS Policy and Law Review

1 2 3 (15%) 4 (42%) 5 (42%)

Final Reports
1 2 3 (18%) 4 (21%) 5 (61%)

Info Sheets
1 2 3 (4%) 4 (27%) 5 (69%)

Participants were asked to specify one thing that stands out regarding Legal Network publications. Generally, participants felt that the publications are extremely thorough, comprehensive and well researched. The publications are valuable resources and excellent reference materials for policy makers and advocacy groups. Overall, stakeholders felt that the publications were useful tools for both education and advocacy. They are provided in a well-organized, clear and easy-to-read format. Several participants mentioned that they felt that the publications delve into areas where little thinking has been done before. In this sense, they felt that the publications were logical and very thoughtful.

Comments from those interviewed include:

"The Legal Network documents are the gold standard in terms of bringing together all research."

"Everything they produce is top-flight, excellent; (there is) no better work done anywhere in Canada."

"Their thoroughness, thoughtfulness and awareness of priority issues are great. They provide 'reference books' as a starting point for a number of groups to carry out their work. Often their recommendations will impact lots of groups – who start their efforts with Legal Network materials."

"Their info sheets are strategic, content-focused and have a long shelf-life. They address issues at right level, and engage people. They make working on the issue easier, by bringing a short learning curve into it, (which) helps build our capacity very quickly."

## 3.1.1 Suggestions for improvements to Legal Network publications

Generally, participants thought Legal Network publications were well done. Several stakeholders felt that the final reports and the *Canadian HIV/AIDS Policy and Law Review* were too long and were written at too high a level for the general public and people who do not have a legal background. As one person pointed out, "(It is) not practical for busy people to receive and review that much information. The sheer volume dilutes the great content."

Although participants felt that the info sheets addressed these issues to some extent, they believed that there was still a need for alternative formats to increase accessibility and effectiveness for a variety of groups. For example, articles written for community press, summary pieces that prioritize the issues in a succinct manner and audio report tapes were requested.

Many participants indicated that there was a need for broader dissemination to the public and a higher profile with the media to discuss findings.

Finally, some participants indicated that the reports are not always as well rounded as they could be. One participant suggested that the legal aspect of Legal Network reports is extremely strong but the ethical aspects are weaker due to the lack of experts available in Canada who focus on this area. A couple of participants felt the reports do not always address all the influences affecting the specific topic. They suggested, for example, that regional and environmental aspects be addressed, as well as perspectives from all populations affected by HIV/AIDS.

### 3.2 Collaboration and Consultation

The majority of those interviewed (25 of 33) have participated in a Legal Network event or collaborated with it on a project. Although collaboration varies, the majority of participants interviewed attended at least one workshop hosted by the Legal Network, provided input on draft reports or responded to the final reports produced.

The vast majority of participants had a positive experience working with the Legal Network or participating in one of its events.

- Over three quarters of stakeholders participating in this evaluation thought that their experience with the Legal Network was collaborative and open, allowing a great deal of opportunity for input.
- Three participants noted that the Legal Network collaborative process was somewhat collaborative and open, allowing some opportunity for input.
- One participant thought that there was limited opportunity for input based on a workshop experience that was lacking in regional representation.

### 3.2.1 Best aspects of Legal Network collaboration

A large portion of participants identified the open, inclusive and broad representative nature of the Legal Network's collaboration as one of its successes. Many participants felt that the Legal Network is often able to gather a lot of good people together to discuss issues. Some participants were also impressed with the Legal Network's willingness to incorporate their comments into the Legal Network's work. There is an overall feeling that its collaboration process is really about getting meaningful input from stakeholders and not just a rubber stamp. Participants in general are satisfied with the amount of time given to provide input and find that the collaboration process is a learning experience for them as well.

"One of the Legal Network's strengths is their consultative process. I learn as I contribute."

### 3.2.2 Suggestions for improvement in the collaborative process

Participants expressed an interest in improving the way in which stakeholders are asked for responses to draft reports. Because the reports are so lengthy and detailed, some participants thought it would be useful for the Legal Network to articulate more clearly areas where input is required and identify that to members. A preamble that describes who has been asked for input and why would be useful.

Participants also expressed an interest in receiving more feedback regarding recommendations or suggestions they made to the Network. For example, how helpful is a local perspective on the issue?

Another area in which participants felt there was room for improvement was in the follow-up activities of the Network. They indicated a desire to be kept more informed of ongoing work in specific program areas. For example, what have the recommendations produced? Where are we a year later? What was the response to the report?

Other comments from participants:

- Develop an individual research and opinion writing function (e.g. the Network could provide assessments of particular situations for members, either as fee-for-service, or as a part of its research mandate). The listserv fulfils this function to some extent by providing access to many experts.
- Be more physically accessible (provide more seminars and workshops).
- Provide more opportunities for input; "Analysis sometimes seems to be done in isolation, there is not much connection with front-line workers."

### 3.3 Effectiveness of the Legal Network

Some participants expressed concern that it is difficult to measure the impact of the work of the Legal Network. The majority of stakeholders agreed that it has had success to varying degrees and in collaboration with other groups' efforts.

When asked, unprompted, if the Legal Network was successful in meeting its goals, participants responded as follows:

- 55% of participants immediately responded by stating that the Legal Network was successful,
- 26% of participants felt that the Network's efforts had contributed to their goals to varying degrees,
- 19% of participants were not familiar enough with the work of the Legal Network to comment,
- None of those interviewed stated that the Legal Network had not been successful.

Of those participants who stated that the Legal Network was successful in meeting its goals:

- 40% felt the Network was very successful,

- 33% felt the Network was quite successful,
- 27% felt the Network was somewhat successful.

When participants were prompted and specifically asked if the Legal Network was successful in meeting certain objectives (listed below), they felt the Legal Network was successful, to varying degrees, in:

- raising awareness of the legal and policy issues around HIV/AIDS (81%),
- providing information on the issue (84%),
- stimulating discussion and collaboration in this area (81%),
- putting the issue on the agenda of policy makers (68%),
- changing the practices of those working with people with HIV/AIDS (68%),
- increasing skills and capacity of organizations to undertake advocacy efforts to address these issues (71%).

When asked to describe what the Legal Network did to achieve its success, a large portion of stakeholders agreed that the depth and high quality of its research, combined with the comprehensive and thorough analysis of the issues, were important factors. Participants also considered the Legal Network's broad and inclusive consultation process, its collaborative nature and commitment to the issues, as well as its credibility and integrity, to be key reasons for its success. Several participants also acknowledged that an analysis rooted in advocacy and the influence of community and grass-roots values contributes to the overall effectiveness of the Network's work.

Participants pointed to several examples of success for the Legal Network, including:

- the Network's involvement in the area of injection drug use and HIV/
   AIDS, and Canada's Drug Strategy (excellent media coverage);
- the growth of its the Canadian HIV/AIDS Policy and Law Review, to the Canadian HIV/AIDS Policy and Law Review;
- the Network's contribution to the IDU federal/provincial/territorial (F/P/T) report;
- the popularity of its web site;
- the quick response garnered to the issues of immigration, rapid testing and prisons;
- the Legal Network's final reports, which exemplify its success by guiding Canadian policy and by being referred to by other groups, governments and nations.

Comments offered included the following:

"No other group has managed to sustain work on the social front as they have."

"Since the presence of the Legal Network on the Canadian and global scenes significant changes have occurred. As a result of their work we now have enhanced or new rights for those with HIV/AIDS, better access to treatment,

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more attention to social, legal, ethical, human rights issues. Their presence has totally impacted the way we look at HIV/AIDS in Canada."

"Their credibility, at the national level, is incredibly high. Without their ongoing efforts, many advancements would not have happened. No other organization takes on the task in the way they do. Their role is key."

"They provide an incredible amount of information and valuable tools to organizations that allow them to advocate for these issues. They use the media extremely effectively and they are able to respond to issues extremely rapidly."

"Their integrity (is the one thing that stands out). Since day one, they have produced excellence and as a result have earned the credibility and respect of everyone in the movement, our government and at the international scene. Their incredible attention to thoroughness and precision, totally influenced by community values and the grass-roots influence, make them the most effective group ever to emerge in Canada."

### 4.0 HIV/AIDS in Prisons

The Legal Network began its efforts to reduce the incidence and impact of HIV/AIDS in prisons over five years ago. A great deal of activity has taken place by many groups inside and outside the prison system, including reports from the Legal Network and the Expert Committee on AIDS in Prisons (ECAP), convened by Health Canada. This evaluation looked at that time period to review actions taken by the Network and views of the impacts that have resulted.

### 4.1 Goals of the Program

The stated goals of the final report on HIV/AIDS in Prisons are:

- 1. To assist Correctional Services Canada (CSC) and provincial prison systems in their efforts to:
  - reduce HIV transmission in prisons and to staff and the public;
  - increase their prevention efforts, by proposing concrete solutions;
  - fulfil their legal and ethical obligations toward inmates, staff and the public.
- 2. To widely distribute HIV/AIDS in Prisons: Final Report (September 1996);
- 3. To carry out further activities to ensure that the report's recommendations are implemented.

The second goal has been completed, and is summarized in 4.2. Fulfilling goals 1 and 3 relies heavily upon the actions of others. In the interviews, questions were posed to determine which of the recommendations made by the Network had been implemented or were under consideration. A series of questions then probed factors to which changes could be attributed, including but not limited to the work of the Network.

### 4.2 Review of Activities

The Legal Network has undertaken a number of activities with respect to HIV/AIDS and prisons. In summary, the Network has:

- published a series of 13 info sheets;
- revised and published a second edition of the series of 13 info sheets;
- published over 100 articles on HIV/AIDS and prisons in the Canadian HIV/AIDS Policy and Law Review;
- produced a section on HIV testing of prisoners in HIV Testing and Confidentiality: Final Report (1998);
- produced two domestic and one international edition of HIV/AIDS in Prisons: Final Report (September 1996);
- made presentations at numerous conferences, including the 1998 World HIV/AIDS Conference, Geneva;
- continued research in this area to remain up to date on important issues;
- conducted several meetings with staff of CSC.

The Legal Network maintains an up-to-date web site, containing all the information mentioned above, and has recently started a list-serv dealing with the legal, ethical and human rights issues related to HIV/AIDS. The Network has also been proactive in building and strengthening existing partnerships in the area of HIV/AIDS and prisons.

### 4.3 Review of Outputs

### 4.3.1 Documents produced and distributed

The Legal Network's activities in the area of HIV/AIDS and prisons have resulted in distribution of a minimum of the following, (according to available records):

- Over 1200 copies of the final report were distributed by the AIDS Clearinghouse.
- Over 1400 copies of the information sheets on HIV/AIDS and prisons were distributed over the past year.
- More than 2500 people downloaded materials on HIV/AIDS in prisons from the web site between November and December 2000 and February and March 2001 (periods where this was recorded).

The Network received 33 letters as a result of an invitation to respond to the final report. Of these responses,

- Five letters acknowledged the receipt of the final report and thanked the Legal Network for its ongoing work.
- Five responses indicated that the report and its recommendations would be placed on the agenda for the next meeting of the organization and/or government department.
- The remainder of the responses (22) indicated that the report would be a useful contribution to a variety of processes and respondents would disseminate the report appropriately within their organization and/or province.

In addition, a number of articles have appeared in peer-reviewed journals and books.

### 4.3.2 Analysis of media efforts

The Legal Network makes good use of the media to promote its issues. This brief analysis will review its success in getting media coverage on its final report on *HIV/AIDS* and *Prisons*. This analysis is based upon print clippings and a report of electronic media provided by the Network for the period immediately following a news conference held on this issue on September 17, 1996. Its limited nature can provide only a snapshot of media success.

In the days and weeks following the news conference, the issue was covered in at least 57 media reports. Of these reports:

- 22 were radio
- 10 television
- 24 print
- 1 Internet

Among these reports, 11 were national and 43 were local. Most stories (31) were simple reports; 20 featured interviews; 3 were letters to the editor (2 written by Ralf Jurgens), 2 were journal articles; and 1 television story was a "special report." The relatively high rate of interviews (over one third of the reports) is a good indication that the messages of the Legal Network were well communicated.

Most reports (26) were issued on the day after the news conference (September 18), with print and local radio providing most of the coverage. On the day of the press conference, national radio and television (8) accounted for almost half the coverage received (18). Coverage dropped off dramatically after that, with only 8 reports issued over the next month.

In all the articles reviewed (mainly print, as only a few electronic reports were made available), the key message of the news release of the Legal Network was clearly conveyed. The Legal Network received mention in 17 of 29 reports reviewed. Mr. Jurgens was mentioned in 26, and he was quoted, but the Legal Network was not mentioned in the Canadian Press (CP) story. This is unfortunate, as CP tends to receive broad coverage across Canada.

Overall, the Legal Network was very successful in coverage received immediately after the news conference.

### 4.4 Review of Impacts

To determine the impact of the Legal Network's efforts in the area of HIV/AIDS in prisons, a total of 21 people were interviewed. There were:

- 3 from CSC.
- 1 from Health Canada,
- 3 from provincial prison systems,
- 2 from provincial health departments,
- 6 from inmate organizations or groups doing work in prisons,
- 5 from other AIDS organizations,
- 1 from a human rights commission.

*Note*: One person had recently changed from the provincial system to the federal, so responded on both fronts where appropriate.

### 4.4.1 Use of publications

Everyone interviewed said they have used the documents produced by the Legal Network. Most use them as reference material to prepare presentations

and documents, as follows:

- to prompt policy development (3), or help develop or coordinate policy
   (9);
- to guide or validate current or proposed programs (5);
- to represent the interests of prisoners in court cases or with CSC staff
   (5);
- to inform staff of institutions wardens, health care staff (4);
- to inform the public of the issue students, health care workers, educators (4);
- to help secure funding for programs, both inside government and by outside groups (3);
- to research options for prisoners upon their release (1).

Clearly, the most common use of the documents is to promote policy or program development, with people both inside and outside the prison system citing the work of the Network as instrumental in that area. Several stated that the work of the Network succeeded in getting the issue on the agenda of policy makers, and prompted the development of policies or programs regarding HIV/AIDS. One person felt the recommendations of the Network led directly to the hiring of an Aboriginal prison worker.

Education is another common use of Network documents, inside and outside the prison system. They appear to be in use both in formal settings, such as training programs for health care professionals and informally, for staff themselves and for use with the public or prison populations.

### 4.4.2 Changes in policy/approach

Questions probing changes that have occurred in the last five years in prisons revealed a clear difference between the perceptions of those working in the prison system and those outside it, among the sample interviewed. There was fairly close agreement on some changes that had been made, notably in education and some preventive measures, such as availability of condoms and bleach.

However, in questions regarding care of inmates, testing and confidentiality, and programs for Aboriginal inmates, federal employees felt vast improvements had been made, while AIDS organizations or those working with inmates (henceforth referred to as "organizations") saw little evidence of change.

- Only 25% of respondents outside the prison system felt improvements had been made to the care and treatment of inmates in the past five years, while 78% of government employees did.
- In issues regarding testing and confidentiality, 78% of those within the prison system felt improvements have been made, while only 42% of organizations agreed.

- Similarly, 78% of those within the prison system felt programs for Aboriginal inmates had improved, while only 42% of organizations did.

All agreed that areas where little progress has been made include needle exchange programs and methadone treatment (phase II - commencement in institutions). Three organizations felt no discernible change had taken place over the past five years.

### The Nature of Changes Made

Respondents were asked about changes they felt had occurred in the prison system in the last five years. They were subsequently prompted on potential changes, taken from the list of recommendations made by the Network. Two respondents, from Ontario and British Columbia, felt that substantial programs had been in place for more than five years.

### <u>Unprompted</u>

When asked, unprompted, about changes over the past five years, those most frequently cited by all respondents were:

- access to condoms and lubricant (8 times) (although some stated that these have been available for more than 5 years);
- access to bleach (8 times)
- educational programs for inmates (8 times);
- methadone phase I (8 times) (continuation of treatment begun before incarceration).

Respondents representing AIDS and inmate organizations most frequently focused on:

- phase I methadone treatment (5 times);
- policies on testing and confidentiality, although there was some discrepancy between those who said policies were only now being developed, and others who felt the implementation of existing policies was the issue (4 times);
- access to condoms and lubricant (4 times);
- access to bleach (4 times).

*Note*: When prompted, changes to testing and confidentiality were cited by only one organization, yet it was raised, unprompted, by four. It may be that specific groups are involved in discussions and therefore more aware of this as a changing issue.

The change most frequently cited by government employees, unprompted, was the provision of educational programs for inmates (6 times).

### Prompted

When provided a number of suggestions, organizations agreed that the following changes have been made over the past five years:

- educational programs for inmates (8 times);
- access to bleach (6 times);
- access to condoms and lubricant (5 times);
- education programs for staff (5 times).

Employees of government departments agreed that the following had changed:

- education programs for staff (5 times);
- programs for Aboriginal offenders (5 times);
- policies on testing and confidentiality (4 times);
- phase I methadone treatment (4 times).

### **Extent of Implementation**

One issue which may account for the varying views on whether changes have been implemented or not is the belief that little consistency exists in program delivery and enforcement of policies in Canada's correctional systems. This view is echoed by both organizations (8 of 12 don't believe delivery is consistent), and government employees (4 of 10). This was felt to be particularly true at the provincial level.

Some organizations put this down to the lack of accountability in the prison system or the views of individual prison wardens. They feel the prison system operates with a very "closed" culture, and without strong public scrutiny, prisons will not comply with standing policies or create new ones to address the issues of inmates with HIV/AIDS. Cost was cited as a factor for the lack of some programming. A small prison population of one particular group (e.g. Aboriginal people or women) was named as a barrier to implementation of programming in some cases.

Respondents who felt practices were consistently applied supported this with the fact that audits are conducted across the system. In some federal audits, inmates are included on review committees.

### **Changes in Approach**

It is clear that government employees feel they have made huge advances in how they address HIV/AIDS in prison, the federal government somewhat more than provincial employees. The first three of four statements (listed below) were agreed to by all federal government employees interviewed (4 of 4), with less agreement at the provincial level (4 of 6). Fewer agreed with the fourth statement that, "care and treatment for HIV-positive prisoners

have improved" at both the federal (3 of 4) and provincial levels (3 of 6).

Few outside of government could agree with the statements, with many qualifying any agreement they gave with words such as "slightly agree" and "agree a little bit." Of 12 respondents:

- 6 (including 1 somewhat) agreed with the statement that, "Prisons now have a longer term, more coordinated approach to preventing the further spread of HIV."
- 7 (2 somewhat) agreed that, "Prisons are more fully committed to preventing the spread of HIV," with 15% agreeing only "mildly."
- 4 agreed somewhat with the statement that, "Prisons are taking a more pragmatic approach to drug use."
- 8 (4 somewhat) agreed that, "Care and treatment for HIV-positive prisoners have improved," and then, usually because care has improved so much outside the prison system.

### 4.4.3 Key factors that led to changes

### Unprompted

The main factor cited by all respondents, unprompted, as key to initiating change in the prison system is the work of AIDS and inmate advocacy groups, including the Legal Network. Community pressure, via groups like the Legal Network, British Columbia Persons With AIDS Society (BCPWA), HIV/AIDS Legal Clinic Ontario (HALCO) and Prisoners with HIV/AIDS Support Action Network (PASAN), was cited as key in 13 of the 16 interviews where this question was answered. (The remainder said they did not know, or felt no changes had been made.) Specific mention of the role of the Legal Network was made 9 times, but the combined effort of many groups was cited more often (11 times). Inmate self-advocacy was named as a key factor by one person.

### Other key factors were:

- increased education and awareness of HIV/AIDS in general, which contributes to overcoming fear of the disease, and better understanding of care and treatment issues (7 times). Prevalence and epidemiological studies were cited as important in changing the approach to HIV/AIDS.
- a commitment from the government, including the Minister of Health and Commissioner of Correctional Services Canada (7 times). The Expert Committee on AIDS in Prisons, creation of the Ministerial Council and better coordination among departments and between federal and provincial levels of government were also felt to be key factors of change.

Less important was media coverage of the issue. Pressure from staff and unions within the prison was cited once as a factor in provoking change.

Some comments noted the importance of change coming from both the grass-roots levels, including inmates themselves, and senior levels of government. The bottom-up and top-down combination was seen as key.

All organizations that felt no real change had occurred commented that CSC is extremely slow moving, without clear accountability. They saw a reluctance to work with community-based organizations, compounding the problem. The mandate of CSC to deal with security issues was felt to be an excuse not to deal with inmates' health issues.

### Prompted

No real change to the above profile emerged when respondents were prompted with suggested factors of change. Agreement with the factors was fairly high between organizations and government departments, with the organizations putting slightly higher emphasis on the impact of the media.

### **Role of the Legal Network**

As stated above, the Legal Network was raised as a key factor in prompting changes to the prison system in 9 of the 21 interviews, unprompted, and in a further 7 cases, prompted. Overall, the Legal Network was mentioned by all but three respondents who felt change had taken place.

When asked to rate the influence of the Network on this issue, over half the respondents felt it had "a great deal of influence," with government employees putting the Network's influence somewhat higher than organizations (55% vs. 46%). The remainder felt the Network had "some influence," with the exception of one person, who felt that nothing had changed; therefore, the Network had no influence at all.

### Unprompted

When asked about the effectiveness of the Network in making changes, most unprompted remarks indicate that the Network has been successful. The Network's credibility, tenacity and clear articulation of the issues were praised, supported by comments such as:

"Their final report was instrumental."

"The Legal Network provided the ammunition, and put the issue on agenda for community groups, mobilizing them to advocate to the prison system. They have the persistence to force things to happen eventually. Because they are so credible, they have the ability to effectively put pressure on CSC."

"The Network has been extremely effective in the area of prisons. They have taken on a sector that has a history of being a very closed environment that

is very resistant to change. The Network has succeeded in keeping the pressure on and this has forced Corrections to look at the issues. The results have been invaluable."

Others felt the Legal Network is not as successful as it could be in putting the issue on the agenda of policy makers, for a variety of reasons, including:

- Efforts are mainly directed at the national level, which is very different from the provincial scene.
- Policy changes do not necessarily translate into local action.
- Policy efforts are not being directed to the appropriate level of bureaucracy; change occurs at higher levels than are being targeted by the Legal Network.

A number of people felt the Network could not do more than it has because of the nature of the penal system. As summarized by two respondents:

"The Network has a lot of credibility and they present reasoned and comprehensive work, but trust and openness towards outside organizations does not exist from CSC. Political will and accountability are required for CSC to make changes."

"The value of the Network is as a focal point for serious discussion around prison issues. They lend credibility to grass-roots organizations to do this work, and have given us access to decision makers. It's hard to know what will influence change in CSC, however, due to the nature of the system – closed, slow and resistant to change."

### Prompted

When prompted, there is general agreement that the Network has been successful in achieving the following:

- 100% of respondents agreed that the Network is successful in raising awareness of the issue.
- 100% of respondents agreed to its success in stimulating discussion in this area. There was slightly less agreement that the Network stimulates collaboration.
- 100% of respondents agreed that the Network is successful in providing information on the issue.
- 85% of organizations and 66% of government employees felt the Network is successful in putting the issue on the agenda of policy makers. Three of the nine government employees felt the Network is only somewhat successful in this area, with one noting that other groups are better at raising issues, but the Network puts a better focus on the policy aspects.
- Both government employees (66%) and organizations (54%) felt the Network is at least somewhat successful in changing the practices of those working with prisoners. Several believed that it was not within the power or mandate of the Network to change people's practices.

### 4.5 Conclusions

Based on the review of activities, outputs and impacts conducted, the Legal Network has achieved the goals it set out for this project.

### Goal 1

It has clearly met its goal to assist CSC and provincial prison systems in their efforts to:

- reduce HIV transmission in prisons and to staff and the public;
- increase their prevention efforts, by proposing concrete solutions;
- fulfil their legal and ethical obligations toward inmates, staff and the public.

This evaluation demonstrates that publications of the Legal Network are used to prompt or guide policy development in this area; to guide or validate current programs; and to inform the staff of institutions (Section 4.4.1 *Use of Publications*).

Although there is some disagreement on the type and extent of changes made over the past five years, the efforts of the Legal Network are cited as a factor of change by over three quarters of the respondents (prompted and unprompted, combined) (Section 4.4.3 – *Key factors that led to changes*).

Further, all respondents except one, who felt no changes had taken place, felt the Network had either "a great deal" or "some" influence in affecting changes. All respondents agreed that the Network was successful in three of the five areas suggested; three-quarters in the fourth area; and half in the final one (Section 4.4.3 – Role of the Legal Network).

### Goal 2

Although no firm figure was targeted for the number of reports to be distributed, they were widely disseminated to key audiences in Canada and internationally, as detailed in section 4.3.1. This goal appears to have been met.

### Goal 3

Some of the Network's recommendations toward this goal have not yet been implemented, nor is it clear whether those that have are in place throughout the prison system. However, the Network continues to direct efforts toward this issue, as evidenced by the fact that more than three quarters (76%) of respondents had heard from it on this issue within the last two months. Many cite the Network's tenacity as a key feature to advancing this cause.

### 4.6 Suggestions for Future Action

Suggestions were drawn from those interviewed on further action the Network could take. Some (7) suggested it should simply continue with current efforts, particularly to raise awareness, stimulate discussion and put the issue on policy makers' agendas. Two felt the Network should not try to change practices or develop skills, feeling this was outside their mandate. One of these people felt, "The Network should focus on what they do well, and not take on new tasks." Another expressed concern that the Network could spread itself thin by responding to too many issues with the resources it currently has.

Some concrete suggestions were made regarding actions that would move the issue forward.

### Efforts with CSC:

- Issue a report card on changes it has made (or not made), in an attempt to make CSC more accountable.
- Create dialogue with those who can directly influence policy, rather than at lower levels where efforts seem to be directed now. "The Network must become more proficient, strategically and politically," was one opinion.
- When making recommendations, take into account the environment in which they must be applied (federal vs. provincial institutions, variability within them).

### Increase legal intervention:

- Sue CSC for allowing infection rates to grow.
- Intervene in court cases against CSC.
- Review the whole issue of prison inquests and make recommendations for increasing their authority and enforcement abilities. At present, the good recommendations that come from inquests are not acted upon – the coroner's office has no authority to enforce those recommendations and CSC is not required to respond.
- Get the legal profession more involved: keep it better informed and advocate for it to be more involved (e.g. more pro bono work, greater involvement of larger firms at policy discussions).

### Education/Information:

- Issue a very short monograph around care issues. There have been rapid changes in palliative care, and focus is required on exiting prison and linking up with care in the community.
- Prepare a comparative study on treatment regimes provided in prisons.
- Help determine a creative, appropriate approach to estimating seroprevalence in prisons.
- Educate specific pockets: individual MPs must be informed of the urgency of the issue; people who work in institutions must be informed about the legal and ethical issues.

### Communication:

- Issue success stories to be emulated. For example, how policy that has been implemented federally could be transferred to the provincial level.
- Provide a single-page synopsis of current Network activities and upcoming research.
- Disseminate information to the general public. The Network should work to advance its profile and help Canadians understand the terrible breach of human rights that is taking place.
- Facilitate access to prisons by other groups.

### 5.0 Rapid HIV Testing

At the time of this evaluation, rapid testing of HIV at the point of care was still a fairly novel approach. From the information gathered during the interviews, it appears only Quebec and British Columbia were using the tests at all. In some cases, discussions were taking place, and this report captures the issues being considered.

### 5.1 Goals of the Program

The Network identified the study of rapid HIV screening at the point of care as an emerging issue. In its 2000/2001 Workplan, goals for emerging issues are stated as follows:

- 1. to provide prompt analysis of new, emerging and/or pressing legal, ethical and human rights issues raised by HIV/AIDS in Canada within a short time frame;
- 2. to obtain input from the membership and from concerned stakeholders on the issues addressed.

In addition, the deliverable was identified as a short paper/plan, developed through the following activities:

- identification of a new/emerging/pressing issue that is not addressed elsewhere, in consultation with membership, governments and other stakeholders;
- writing of a first draft of the paper/plan, and a process to obtain input;
- obtaining input regarding the analysis of ethical issues;
- publication of the paper/plan, in both English and French;
- dissemination of the paper/plan and follow-up.

The focus in its final report, Rapid HIV Screening at the Point of Care: Legal and Ethical Questions, is on recommendations for action. These recommendations have been grouped into the following areas:

- licensing and labelling,
- post-approval monitoring,
- research,
- education and training,
- availability of rapid screening tests,
- preventing perinatal transmission,
- preventing testing without consent.

In all cases, the recommendations require action by outside groups. The evaluation attempted to determine whether action had been taken, or with so few provinces using the rapid tests, was under discussion regarding these recommendations.

### 5.2 Review of Activities

The Legal Network has undertaken a number of activities regarding rapid HIV screening at the point of care. In summary, from January to November 2000, the Network:

- released Rapid HIV Screening at the Point of Care: Legal and Ethical Questions, as well as info sheets on rapid testing for HIV;
- organized a workshop pertaining to this issue;
- submitted letters to government departments;
- wrote articles for the Canadian HIV/AIDS Policy and Law Review;
- made several oral presentations on rapid HIV screening at Canadian and international conferences;
- organized a skill-building workshop at the Network's Annual General Meeting in Toronto;
- continued research in this area to remain up to date and to allow the Network to respond to new and emerging questions and developments.

The Network has strategically disseminated relevant materials and has been proactive in building and strengthening existing partnerships.

### **5.3 Review of Outputs**

### 5.3.1 Documents produced and distributed

As a result of the Legal Network's activities in the area of rapid HIV screening, a number of outputs resulted. They are summarized as follows (according to available records):

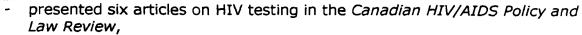
- Over 800 copies of the report entitled Rapid HIV Screening at the Point of Care: Legal and Ethical Questions were distributed (March-November 2000).
- Approximately 400 copies of the info sheets on HIV testing were distributed (April-November 2000).
- Over 1200 copies of the report (pdf version) were downloaded from the Network web site between November and December 2000 and February and March 2001.

The Network received 33 letters as a result of an invitation to respond to the final report. Of these responses,

- 16 letters acknowledged the receipt of the final report and thanked the Legal Network for its ongoing work.
- The remainder indicated that the report would be a useful contribution to a variety of processes and respondents would disseminate the report appropriately within their organization and/or province.

In addition, the Legal Network:

- wrote two letters to government emphasizing the importance of broad community consultation related to new testing technologies,



conducted a workshop for 50 people on rapid HIV testing.

### 5.3.2 Analysis of media efforts

The Legal Network's announcement of its findings on the issues around rapid HIV testing at the point of care was extremely well timed, preceding by one day that of the pharmaceutical company licensed to sell the product. Media coverage, assessed through the clippings provided by the Legal Network, was very good, considering the amount of effort applied. Only a news release was issued, and it resulted in 29 stories. This brief analysis will review the nature and quality of coverage received. It is based upon media reports for the period immediately preceding and following the Legal Network's announcement on March 22, 2000. Its limited nature can provide only a snapshot of media success.

### Of those 29 reports:

- 3 were radio;
- 8 television;
- 13 print, including 5 journal articles;
- 5 Internet.

Among these, 7 reports were national, 2 regional and 10 local. The journal and web articles are not included in this count, as they are not directed to a specific geographic audience. The CP story is significant among these, as it would probably have been picked up in papers across Canada. Most stories, including all the journal and web articles (23) were simple reports; 6 featured interviews.

Most reports (15) were issued in the two days following the announcement, with print and television providing most of the coverage. Coverage dropped off dramatically after that, with mainly journal articles issued over the next month.

In all the articles reviewed (17 – mainly print, some electronic reports and some web), the key message of the news release of the Legal Network was clearly conveyed. In fact, many repeated the first two paragraphs of the Network's news release in their opening sentences. The Legal Network was mentioned in all reports and either Ralf Jurgens or Richard Elliott was quoted in the majority of articles (12).

From the clippings reviewed, it appears the Legal Network achieved highquality media attention, with a good amount of coverage.

## 5.4 Review of Impacts

The impact of the Legal Network's efforts in rapid HIV testing at the point of care was assessed through interviews with 16 people:

- 2 from Health Canada,
- 5 from provincial health departments,
- 5 from AIDS organizations,
- 2 from health groups,
- 2 from professional associations.

### 5.4.1 Use of publications

Most people interviewed were aware of the Network's reports and resources, and slightly more than half had used the materials. People in British Columbia had been involved in the issue of rapid testing before the Network's involvement, and indicated that they did not find the materials as useful as those elsewhere in Canada.

Those who used the materials did so in the following ways:

- as a reference document (2);
- to help prepare proposals, reports and deliver workshops (2);
- to assist in advocacy efforts (2);
- to help develop policy, or stimulate discussion at policy level (4);
- to stimulate discussion in the community (3);
- as a tool in teaching and clinical settings (2).

The Network's role in this issue was lauded, as "Asking enough questions to help broaden thinking."

A government employee appreciated the fact that the Network's early focus on the issue allowed it to address the issues before the kits were in demand from the community. "It allowed the government to be proactive, rather than reactive, which was critical, in that it made for an intelligent debate at policy level before it became an emotional issue. We used the Legal Network's documents to guide our discussions."

# 5.4.2 Effectiveness of collaboration/consultation

About half the people interviewed were invited to provide input to the report, or attended a workshop on the issue. Comments on the consultation were generally positive. According to one person, "One of the Legal Network's strengths is their consultative process. At the first draft stage, I am able to learn as I contribute."

On the downside, one organization felt its position was not made clear in the report. It felt that responses to Network reports should be made public, either in the final report or elsewhere.

## 5.4.3 Changes in policy/approach

At the moment, very few provinces use the rapid HIV tests. Quebec is using it in some clinics. In other provinces, discussions are under way and some pilot tests are being conducted. British Columbia is currently piloting the test and plans to introduce it to specialized HIV clinics at some point in the future. (Note: this is not an exhaustive summary – not all provinces were polled on their use of the tests; however, as part of this evaluation, it was determined that Newfoundland, Nova Scotia, Ontario and Manitoba are not using the tests.)

As so few provinces are using the test kits, little information was gathered regarding policies for their use. The Canadian Medical Association guidelines on AIDS testing were cited by one respondent as the model to be applied to rapid test kits. Regulators interviewed were quite familiar with the need to provide policies regarding labelling, counselling, training and administration of the test kits by health care professionals. In British Columbia, where training is currently taking place, the materials used derive their content from publications of the Network. Regulators were less familiar with legal liability regarding the tests.

In British Columbia, "A lot of thought has been put into how to use them and best practices (to follow)."

The College of Family Physicians of Canada noted that it has publications and a workshop available on this issue for Quebec physicians. It also mentioned the increased training available on HIV/AIDS in family residency programs. The College is supporting this effort with a new book that will be sent to all newly certified family physicians and members.

# 5.4.4 Key factors that led to change

#### Unprompted

As very few provinces have policies in place regarding rapid test kits, this question was broadened to include deliberations about use of the kits. When asked what key factors led to discussion, the following emerged, unprompted:

- the fact that British Columbia was a pilot site for rapid testing focused attention on the issue in that province;
- within the medical community, concern about who should administer the tests sparked discussions with Health Canada, which then initiated broader discussion:
- availability of information on the issue;
- efforts of the Legal Network.

### Prompted

When prompted with potential triggers of the discussion, 11 of the 16 people interviewed felt none of the factors listed below was relevant. Agreement was met in the following statements, by the five people who answered this question:

- All agreed that the Legal Network's reports and information on the issue were key factors.
- One agreed that media coverage was a factor.
- Four felt the efforts of many AIDS-related organizations were important.
- Two agreed that directives from senior policy makers had been key.

#### **Results Achieved in Short Time Frame**

In the short time since the Network issued its report, those interviewed felt they had been able to contribute to the issue in a number of ways.

### Unprompted

Respondents offered the following comments on the Network's efforts, unprompted:

- alerted people to concerns associated with rapid testing, sparked debate and set the tone of the discussion, by pre-empting the manufacturers in their announcement;
- initiated discussions in some provinces, and focused attention on different situations in each province;
- allowed Quebec to introduce testing, while ensuring that it was being used effectively;
- raised awareness of the issues, and provided educational opportunities;
- identified need for further action and areas where work is required;
- addressed the implications from an insurance and legal point of view.

### **Prompted**

When provided a number of suggestions on the impact of the work of the Network:

- a little over half (8 of 14 who responded to this question) felt the Network raised awareness of the issue; however, 2 noted that this occurred only with stakeholders and not the general public;
- all but one person felt the Network succeeded in encouraging regulators to take a closer look at the kits;
- half felt the Network forced manufacturers to address the issues raised in the report, although many noted that the Network was not alone in this effort.
- Almost all those interviewed (12 of 14) felt the Network encouraged open, informed discussion among stakeholders.

### **Role of the Legal Network**

When asked to characterize the role of the Legal Network in influencing change in this area, 9 of the 10 respondents who answered this question felt the Network had some (3), considerable (2) or a great deal (3) of influence. Two, both from British Columbia, felt the Network had no influence at all, as the issue had been largely addressed before it got involved.

All nine people who voiced an opinion felt the Network had responded quickly to this issue.

#### Unprompted

When asked about the role of the Legal Network, four respondents provided unprompted answers. One felt the role of the Network was crucial, and explained, "Because it was a smaller, more focused issue, they were able to have a bigger effect." The others commented that the Network had brought good information and thinking to the issue, in some cases putting the issue on the table and in others assisting in promoting informed decision making.

#### **Prompted**

When prompted, 8 of 10 respondents agreed that the Legal Network had been successful in the following:

- raising awareness of the issue,
- stimulating discussion and collaboration,
- providing good analysis of the issue.

Five felt the Network had successfully put the issue on the agenda of policy makers, with one of these noting that other groups had also been involved.

#### 5.5 Conclusions

The following goals identified for emerging issues were clearly met by the Legal Network:

- to provide prompt analysis of new, emerging and/or pressing legal, ethical and human rights issues raised by HIV/AIDS in Canada within a short time frame;
- 2. to obtain input from the membership and from concerned stakeholders on the issues addressed.

This evaluation determined that all stakeholders felt the Network responded to this issue quickly and that its analysis was effective (Section 5.4.4 Role of the Legal Network). Most of those who provided input felt it was a positive experience (Section 5.4.2 Effectiveness of collaboration/consultation), and that the Legal Network had succeeded in stimulating open, informed

discussion and collaboration on the issue (Section 5.4.4 Results Achieved in Short Time Frame and Role of the Legal Network).

In addition, the deliverable for this program was identified as a short paper/plan to be disseminated to stakeholders. Follow-up on actions taken toward the recommendations of the Legal Network were to follow.

In assessing the impact of the Legal Network's efforts, it should be noted that respondents felt the lack of adoption of the rapid tests made it difficult to determine what changes, if any, had been made. Respondents agreed, however, that the Legal Network had been successful in alerting people to potential concerns and sparking a more detailed analysis of the use of the test kits. The Network is credited with initiating discussions on this issue in some provinces and identifying the need for further investigation. Those who have implemented the tests on a limited basis credit the Network with helping to ensure the tests are being used effectively.

Again, due to the infrequent use of the rapid test kits, the overall influence of the Legal Network in promoting changes in this area is somewhat unclear, with almost an equal number of respondents feeling they had none, some, considerable or a great deal of influence.

### **5.6 Suggestions for Future Action**

Most of the comments regarding future action called for a monitoring of activities, and communication regarding the findings:

- press for guidelines and regulation in each province,
- monitor the impact on patients where kits are in use,
- provide an update to the situation for the AIDS community.

One person felt that greater awareness of the tests was required among the general public. Other individuals wanted further clarification on the following:

- clinical practice issues, including the perspective of those carrying out the tests and counselling people;
- clear definition of who can administer the tests.

Several people commented that the Network has done all it can in this area, and it is up to others to continue the effort.

## 6.0 Injection Drug Use

Since the Legal Network first made a presentation to the Senate Committee on Constitutional Affairs in 1996, it has focused a great deal of effort on this issue. In 1999, the release of its report, *Injection Drug Use and HIV/AIDS:* Legal and Ethical Issues, created significant media attention. Recently, an F/P/T report on the issue was released and a response to the Legal Network's paper is expected shortly from the federal Minister of Health. This evaluation reviews actions taken by the Network and views of the impacts that have resulted.

### 6.1 Goals of the Program

Objectives for this program are provided in the "Overview of the Project" in the final report, and are as follows:

- to bring together key participants from across Canada with knowledge and experience in issues related to HIV/AIDS and injection drug use (IDU);
- to identify the legal and ethical issues related to (1) providing care, treatment and support to drug users with HIV/AIDS, and (2) reducing the harms of drug use;
- identify priority issues that need to be analysed in more detail;
- 4. analyse these priority issues from the perspective of policy, law and ethics in three background papers;
- 5. prepare a report that summarizes the discussion of the participants on the priority issues and potential solutions, as well as a volume of background materials, including the background papers.

In addition, the report makes recommendations for action in the following areas:

- the legal status of drugs,
- drug use and the provision of health and social services,
- treatment of drug users with HIV/AIDS,
- prescription of opiates and controlled substances,
- research into drug users and HIV/AIDS,
- information and training about the use and effects of illegal drugs,
- needle exchange and methadone maintenance treatment.

In addition to assessing success in achieving the program goals, the evaluation attempts to determine whether action has been taken, or is under discussion regarding these recommendations.

#### 6.2 Review of Activities

The Legal Network has undertaken a variety of activities with respect to IDU and HIV/AIDS. In 1999 and 2000, the Network:

- published Injection Drug Use: Legal and Ethical Issues and a volume of

- background materials with papers on legal, ethical and policy issues raised by IDU and HIV/AIDS;
- produced a series of 11 info sheets on IDU and HIV/AIDS;
- written several articles for newspapers, journals and the *Canadian HIV/AIDS Policy and Law Review*;
- made presentations at national and international events, and submitted several abstracts for conferences:
- organized a workshop on IDU and HIV/AIDS;
- participated on the Advisory Committee to plan a conference on harm reduction and HIV/AIDS and human rights;
- organized a skill-building workshop at the Network's Annual General Meeting in Toronto;
- continued research in this area to remain up to date and to allow the Network to respond to new and emerging questions and developments.

The Legal Network has also strategically disseminated all relevant materials and has been proactive in building and strengthening existing partnerships.

### **6.3 Review of Outputs**

### 6.3.1 Documents produced and distributed

A number of products have results from the Legal Network's activities in the area of IDU and HIV/AIDS (according to available records):

- Over 2200 copies of the report entitled *Injection Drug Use and HIV/AIDS:* Legal and Ethical Issues were distributed (January–November 2000).
- Over 1700 copies of the info sheets on IDU and HIV/AIDS were distributed (January–November 2000).
- The web site has been used extensively to distribute materials: over 300 people downloaded its materials relating to IDU and HIV/AIDS between November and December 2000 and February and March 2001.

The Network received 70 letters as a result of an invitation to respond to the final report. Of these responses:

- 47 letters acknowledged the receipt of the final report and thanked the Legal Network for its ongoing work.
- 15 letters responded with specific comments on the recommendations in the final report.
- The remainder of the responses indicated that the report would be a useful contribution to a variety of processes and respondents would disseminate the report appropriately within their organization and/or province.

As of the writing of this evaluation, the Legal Network was still waiting to hear an official response from the federal Minister of Health.

Additional results of the Legal Network's activities in this area are:

- a workshop on IDU and HIV/AIDS for 50 participants,
- strategic dissemination of materials at two conferences,
- 28 articles for the Canadian HIV/AIDS Policy and Law Review,
- one journal article,
- four conference presentations,
- three abstract submissions for various international and national conferences.

## 6.3.2 Analysis of media efforts

The Legal Network's news conference announcing the release of its report, Injection Drug Use and HIV/AIDS: Legal and Ethical Issues, received tremendous coverage, with at least 153 reports. Media coverage, assessed on the basis of a report and clippings provided by the Legal Network, shows in-depth and widespread reporting on the report, and the issue of IDU and HIV/AIDS. A number of reports included a local angle, interviewing residents personally affected by the issue.

Of the 153 reports reviewed:

- 130 were radio,
- 7 television,
- 16 print,
- 5 Internet reports (mostly on the sites of media outlets).

Among these, 15 reports were national, 131 were local. An additional 2 articles appeared in journals and 1 in an international newspaper. Radio stories appeared most frequently as a result of local pick-up of a CBC national story. The CP story resulted in at least 12 local repeats. Most stories (128) were reports, 21 featured interviews; 2 were commentaries; 2 were special reports or features. The number of interviews, as opposed to simple reports, the CBC Radio special report and the *MacLean's* feature, showed significant media coverage.

Most reports (128) were issued on the day before, or the day of, the news conference, with radio providing the lion's share of the coverage. A further 20 reports were issued in the week after the news conference.

In all the articles reviewed, the key messages of the Legal Network were clearly conveyed. In some cases (11), the articles took a broader view of the issue, or focused on the local implications, so the Legal Network and the report itself were not mentioned. The local angle increased pick-up of this national story; however, not mentioning the source of the story provided no coverage for the Legal Network. The CP story clearly conveyed the key messages, named the report and mentioned the Legal Network and Ralf Jurgens. As a full transcript was not provided, it is unclear whether the most frequently repeated report, that of CBC's Maureen Brosnahan, mentions the

Legal Network.

From the clippings reviewed, it is clear the Legal Network achieved highquality, extensive coverage of this issue.

## **6.4 Review of Impacts**

The F/P/T report on IDU and the pending federal Health Minister's response to the Legal Network's report are two significant formal responses to the issue of IDU. In addition, those interviewed provided their views on the impact of the Network's work.

### **Formal Responses**

The fact that Canada's Minister of Health is making a formal response to the Legal Network's report is, in itself, significant. The contents of his response were not public at the time of this evaluation.

The report by the F/P/T committees on this issue, "Reducing the Harm Associated with Injection Drug Use in Canada," mentions "recent, well-researched reports," including those of the Legal Network. It clearly supports a harm reduction approach and makes specific mention of a number of recommendations made by the Legal Network in its final report.

More specifically, the report calls for immediate action in the areas of prevention; outreach; treatment and rehabilitation; research, surveillance and knowledge dissemination (all of which were recommended by the Legal Network); and national leadership and coordination.

#### **Results of Interviews**

The impact of the Legal Network's work in IDU was evaluated through interviews with 17 people:

- 1 from Health Canada,
- 4 from provincial health departments,
- 8 from AIDS organizations,
- 2 from health groups,
- 1 from a professional association,
- 1 academic.

### 6.4.1 Use of publications

Everyone interviewed was aware of the efforts of the Legal Network in relation to IDU, and had read at least some of the documents.

They used them in the following ways:

- as a resource to inform others, including health professionals (8);
- to inform themselves and their organizations (5);
- as background in developing the FPT report (3);
- to guide policy and programming (3);
- to facilitate discussion in the community (2);
- as background in a legal case (1).

"The Legal Network is the first place I send people (for information on this issue)."

"The Legal Network's material tends to be our check-list, to be sure we're following good guidelines."

## 6.4.2 Effectiveness of collaboration/consultation

Slightly over one third of respondents (6 of 17) were involved in the issue with the Legal Network, and mentioned workshops specifically. Over half (10) provided input to the issue, with all indicating that they were satisfied with the process. Several people noted that they were only "somewhat" satisfied and noted that the process could be improved by:

- being more inclusive of the issue in all regions of Canada: "The size of the problem in large cities tends to dominate discussion, overshadowing issues in smaller centres, which are often different." Compounding this is the fact that budget constraints limit participation of those from outside central Canada.
- being more specific of the areas requiring input: "Documents by the Legal Network are often so large, and apparently complete that it is difficult and sometimes intimidating, to know where, or how, to contribute."

## 6.4.3 Changes in policy/approach

Those interviewed were asked whether they had noticed any changes in practices or approaches, with regard to the treatment of ID users. Nine indicated that they were aware of the recently released F/P/T report on IDU. Three commented, unprompted, that the work of the Legal Network had a significant impact on that process, one saying that the Network created the impetus for the discussion.

## **Changes Made to Policy**

### <u>Unprompted</u>

Asked whether there had been changes noted in the past year in the treatment of ID users, respondents offered the following:

- more discussion of harm reduction and what that means (6);
- more evidence of harm reduction approach in practice (more methadone

programs) (2);

- increased HIV/AIDS treatment, care and support for ID users (3);
- increased advocacy for needle exchange programs (1);
- greater understanding of drug interactions (1).

Respondents noted that small, positive changes are being made at the community level, but no big breakthroughs have occurred.

In discussing changes that affect people providing care or support to ID users, none of the respondents felt significant changes have been made. They noted that there had been some movement toward increased support for a harm reduction approach, and greater involvement of practitioners in the discussion. A supporting comment was provided: "Their bosses have more knowledge and sympathy for what they are trying to do."

The materials from the Legal Network were welcomed as, "provid(ing) a good resource and advocacy tool." Also noted, however, is that with increased attention has come an increase in the backlash to IDU, "The anti-drug movement is alive and well."

One concrete policy, although it was unclear whether this is a recent change, is that in British Columbia, the Ministry that funds addictions treatment agencies will not fund programs that refuse people who are taking maintenance drugs.

#### Prompted

When probed on changes that were recommended by the Legal Network, agreement was as follows for the 15 people who responded to this question:

- Slightly under half (7) believed treatment programs are now more accessible. Eighty percent of government employees agreed with this statement, while only 30% or those from organizations did.
- Ten believed methadone treatment is now more common, with all government employees, and half of those from organizations agreeing.
- Nine felt heroin maintenance programs were being considered, including an equal number from government and organizations.
- Only three felt more physicians are available to treat drug users, all of them from organizations.
- Six felt research had begun to include ID users in clinical trials, with 60% of government employees and 30% of organizations agreeing.
- Eight believed needle-exchange programs are now more common, with a marked difference between the views of government employees, 100% of whom agreed, and organizations, where only 30% agreed.

## **Changes in Approach**

Respondents generally agreed that a change in approach toward IDU was evident. No marked difference was noted between those responding from government positions, as opposed to other organizations, although those from organizations tended to qualify their agreement with statements such as "a bit" and "slightly."

- 13 of 17 respondents, or 76%, agreed that Canada's drug policies seem to be moving toward a harm reduction approach;
- 15 (88%) felt that IDU issues are more on the agenda, although one noted this to be true for professional associations and community organizations, but not policy makers;
- 16 (94%) agreed that there is greater recognition of the need to include drug users in the development of programs and policies, although three respondents from organizations felt there was only a slight change in this area, or verbal recognition, with no action to accompany it;
- 11 (65%) felt that there is greater political will to make changes. One person noted that the will exists far more at the community level than at higher levels of government, another pointed out the marked differences across Canada on this measure;
- slightly over half of the respondents, 9 (53%), agreed that a research agenda regarding IDU is moving forward.

## 6.4.4 Key factors that led to changes

### Unprompted

When asked about key factors that led to the changes they cited previously, respondents provided a wide range of reasons:

- efforts of a number of community and AIDS groups, including fledgling drug user groups (7);
- surge of IDU and related health problems (overdose, HIV and HEP C) (6);
- visibility provided through Vancouver's horrible health situation with relation to IDU, HIV/AIDS and Hep C (6);
- efforts of the Legal Network and its paper (6);
- emergence of data on more successful, harm reduction models, in Canada and internationally (5);
- greater awareness and acceptance of drug use as a health issue, in Canada and internationally (4);
- cost of health care for ID users, which has forced diverse groups to work more closely together to provide better services (3);
- failure of traditional strategies (including "war on drugs") (2);
- government efforts (F/P/T report, British Columbia's "Pay now, pay later" report) (1).

#### Prompted

Many people had provided unprompted responses, so were not asked this

question. The 12 who responded provided support for the following reasons:

- 9 felt the work of the Network was a factor,
- 7 agreed that media attention on the issue contributed,
- all 12 felt the efforts of other AIDS (and IDU) groups had an impact,
- 5 agreed that senior policy makers had made a difference.

#### **Results Achieved in Short Time Frame**

In the short time since the Network's report, those interviewed felt the Legal Network had been able to contribute to the issue in a number of ways.

#### Unprompted

The following unprompted responses answered the question of what has been achieved:

- increased awareness of the health issues around IDU (8);
- focused attention on the need for a policy response (6);
- put more focus on policy issues, legal and ethical issues (2);
- created materials and a framework that supported advocacy work (2);
- heightened awareness of the harm reduction approach (2).

## Comments included the following:

"The IDU report woke people up. It was definitely a catalyst to the way in which we look at addictions and substance abuse issues."

"The Legal Network created the dynamic that allowed this issue to be addressed. The report and materials are repeatedly brought out with needle exchange groups in pushing dialogue and response."

"We have a new community methadone program, secured in part by the solid rationale provided in Legal Network documents."

Others were not so hopeful, and did not expect the work of the Legal Network to result in very much, "Don't expect a lot of progress on this issue. Other cases take more priority."

#### Prompted

In responding to prompts provided, respondents agreed that the Legal Network had been able to make the following changes:

- 13 of 15 respondents agreed that the Network had raised awareness of the issue, including all those from organizations;
- 11 of 15 felt the Network had gotten the issue on the agenda of policy makers:
- all respondents agreed on its success in encouraging open, informed

discussion among stakeholders;

only 5 felt the Network had been able to change policies or procedures.

With the exception of the first statement, noted above, respondents from government and organizations agreed on these issues.

### **Role of the Legal Network**

All respondents believed the Network had either "some" (10 of 17) or "a great deal" (7 of 17) of influence in this area. When asked about key factors of change, those interviewed cited the Legal Network a total of 11 times, 6 unprompted and a further 5 in prompted responses.

#### Unprompted

Most remarks about the role of the Legal Network indicated respondents felt it has had a very positive impact on this issue. The depth of the research and its role in advocacy were lauded. One person was impressed with the manner in which it was announced.

"They bring a credible, ethical point of view to the debate, so critical in quiding discussion and creating policy."

"They deal with difficult issues and aren't afraid to make what might be seen as controversial recommendations."

"The Legal Network's activities have created groupings of people who may never have paid much attention to this at all, but were stimulated and brought together by the Network. Have been successful in 'teaching the teachers.'"

One respondent differentiated between the Network's impact on this issue, and any real change occurring: "They have not really influenced change. Their work came after major increases in infections had already captured everyone's attention."

#### Prompted

When provided prompts characterizing the role of the Legal Network, respondents agreed with the following:

- 12 of 13 who responded to the question agreed that the Network had raised awareness of the issue;
- 12 agreed that the Network had simulated discussion and collaboration;
- all respondents agreed that it provided good information and analysis of the issue;
- 11 felt the Network had succeeded in putting the issue on the agenda of policy makers, including all government respondents.

### 6.5 Conclusions

The objectives for this program related to process have clearly been met. In developing its background papers and final report, the Network brought together key stakeholders to identify and analyse priority issues. Its report made a number of suggestions regarding further research required and potential solutions.

All those interviewed who had input to the process were at least somewhat satisfied (Section 6.4.2 *Effectiveness of the collaboration/consultation*) and all respondents agreed that the Network had succeeded in encouraging open, informed debate on the issue in the short time frame it had been active. (Section 6.4.4 *Results Achieved in Short Time Frame*).

When asked about the role of the Legal Network, respondents agreed that it had had a very positive impact in all areas probed, and that its influence had been substantial (Section 6.4.4 Role of the Legal Network). The recommendations made by the Network are addressed in the F/P/T Committee report.

Respondents agreed that a change in approach is noticeable, notably, increased discussion and acceptance of a harm reduction approach. Although progress is being made, with some evidence of change noted, there were mixed views on whether concrete changes have yet been implemented in the community.

In closing, these remarks were made by those interviewed:

"When things change - and they will with time - and this country moves towards a harm reduction approach, the Legal Network will be largely responsible."

"IDU report definitely had an impact at the federal level. They identified an obligation that needed to be addressed."

"The Legal Network has made a significant contribution to awareness of the general public and authorities on the drastic needs of injection drug users. They have heightened the need for a harm reduction approach and the senseless waste of enormous sums of money on the 'war on drugs'. They focused attention on the largely unmet need for methadone and heroin treatment programs and the need to treat injection drug users as human beings, not criminals."

## **6.6 Suggestions for Future Action**

Those interviewed made a number of excellent suggestions for future actions:

### Raise awareness:

- Increase public awareness; get advocacy campaign going to apply pressure to politicians (5).
- Tie recommendations to real situations to increase attention to the issue. Get "closer to the ground," providing examples of deaths or harm that could have been avoided through the adoption of its recommendations.
- Take on a court challenge in a high-profile area (perhaps a prison case in conjunction with PASAN).

#### Communicate:

- Provide status reports of efforts. Conduct a detailed analysis of specific changes resulting from its recommendations.
- Modelling of success achieved elsewhere would be very helpful.

### Focus efforts:

- Focus on top recommendations, and make them more relevant to the regulating body or region. For example, situation in each province is different (2).
- Apply information more directly to promoting change (2).
- Continue to stick to what it is good at (2).

#### Research:

- There is a need to determine what optimum treatment programs are, and associated ethical and legal issues.
- Broaden beyond legal approach. Include other disciplines in studies to create better sense of current, "real-life" situation.

# 7.0 Suggestions for future action

During the interviews, respondents were asked for improvements to materials and consultations, and suggestions for future action the Legal Network could take. Specific recommendations are made in each section; overarching ones are presented here. These suggestions are provided for the consideration of the Legal Network, without comment on their feasibility or validity.

#### 7.1 Process

Suggestions are provided to improve consultation, communication and representation of the Legal Network.

### Consultation

- Provide more specific direction to reviewers, requesting input where groups have strengths, or where the report requires greater scrutiny. A preamble describing who has been asked for input and why would be helpful.
- Be regionally sensitive, perhaps by holding some workshops/consultations outside major centres (Montreal, Toronto and Vancouver); by ensuring that those from smaller centres have full input to agenda, or providing break-out sessions focusing on their issues.
- Ensure adequate time is provided for critical peer review, and for feedback on draft documents.
- Provide feedback on recommendations to drafts.

#### Communication

Provide regular status reports on issues.

#### Representation

- Seek out more diverse representation in activities and reports; include female, Aboriginal, non-gay perspectives.

#### 7.2 Activities

- Increase follow-up activities. (See Section 7.4 Impact Collaboration, for details.)
- Be more accessible to front-line workers, who need to be aware of issues, but do not have the legal perspective required to interpret reports/issues. Note: Workshops were noted as effective for this. Web site redesign and list-serve were cited as recent changes that have improved accessibility. "They are no longer just a think tank."
- Staff Western and Atlantic offices to increase accessibility.
- Provide research and opinion writing service, whereby the Network provides assessments of particular situations for members, either as fee-

for-service, or as a part of its research mandate, being responsive to community needs. *Note:* The list-serv goes some way to fulfilling that function, providing access to many experts.

### 7.3 Outputs

#### Reports/Materials

One clear recommendation from those interviewed is that the reports need to be more accessible and succinct. Although the info sheets do this to some extent, additional formats are called for. It should be noted that some felt the detailed reports made excellent reference documents, citing the extensive bibliographies. Two versions of reports may be an answer.

- Provide condensed versions of reports, focusing on recommendations and their rationale.
- Prepare articles for newsletters, community papers.
- Create audiotapes of materials to provide greater accessibility, particularly for disabled stakeholders.
- Provide more graphs and charts, making the information detailed yet easy to grasp.
- Improve the peer review process.

### Communications

- Increase efforts to raise awareness with the general public.
- Produce one-page digests of ongoing activities, perhaps appended to the Canadian HIV/AIDS Policy and Law Review.
- Encourage two-way reporting. Rather than just provide information, request updates on the status of issues by stakeholders and government representatives, to complete the circle of communication.

## 7.4 Impact

### Recommendations

- Prioritize recommendations, and qualify as immediate, short term and long term.
- Make recommendations more specific regionally and according to discipline (government policy makers, professional associations, regulators, AIDS organizations, IDU organizations, caregivers, etc.).
- Be practical take into account the environment in which recommendations must be applied ("front-line" view); provide flexibility for implementation.
- Be more specific in requesting responses what exactly is being requested of the group addressed?

### Collaboration

- Engage other organizations more fully in follow-up. Although the Legal Network is extremely knowledgeable on a number of issues, it has limited resources. To increase its impact, the Network should go beyond

providing information, and develop joint action plans with other organizations to spread the effort of follow-up and involve other groups more fully. This would both increase knowledge transfer and have the added benefit of building other organizations' advocacy capacities more fully. This is more fully described below, in Section 7.5.1 *Follow-up – Joint Efforts with Member Organizations*.

### 7.5 Recommendations for Ongoing Evaluation

The following recommendations are made by The Alder Group to assist the Network in the ongoing evaluation of its programs. They are divided into two main sections: setting clear, measurable goals at the outset, and tracking activities against those goals on an ongoing basis.

## 7.5.1 Goal setting

Establishing clear, measurable outcome and process goals is key to effective evaluation. Although the programs evaluated in this report had clear process goals, the expected outcome goals were not well articulated. For the purpose of this evaluation, these were drawn from the recommendations in the final reports. For example, in the final report on IDU and HIV/AIDS, a number of recommendations for action were made, including a review of the legal status of drugs, the treatment of drug users with HIV/AIDS and needle exchange programs. The recommendations were then probed in the interviews to determine potential impacts.

Goals should be set at two points. The first, at the outset of the work, will focus on the process. As had been done up until now, goals will focus on consulting with knowledgeable stakeholders (experts, people directly affected by the issue, members, etc.), determining the key issues, and writing and disseminating the findings.

After the consultation and research phase, however, a second set of goals should be developed, focused on desired outcomes. The draft recommendations would be reviewed, with a view to setting goals. Related recommendations – in prevention, for example – could be grouped to form outcome goals. They would then be broken down in time, by forecasting what can be accomplished immediately, in the short term and in the longer term. In addition, the Network should specify the body called upon to make changes, and group goals according to target audience.

More specific recommendations, as called for by a number of stakeholders, will greatly assist in the evaluation process. It will also have repercussions on follow-up work, as identified below.

### Follow-up

#### Outputs - Publications and Other Activities

Following the direction determined through establishing clear, time-specific goals, publications and workshops would clearly reflect more specific outcomes and audiences:

- Final reports would specify priority goals, as well as immediate, long- and short-term ones.
- Cover letters to various types of groups (e.g. policy makers, professional associations, health groups) would specify goals in which their group can have a direct effect. They would be asked to respond, with any actions they may consider as a result of the report, and invited to discuss the issue further with the Legal Network.
- Materials could be developed that focus on a particular outcome goal and the group of recommendations made to achieve it. A focused mailing could be directed to the group implicated – policy makers responsible for this area, if policy is at issue, or the health care professional associations, if increased training is required.
- Info sheets could be directed to particular groups, with specific goals for those groups identified. A targeted mailing would ensure they received this highly relevant information.

The agendas of workshops, as well, would focus on particular goals set for the program area, with the audience targeted to participate.

#### Joint Efforts with Member Organizations

The Legal Network has clearly established an excellent reputation with regard to its research and analytical abilities. Its reports are well used, often as a tool to stimulate discussion on a particular issue. Having laid the groundwork, more detailed follow-up with member organizations will go far to advance common issues.

Clear outcome goals will make for clearer direction with regard to follow-up. To pick up on the suggestion of members, the Legal Network may be able to increase its follow-up and monitoring activities by engaging some of its members more fully in a true network of like-minded organizations working together. Specific outcome goals can form the basis of joint action plans. Although some of this is currently taking place, with the Legal Network working with particular groups as needed, a more formal process may be required to make this effort fully successful.

At the draft stage of a report, as members provide their input, they could be asked to consider participating in a loose coalition of members to follow up on the issue. The Network would act as the coordinating body. Members with specific expertise or ties to a particular area under study would identify which

of the goals they feel they could move forward. Once the Network received that input, it could call a meeting or teleconference of interested parties, identifying who had agreed to work on each section. A brief, written proposal would be requested of those members, and reviewed by a sub-set of the coalition, or outside experts in the area. The proposal would outline concrete actions the member proposes to take in these areas, and an indication of why it feels it can be successful.

Members whose proposals had been accepted would then take on the followup in that area, reporting back to and informing the coalition as a whole. Changes in policy or practices would be recorded in the Legal Network's database, and reported back to all members. The Legal Network's coordinating and recording role would thus benefit all members. The added effort required to coordinate activities should be more than offset by the increased impact of the work of many groups working together toward a common goal.

This approach requires discussion with members to be fully developed. As proposed, it may be viewed as being overly proscriptive; however, it is necessary to ensure that groups understand that they are making a commitment that must be met to ensure the issue moves forward and the quality of work remains high. Steps are in place (e.g. review of draft documents, workshops), or have been proposed (e.g. input to goal setting, based on draft recommendations) to ensure members are part of the process to develop the goals. These steps build on the sense of common community that already exists among AIDS organizations, to help develop a sense of joint ownership of issues. On this basis, it is expected that members will recognize the importance of closely reviewing proposed joint activities to ensure everyone's efforts are best directed toward advancing the issue.

The quality of work and reputation of the Legal Network is well recognized by members. This process would ensure that no member is compromised in joint follow-up activities. Members would, of course, continue to be free to address issues on their own as they see fit.

# 7.5.2 Effectively tracking against goals

Evaluation is much less onerous when done on an ongoing basis. A major effort is often required up-front, to establish the processes and database required to track activities, but done effectively, reports on activities and outputs become simple to create. Evaluating impact will always require greater effort, but can be simplified through effective tracking as well.

## **Activities and Outputs**

A flexible, easy-to-use database should be established to track activities

currently being done by the Legal Network:

- distribution of reports, info sheets and other products, by date, type of distribution (mail-out, via the AIDS Clearinghouse, at a conference), and specific goal being promoted. For example, if an info sheet is prepared focusing on prevention efforts with ID users, the distribution data would be coded against that goal.
- responses to reports received from groups in a position to act on specific recommendations (governments, professional associations, etc.), coded by level of activity they propose against the goals defined. For this evaluation, responses from organizations were reviewed and grouped as: (1) simple acknowledgement, (2) suggestion that the contents would be referred to or discussed sometime in the future, or (3) a clear indication that the information would be used for a particular activity.
- evaluation of workshops and meetings, linked back to the goals set for the program as a whole. For example, if the issue under discussion is changing practices of those working with people with HIV/AIDS, questions on the evaluation form distributed should probe what actions those attending the workshop intend to take, as a result of what they learned. Data from those forms would be entered into the database, recording the number of participants, number of evaluation forms completed, goals set and achieved for the workshop, and activities proposed by those attending against the program goals.

A number of new initiatives are also suggested, the results of which would also be tracked in the proposed database:

- Insert reply cards to major reports, requesting immediate feedback on the product and the process used to develop it, again linked back to the goals of the program.
- Create a pop-up survey on the Legal Network web site, to request feedback as viewers download documents, or leave the site. This information could provide general feedback on the web site itself, and more specific data on the document downloaded, including its planned use.
- Conduct reader surveys to determine:
  - responses to a new publication or format;
  - whether all members want to receive full reports, if summaries are available;
- whether printable, web-based info sheets would meet their needs. Although the surveys would take some effort and cost to conduct, savings would be generated by printing fewer of the large reports or info sheets.

In addition, two suggestions are made to make better use of existing resources:

Purchase more sophisticated statistical tracking software, to monitor use
of the web site. The free version currently being used does not provide
the detailed assessment necessary to fully understand use of the site and
potential improvements that could be made.

- To determine organizational efficiencies, track the use of internal resources and evaluate them on an annual basis. Tracking staff time and resources back to organizational goals can help determine whether they are being used most effectively.

### **Impact**

A detailed, empirical study, including incidence data, is the only way to unequivocally determine the impact of the work carried out in each program area. This represents a major effort, however, and given the many factors that affect changes in policy and practices, it would remain difficult to tie results directly to the efforts of the Legal Network. Given these limitations, this is not recommended at this time.

Alternatives that should be pursued are:

- working with Legal Network members in more intensive, active follow-up on goals identified (as described in Section 7.5.1 Goal-setting, Joint Efforts with Member Organizations). The reports back to the coalition by each member would provide ongoing feedback on the impact of programs. Qualitative and quantitative measures could be more easily applied with a broader group assessing impacts on an ongoing basis.
- conducting periodic surveys of stakeholders and others to focus on the impacts they perceive to have taken place on particular issues. Combined with the other tracking efforts described, this could form a much more abbreviated effort than was required for this evaluation.

The work of the Legal Network has been shown in this evaluation to be extremely well respected and effective. Closer tracking of outputs and activities, and evaluation of impacts will assist the Network in fine tuning its efforts for even further excellence in its work.

# 8.0 Appendix A - Interview Guides

## Canadian HIV/AIDS Legal Network Evaluation of Programs

General Module: (20-30 minutes)

### Information/Publications

- 1. How familiar are you with the work of the Legal Network?
  - 1 = not at all familiar
  - 2 = not very familiar
  - 3 = somewhat familiar
  - 4 = very familiar
- 2. Do you receive information from the Legal Network
  - regularly (for example, the quarterly the Canadian HIV/AIDS Policy and Law Review),
  - periodically or
  - infrequently (less than once per year)?
- 3. Have you used the Legal Network web site? In what way (read, download docs, refer to others for info, etc.) How often?
  - regularly
  - periodically or
  - infrequently (less than once per year)?
- 4. Which of the following publications do you recall seeing?
  - The Canadian HIV/AIDS Policy and Law Newsletter/Review
  - A final report on: HIV/AIDS in Prisons; Injection Drug Use and HIV/AIDS; Rapid HIV Screening at the Point of Care
  - info sheets on injection drug use and HIV/AIDS, HIV/AIDS in prisons or HIV testing

(If respondent does not recall seeing information, go to guestion 8).

5. How would you rate the value of these publications, where 1 is not at all effective and 5 is very effective?

| - | Newsletter/Review                | 1   | 2      | 3         | 4       | 5     |
|---|----------------------------------|-----|--------|-----------|---------|-------|
| - | Final Reports*                   | 1   | 2      | 3         | 4       | 5     |
| - | Info sheets*                     | 1   | 2      | 3         | 4       | 5     |
|   | (* - Specify if rating refers to | one | two or | all three | e iccue | 21020 |

- (\* Specify if rating refers to one, two or all three issue areas)
- 6. What is the one thing that stands out about Legal Network publications?
- 7. What would you say needs improvement?

## Collaboration and Consultation

- 8. Have you participated in a Legal Network event, or collaborated with them on a project?
- 9. What type of event or collaboration was it?
  - attended a workshop
  - was asked to review and provide input to a draft issue document
  - was asked to respond to a final report

| - | other |  |
|---|-------|--|
|   |       |  |

- 10.If so, how would you rate the experience, where
  - 1 = not at all collaborative and open (very little opportunity for input);
  - 2 = not very collaborative and open (limited opportunity for input);
  - 3 = somewhat collaborative and open (some opportunity for input);
  - 4 = collaborative and open (a great deal of opportunity for input). (If more than one experience, ask for information about the most recent collaboration.)
- 11.Based on your experience, what would you say was the best aspect of the collaboration?
- 12. Where is there room for improvement?

#### Effectiveness

I'm going to ask you a few questions regarding the effectiveness of the Legal Network as a whole. Are you familiar with their goals? (If not, provide the following information:

The aims of the Canadian Legal Network are to promote responses to HIV/AIDS that:

- respect the rights of people with HIV/AIDS and of those affected by the disease;
- minimize the adverse impact of HIV/AIDS on individuals and communities;
- help prevent the spread of HIV;
- facilitate care, treatment and support for people living with HIV and AIDS; and
- address the social and economic factors that increase the risk of infection.
- 14. Do you feel the Legal Network is successful in meeting its goals? (probe): Were they successful in:
  - raising awareness of the legal and policy issues around HIV/AIDS?
  - providing information on the issue?
  - stimulating discussion and collaboration in this area?
  - putting the issue on the agenda of policy makers?

- changing the practices of those working with people with HIV/AIDS?
- increasing skills and capacity of organizations to undertake advocacy efforts to address these issues?
- 1 = not very successful
- 2 = somewhat successful
- 3 = quite successful
- 4 = very successful
- 15.A (If yes to 14) What do they do that makes you feel they are successful (probe):
  - the depth of their research,
  - a particular strategy they use (e.g. effective media relations),
  - their way of collaborating,
  - their choice of issues.
  - B (If no to 14) What makes you say they are not successful?
- 16.Can you provide an example of something they have done that demonstrates their success/lack of success?

## HIV/AIDS in Prisons Module (20-30 minutes)

I understand you are aware of the Legal Network's program regarding HIV/AIDS in prisons. We hope that you will be able to provide us with your views on the Network's work in that area. (Questions will need to be adapted depending on whether we are speaking with staff from a federal or provincial correctional service, or an organization trying to promote change within the prison system. Adaptations for organizations are shown in brackets.)

- 1. How have you used Legal Network materials or resources in this area? Have you been involved in any other way? (Note: This question may be repetitive to #8 in the General Module. Try to determine depth of involvement as recipient of materials, collaborator?)
- 2. Has your organization made any policy changes regarding the way it deals with HIV/AIDS in prisons, in the past five years? (Are you aware of any policy changes regarding the way prisons deal with HIV/AIDS, in the past five years?) Are you aware of any changes proposed?
- 3. What changes have been made or are under discussion? (Are you aware of any changes have been made or are under discussion?) (probe)
  - education and protective measures for staff (in what form? how often?)
  - education for inmates (ibid)
  - policies regarding testing and confidentiality,

- preventative measures, including:
  - the availability of condoms and lubricant,
  - the availability of bleach,
  - needle exchange programs,
  - methadone treatment phase I (continuation for those who were on treatment outside),
  - methadone phase II (allowing to start treatment inside when medically indicated)
  - care of inmates,
  - compassionate release,
  - programs specific to:
    - women,
    - aboriginal inmates,
    - young inmates (provincial prisons only),
    - others?

(If changes are planned, ask when they will be made.)

- 4. Do you feel these changes have been implemented throughout your system? (the federal and/or provincial penal system?) Are you aware of other prison systems in Canada that have implemented these changes? To what extent? What makes you say that?
- 5. Would you agree with the following statements? As opposed to five years ago...
  - prisons now have a longer term, more coordinated approach to preventing the further spread of HIV.
  - prisons are more fully committed to preventing the spread of HIV.
  - prisons are taking a more pragmatic approach to drug use
  - care and treatment for HIV-positive prisoners have improved.

(If there is agreement, ask for elaboration: What demonstrates that in your organization? If no agreement, probe why.)

- 6. What are the key factors or events that led to the changes you described above? (probe)
  - The work of the Network (reports, discussions with CSC staff, articles, joint work with other organizations)
  - Media attention paid to the issue;
  - Efforts of other AIDS groups;
  - Directive from senior policy makers;
  - Other.
- 7. How would you characterize the effectiveness of the Legal Network in this area? (probe): Were they successful in:
  - raising awareness of the issue?
  - stimulating discussion and collaboration in this area?
  - providing information on the issue?
  - putting the issue on the agenda of policy makers?

- changing the practices of those working with prisoners?
- 1 = They had no influence at all; (the changes would have happened anyway);
- 2 = They had very little influence; (very little happened as a direct result of their work)
- 3 = They had some influence; (some policy changes resulted from their work)
- 4 = They had a great deal of influence; (they are the reason a lot of these changes were made.)
- 8. When did you last hear from the Legal Network on this issue? Do you recall the specific issue being addressed?
  - in the past two months,
  - in the past 6 months,
  - in the past year,
  - can't recall
- 9. What do you think the Legal Network should do, that they are not already doing, to advance this issue?

## Rapid HIV Testing at the Point of Care (20-30 minutes)

(Questions will need to be adapted depending on whether we are speaking to a regulator, an association of health care professionals, or a group supporting people with HIV/AIDS.)

- 1. Are you aware of the Legal Network materials and/or resources in this area? Have you been involved in any other way? (*Again, this question may be repetitive to #8 in the General Module.*
- 2. Did you have input into this issue? If so, were you satisfied with your level of input? Do you feel your views were taken into account?
- 3. Did you read the final report? Have you used it to deal with the issue of rapid HIV testing? Did you find the resources helpful? In what way?
- 4. Given the short time frame since its report was release, what do you feel has resulted from the Legal Network's efforts? (probe)
  - Raised awareness of the issue with the public;
  - Encouraged a closer analysis of rapid test kits by regulators;
  - Forced the manufacturers to address the issues raised in the report;
  - Encouraged open, informed discussion among stakeholders;
- 5. Are you familiar with the test kits? Do they:
  - have clear labelling regarding its sale or use?
  - include clear, plain-language material explains potential test results?

6. Can you explain the testing process, as you know it? (As your group/health care professionals administer it?)

### To regulators (provinces, colleges and health professional associations)

- 7. Is rapid HIV testing offered in your province? (If not) Do you have plans to introduce it? If so, when?
- 8. Are you aware of/Does your organization or province have policies governing the use of rapid HIV testing? If not, is your organization or province considering adopting a policy/discussing the issue?](probe)
  - Tests must be administered by certified health care professionals;
  - Pre and post-test counselling is required;
  - Test kits cannot be sold for personal or home use.
- 9. (When tests become available, do you plan to...) Does your organization provide training for health care professionals on counselling specific to HIV/AIDS? Use of the kits? If so, can you explain the process?
- 10. Are you making your members/health care professionals aware of their legal liabilities with regard to administering the tests? How?

#### All

- 10. What are the key factors or events that led to the processes/policies you described above? (probe)
  - Legal Network reports and information on the issue;
  - Media attention paid to the issue;
  - Efforts of many AIDS groups;
  - Directive from senior policy-makers;
  - Other.
- 11. How would you characterize the role of the Legal Network in influencing the process/policies regarding rapid HIV testing? (probe): Were they successful in:
  - quickly raising awareness of the issue?
  - stimulating discussion and collaboration in this area?
  - providing good analysis of the issue?
  - putting the issue on the agenda of policy makers?
  - changing the practices of those manufacturing and administering the tests?
  - 1 = They had no influence at all; (the changes would have happened anyway);
  - 2 = They had very little influence; (very little happened as a direct

- result of their work)
- 3 = They had some influence; (some policy changes resulted from their work)
- 4 = They had a great deal of influence; (they are the reason a lot of these changes were made.)
- 12.Do you feel the Network reacted quickly enough to this issue?
- 13. What do you think the Legal Network should do, that they are not already doing, to advance this issue?

### Injection Drug Use and HIV/AIDS

- 1. Are you aware of the Legal Network materials and/or resources in this area? Have you been involved in any other way? (Note: This question may be repetitive to #8 in the General Module.)
- 2. Did you have input into this issue? If so, were you satisfied with your level of input? Do you feel your views were taken into account?
- 3. Did you read the final report? the info sheets? the volume of background materials? Have you used them to deal with the issue of injection drug use and HIV/AIDS? In what way?
- 4. Given the short time-frame since the report was release, what do you feel the Network was able to accomplish with it and its efforts around the issue? (probe)
  - Raised awareness of the issue with the public;
  - Got the issue on the agenda of regulators;
  - Encouraged open, informed discussion among stakeholders;
  - Changed policies and procedures.
- 5. Are you aware of the recently released F/P/T report on injection drug use?
- 6. Within the past year or so, have you noticed any changes in practices or approaches, with regard to the treatment of injection drug users? (Probe. Ask for elaboration on any cited.)
  - Treatment programs are now more accessible to drug users;
  - Methadone programs are becoming more common;
  - Heroin maintenance trials are considered as an additional treatment option;
  - More physicians are available to treat drug users;
  - More research has begun to include drug users in clinical trials;
  - Needle-exchange programs are becoming more common.
- 7. Are you aware of changes that affect service providers who care for drug users? (probe)

- Ethical and practice guidelines are now being developed for those who provide treatment to people with HIV/AIDS who are drug users;
- Education programs for health-care professionals promote a harm-reduction approach.
- 8. Would you agree with the following statements?
  - Recently, Canada's drug policies seem to be moving towards a harm reduction approach, rather than focussing solely on reducing drug use.
  - Issues related to HIV/AIDS and injection drug use are more on the agenda of policy-makers, professional associations and community organizations;
  - There is a greater recognition of the fact that drug users need to be involved in the development of programs and policies affecting them;
  - There is a greater political will to make changes that will facilitate prevention efforts and efforts to provide care;
  - Development of a research agenda regarding injection drug use is moving forward.

(If there is agreement, ask for elaboration: What demonstrates that to you? If no agreement, probe why.)

- 9. What are the key factors or events that led to the changes you described above? (probe)
  - The work of the Network (reports, discussions with CSC staff, articles, joint work with other organizations)
  - Media attention paid to the issue;
  - Efforts of other AIDS groups;
  - Directive from senior policy-makers;
  - Other.
- 10. How would you characterize the role of the Legal Network in influencing changes in attitudes and policies regarding injection drug use? ? (probe): Were they successful in:
  - raising awareness of the issue?
  - stimulating discussion and collaboration in this area?
  - providing information/analysis on the issue?
  - putting the issue on the agenda of policy makers?
  - 1 = They had no influence at all; (any changes would have happened anyway);
  - 2 = They had very little influence; (very little happened as a direct result of their work)
  - 3 = They had some influence; (some policy changes resulted from their work)
  - 4 = They had a great deal of influence; (they are the reason a lot of these changes were made.)

(Where all efforts are rated as successful, ask which ones have the greatest impact on advancing the issue, i.e. Where should the LN be devoting most effort?)

- 11. What do you think the Legal Network should do, that they are not already doing, to advance this issue?
- 12.Is there anything else you would like to say about the Legal Network, overall?

## 9.0 Appendix B - Interview List

Individuals were interviewed from the following groups:

AIDS Committee of Toronto

AIDS Vancouver

BC Centre of Excellence

BC Human Rights Commission

BC Ministry of the Attorney General

BC Ministry of Health

BCPWA - British Columbia Persons with AIDS Society

Canadian Association of Elizabeth Fry Societies

Canadian Medical Association

CAS - Canadian AIDS Society

Centre for Bioethics, IRCM

COQC-sida – Coalition des organismes communautaires québécois de lutte contre le SIDA

Correctional Services Canada, Health Services, Ontario Region

Correctional Services Canada, National Headquarters

CPHA - Canadian Public Health Association

CTAC - Canadian Treatment Advocates Council

HALCO - HIV/AIDS Legal Clinic Ontario

HARS (HIV/AIDS Regional Services - Kingston)

Health Canada - Atlantic Division

Health Canada, Medical Devices Bureau

John Howard Society of Canada

Manitoba Health

Ministerial Council on HIV/AIDS

Newfoundland and Labrador AIDS Committee

Nova Scotia Dept. of Health

Nova Scotia Dept. of Justice, Health Care Division

Ontario AIDS Bureau, Ministry of Health

Ontario Ministry of Justice

Ontario Substance Abuse Bureau, Ministry of Health

PASAN - Prisoners with HIV/AIDS Support Action Network

Provincial Health Officer, British Columbia

The College of Family Physicians of Canada (Quebec office)

One member of the Board of Directors of the Canadian HIV/AIDS Legal

Network