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Collection of Project Case Studies

Hepatitis C Prevention, Support and Research Program

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Prepared for:
Hepatitis C Prevention, Support and Research Program
Population and Public Health Branch
Health Canada

By:
Barrington Research Group, Inc.
April, 2003

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Case Studies Overview

The following case studies were conducted as part of the mid-term evaluation of the Hepatitis C Prevention, Support and Research Program. Case studies were conducted in seven locations across Canada. A print version of the case studies is available and can be obtained through the Hepatitis C Program, Health Canada.

Complete list of case studies:

- Kamamakus Theatre Troupe (Prince Albert, Saskatchewan)
- Kingston Street Health Centre (Kingston, Ontario)
- Lethbridge HIV Connection (Lethbridge, Alberta)
- Hepatitis C Moncton Inc. (Moncton, N.B.)
- Hepatitis C Foundation of Québec (Verdun)/
Fondation de l'hépatite C du Québec (Montreal, Quebec)
- Winnipeg Hepatitis C Resource Centre (Winnipeg, Manitoba)
- YouthCO AIDS Society (Vancouver, B.C)

Case Study Methodology

The case studies were conducted for the purposes of:

- understanding the environment in which the Hepatitis C Prevention, Support and Research Program operates at the community level; and
- providing illustrative, in-depth examples of hepatitis C community-based support projects that have been funded by Health Canada.

Methodology

Upon completion of the case study on-site visits, the Barrington Group research team met for an entire day to share perceptions and to draft a report template that consisted of a standard series of questions that would be answered for each case study. Following this meeting, the Eastern and Western research team leaders organized the case study data using the report template. These outlines were given to the project director who then drafted the initial case study reports. Prior to external distribution, case study reports were reviewed by the research team for accuracy. This collaborative process among members of the research team provided several opportunities to debate the interpretation of the findings, thereby reinforcing the validity of the findings.

Case Study External Review

Prior to inclusion in the final report, the case study reports were sent to the coordinators/directors at the case study sites with a request for their comments on accuracy (both factual and interpretive aspects), tone, appropriateness and balance, thereby strengthening the reliability and validity of the findings.

Data Collection Instruments and Protocols

The following data collection instruments and Protocols were developed in preparation for the case studies.

- Community Case Study – Primary Client Interview
- Community Case Study – Secondary Client Interview
- Community Case Study – Staff/Volunteer Interview
- Community Case Study – Project Coordinator/Director Interview
- Community Case Study – Primary Client Survey
- Community Case Study – Board/Advisory Group Interview
- Ethical standards Protocol

Terminology

Several terms have been used in direct quotations throughout these case studies. For clarification, we include the following definitions:

“Hep C” – hepatitis C

IDU – injection drug use

Case Study:

Kamamakus Theatre Troupe

Prince Albert, Saskatchewan

The Development of Kamamakus

A young woman called Stephanie demonstrates a dynamic hip-hop dance routine at the front of a schoolroom in Montreal Lake, Saskatchewan. To the pulse of music emerging from the speakers, a positive message is delivered, “Live a healthy lifestyle.” Many of the 60 junior high school students in the audience try out the dance routine with much laughter and joking. Some mimic the stars they have seen on TV. Stephanie is joined by seven other troupe members who perform various skits and songs. They tell personal stories about the dangers of drug use, needle sharing, peer pressure and hepatitis C. The presentation lasts for about an hour and everyone—troupe members, teachers and kids—seems to enjoy it a great deal.

These young people have travelled for an hour and a half from Prince Albert to put on this presentation. They are not being paid. The funding from Health Canada for this two-year project has run out. The troupe has been driven there by a volunteer mother who put some of them up for the night, paid for the gas, and fed them pizza and breakfast. The Health Centre across the road from the school also feeds them, contributing a lunch of sandwiches and cake before the troupe performs a second time, now for the senior high students. By the time they get back to Prince Albert, they have had a pretty full day but some of them still have to go on to their part-time jobs; others have homework ahead of them to prepare for their own school the next

day. Their commitment to their troupe is remarkable.

The theatre troupe is known as Kamamakus, the Cree word for butterfly. This name was chosen to capture the nature of a butterfly—a creature of change, metamorphosing from a sluggish, unappealing insect to a beautiful, airborne creature. However, this change does not happen overnight. The butterfly must struggle to achieve greatness and so too the members of Kamamakus have struggled. Some were submerged in the ugliness and pain that exists in the cycle of drugs, alcohol, violence and abuse but with courage, they fought to reach their goals. The act of “breaking through” has become the motto and philosophy of the troupe.¹

Members of Kamamakus live either in Prince Albert, Saskatchewan, which, in 2001, had a population of 34,291 or on neighbouring reserves. The Prince Albert Health District (PAHD) encompasses several reserves and rural municipalities and serves nearly 76,000 people.² There is a great deal of mobility in and out of town as residents deal with issues of employment, incarceration, addiction, and poverty. Prince Albert is a hub for many services, particularly corrections. There are three federal institutions—the Saskatchewan Penitentiary, the Prison for Women, and Riverbend Institution; two provincial correctional centres—Pinegrove Correctional Centre (for women) and Prince Albert Correctional Centre (for men); and four youth facilities. Prince Albert is also a gateway

Sample Kamamakus Program

Poet's Prayer	Opening prayer, sweetgrass burning and song written/performed by Cory
Fresh Fried Bread	Song written/performed by Cory
The Vampire Skit	Skit explores dirty needles and the effects of hepatitis C
The Running Skit	Skit explores peer pressure, drugs and exercise
Hip Hop Dance	Dance by Stephanie/Jolene with audience participation
Breakdance Demonstration	Dance by Chad & Steven
Bullying Sketch	Discussion of peer pressure, gangs and suicide
Jigging Demonstration	Traditional dance by Chad & troupe member
Seven Days from Midnight	Sketch about IV drug use
Personal Stories	Stories by troupe members about personal experiences with drugs and alcohol
Fruit Basket	Game with audience participation
Circle Dance	Dance with all asked to participate

to the North. As a community stakeholder explained to the evaluators:

Kids come here from northern rural communities and reserves and they are looking for a better life. They can fall prey to people who take advantage of them.

It has been estimated that up to 200 children live on the streets of Prince Albert at certain times of the year. Overall, in the PAHD, population characteristics include:

- 15% of the population have less than a grade nine education; 26% do not have a grade 12 diploma;
- Average family income of Prince Albert residents is \$46,309.00 per year;
- 32.7% of families in Prince Albert are single-parent families;
- Over half of the population in Prince Albert has an income under the national average;

- 25% of the population's income is less than \$20,000 a year;
- 35% of families are considered low income compared to the national average of 22%;
- 34% of families are of Aboriginal ancestry.³

Other social issues identified by the PAHD include the negative impact of shift work on family time and youth supervision, and high rates of teen pregnancy, youth crime and child prostitution.⁴ Some schools in the area experience a 100% turnover in the student population during the year.⁵ According to a staff member we interviewed from the Methadone Assisted Recovery Program, Ritalin® use is a serious problem in Saskatchewan where more prescriptions for this drug are issued than in any other province. The prescriptions are sold for cash and the Ritalin (or another drug, Dilaudid®) is melted down and injected. (Ritalin, or methylphenidate HCl, is a central nervous system stimulant commonly prescribed for atten-

tion-deficit hyperactivity disorder. Dilaudid is a prescription analgesic.)

In Prince Albert there are several organizations that offer services to individuals infected with or affected by hepatitis C. In particular, the Sexual Health Clinic tests for HCV and STD's, provides transportation for patients to access treatment in Saskatoon, offers support to families, and provides sexual health education in schools and correctional facilities. Prince Albert also has a methadone clinic and a needle exchange that, at the time of our visit, was providing 6,000 needles per month. However, the incidence of intravenous drug use appeared to be even greater; the PAHD Population Health Director commented, "We get back more[needles] than we give out".

In response to the high number of HIV cases diagnosed in the Health District between September 1996 and February 1997, the Prince Albert Seroprevalence Study was conducted. The study's objectives were to estimate the prevalence of HIV, HBV, and HCV among injection drug users and their sexual partners in Prince Albert, to describe high-risk behaviours and the risk factors associated with them, and to determine service needs and barriers. The study accessed 247 injection drug users and/or their sexual partners. Key results included:

- 40% of all participants had hepatitis C
- 66% had a history of abuse (abuse before age 16: sexual 38%, physical 41%)
- 65% experienced alcohol abuse in the home
- 58% left home before age 16
- 34% experienced mental health problems in the home
- 20% experience drug abuse in the home

- Injection drug users engaged in risky behaviours
- Their sexual partners also engaged in risky behaviours
- Alcohol dependence was high⁶

The high prevalence of hepatitis C and needle use in Prince Albert was a concern for the Meyoyawin Circle Corporation, an Aboriginal health organization committed to holistic health and striving to represent the health concerns of the Aboriginal community to the PAHD. On February 2, 2000, with the support of Health Canada's Hepatitis C Prevention, Support and Research Program, Prevention and Community-based Support Regional Project Funding, Meyoyawin and the PAHD held a one-day conference on hepatitis C. Approximately 70 people attended and their discussion resulted in the creation of a working group to address the critical needs of at-risk youth and issues related to injection drug use. Some of the group's members had dramatic experience and they thought that drama and dance would provide a better means of communicating health promotion messages to youth than would traditional techniques.

The group worked with the Health Promotion Facilitator at the PAHD to prepare a formal proposal for the Prevention and Community-based Support Regional Project Funding. Members included:

- Health Promotion Facilitator, PAHD;
- Sexual Health Clinic Nurse/Manager, PAHD;
- The Youth Activity Centre;
- West Flat Citizens Group, Inc.;
- Prince Albert Indian and Metis Friendship Centre.

A member invited his drama coach to attend one meeting. She became involved in the development of the project proposal and subsequently became the troupe's acting instructor. The proposal was submitted at the end of March but there was a delay in the approval process. On August 8, 2000 the PAHD received \$61,990 for Kamamakus for a 22-month period ending June 30, 2002. Along with many in-kind contributions, the PAHD also contributed approximately 15% of the project's budget.

The project's purpose was described as follows:

To take at-risk youth who feel that they have no direction or purpose, including those that have hepatitis C, and provide a learning opportunity for them to find their strengths in a creative and disciplined environment. By involving these youth in the education process, we hope to help them build self-esteem and see the value of their contribution in a larger social context. As these youth become advocates, they also learn to use their own voices and talents in a productive and hopeful enterprise.

Kamamakus Proposal for Hepatitis C Funding,
March 27, 2000

It was the intent of the project to:

- Raise awareness about the risk factors associated with hepatitis C;
 - Raise awareness about the implication of personal health and lifestyle choices in contracting the virus;
 - Involve at-risk youth in raising peer group consciousness to affect a broader population of young people;
 - Involve the participants in decision-making and problem-solving skills;
 - Serve as a catalyst to accessing different and positive social environments for youth;
- Build self-esteem, self-concept, interpersonal social skills and whole life discipline;
 - Incorporate a multicultural aspect of learning focusing on mental, physical, emotional and spiritual health; and
 - Involve the audiences in the measurement of success.

Kamamakus Implementation

Activities

In the fall of 2000, a core group of youth solidified to form a troupe. They were mainly Aboriginal and included one individual with hepatitis C. Twice a week, they attended four-hour workshops on stage performance and technology, stagecraft and general technical skills. Specific skill areas included the following:

- **Self-esteem/self-concept**

- Introduction to acting
- Improvisation and its uses
- Vocal development
- Body language skills

- **Communication skills**

- Oral interpretation
- Reading skills
- Vocal projection
- Oral tradition

- **Self discipline**

- Cultural studies
- Directing

- **Interpersonal/social skills**

- Performance techniques
- Peer coaching

The troupe members began to acquire information about hepatitis C, risk behaviours and prevention strategies. They attended workshops provided by staff from the STD clinic, observed

public health nurses in school classrooms and interviewed people living with hepatitis C. They read about hepatitis C and discussed their own experiences and those of their friends and families. They attended a series of writing workshops conducted by Maria Campbell, a well-known Métis playwright. They began to incorporate all this knowledge into skits, songs and a question and answer session.

In November 2000, Kamamakus presented their debut performance in Prince Albert as part of Drug Awareness Week. By the end of March 2001, they had completed 15 performances in schools and community halls in the Prince Albert area and had reached approximately 1000 students and adults with their hepatitis C message.⁷

One of their early performances was attended by a member of Operation TARGET—Together Accepting Responsibility Giving Enhanced education Towards youth—a partnership involving the Prince Albert City Police, the RCMP, Addictions Services, the Sexual Health Clinic, Prince Albert Correctional Centre, Prince Albert Youth Activity Centre and various community role models. This program was designed to deliver a consistent message to northern Saskatchewan on battling the effects of drugs, gangs and child exploitation.⁸ The TARGET member was moved by the power of the Kamamakus message and immediately saw that the young actors connected with youth in a way that the officers could not. TARGET quickly incorporated Kamamakus into their own presentations. Troupe members accompanied them in their police airplane to over 20 northern communities. After seeing them perform in the TARGET program, several northern bands paid for Kamamakus to return and perform at various health conferences and other special events.

By the end of their second year, the troupe had developed approximately 30 songs, dances, skits and informative pieces. Their understanding of youth and their needs led to some important program changes. As the project evaluator explained:

Very quickly the Kamamakus troupe realized that the youth audiences had a short attention span and so they modified the pacing, timing and type of presentations, alternating from song, dance and short skits with the information they wanted to deliver. They also recognized the need for the youth to not sit passively and so there are several songs and dances where the audience becomes actively involved in the performance.⁹

The information they provided was direct and non-judgmental. As one of the youth leaders, Jolene, explained:

You can't preach to kids because they don't like that. Their parents preach and the kids see them as hypocrites because they engage in the same behaviour. We just let them know how they can be safer about some of the things they might do. We have information and give it to them. The kids are sick of hearing "Don't do that!" and will do it anyway. Especially here because there is little else to do in terms of sports and recreation.

They also tried to personalize the information they provided. According to Jolene:

We try to make the performance a personal experience, share our personal stories. People identify with that.

They made the information as simple as possible. For example, when talking about tattoos:

We tell kids to make sure the places are safe, clean and have autoclaves. If they can't remember "autoclave", we tell them to ask if the place has a machine that cooks everything at a high temperature. Put it in simple language.

Finally, they made the experience fun.

Between April 2001 and March 2002, Kamamakus performed in approximately 75 venues.¹⁰ These included health and health educator conferences, correctional institutions, community schools and high schools in the Prince Albert area, schools located in northern communities, the Aboriginal Winter and Summer Games, and many other health and educational events. As the project evaluator commented:

*The overwhelming number of requests by schools, institutions and groups for Kamamakus to perform, coming from all areas of the Province, is a clear sign that the format and style of the message is connecting with youth and adults as well.*¹¹

Administration

This tremendous success, however, was not reflected behind the scenes, in particular because the management structure for Kamamakus had been poorly defined. The original agencies had come together for the sole purpose of preparing the proposal. When the project was funded, the PAHD held the contract and thus was responsible for the financial administration but the structure of the board, hiring policies and project management were not clearly defined. As one board member explained:

This is not an organic board. The board never had control of the budget. There was/is some confusion about who is in charge and who pays the bills. From the beginning the structure wasn't there to move the project along. There was never a set number on the board— one week someone might bring an interested friend along who then became a board member. There were a few key players who were around from the beginning.

Another board member commented:

We weren't really a board with a mandate, or a president or anything like that. We were more of a committee. This committee got less and less involved over time.

And a third added:

Kamamakus youth were not always represented at board meetings. Initially the [Acting Instructor] represented them, but this was not a good system. It was not a good advisory group—[it] needs to have people involved who care about hepatitis C.

Issues related to control, discipline, reporting and expenditures surfaced; personality clashes emerged; the relationships that the acting instructor had with both troupe members and the external evaluator deteriorated; troupe members were confused by the lack of structure, leadership and trust. As the Project Progress Report indicated:

*It was very surprising to see how quickly a highly successful project could fall to pieces due to poor initial structuring... The youth had never been part of the board meetings to any meaningful degree. The project had been designed and funded on the [presumption] that adults could find, train and use youth to educate youth and did not recognize the inequity of the power relationships.*¹²

Eventually, in the fall of 2001, the Acting Instructor resigned. Around the same time, the Health Promotion Facilitator position also became vacant. Then, as one of the board members explained:

They really lost momentum. There was no one to call, no one to organize meetings and keep people informed.

The board was basically rudderless and funding was running out, yet Kamamakus continued to perform.

The Troupe

The key to sustainability lay with the troupe members themselves. In the early days of the project, the core group of youth wrote their own goals and objectives. They all signed the following Vision Statement:

Kamamakus Vision Statement, October 12, 2000

Mission: To inspire the youth in all communities by conveying the message that they are the future and they can make their dreams happen.

Goal: The main goal of Kamamakus is to raise awareness of hepatitis C prevention and the importance of living a positive, healthy lifestyle.

Vision statement: We the Kamamakus Theatre Troupe have discussed and decided the vision and direction of the group:

- **Help** youth become as informed as possible on the hep C virus
- **Communicate** the dangers of hep C to as many youth in the schools as possible
- **Participate** in plays, monologues and music, as a creative way to reach as many youth with the message as possible.
- **Create** an awareness on the streets of the hazards of this disease
- **Persuade** the adult community to have a more caring attitude towards the youth of this city
- **Encourage** and assist youth to make the right choices
- **Increase** our own knowledge and experience
- **Improve** our own performance and life skills
- **Succeed** in being a role model to my peers

They forged a pact with each other to remain drug- and alcohol-free, to attend rehearsals and hepatitis C workshops, and to be on time for all planned meetings.¹³ When a member's dedication or interest flagged, the group voted to decide whether or not to give him or her a second chance. When life issues intervened, they tried to counsel and support their peers as best they could.

The heart of the project lay in the twice-weekly sessions at which the group met to:

*Develop, rehearse and share ideas to create strong presentations for delivery to their peers. Here they support and encourage each other and maintain the discipline to keep their troupe together and their goals moving forward.*¹⁴

Another management tool was the use of a talking circle. As troupe members described:

At practices we have a talking circle and we make decisions about what to do, who is going to do what, and how we will get the message out there. Everyone has a chance to get their input in.

Group support was a significant factor in the development of troupe members as individuals. As the project's most recent Progress Report stated:

All members are now back in the school system or work place. Risk behaviours have been reduced as members have taken and stuck to a pledge not to drink alcohol or take drugs. They are very serious about their chosen path of being role models to their peers. They all celebrated a year of being alcohol- and drug-free.

When asked how Kamamakus had changed their life, troupe responses included:

- *I was getting peer pressure to try drugs. I did this instead.*

- *Bad lifestyles lead to disease. It wasn't fun any more.*
- *This is about positive lifestyles. It helps you.*
- *People with bad lifestyles are unemployed. They have no food, no house. It has let us see what is not a good lifestyle.*

The Prince Albert Chief of Police could see their personal growth. He commented:

Since September 2000, I have seen a great change in the young people's self esteem and development. They continue to grow and it is obvious that they are confident in their performances. The young people's message to their peers is a great part of what they do. I have no doubt the youth will continue to do great things.

At the peak of the project's management problems, a number of troupe members dropped out. Two of the remaining four members got together and held auditions. By October 2001, they had 10 members again and at the time of our visit in April 2002, they had 13 members.

A new, youth-centred structure emerged. The position formerly held by the acting instructor was changed to that of Theatre Manager and one of the young troupe members was hired to fill it. Kamamakus members began to attend all board meetings and were able to make suggestions about future directions for the troupe.

With the change to self-management, school became a clear priority for troupe members. As Cory, the lead singer, commented:

If Kamamakus affects their schooling, they are put on probation. School comes first... Their grades have gone up. We ask to see their report cards.

And troupe members added:

If someone gets behind in school, they get pulled out until their grades improve.

They were also getting involved in other activities as well such as circle dances, sports and air cadets. Cory was planning his own talk show.

Kamamakus Theatre Troupe Project Accomplishments

1. Impact on level of public awareness

It is evident from the information we were able to collect on our case study visit that Kamamakus has had an impact on public sensitivity to and awareness of hepatitis C in Prince Albert and northern Saskatchewan. To begin with, being involved with the project was an educational experience for board members. As one explained:

Each one of us on the project knew hepatitis C as just a word—we all learned. The information is just not out there, especially for youth with the dangers of tattooing and piercing. This is a city with a lot of needle use and poverty. There is a great need for information that is accessible—they need Kamamakus. There is a lot of success with this, they have reached a lot of kids—to change kids' lifestyles and behaviours they need the information and it needs to come from youth.

In terms of accessing the public, between March 14, 2001 and April 12, 2002, approximately 9,410 people saw Kamamakus perform in approximately 36 different venues —some venues had multiple performances.¹⁵ The largest audience was the Aboriginal Winter Games, which was attended by approximately 5,000 people; the smallest was at the Cosmetology Department at the Saskatchewan Institute of Applied Science and Technology (SIAST) where

there were only 20 in the audience. However, even this performance had a lasting impact because the information they provided precipitated the addition of “precautions” to the cosmetology curriculum. A frequent venue for the troupe was the Youth Activity Centre, where they played every two months. As Cory described it:

It is electric when Kamamakus gets there. People come in, they fill the place and they stick around.

The ability of the troupe to interact with young audiences was its greatest strength. The use of music, dance and personal anecdote combined into a powerful prevention message that was well received by a high-risk target population. Troupe members also felt that they have made a positive difference for many individuals, particularly for the kids who see them as role models. Troupe members commented in their interview:

We sometimes hear the kids singing the songs we do while they are walking down the street. The songs and skits we do are pretty well known in the community. Sometimes Cory gets recognized walking down the street, some of the other youth have been recognized as well.

When asked if the project had made a difference in the community, Cory and Jolene described a number of interactions where they had been able to raise awareness about hepatitis C. They described visiting correctional centres, making a presentation at the annual school principals’ meeting, and working with troubled youth. In each case, they had been able to promote prevention messages and model a positive life style. One striking example occurred at the Aboriginal Youth Summer Camp in LaRonge, where the troupe had performed all week to Saskatchewan youth. As Jolene recalled:

At the end of one of the performances kids kept coming into the tent. Cory told stories about his life, gangs and other things associated with hep C [hepatitis C]. One kid was wearing a bandana to represent [his gang], and he took it off and put it in his pocket as Cory was talking.

Everyone concerned is certain that, as a result of the Kamamakus presentations, over 9,000 Saskatchewan children, teens and adults now know about hepatitis C, the disease, the pathways of infection, risk behaviours and prevention strategies.¹⁶ At the time of our case study visit, the troupe was looking forward to performing at the First Annual Aboriginal Hepatitis C Conference that was held in April 2002, in Edmonton. They were also going to do a presentation at the conference on peers as educators. They had also done some videotaping to show groups how to develop a popular theatre troupe in their community.

2. Development of Capacity of Board Members

Another Kamamakus accomplishment related to increasing understanding in the community about hepatitis C. The board had experienced a positive change and was clearer on how to interact with these independent young people. It had become:

A circle of adults who are active in public health administration and programming and who hold great respect for the youth involved.

When this description was compared to early interactions when the young players were completely shut out of the decision-making process, this was progress indeed. The board had developed work plans for the coming year and planned for Kamamakus to become administratively and financially independent. However,

there was still board development work to be done; a stronger management structure and clearer role definitions were still required.

3. Development of Effective Partnerships

Some strong partnerships had developed in the community and continued to make significant contributions to the project, as follows:

Prince Albert Health District

- Project coordination by the Health Promotion Facilitator; education by Sexual Health Clinic Nurse/Manager; support and commitment by the Medical Health Officer and the Executive Director of Population Health
- Office space provided for the Theatre Manager and boardroom space for meetings
- Technical support, supplies and training workshops provided for troupe members on public health issues and presentation skills

Prince Albert Grand Council

- The Sexual Wellness/Prenatal Nutrition Coordinator was very active on the board
- Provided access to key venues for presentations

The Youth Activity Centre

- Director was a key player on the board
- Rehearsal space provided twice a week
- The first point of contact for many youth

TARGET (Prince Albert Police Department/ Royal Canadian Mounted Police)

- Provided access and transportation to northern venues
- Provided on-going support and publicity

The most important lesson learned through the project was how an atmosphere could be created in which the young players could find a successful, culturally appropriate outlet for their creativity. The sense of cohesion and teamwork experienced by troupe members caused their communication, decision-making and theatre skills to improve significantly. Their success had a positive impact on their self-esteem and such lifestyle choices as staying in school and being drug- and alcohol-free. The theatre proved to be a catalyst for them. They could then communicate these positive experiences to their young audiences in engaging and acceptable ways to spread the hepatitis C prevention message.

The Challenge Faced by Kamamakus

One over-riding challenge faced the troupe and that was the issue of sustainability. They had hoped that Health Canada funding would be extended, but the proposal process was very lengthy and feedback was slow to come. At the time of our visit in April 2002, the project was without funding. They had received \$15,000 from the Saskatchewan Entities Program to support members' extended time and travel commitments over the winter. The troupe was preparing a documentary film for which they were seeking a funder and the board was exploring charitable status to make fund-raising easier. However, as the project's final Progress Report stated:

It is critical that the PAHD and the board find funding for one more year to train the Kamamakus Theatre Manager in the necessary skills in order for the group to self-manage. It is unrealistic to believe that such a youth theatre group can ever be self-supporting in a city the size of Prince Albert but they can certainly continue to carry on with their mandate by

forming new partnerships with other groups and institutions who want and need to work with youth directly on like issues.

The future of the troupe seemed problematic but as far as the troupe members were concerned, they would continue. As an early troupe member had written:

The butterfly will continue to carry its message upon wings of concern and hope, and [will] fly with the grace and skill of a thespian plying his trade in the spotlight on centre stage.¹⁷

The following types of documents were reviewed in the preparation of this case study:

- Project documents from Health Canada
- Various scenes the troupe performs
- Original project proposal
- Kamamakus brochures
- Listing of past gigs, including approximate number of people who saw the performance
- Kamamakus vision statement, goals and objectives
- Letters of support
- Newspaper clippings

Case Study Information:

The case study was conducted April 15 to 17, 2002.

The case study research team included: Joyce Pearson and Jennifer Chandler. The analysis was conducted by Joyce Pearson. The case study was prepared by Dr. Gail Barrington. It was approved for distribution by the Executive Director, Population Health, Prince Albert Health District on August 26, 2002.

In total 10 interviews were completed and the troupe's performance was observed twice. The breakdown is provided below:

Staff and volunteer interviews:

3 (2 were group interviews; total of 11 individuals)

Board member interviews:

3 (1 was also a secondary client)

Primary clients:

1 focus group with 5 youth

Secondary client interviews:

3 (1 was a group interview with 4 individuals)

- Dr. Lanoie
- Director of Population Health; Health Promotion Facilitator – Prince Albert Health District; Methadone Case Manager; Manager of Sexual Health Clinic
- Youth Activity Centre and board of directors for Kamamakus

External evaluator: 1

Observation of Kamamakus theatre troupe performance: 2

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Case Study:

Kingston Street Health Centre

Kingston, Ontario

Development of the Street Health Centre

The Street Health Centre (SHC) in Kingston provides primary care, prevention and support services to hard-to-reach and high-risk groups including people who inject drugs, street-involved youth and people involved in the sex trade. It is housed in an older building, occupying what was once three small stores located in one of the oldest parts of the downtown core. It is only a few steps from the Hôtel Dieu Hospital and the Youth Drop-in and Alternative School. The SHC is a busy place, bubbling with activity both inside and out on the street. People come and go, some linger and chat with clients or staff. Frequently, staff members can be observed walking around just to talk with the clients. During our three-day visit on-site, we observed many “regulars” that seemed to be quite happy to have a place to call their own and to have friends (either staff or other clients) to meet there.

The Centre is subdivided into three major areas:

- *The Needle Exchange and Methadone Dispensing Area* where people who inject drugs go to get needles and kits as well as methadone treatment. The clinic is open seven days a week. This area is closed off from the other areas of the SHC during the weekends.
- *Medical, Counselling and Outreach Services* where many clients go to access the nurse practitioner, the doctor and the counsellor.

Some people also get together in this space to have a chat or get information/brochures or used clothing. This space includes the reception area and office, some examination rooms, a counsellor’s office, and storage space.

- *The Quiet Area* which includes an area for support group meetings, administrative offices, a community kitchen area, and a children’s room with a television and many toys and supplies to keep children busy and happy while their parents are taking part in a support group in the next room.

The populations targeted by the Street Health Centre include:

- People who inject drugs and individuals involved in behaviours at high risk for hepatitis C, HIV and other drug-related harm;
- Individuals infected with hepatitis C and those affected by it;
- People marginalized from mainstream social supports and negatively affected by determinants of health (street-involved youth, homeless, co-infected, ex-prisoners);
- Health service and community service providers working with HCV-affected populations (medical professionals, shelters, addictions agencies, etc.); and
- The local general public, in their understanding of HCV and injection drug use issues (addressing issues of stigma).¹

The evolution of the SHC over an eleven-year period is an interesting example of the development of a comprehensive care and support model. It originated at the Kingston AIDS Project in 1990 as a health education outreach program. It had one staff member working half time in the community and half time in the local prisons. It was quickly apparent that a needle exchange program was needed and so in 1991, the Keep Six! Needle Exchange Program was developed, the first such program in a mid-sized Ontario city. Using a community development approach, clients were engaged in the program and a Community Advisory Group² was established. In 1992, as there was a significant incidence of HIV positive test results attributable to injection drug use, the needle exchange program received funding from the Kingston, Frontenac, Lennox and Addington (KFL&A) Health Unit and more staff were hired.

In 1995, the program came under the direct management of the KFL&A Health Unit. As the original location was far from downtown and not adapted to the needs of these clients, the Street Health Centre opened in its current location in 1996 as a satellite office of the Health Unit, under the administrative direction and support of the Sexual Health and Sexually Transmitted Disease (STD) Program. The individual who had been with the program from the beginning was hired as Coordinator. In 1997, the Mandatory Programs legislation was introduced by the Ontario Ministry of Health and *Keep Six!*, like other public health programs, was funded 50-50 by the municipal and provincial governments.

Also in 1997, after a year of needs assessment and program and policy development, a Methadone Treatment Clinic was devel-

oped in partnership with a local family doctor who strongly believed that a significant number of individuals with chronic opioid dependence would access methadone treatment if it were locally accessible. In early 2000, a full-time nurse practitioner was added to the SHC staff complement on permanent secondment from the North Kingston Community Health Centre. Thus, by 2001, the incremental and targeted response to various community-based needs had resulted in the following roster of services and programs at SHC:

1. Keep Six! Needle Exchange Program;
2. Methadone Treatment Clinic (with a roster of over 200 patients and with five participating physicians);
3. Full-time on-site nurse practitioner;
4. On-site medications dispensary;
5. Injection Drug Use Outreach Strategy worker;
6. Hepatitis C Strategy (the subject of this case study);
7. High-risk youth medical clinic;
8. Youth, opiate users, men's and women's support groups; and
9. On-site, part-time respite care for children of SHC client families.³

While the Street Health Centre itself has no legal incorporation status, it is the centre of a web of important partnerships,⁴ including:

- **KFL&A Health Unit** – the main sponsoring agency, provides core funding for the Keep Six! program and supports for the Coordinator's salary and utilities.

- **North Kingston Community Health Centre** – supports the Methadone Treatment Clinic and funds key administrative support staff; provides the permanently seconded Nurse Practitioner.⁵
- **Lily-King Primary Care Group** – supports the Methadone Treatment Clinic and the provision of physician, nursing and dispensing services on site.
- **Hôtel Dieu Hospital** – provides the storefront clinic office.

Managing these key partners and multiple streams of funding was a complex task. As one Advisory Committee member commented:

Collectively, it is not conventional. It is a nightmare for the money. It is amazing that they can survive!

Looking at the SHC's incremental growth and continued response to emerging community needs, it appears that some successful marketing and management practices have made this unconventional organization continue to function and grow.

By 2002, the evolving nature of the services offered, including the expansion of the SHC into primary care, suggested yet another change. The plan was that while the needle exchange would remain a mandatory public health program, the SHC would become a satellite of the North Kingston Community Health Centre (funded by the Community Health Branch of the Ministry of Health and Long-term Care).⁶ In April 2002, the brief, *Health for All? A Primary Care Profile of the Street Health Centre* was commissioned for the purpose of program planning and to aid the transition process and negotiations were under way at the time of our visit. As the document explained:

The possibility of a primary care centre for the priority populations of the SHC is very real and would be of great benefit to the current and potential patient population. Such a concrete development would be a further, and perhaps most pivotal, step in the movement to bring injection drug use out of the margins of society and into the mainstream of universal, equitable and community-responsive health services.⁷

Context

The catchment area for the SHC is the city of Kingston and the counties of Frontenac, and Lennox and Addington. Including Kingston's urban core and the two surrounding rural townships, the combined population is 175,568. However, as the Methadone Treatment Clinic is the only methadone provider between Ottawa and Oshawa, the Centre also serves clients from Hastings and Prince Edward Counties to the West, and Lanark, Leeds and Grenville Counties to the East, for a combined district population of 475,487.

The district has a pronounced demographic bulge of baby-boomers, a slightly older population than the provincial average, with higher percentages in the elderly and near-elderly age groups. There is a high number of "lone parents" in Kingston; the level of youth unemployment is higher than the provincial average; and the number of households living below low-income cut-offs is also higher.⁸

The SHC principally serves the area of North Kingston, a socially and economically disadvantaged area of the city with high poverty levels. It is also the primary area for the sex trade and drug activity. A community needs assessment conducted by the North Kingston Community Health Centre (2000) found poverty, housing,

transportation and access to health services to be pressing community issues.⁹

Kingston has a pronounced prevalence of injection drug use, having been the main Ontario city for the production and distribution of methamphetamine in the 1970's. The region includes 11 federal prisons and one provincial detention centre. Over 7,000 federal inmates are detained in these institutions and their families often relocate to the area. It is also the home of Queen's University which has a large school of medicine, a school of nursing and a centre for family medicine.

A review of positive HCV lab results reported to the KFL&A Public Health Unit was conducted by its Communicable Disease Department for the years 1995 through 1999. Note that these results include the local federally incarcerated prison population:

**Lab Results, KFL&A Public Health Unit¹⁰
1995-1999**

Year	HCV+ Result
1995	490
1996	627
1997	585
1998	790
1999	593
Total	3,471

The prevalence of hepatitis C among federally sentenced prisoners was estimated to range between 33% and 41%.¹¹ Seroprevalence of HCV in one medium-security institution for men increased from 28% to 33% from 1994-1998.¹² A 1998 study found that 24%¹³ of the prison

population reported chronic injection drug use while incarcerated, an increase of 100% over a four-year period.¹⁴ Federal prisoners who use injection drugs do not have access to sterile syringes and only a small number are on methadone therapy. Given the movement of such individuals in and out of these prisons, the Kingston population is seen to be at risk for diseases such as hepatitis C.¹⁵

Hepatitis C Strategy Project

Over the years, the SHC conducted a number of needs assessments and other research activities which helped to formulate SHC's first proposal for Health Canada's Hepatitis C Prevention, Support and Research Program, Prevention and Community-based Support Regional Project Funding. These included:

- *Health and Treatment Needs Assessment of Opiate Users (1996)* – led to the development of the Methadone Treatment Clinic and indicated a strong prevalence of HCV infection, in addition to client demand for information, education, advocacy and support.
- *Community Needs Assessment (1998)* – identified the need for enhanced primary care services to people who inject drugs, street-involved youth and sex trade workers. Again, this assessment indicated a strong presence of HCV in the client community and identified unmet health counselling, treatment, educational and support needs.
- *Environment Scan (1998)* – led to the funding of an IDU Counsellor position to assist in identifying community and client-identified need for outreach, support and education to people who inject drugs. This scan presented data on epidemiological trends, including HCV

prevalence and the rise of HCV-specific needs.

- *Chart Reviews* (ongoing) – determined a 73% seroprevalence of HCV infection among methadone clients and 87% seroprevalence among participants in the SHC *Creating a Better Life for Women* program, a series of information and discussion sessions aimed at local sex trade workers. Only 1% of SHC clients receiving medical services were engaged in anti-viral treatment for their HCV.

Informal consultations were also conducted prior to applying for funding from Health Canada. Individuals living with, affected by or at-risk of HCV were consulted along with health professionals, including social workers and specialists in the area of gastroenterology, family practice, hepatology and internal medicine.

A pronounced need for hepatitis C-specific education, counselling and support for SHC clients was identified. As the agency commented in its proposal to Health Canada, a combination of epidemic-prevalence and poor relationships with mainstream health and medical services has resulted in a marked increase in utilization of our staff resources for issues related to hepatitis C.¹⁶ Primary areas of need identified by the consultation process included:

- Basic information was needed in a variety of media, including one-to-one counselling and group seminars due to high levels of illiteracy which reduced the efficacy of written information;
- Health teaching and counselling were needed in the areas of self-care and lifestyle issues;
- Education and counselling related to HCV risk reduction were needed;

- Emotional support related to diagnosis, infection, illness and treatment was needed;
- Advocacy for access to treatment and for addressing discrimination and stigma issues was required;
- Education (presentations and in-services) in the general community and other social/health services was required; and
- Peer and group support was needed for those infected with or affected by HCV.

In October 1999, the SHC submitted their proposal to Health Canada for the Hepatitis C Strategy project. It had the following goal:

To develop the capacity of the local community to respond in a healthy manner to the many health and social issues faced by those living with, at risk of or infected by hepatitis C.¹⁷

The project was funded for a total of \$125,000 from September 2000 to September 2002 (\$50,000 in 2000-2001 and \$75,000 in 2001-2002) accounting for approximately 9% of the total agency budget of \$600,000. At the time of our visit, there were ten full-time-equivalent (FTE) staff positions at the Street Health Centre, one of which was supported by this project:

- *Keep Six! Needle Exchange Program*: 1 FTE Coordinator, 1 FTE Outreach Worker
- *Methadone Treatment Clinic*: 1 Medical Director, 2 Clinic General Practitioners, 2 FTE registered nurses, 1.75 FTE administrative/support staff
- **Hepatitis C: 1 FTE Outreach/Strategy Coordinator**
- *IDU Outreach Program*: 1 FTE Counsellor, 0.5 FTE Peer Outreach Worker
- *Aboriginal HIV/AIDS Strategy*: 1 FTE Counsellor/Educator

■ Nurse practitioner: 1 FTE

In addition, approximately 10 volunteers worked at SHC. They assisted in reception duties, answering the telephone, stocking shelves and preparing kits for the needle exchange.

While there is no board of directors, the SHC has had an Advisory Committee since 1991 which has included current clients as well as community members such as representatives from Options for Change (an alcohol and drug treatment centre), the Centre for Addiction and Mental Health, the Homeless Centre for Youth, the drug use intervention facility, HIV/AIDS Regional Services (HARS), Public Health and, occasionally, medical staff. Typically, eight to ten people are members at any given time. Members are nominated and if interested, they are invited to participate. There is no time limit but most stay an average of three years.

The role of the Advisory Committee is to provide advice and recommendations to the SHC Coordinator but they are not in a supervisory role. The Coordinator reports to the Supervisor of the STD program at the Public Health Unit, and takes advice from the Advisory Committee, staff and clients. As he explained, before the Centre develops a project, all of these groups have to be consulted. Staff meetings were held twice a month to talk about program issues and the counsellors met once a week to discuss direct client issues.¹⁸

The philosophy of SHC is one of respect for clients. As the Coordinator explained:

We don't consider drug users as criminals, and we don't judge people. Injection drug use is directly linked to poverty, and to sexual abuse. We understand people. We connect with them.

Our clients don't have the same services in the community because people judge them. We want their long-term health condition to get better. We create a comfortable environment for people. We are very protective of our clients. Society did not treat them well — it punished them.

An Advisory Committee member reflected this view as well:

The clients and their lives are important to us. They have to be respected. We care for them—their life is important. They don't need a lecture nor to be pushed. Here, they make better choices to advance in their life.

And typical client comments about SHC suggested that this philosophy was borne out in practice:

I have the feeling that somebody really cares. These guys care. It is not only a job.

The Street Health Centre helps me a lot. I have a doctor here. She really understands me and what's going on. Before, they just pushed me away.

Apart from the SHC, the other agency in Kingston that provides services for individuals infected with hepatitis C is HIV/AIDS Regional Services (HARS), a community-based voluntary organization with a focus on HIV/AIDS. It also received Hepatitis C Prevention, Support and Research Program, Prevention and Community-based Support Regional Project Funding. HARS provides prison-based hepatitis services, integrates HCV information into its community education component and sponsors a hepatitis C support group.¹⁹

The two agencies developed a common Hepatitis C Advisory Committee. As one Advisory Committee member explained:

It just seemed logical that the two organizations team up to make links between the different regional initiatives.

Each agency provided two members to the committee and other members included representatives from the KFL&A Health Unit (Infection Disease Prevention Program), Options for Change, the North Kingston Community Health Centre, the Canadian Liver Foundation, and addiction services. Clients who were stable enough to participate in the meetings were also members.

Hep C Advisory Committee Terms of Reference

- To monitor the progress of the two projects funded under Health Canada: HARS & SHC
- To identify issues which are being missed; what do people living with HCV need?
- To share and distribute resources
- To educate the members of the Advisory Committee and people living with HCV about treatment issues
- To ensure community involvement in shaping project initiatives
- To improve collaborative and networking efforts
- To identify future plans so as to ensure sustainability of HCV activities upon completion of current projects

At each meeting an activity report was presented, ideas were generated and information shared. Meetings were held bi-monthly and the Chair rotated among the members. Reported outcomes included:

- Greater visibility for hepatitis C;
- Strengthened working relationships with community partners; and

- Better coordination, planning and an improved referral system.²⁰

When asked how the many players at SHC communicated with each other, the Coordinator explained:

We communicate with our clients on a daily basis. The client is a partner with whom we have a good long-term relationship. We talk to the clients each day. We build a relationship. We have to listen to them — that is our first goal. There are meetings with the service providers around big projects. We are not very strong on meetings. We prefer working directly with the agencies. A lot of the agencies are here [on site]. They spend half a day per week working directly with the clients at the Street Health Centre. We have a newsletter that is published two or three times per year to keep the agencies informed. Our staff goes to them to find out what their needs are, and what is happening.

The Hepatitis C Strategy project was still under way at the time of our visit. Planned activities included:

1. A comprehensive HCV community needs assessment to determine the requirements of those infected with and at risk of getting HCV;
2. The establishment of a local resource centre with information on support;
3. Educational and prevention services for people at risk;
4. The hiring of an outreach worker to help develop the capacity of high-risk populations (i.e., people who inject drugs, sex trade workers, street youth and ex-prisoners) to demonstrate self-care and provide on-going peer education and support.²¹

1. The Needs Assessment

The needs assessment, entitled No Common Cold, Hepatitis C Community Needs Assessment, was conducted in the Spring of 2001. The study included a literature review, a questionnaire to local organizations which might be in contact with people infected with, affected by or at risk of HCV, and 46 key interviews including 31 with individuals living with the disease and 15 with individuals affected by it. Of the individuals interviewed:

- 67% reported social assistance as their main source of income; 62% had not completed their high school education; 59% reported living on annual incomes of less than \$8,000; and 35% were on Ontario Disability Support.
- 67% had tested positive for HCV. Of these:
 - 68% of those testing positive had not received any support after being diagnosed;
 - 32% had not received any information prior to testing; and
 - 16% were unaware that they had been tested prior to receiving their positive test result.
- 26% reported having had hepatitis B and 19% reported past infection with hepatitis A.²²

The needs assessment also reported some interesting findings about beliefs, attitudes and knowledge about HCV. When respondents were asked why they had not received treatment, the most frequent responses were that the disease was not active or that there was no cure.²³ When they were asked what could be done to make their HCV easier to deal with, the most common responses were “nothing” and “more public education/reduced stigma”. Many had “no concerns” because they were “not ill yet”

and until then, they had more pressing issues to deal with (HIV, drug dependency, housing issues, disability, welfare, etc.) The report concluded:

There seems to be an underestimation of the importance of lifestyle changes in living with hepatitis C. The importance of reducing, or preferably eliminating, alcohol consumption was hardly mentioned. The tendency to put things off “until I get sick” may be in recognition of the severity of other issues facing individuals, or may be a failure to recognize the importance of managing the disease prior to liver failure.

In terms of their information needs, most people interviewed believed that they had a good understanding about the routes of transmission for hepatitis A, B, and C but in fact only one of the 46 interviewed correctly identified all routes. While some wanted information on treatment options, others thought, “I know all I need to know.” Over half wanted information on HCV presented to them in person rather than through other media; others preferred pamphlets; most often, they wanted information about transmission and effects of the disease on their body.

Those interviewed who were not HCV-positive themselves were affected through their relationships with infected individuals such as friends, parents, and spouses. A total of 87% believed that people with HCV were treated differently by others because of their disease and 23% had experienced discrimination themselves due to their relationship with their infected significant other. The report concluded:

The affected cohort predominantly reported that HCV positive individuals are treated differently because others “think you can catch it”

through casual contact. Many identified that HCV positive people are “treated like they have HIV”, and that others treat them as if they had done something wrong and that there was an element of blame or moral judgment.²⁴

Only four of 20 targeted organizations responded to the survey despite multiple telephone call-backs. Informal feedback obtained by SHC staff indicated that some of the non-respondents felt that HCV had little or no relevance to their mandate or services provided. As staff reflected on this:

What is very evident is the community service providers’ lack of education and awareness of the prevalence of HCV. Other responses ranged from “Our clients don’t have HCV”, “Only druggies get those things (HIV/AIDS and HCV)”, “We don’t work with anyone who has HCV”. Another respondent indicated that they will take HCV seriously when the government does—until then, it wasn’t their concern.²⁵

However, these observations were not viewed as a generalization across non-respondents but were simply an indication of some community perceptions about HCV.²⁶

Overall study conclusions included these thoughts.

- Individuals living with, affected by or at-risk of HCV are influenced by the overwhelming prevalence of the disease; aware of their risk, but not fully informed or supported in grasping the particulars of transmission, prevention, treatment and (in the case of hepatitis A and B) vaccination.
- Community providers, in general, are ill-equipped to address the needs of prevention and support; there exists a pervasive passivity in failing to recognize the seriousness,

preventability or impact of HCV on the community.²⁷

In particular, the pronounced experience of stigma identified through the needs assessment indicated the need for a general anti-stigma campaign:

Such an initiative is needed to address the underlying and socially-constructed stigma-theory: that hepatitis C is a self-wrought disease of addicts, and that injection drug use is a sign of weakness, a moral failing. Hepatitis C, as a disease of the liver, is laden with experiences of shame, blame and moral judgment. Judgmentalism and social stigma remain as strong indicators of continued HCV transmission and may hinder access to and the provision of quality care and treatment.

Because of their on-going involvement with people who inject drugs, the staff at SHC has given considerable thought to the issues of stigma and health. Because injection drug use is a criminal offence under current legislation, the resulting secrecy, shame and underground criminal behaviour contribute to the formation of a specific sub-culture. As project documentation explained:

The unique culture of IDUs includes distinct codes, behaviours, rituals and identity construction. The distinct IDU cultures will be locally-based and varied. While IDU cultures are socially-based networks of peer interaction, the heart of IDU cultures is the very powerful, distinctively personal and quite functional act of injection drug use itself.²⁸

The findings of this important needs assessment have been used to train community agency service providers, to identify gaps in programming and to support further funding proposals.

2. The local resource centre

Originally, the SHC had planned to develop a local resource centre on hepatitis C, in order to coordinate and consolidate access to information and educational/prevention materials, the provision of health information and referral, with targeted education and training provided to the local community, health and social services.²⁹ However, it appeared that the development of a physical site for print resources proved to be problematic. As the agency reported to Health Canada:

We have...struggled with the logistics of a "resource centre" due to space limitations and the dynamics of this high-risk culture.³⁰

From their interactions with people who inject drugs, staff members were aware that many clients preferred one-to-one or small group communication due to literacy and/or attention deficits. This was borne out by the findings of the needs assessment in which 53% of respondents preferred to get information in person.³¹ However, one staff member commented on the problems associated with verbal communication with this group:

Our clients don't remember the information we give them. We constantly have to repeat the information to our clients or to people infected. Just yesterday, I spoke to a guy and he had the wrong information.

As an example of their communication process, the Coordinator explained how the Hepatitis C Strategy project had been communicated:

To make the project known to the client, we didn't have a lot of written material because we felt that none of the existing materials were adapted to the literacy level so we talked with them. Fundamentally, we pass on information

by talking with our clients. Some public conferences may bring clients. We also had an open house where we invited everyone from the community.

In terms of targeting community agencies and the general public, he continued:

We told the local agencies about the project by mail, pamphlets, meetings and the open house. We reach the general public through the Liver Clinic, advertisements, and conferences.

Overall, it appeared to be the experience of the SHC that a physical "resource centre" was not the best way to communicate with this target population. It appeared that the clients at SHC felt that their information needs were being met. As different clients commented:

It is easy. If we need information, we can go to the doctor here at Street Health.

It is very easy to get information if you know people around here. I got a lot of information from here.

It is very easy to get information from the Street Health Centre and the way it is presented is appropriate and it responds to my own needs.

3. Educational and prevention services

As a general rule, however, clients came to the SHC ill-informed. As the Coordinator commented,

There is a lack of appropriate education and information. The Street Health Centre is a catalyst for the hepatitis C work in this community. We offer information to clients, liaise with different agencies, and do hepatitis C awareness.

A key educational and prevention service provided by the SHC was the Methadone Treatment Clinic. SHC looked at the incidence of HCV over time through the use of the Patient Database and agency documentation suggested:

Looking at incidence over a significant period of time helps to understand the evolution of risk and may serve as some sort of measure of prevention efficacy. In the case of Street Health, the dramatic increase in absolute number of screens conducted since 2000 illustrates the pragmatism and public health benefits of locating a full-time Nurse Practitioner at Street Health.

HCV Screens by Year

Year	Negative	Positive	Annual Incidence
1997	3	1	25%
1998	17	10	37%
1999	35	18	34%
2000	113	19	14%
2001	144	17	11%
Total	312	65	19% (average)

Staff noted a decline in the annual incidence of HCV since the peak year of 1998 and linked this observation with the fact that lab screens from the SHC patient population had increased noticeably since that time. As the Coordinator commented:

The methadone program is the entry door to meet people that may have hepatitis C. Methadone comes first, hep C second. In 1996 we realized that hepatitis C was a big issue and that there was a high rate.... Now the percentages of newly tested clients having hep C is

lower, which means that prevention could be working.

However, the Coordinator also stressed the importance of the reach of their needle exchange—one of the busiest exchanges in Ontario by volume and numbers, with a very aggressive history of outreach and distribution. He felt that some needle exchange programs focused too much on exchange and not enough on addressing overall need.³²

Hepatitis C information was integrated into many activities at the clinic and, in fact, into all SHC programs. As one client we interviewed commented:

I have the information I need on hep C [hepatitis C]. They're monitoring my blood regularly. In general, I love the staff. This is a very good support centre.

For others, though, prevention information came too late. As one client explained:

I was concerned about AIDS, not hep C. The last test I passed before I got clean, I found out I had hep C. If I would've had the information, I would have been more careful.

When staff were asked if the project had made a difference in the community, they all commented about project impact:

It is hard to say. Our interest is with the client. We know they receive more information. The agencies are better educated. The health professionals refer more people here. In the community, people are more aware about it.

It has to have made some impact. We had some exposure in the newspaper, we did interviews, workshops, mail out. Ten years ago, we tested drug users and everybody had hep C. We did not have any information, any pamphlets. We

knew nothing about the medication. There is a big change now.

A lot of work has been done. Other agencies did take advantage of us being here, especially the shelters.

Further, they saw that the project had made a difference in clients' lives:

There is some evidence that our clients know more, and that they are more effective in making decisions. Since we have been doing something about hep C, the number of new hep C cases is lower. We've tested everybody, and less new people have it now. People know more about it. This may be an impact of the prevention work we've been doing. The staff and physicians are more aware of the issues. Our clients are more educated, i.e., on the different types of hepatitis. The clients are less confused. They can prevent.

People are more confident. We bring them together. They have a common interest. They see that they are not the only ones.

I think it helps the stigma problem. People are more aware of how to have a healthy life. There is also more awareness for the clients who don't have hep C. Since hep C has become an issue, the testing on hep C is much higher. There is more awareness on the risks. They have more information.

It was early to draw conclusions, but it appeared that the combined strategies of the Methadone Treatment Clinic, the needle exchange, and the integration of hepatitis C information into all SHC activities, were having a positive impact on prevention.

4. The Outreach Worker

At the time of our visit, the Hepatitis C Outreach/Strategy Coordinator has been in that

position for two years but in fact had been working full time for the organization for over five years. As part of a multi-disciplinary team, she provides front-line care, assessments, counselling, referral, and education to the Centre's clients and assists in the provision of group therapy. She also provides outreach intervention through Keep Six! and offers counselling and support to clients of the Methadone Treatment Clinic. About 75% of her work relates specifically to issues associated with hepatitis C.

Typical activities include meeting with clients (about 50 per month), sending information packages to health professionals and community agencies, media relations, liaising with the Hepatitis Clinic in the Hôtel Dieu Hospital, and preparing workshops and presentations.³³ For example, a workshop was held in March 2002 on hepatitis C and injection drug use. Approximately 50 individuals attended.

Other staff at the SHC who spent a lot of time on hepatitis C-related issues included the nurse practitioner and the Peer Outreach Worker. For the last two years, the nurse practitioner has offered primary health care to many SHC clients. As 57% of the individuals in the patient database have no family doctor, they rely solely on SHC for primary care services.³⁴ She works with the Methadone Treatment Clinic and assesses people by testing for HIV/AIDS, hepatitis C, STDs, and doing PAP tests for women. As she described her job:

I do a lot of teaching on weight and health issues.... If they have hepatitis C, I talk about treatment, alcohol. The clients are very interested in getting more information. When they start the Methadone they don't eat well. I also have my own caseload. I work with drug users that can't have methadone. I see them on a reg-

ular basis. We talk about birth control, safety issues. I also see prostitutes, but they are also drug users.

The Peer Outreach Worker spends about half of her time working on hepatitis C-related issues. Although she has been in this position for only three years, she volunteered at the Centre for the previous ten. Her role is to advocate for the clients. As she explained:

I support the clients when they go through a crisis phase. I get them to the point that they can see better and carry on with their life.... So many people have it or their girlfriend has it. When people get the test results, they need help. When people come here, they know that we test everybody. But, some people find out they have it when they [turn] yellow. We had two deaths from liver disease.

The involvement of these key staff members in issues related to hepatitis C was evidence of the integration of hepatitis C prevention and education activities into the mainstream functions of the SHC.

The overall impact of Health Canada's funding of this project is that a focus on hepatitis C has emerged in all SHC services. Staff observed the positive difference that this has made to the agency, as the following comments suggest:

The money spent by Health Canada's Hepatitis C Program is money well invested ... The kind of project we offer is very good.

Since the hepatitis C program started, I find it incredible to be able to refer clients to [the Hepatitis C Outreach Worker]. Since the Program started, there is a big difference in my ability to explain to the clients about hep C [hepatitis C].

Hepatitis C Strategy Project Accomplishments

1. Agency Developed Using Community Networks

Many specific project successes have already been described above but what is of particular interest to the mid-term evaluation of the Hepatitis C Prevention, Support and Research Program is the example which the SHC provides of an agency that is demonstrating how to "enhance the capacity of the community to provide ongoing natural and sustainable enhanced care networks"³⁵ to address issues of hepatitis C. By tapping into or expanding on the roles of other community agencies and government programs, SHC has continued to flourish and grow

The web of partnerships which, when taken together, create the SHC can be further studied to gain an understanding of how a tiny education program can grow to become a multi-purpose agency with both primary care and prevention, education and support functions.

2. Research into the Injection Drug Use Population

The Street Health Centre's close, extensive and long-term interaction with people who inject drugs provides insight into this important target group. The agency had developed a patient database with information about 750 patients at the SHC who have received care from either a physician or the nurse practitioner and whose charts met the criteria of recent clinical service and a current, completed problem list. An additional 192 charts, developed since 1997 but currently inactive, were also entered.

An analysis of the database revealed that these individuals had a total of 433 unique health con-

ditions. The most common diagnosis was drug dependence and injection drug use was the most common health condition. Second, however, were issues of infectious disease: 251 of the 750 patients were HCV positive, for an overall HCV prevalence of 33%; and 18 of the 750 had been diagnosed with HIV, for an overall HIV prevalence of 2.4%.³⁶

These and other emergent findings can be of use to more than just the SHC staff as little is known about hepatitis C in this target population. It is hoped that findings such as these will become part of the research literature on this disease.

3. Holistic Prevention and Care and Treatment Model

The incremental growth of services at Street Health is in direct response to the multiple needs of the target group. The interaction of primary care, the needle exchange, counselling, education and support all create a holistic approach to both prevention and care and treatment, a model which works well with SHC clients. As one community stakeholder commented:

This population is so marginal. It is so complicated. They are living in poverty, have no stable housing, and don't have access to a family doctor. Drug users are really stigmatized by health professionals.... People are blamed for their life. The programs have to be multi-faceted.

As has already been noted, people come to SHC for the Methadone Clinic or the needle exchange and then receive a variety of services to help them improve their health status and life in general.

Challenges

In their interviews, staff identified two significant challenges to an adequate response to hepatitis C in Kingston. These included the following:

1. Not enough physician education

The staff members interviewed identified a lack of physician education and as a result, not enough physicians were prescribing methadone or following up on those who were diagnosed. As one staff member commented:

There are not enough family physicians. There is no place for people to be assessed. For example, if a person is tested positive, because there are not enough family physicians, there is no follow-up. If we refer a person to the liver specialist, they encounter the same problem. Physicians need to be educated. They don't know what to say. They don't know how to do an assessment. There should be some funding from Health Canada to educate the physicians.

Another described how the lack of physician education had an impact on their agency:

I often get frustrated. Most of the people don't talk to their family doctor nor to their family about hep C. A lot of family doctors miss the issue. Some people won't go get their blood test. They come to me. They are afraid of the stigma. Family doctors don't address this issue. People from the hep C clinic [at the hospital], come here to talk. They don't know where to go.

One client described how a lack of physician education had affected his life:

I was out of drugs for seven years. It [hepatitis C] destroyed me. I went for a blood test, they told me I had hep C. The doctor never told me that my chances to infect my partner were low; he just told me the bad things. I broke up with

her. Within a month and a half, I lost everything. This was the pretext to start again, to take drugs again.

This perspective was supported by a staff member who commented:

Too often, their doctor doesn't offer any follow-up after they test positive for hep C because they are drug users. The doctors are passing judgment that the clients are doing something they shouldn't do.

2. Issues associated with stigma

The many individuals we interviewed repeatedly returned to issues associated with the stigma experienced by the SHC client group. As one community stakeholder explained:

They feel shame about being infected, they feel unsafe [regarding sex]. They worry about transmission. They feel dirty. They already have more problems than they can deal with.

One staff member suggested that even at SHC, clients continued to be afraid:

Stigma is the biggest challenge they have to face. Our people have been treated differently because of their lifestyle, and because of the poverty. When they come in to see a doctor at the clinic here, they are impressed. When they come here to talk about their life, they're afraid to be judged. For example, a guy didn't want to go out with a woman who had hep C. People don't know enough about it. They have so many problems. Often hep C comes last. People who have it don't want to tell others.

However, as one community stakeholder explained, the context in which the stigma occurs can have unexpected results. In prison, conflicting issues associated with stigma, such

as HIV/AIDS and HCV, affected inmate decisions, as follows:

For example, in jail, an inmate has AIDS and hep C and he doesn't want to take the treatment for AIDS because of the stigma attached to it. The drug users in jail will share needles, even if they know they shouldn't; they are addicted. In jail, the stigma is less important for hep C than it is for HIV, because being a drug user is more acceptable than having same-sex relations.

To begin to deal with the continued concern expressed by staff on the issue of stigma, the SHC has built on the results of their needs assessment and their experience with people who inject drugs to develop another proposal for funding which has been submitted to Health Canada's Hepatitis C Prevention, Support and Research Program, Prevention and Community-based Support Regional Project Funding. Entitled Reducing Harm/Reducing Stigma: A Hepatitis C Strategy for a Healthier Community, the purpose of this project is:

To strengthen our community's understanding, quality of intervention and support for people infected with or at-risk of HCV infection. The proposed project will also enhance the capacity of the community to provide ongoing natural and sustainable, enhanced care networks. The strategy will serve as a focal point for a community-based response to issues of hepatitis C, as well as to the health and community determinants associated with hepatitis C. In particular, issues of poverty, marginalization, stigma, quality of medical care and drug use will be addressed by the strategy.³⁷

Concluding Remarks

It appears that the SHC will continue to grow and pursue these issues of such concern to their marginalized population. Through experience, the agency has developed a recipe for success which suggests that sustainability and community adoption of hepatitis C issues will prevail. The staff's belief is that:

Ultimately, it is the long-term capacity of the community to accept and understand injection drug users as citizens and valuable community members that will result in real improvements in both individual and social health.³⁸

The following types of documents were reviewed in the preparation of this case study:

- Project documents from Health Canada
- Original Project Proposal (October 1999)
- Upcoming Project Proposal (May 2001)
- Street Health Centre Organizational Flow-Chart
- Community Advisory Group Membership
- Hepatitis C Advisory Committee Members
- Hepatitis C Advisory Committee Meeting Minutes (April 2001 to May 2002)
- Hepatitis C Advisory Committee Terms of Reference
- *No Common Cold, Hepatitis C Community Needs Assessment*
- Power Point Slides: Presentation of the Hep C Needs Assessment
- *Health for All?, A Primary Care Profile of the Street Health Centre*
- Hepatitis C Community Workshop Kit (March 2002)
- *Word on the Street, Street Health Centre Newsletters*
- Job descriptions
- Street Health Centre resources including pamphlets and a poster

Case Study Information

The case study was conducted May 7 to May 9, 2002.

The case study research team included Chantal Cholette and Sylvie Rossignol. The analysis was conducted by Chantal Cholette. The case study was prepared by Dr. Gail Barrington. It was approved for distribution by the Street Health Centre Coordinator on October 23, 2002.

In total, 15 interviews and focus groups were conducted and 22 individuals took part in the case study in Kingston. Below is a breakdown of the number and types of interviews/focus groups conducted and of the number of individuals that took part in the case study:

	# Interviews/Focus groups	# Participants
Advisory Group Members:	1	2
Board Members:	1	1
Primary Clients:	3	8
Project Coordinator:	1	1
Secondary clients:	2	3
<ul style="list-style-type: none"> ■ Executive Director and the Education Coordinator – HIV and AIDS Regional Services ■ Addictions Counsellor – Options for Change (Alcohol and Drugs Addiction Centre) 		
Staff:	7	7
<ul style="list-style-type: none"> ■ Dr. Adam Newman – Methadone Clinic ■ Director Infectious Disease Program, Kingston, Frontenac, Lennox and Addington Health Unit ■ Hepatitis C Strategy Coordinator ■ Nurse Practitioner ■ Counsellor ■ Nurse Case Manager, Methadone Clinic ■ Community Peer Outreach Worker 		

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Case Study:

Lethbridge HIV Connection

Lethbridge, Alberta

The Development of the Lethbridge HIV Connection Society

Lethbridge HIV Connection Society (LHC) resides in Rylands House, an 85-year old two-storey clapboard house in the historic London Row district of Lethbridge (population 72,717), not far from downtown. The old trees, gardens and front porches of this spacious residential area welcome you and provide a sense of continuity in this sunny, windswept city located on the high plains of southwestern Alberta. The house was purchased in 1998 to offer clients a comfortable and confidential environment. The Board also saw advantage in owning the site rather than using a rented facility.

LHC is a non-profit organization with a mandate to create a compassionate and effective community response to HIV and Hepatitis C through support and education. It serves the Chinook Health Region, covering the entire southwestern corner of Alberta, including two large reserves for the Blood and the Peigan Nations as well as the urban area of Lethbridge. Nearly 11% of Aboriginal people in Alberta live in this region.

The agency was founded in 1986 by a group of concerned individuals, including members of the gay community and representatives of various health and social service agencies and was registered as a non-profit charitable organization under the Societies Act of Alberta in 1988. At that time it lost some of its grassroots character

and some of its gay supporters left, not wanting to be openly associated with an AIDS organization in this small, conservative community.

In the mid-nineties, the clientele was mainly middle class males with no indication of drug problems but by 1997 there were a few clients who were IV drug users. At that time, hepatitis C (HCV) was still largely unknown. However, by 1999, the rate of newly diagnosed cases of HCV reported in the Chinook Health Region was 58.4 per 100,000 (slightly less than the national average at that time of 63.6). Fifty-eight% of the newly diagnosed people indicated that they injected drugs; nearly half reported having some body piercing. The reported cases were primarily Caucasians (80%) while 12% were Aboriginal/Metis.¹

Other high risk groups for HCV represented in Lethbridge and the surrounding rural area include inmate populations, homeless and street-involved intravenous drug users, sex trade workers, migrant seasonal farm workers from other countries (particularly Mexico), youth and postsecondary students with high risk behaviours, and athletes who could be using performance enhancing IV drugs or steroids.²

LHC is one of the few places in the community that people can get information about hepatitis C. Other sources of information and support include:

- Lethbridge Regional Hospital – an outpatient nurse devotes eight hours per month to issues

associated with hepatitis C such as providing support for individuals who are going through treatment;

- Lethbridge Regional Health Authority – all positive HCV test results are investigated; referrals are made primarily to LHC and/or the John Howard Society;
- Lethbridge Corrections – can provide a transfer to an Edmonton institution if treatment is required;
- TRAC youth outreach program – primarily makes referrals to LHC.

This shortage of information and support is reflected in a comment from the Chief Medical Officer for the Chinook Regional Health Authority:

[I] estimate that we have identified only half of the individuals believed to be infected in the Lethbridge area. We are not doing as much about hep C [hepatitis C] as I would like, but we don't have the infrastructure or the experience to do more.

At the time the case study was conducted, there was a gastroenterologist in Lethbridge who was treating some patients with hepatitis C but individuals had to travel to Calgary or Edmonton to see a hepatologist. The only methadone clinic in the province was located in Edmonton.

Project History and Implementation

The evolution of this HIV/AIDS-driven agency to respond to the emerging need for HCV services is an interesting example of agency responsiveness. LHC is currently in receipt of its third round of funding from Health Canada's Prevention and Community-based Support Regional Project Funding and it is how the agency used this funding that is the subject of

this case study. However, the development process leading up to this contribution is also instructive.

a) 1999 – NPNU Outreach Project

In 1999, LHC received \$3,500 from Health Canada's Hepatitis C Prevention, Support and Research Program, Prevention and Community-based Support Regional Project Funding for a program entitled NPNU Outreach. Its purpose was to support people who injected drugs by protecting and improving their health in matters relating to hepatitis B, C and HIV. Planned project activities for this small sum were very broad and included community training on hepatitis C prevention and education, pre/post-test counselling to HCV clients, lifestyle counselling, assistance in accessing hepatitis C services, outreach services, assessment, STD testing, and a needle exchange program. Partners included Mobile Urban Street Team (MUST) Consortium, Safeworks Calgary, HIV Edmonton, Central Alberta AIDS Network Society and the Hepatitis C Society of Canada, Southern Alberta Chapter.³

During this period, an unanticipated event occurred. A key partner, the local chapter of the Hepatitis C Society, ceased to function. It had developed packages of hepatitis C information but LHC was refused access to the materials. Fortunately, the Canadian Liver Foundation and the Chinook Health Region were able to provide some other hepatitis C materials. In addition, the plan had been for the Hepatitis C Society to offer a fixed site for the needle exchange. Instead, in November 2000, a mobile service plan had to be developed.⁴

LHC contracted with the John Howard Society to offer the mobile service. Within a few months, this relationship became strained and

the two organizations separated, each offering the service separately. During the brief program period, 87 needles, along with harm reduction information and community referrals, were distributed to eight individuals. Education and support were also provided to family members and to significant others.⁵

Program documents did not record outcomes for any of the other planned program activities, so it appears that the needle exchange was the focus of funding utilization. The experience did provide several important lessons about how to operate a successful mobile needle exchange, including the need for:

- Adequate numbers of trained staff to ensure the health and safety of clients and staff members;
- Hours of operation in accordance with the demonstrated needs of program users; and
- Cooperation of community partners and agencies in providing referrals and assessments.

A positive outcome of this early project was the support of the Chinook Health Region's Sexual Health Centre and Chief Medical Officer. The Region provided all the needle exchange supplies at no cost and continues to do so to this day. This set a precedent throughout Alberta and influenced other regional health authorities to consider their involvement in community harm reduction efforts.⁶

b) 2000 – Rylands House Hep-C Project

In 2000, LHC received \$15,000 from Health Canada for the Rylands House Hep-C Project. The purpose of the funding was to establish a strategic inter-sectoral approach to hepatitis C community-based support and prevention. Planned activities included the identification of

partners throughout the region to develop a community-based strategic plan to address education, awareness, and support for those infected with, affected by and at risk for hepatitis C among specific target groups. These plans failed, however.

According to a report on organizational capacity (prepared by an external consultant for the LHC Board of Directors), management issues, insufficient or missing internal control, and staff and volunteer turnover resulted in an internal crisis. The agency was unable to translate its mission into meaningful goals and objectives. Forward momentum was lost.⁷

The funding from Health Canada was partially withdrawn and the agency went through a transitional period. The Board removed the former Executive Director and began to search for a new one. New Board members were recruited to bring their number to its current membership of seven. By March 2001, a new Executive Director was hired. She demonstrated her insight into the emerging HCV context by commenting in the press soon after her arrival:

*HIV and Hepatitis C are not just medical problems, they are social issues.*⁸

The new Executive Director's experience as a physician working on international community development projects proved very useful in getting this small community-based agency on track. Monthly Board meetings, weekly staff meetings and regular community network meetings quickly improved communications. It became a regular practice to evaluate and report on progress towards formal work plans that included clear goals and objectives.

More staff members were hired as the agency's limited resources were stretched creatively to

increase staffing capacity. Positions include the Executive Director position (full-time), a full-time Program Coordinator position (filled for ten months and now currently open), a Resource Coordinator (who fulfils three part-time activities including administration, bookkeeping and volunteer coordination) and three part-time positions that are each about one-third of a full time position: a Community Development Officer, a Hepatitis C Officer and a Social Worker/Client Services Worker. In addition, there is a pool of 40 volunteers. Overall, the transition experienced by LHC had a net positive effect and the external consultant concluded that the agency was now “stable, capably governed, well-run operationally and responsive to its environment.”⁹ She did suggest, however, that new policies and by-laws be developed.

LHC conducted a needs assessment with HCV positive clients and/or their significant others to identify some specific needs and suggestions for HCV programming in the Region.¹⁰ Client needs had shifted over time at LHC and by 2001, more than 80% of the clients accessing the agency’s outreach services were co-infected. Most of them had a limited understanding about hepatitis C, how they had contracted it or how the disease might have an impact on their lives. They also did not understand how HCV was treated or what community supports were available.¹¹

The needs assessment indicated that 90% of the co-infected individuals were Aboriginal, although this ethnic group only comprised 7.6% of the total population in the Region. While most lived on the nearby Blood and Peigan reserves, a significant number also lived off the reserves or moved frequently back and forth between the reserve and the city.

LHC staff found that Aboriginal clients were often reluctant to share their health status with friends, families and service agencies in their home communities. Stigma attached to the diseases of HIV and HCV was a significant issue for them. For example, six of the 12 individuals interviewed for the needs assessment indicated that they would not access community services because of confidentiality issues. A need for more peer support was also identified.

The needs assessment helped staff and board members clarify the role of the agency; namely, to serve clients who were co-infected with hepatitis C and HIV with a particular focus on Aboriginal people. They began to position LHC as a leader in community harm reduction. In September 2001, the Board held a strategic planning meeting and decided to incorporate hepatitis C fully into the vision and mission statement of the organization:

- **Vision statement:** All individuals and communities in South-western Alberta have the ability, capacity and desire to eliminate the harm caused by HIV and hepatitis C.
- **Mission statement:** Through support, education and advocacy, LHC facilitates compassionate and effective community responses to HIV and hepatitis C. (*Section 3: Summary of Program – Funding application to ACHF – 03/19/2002*)

As one staff member commented:

I’m glad that we are now working with hep C because we have a lot to offer from our experience with AIDS.

The Board’s new operational plan was submitted to their main funder, the Alberta Community HIV Fund (ACHF), a joint initiative of Alberta Health and Wellness and Health Canada’s AIDS

Community Action Program. It provided a joint plan for HIV and HCV services, demonstrating that the agency's philosophical shift from a single disease to a broader harm reduction focus had been institutionalized.

LHC Budget Sources

■ Alberta Community HIV Fund	78%
■ United Way, Wild Rose Foundation and fundraising	13%
■ Health Canada, Hepatitis C Prevention, Support and Research Program, Prevention and Community Based Support Regional Project Funding	9%

c) 2001 – Hepatitis C Community Outreach Services Project

In April 2001, Health Canada funded LHC for \$30,000 over two years (2001-2003) to provide Hepatitis C Community Outreach Services. This project is the focus of this case study. In addition, in September of the same year, the agency also received \$94,000 for a separate three-year project entitled Aboriginal Partnership of Southwestern Alberta on HIV/AIDS Harm Reduction and Hepatitis C. Most of the funding was provided by the ACHF but Health Canada contributed \$2,000 per year for two years to enhance services to the Aboriginal population through an upward amendment to the Outreach Services project.

The goals and objectives for the Outreach Services project were much more specific and measurable than those of previous projects and included:¹²

1. To promote enhanced health and wellness of persons living with, affected by or at risk of contracting hepatitis C within the Chinook Health Region by:
 - Designing/compiling educational packages;
 - Increasing the number of community agencies participating in the Outreach Services;
 - Providing information to link clients with appropriate community resources; and
 - Providing the Aboriginal community on the Peigan reserve with appropriate information and linkages to resources.
2. To develop an effective hepatitis C program evaluation plan by:
 - Monitoring; and
 - Implementing an evaluation plan.
3. To strengthen, expand and coordinate prevention and support services on HIV, HCV and Harm Reduction focusing on the Aboriginal population of Southwestern Alberta (added in Sept 2001) by:
 - Strengthening partnership and networking between communities, agencies and organizations addressing Aboriginal needs;
 - Making culturally appropriate resources available to communities, agencies and organizations addressing Aboriginal needs;
 - Strengthening prevention, care and support services for the Aboriginal communities; and
 - Documenting and evaluating partnerships and partnership activities on a regular basis.

Regional Partners:

- Chinook Health Region
- Hepatitis C Society—Southern Alberta Chapter
- Lethbridge Community Harm Reduction Network

Members of the Aboriginal Partnership:

- Sik-Ooh-Kotoki Native Friendship Society
- Blood Tribe Department of Health
- Peigan Health Services

During the year 2001-2002, project staff conducted a number of activities: they fielded phone calls requesting information about hepatitis C; built capacity through providing harm reduction and universal precaution presentations to various professionals and community partners; worked toward the development of partnerships in the community; continued to offer a needle exchange (this time in two local pharmacies); provided presentations to a number of community, school and residential groups; conducted a bar coaster campaign; set up harm reduction displays; and, distributed pamphlets and materials.

The Executive Director commented on the differences the agency had experienced in meeting the needs of people with HCV compared to those with HIV/AIDS (the target group most familiar to staff):

The need for support and counselling is not as great with HCV as it is with HIV/AIDS. Hep C individuals seem to be more mainstream with many maintaining jobs, etc. ... We find that we provide support at specific times. First, when they find out they are hep C positive—often they have a lot of questions at this point and they are looking for information and answers.

The next time people are looking for support is when their disease progresses into the chronic stage where they are looking at or receiving treatment.

Hepatitis C Community Outreach Services Project Accomplishments

1. The Development of Partnerships

The development of partnerships was a key focus of LHC during 2001 and at the time of our case study visit in March 2002, staff members were able to point to three successful networks in which they played a key role:

- The Aboriginal Partnership of Southwestern Alberta on HIV/AIDS, Hepatitis C and Harm Reduction;
- The Community Harm Reduction Network; and
- The HIV/Hep C Community Consortium.

In addition, links were strengthened or maintained with the following community partners:

- The Hepatitis C Society;
- The Chinook Health Region and Sexual Health Centre; and
- Draffin's Pharmacy.

As the Executive Director commented:

The LHC Office has become the focus point for hep C community development in the Chinook Health Region. Because we have access to specific hep C funds, we can afford to offer more information sessions and support than other organizations concerned about hep C. Partnership with other stakeholders such as the Community Health Nurse of the Chinook Health Region, the hep C nurse at the Regional Hospital, and the local chapter of the Hep C Society are crucial to ensure collaboration and sustainability of the program.

While Health Canada's Hepatitis C Prevention and Community-based Support Regional Project Funding contributed to the Aboriginal Partnership in a limited way, the Aboriginal Conference on HIV/AIDS, Hepatitis C and Harm Reduction, organized by the Partnership, was a definite accomplishment and raised community awareness about hepatitis C.¹³ Approximately 170 individuals attended the two-day event. Two plenary sessions and one workshop were provided on the topic of hepatitis C.

An unplanned outcome of staff efforts to strengthen partner relationships was the request by the Hepatitis C Society to meet in Rylands House for their monthly support group. The members thought that the location was more convenient and comfortable than the hospital, where they had met formerly. LHC staff were pleasantly surprised that Society members were willing to meet in the offices of an HIV/AIDS service organization.

The continuing needle exchange program was evidence of a successful partnership between two local pharmacies, the Health Region and LHC. In an interview, one of the pharmacists clearly supported the value of risk reduction in the community. She commented:

We are very happy to be involved. Even if we make a difference for one person, it has been a success.

When the individuals with HCV were interviewed about the project, one identified the best thing about LHC as:

... the encouragement they provide. They help you accept and live with hepatitis C. They provided information and counselling — it helped a lot.

Despite positive comments such as this one, only three individuals with HCV were willing to be interviewed during the case study visit. Identification appeared to be an issue in the region. As the Chief Medical Officer pointed out, there were different HCV sub-groups whose needs should be served:

We are still grappling with segregation between the various hep C groups (IDU, blood transfusions and those not identified)—we have three sub-communities that we are trying to serve with a limited community base.

Challenges

In their interviews, staff and stakeholders identified a number of significant challenges to be overcome in order to develop an adequate response to hepatitis C in the Lethbridge community.

1. Learning to Work with the Aboriginal Community

All the staff and stakeholders who were interviewed indicated that access to the Aboriginal community was still very limited and few hepatitis C services existed for this group. As a reserve-based health care professional commented:

The biggest challenge is the entry point.

A significant lesson learned by staff and partners during 2001-2002 was that working with Aboriginal communities takes time and may not go as planned. Originally, LHC staff believed that introducing hepatitis C education and support would be easier on the Peigan reserve than on the Blood; however, more progress was made during the year with the Blood and less with the Peigan. Plans for information meetings and

workshops with chief and council members went unrealized but several elders did participate in hepatitis C workshops.

Overall, the awareness about HCV and the stigma attached to the disease made for slow progress towards project objectives. The conference had helped to raise awareness, particularly among managers of health services in Aboriginal communities (several of whom were part of the conference planning committee) but it became clear that the education of front-line workers and elders at both reserves should be the priority in the immediate future. Several of the individuals interviewed commented on the stigma associated with hepatitis C, likening it to HIV in the early years. As one health care professional from a local reserve commented, there was a:

...lack of information, not knowing what it is and how to deal with it. Many infected individuals go elsewhere rather than live on the reserve. They may come back to die.

Confidentiality was a related issue. The Executive Director indicated that Aboriginal people often left the reserve because they did not want anyone to know of their disease; some did not even want to be treated in Lethbridge because the community is so small.

2. Need for capacity building among professionals

Lack of information among professionals was still a considerable issue and a number of community stakeholders identified the need for more information for professionals—for physicians (on standard care practice, long-term prognosis of the disease and the specific needs of people who inject drugs) and for nurses and clinics (on risk factors and harm reduction strategies). General public awareness was also

required. Employers were identified as needing information on the impact of hepatitis C in the workplace, on workers and on productivity. In the Aboriginal community, health care workers saw their own education as a preliminary step to working with infected individuals and their families:

We [the staff] need more education, more awareness and more counselling.

3. Need for HCV Materials for Specific Target Groups

A need was identified for more specific materials on hepatitis C, not only for Aboriginal groups, but also for low literacy and youth groups, as expressed by the Executive Director:

No one else distributes information but us; therefore there is not enough information. We have been looking for posters, but we can't find them. It is difficult to access information; all is new, scattered and is representative of a specific organization or program.

One of the clients we interviewed supported this identified need for information:

[I] had to find information about care and treatment on my own, [I] found out after transplant that the hepatitis C will come back. Nothing was explained before the transplant. Doctors don't pay much attention to hep C—it is an invisible disease. It is hard to get sympathy and actions from physicians and the general public when you look well.

4. The economic and social burden of the disease

The financial burden associated with having hepatitis C was identified as an obstacle by a number of different stakeholders. As one nurse explained, there were costs associated with an

individual acquiring non-group coverage and there was a three-month waiting period. Loss of income was a real possibility as some individuals had to leave their jobs due to treatment side effects. There were also costs associated with the travel required to obtain treatment. As one of the clients explained:

People from Southern Alberta have to travel to see a specialist [in either Calgary or Edmonton]. It is a big expense for people and there is no fund people can access to help with these expenses. Sometimes [you] need to stay for six weeks, need to bring family support with you, and they have to pay for hotels and meals during this time.

Other costs were more social or inter-personal in nature. As another nurse commented:

The impact it has on an individual's life depends on the severity but could include loss of income, loss of ability to parent when ill, inability to stay involved with family, inability to talk about it and get support, the idea that you have done something bad), and the fear of telling and not getting support.

The impact at the personal level was echoed by one of the clients we interviewed:

I felt tired and isolated, nobody understands what you go through. No one really knows what it's like to not be able to get out of bed. Day-to-day living is hard.

5. The need for long-term program support

Program sustainability was an issue of considerable concern in the region. At the provincial level, the Chief Medical Officer indicated that no strategy was currently in place; the region was trying to respond as best it could to an emerging health issue:

The province [of Alberta] is not looking at prevention and the long-term consequences of the disease . . . We've tried to pull together a quilt/patchwork of responses, but we can't do more until hep C is a priority at the provincial level.

A client at LHC reflected on the need for program support as follows:

People are in desperate need of services similar to what is available in the big cities, and they need to continue otherwise hep C will spread more. It is vital that this is ongoing, but there needs to be a lot more work in the Region.

The Executive Director believed that the new agency mandate—to provide support for both HIV/AIDS and hepatitis C—was the best response to an identified community need. However, long-term support for programming was uncertain and was a cause for concern:

LHC has made the decision to incorporate hep C into its vision and mission. It has made a long-term commitment to be a focal point in the Chinook Health Region on hep C. Decisions on how such a commitment will be carried out if funding stops have, however, not been made, and will depend on the provincial and national discussion and strategic planning efforts.

Concluding Remarks

Overall, the 2001-2002 year was an eventful one for LHC. The agency moved from a focus on HIV/AIDS to the broader perspective of harm reduction. Hepatitis C was now considered to be a significant health risk in the region. Like HIV/AIDS, it not only had medical implications, but had serious social and economic ones as well. Therefore, targeted programming activities in the areas of support and education were required. In an uncertain funding environment, this move demonstrated the agency's commitment and

maturity. It suggested that the project's goals would continue to be achieved, and further, that in the future the agency might play a role as an advocate in support of stable funding.

The following types of documents were reviewed in the preparation of this case study:

- Project funding documents from Health Canada
- Project Progress Report, April 1–September 30, 2001
- Project Progress Report, October 1, 2001–March 31, 2002
- HIV Connection mission and vision
- Needle exchange statistics
- Summary of consultation process for development of an Aboriginal Partnership project
- Hepatitis C statistics for the Chinook Health Region
- Job descriptions
- Newspaper articles
- Newsletters
- Samples of resources available
- Southern Alberta's First Aboriginal Conference on HIV/Hep C and Harm Reduction – Conference program and summary of media coverage

A discussion paper – Integrating Hepatitis C into the Mandates of Community Based HIV Organizations (by Phil Rauch – Central Alberta AIDS Network)

Case Study Information

The case study was conducted March 19 to March 21, 2002.

The case study research team included: Dr. Gail Barrington, Barb Briggs and Joyce Pearson. The case study was prepared by Dr. Gail Barrington. It was approved for distribution by the Lethbridge HIV Connection on June 26, 2002.

In total, 21 interviews and 1 focus group were conducted. Two meetings were also observed. Below is a breakdown of the number and types of interviews/focus groups conducted:

- Staff and volunteers: 7
- Board member: 1
- Primary clients: 3
- Secondary clients: 9
 - Pharmacist – Draffin’s Pharmacy (needle exchange site)
 - Outpatient Nurse – Lethbridge Regional Hospital
 - Nurse in Charge – Brockett Health Centre (Peigan Reserve)
 - Community Health Representative – Blood Nation
 - Communicable Diseases Nurse – Chinook Health Region
 - Sexual Health Worker – Chinook Regional Health Authority
 - TRAC Youth Outreach Worker
 - Chief Medical Officer, Chinook Regional Health Authority
 - Health Care Manager, Lethbridge Corrections
- External consultant: 1
- Focus group with Aboriginal Partnership group: 1
- Observation of Aboriginal Partnership meeting: 1
- Observation of Community Harm Reduction meeting: 1

References

1. Chinook Health Region
2. Hepatitis C Community Outreach Program 2001-2003
3. Funding Approval Form
4. NPNU Outreach Program, Final Narrative Report
5. NPNU Outreach Program, Final Narrative Report
6. NPNU Outreach Program, Final Narrative Report
7. Mary C. Thompson, November 29, 2001
8. Lethbridge Herald, March 1, 2001
9. Mary C. Thompson, November 29, 2001
10. Hepatitis C Community Outreach Program 2001-2003
11. Hepatitis C Community Outreach Program 2001-2003
12. Project Progress Report April 10, 2002
13. The evaluation of the conference indicated that it had been successful in raising awareness.

Case Study:

Hepatitis C Moncton Inc.

Moncton, New Brunswick

The Development of Hepatitis C Moncton Inc.

A Moncton nurse contracted hepatitis C, possibly while working in the Operating Room or from some other source; although she experienced a variety of physical problems, for a time she was unaware of her condition. When she returned home to Canada from California where she had been working, she was finally diagnosed. Using her medical knowledge, she sought out information to help her understand her disease and soon she was sharing that information with others. She became an advocate for the need for the prevention, testing and treatment of hepatitis C and tried to raise the awareness of the New Brunswick public. She received a lot of positive media attention. One newspaper article included her home phone number and people began to call her about starting a support group.

As a result, she founded the Moncton Chapter of the Hepatitis C Society of Canada and then joined with other groups in Saint John and Fredericton to become the Atlantic Chapters of the Hepatitis C Society of Canada (HeCSC). This group was formed in 1995 under the umbrella of the National Office of the HeCSC, sharing information and contributing to national programs, services and workshops. The Chapter's mandate was:

To fight hepatitis C through education, prevention, early detection, support, appropriate treatment and comfort.

Context

According to the 2001 census, New Brunswick has a population of 757,000. The South-East Corporation of Region 1 is the largest health region in the province and covers 10,000 square kilometers, stretching from Nova Scotia through Westmorland, Albert and Kent Counties. It has a total population of approximately 185,000 people. At the centre of the region is the Greater Moncton Area which includes the towns of Riverview and Dieppe as well as the City of Moncton itself and which has an overall population of approximately 100,000. The area also has the somewhat unique linguistic characteristic of being almost evenly split between English (57%) and French (40%). Only 3% of the region's population are immigrants. Moncton is a thriving metropolis with many retail, manufacturing, and service-based industries. Over the past decade, it has gained a reputation as the call centre of the Maritimes, employing thousands of people in this industry. In 1996, Statistics Canada reported that 75% of the labour force in this Region was employed in the service industry, 20% in manufacturing or construction and 5% in resource-based industries.

While the Moncton area had a somewhat lower unemployment rate than the rest of the province, in 2002, there were still more than 10,000 people looking for work. In 1996 the average income was 18% lower than the national average. Most single parent families, a significant number of two-parent families, and many unattached

individuals in the Region lived below the poverty line.¹

The Atlantic Region has the lowest reported hepatitis C rates in the country. In 1999, the rate of newly diagnosed cases in New Brunswick was 24.6 per 100,000, the third lowest in the country² but according to New Brunswick Health and Wellness, the rate of newly diagnosed cases of hepatitis C in Region 1 was 43 per 100,000, much higher than the provincial average. As of October 2001, there were 470 reported cases of hepatitis C in Region 1 of which approximately 150 were federal male inmates in Dorchester and Westmorland prisons. Of those living in the community, 114 were female and approximately 200 were male. The highest rates of infection were amongst people aged 30-49 (66% of all cases).³

An environmental scan published by Health Canada in January 2000 provided a summary of information about hepatitis C in the Atlantic Region.⁴ Overall, it found that the main risk factors were blood product infections and injection drug use. Further, there was a lack of information and infrastructure related to hepatitis C in Atlantic Canada in the areas of education, treatment, support and harm reduction.

Between 24% and 45% of cases in the four Atlantic provinces reported that they had received blood or blood products.⁵ Atlantic region residents who were infected with HCV through the blood supply between 1986 and 1990 are entitled to compensation through the federal/provincial/territorial Settlement Agreement. Over a period of twenty years New Brunswick will receive \$3.6 million. There has been no response to hepatitis C by the provincial governments; no compensation has been provided to those ineligible for the national settlement.

In New Brunswick, 41% of all hepatitis C cases reported that they injected drugs.⁶ The rate of injection drug use in the region had increased over recent years and was a growing concern to health professionals and authorities. According to the Profile of Injection Drug Use in Atlantic Canada, a recent report prepared by Health Canada,⁷ the drugs most commonly injected in New Brunswick were opiates, including Dilaudid, heroin and morphine. The second most common was cocaine. However, there were also indications that a number of people were cross-addicted and used more than one type of drug such as "speed balls" (which combine opiates and cocaine), Ritalin and speed, and other combinations. While all intravenous drug users were at risk of contracting hepatitis C, cocaine users were seen to be at particular risk as their more frequent injection rate (between 12-20 times per day) increased the risk of transmission.

In 1998, there were approximately 88 family physicians per 100,000 people in Health Region 1 but only five gastroenterologists served the area. The closest hepatologist was located in Halifax and was only available for consultation regarding liver transplants or severe liver problems. Hepatitis C Moncton reported that there was only one licensed physician in New Brunswick who prescribed methadone for opiate withdrawal.⁸ At one time he had treated between 80-100 opiate users per week but had decreased his methadone patient load number to approximately 55 per week due to lack of time, office space and support.

Pharmacists in the region were concerned about the spread of blood-borne diseases including hepatitis C and HIV/AIDS and many offered free needles to drug users. However, a community issue arose about how needles were being disposed. Some parents complained of their

children finding used needles close to school grounds and in other public places.

Hepatitis C Community-based Support and Education in Southern New Brunswick: Project History and Implementation

The environmental scan conducted by Health Canada observed that:

...the region's community-based hepatitis C work is being conducted by volunteers. For instance, none of these groups whose main focus is hepatitis C reported any paid staff.

At the Atlantic Chapters, this was certainly the case; the founder/Project Coordinator was a volunteer. The office was located in her modest apartment in a residential part of Moncton. One room was designated as the Hepatitis C Office and was equipped with a computer, filing cabinet, desk, chair and shelves. She used her small living room as a meeting space but it could only accommodate a group of five.

In the early days, her personal address was published in the agency's brochures and materials. People would sometimes knock on her door "at all hours of the day and night" and, as she recalled, sometimes they were "not in a peaceful state of mind." They could also call her and as she described with some frustration:

Sometime it is pretty hard to do this type of work. I find it hard to give support to people who are angry. I have a hard time dealing with them. They just want to yell at me. I tell them, "If you don't stop yelling at me, I will hang up," and I do hang up if it continues. Otherwise, things sometimes get blown out of proportion. How can one person please everybody 100% of the time?

For security reasons, the agency acquired a post office box. However, the phone still rang in her home office and people still came to her door for various meetings. The burden experienced by the Project Coordinator and her fellow volunteers was described as follows:

Over the last several years, the need for accurate information has been continually demonstrated. Our office and toll-free line has received numerous calls from not only the infected with/affected by/at risk of hepatitis C, but also for support, health, and service care organizations requesting information on varied aspects of hepatitis C, obviously showing a lack of educational information with which to make informed choices and decisions. While the expertise of our volunteer base is growing, their energy level is not. This, unfortunately, is not conducive and effective to a quick and ongoing response.⁹

The Chapter's Steering Committee felt that it was certainly time for a paid coordinator to provide consistent education and support and to meet the growing need. After receiving \$10,000 in 1999 from Health Canada's Hepatitis C Prevention, Support and Research Program, Prevention and Community-based Support Regional Project Funding for posters and pamphlets, they decided to apply for coordinator support. As the Project Coordinator recalled:

Through all the years working, we were providing services but on a small scale. Everybody wanted more services and we made the decision to present a proposal. I did not know how to put a proposal together. I went with my experience.

The proposal requested \$100,000 over 24 months and included the salary for a full-time Regional Community Coordinator, as well as costs associated with travel, materials and equipment rentals.

Health Canada approved the proposal for \$25,000 in 2000-2001, \$50,000 in 2001-2002 and \$25,000 in 2002-2003. The project started on October 30, 2000.

The project goals were as follows:

- To promote the health and well-being of persons infected with/affected by/at risk for hepatitis C;
- To increase the awareness and education of persons infected with/affected by/at risk of hepatitis C, as well as community-based support, health, and service care providers and interested general public, of all aspects of hepatitis C;
- To develop a multi-faceted approach to program initiatives currently under development for a more effective, efficient response to those infected with/affected by/at risk of hepatitis C;
- To promote better understanding between community-based support, health, and service care providers in order to facilitate information sharing, networking capabilities and resource referrals; and
- To evaluate the program initiatives on an ongoing basis by incorporating a surveillance component in order to compile the informational data necessary to determine program impact, efficiency, and effectiveness.¹⁰

Target groups included:

- People infected with/affected by/at risk for hepatitis C;
- Hepatitis C support group members, staff, and volunteers;
- Health care and service providers in the community;

- Specialty segments of the population, i.e., prisoners, people who inject drugs, etc.;
- Other interested organizations requiring information; and
- The general public who may have concerns about the virus.¹¹

Partners included:

- Associate HeCSC Chapter of Saint John
- HeCSC Support Group of Fredericton
- Region 1 Public Health
- NB Health and Wellness
- Moncton Addiction Services
- John Howard Society of Moncton
- Correctional Services of Canada
- Canadian Liver Foundation
- Canadian Hemophilia Society
- Harm reduction groups;
- HIV/AIDS groups
- Social service agencies, halfway houses, correctional facilities¹²

The original Project Coordinator was hired as the Regional Community Coordinator because as a Progress Report explained:

Her vast knowledge of the issues of hepatitis C made [her] an obvious choice for the position of Community Coordinator and, while she had never been in an administrative position of this sort in the past, she reached out to those around her to develop good working relationships with people who could help with the challenges she faced.¹³

One of those challenges was the agency's relationship with the HeCSC. Over the spring and summer of 2000, issues of *ownership* had begun to arise and as it was later described:

We began to see that there wasn't really a clear understanding around who was responsible for the management and administration of the project. Over time, some tensions began to mount over this issue and the Steering Committee realized that this needed to be addressed... There were many reasons why this confusion likely arose and no one is really to blame—unclear bylaws, policies, contract information...¹⁴

The Steering Committee contacted both the national office of the Hepatitis C Society and the Regional Office of Health Canada to ask for clarification. In the end, it was determined that it would be in everyone's best interest to have the local chapter set itself up as an independent organization. This was accomplished in December 2001, and the agency became Hepatitis C Moncton. It was incorporated on March 19, 2002.

The agency's mandate broadened somewhat to reflect its new independent status. It became, as the Coordinator described it:

To help reduce the spread and impact of hepatitis C through public awareness and education, information and support for people infected with, affected by, or at risk of hepatitis C and to build community and government partnerships to further our mandate.

She also commented that the mandate was more inclusive than it had been originally:

We offer hepatitis C support, regardless of the way the person got infected. At the beginning, there was some discrimination in regards to the clients.

Late in 2001, a Board of Directors was established with five members, all of whom had been members of the Chapter's Steering Committee and who were infected with or affected by hepatitis

C. While by-laws were still in development, a draft policy for board nominations was established and the term was set at three years. One board member described the selection process as being very serious and confidential:

We approach people and ask them if they want to be volunteers. They go to the support meetings and if they like it, they can apply to sit on the board. We want to make sure that board members want to be there for the good reasons... The rule of confidentiality is read at the beginning of each meeting. The members of the board need to participate and to work. They are not there only to talk and vote on issues.

The responsibilities for each of the board positions were clearly specified, including the role of the Executive Committee (President, Vice-President and Secretary-Treasurer) and the role of the Coordinator. As the board member commented:

We work with the Coordinator. We try to oversee everything. We are not looking over the shoulder of the Coordinator for day-to-day issues. The board makes the big decisions, and the Executive Committee makes the less important ones.

The Coordinator elaborated further:

If there is an important decision to make, like the content of an information booklet or if a decision involves money, the Board of Directors will decide. Basically, the Coordinator is responsible for the operation of the project with the support of the board executive.

However, the need for board development had emerged as a critical problem. The Coordinator observed that there had been a number of examples where the board had not been fully functional or had been disorganized, creating more work and frustration for her. Even when

some members had been replaced, the same problems were being experienced again, suggesting that training on board processes was required.¹⁵

She was the only staff person at the agency but she was also its “senior volunteer” and so she wore two hats. As volunteer Executive Director, she acted as a spokesperson for Hepatitis C Moncton. As Coordinator, she acted as an employee, running support groups and putting together information tools.

Fortunately, approximately a dozen volunteers supported her in the agency. They devoted 100-200 hours each month towards helping with the design, delivery, management and evaluation of activities. The recently established group support program for infected persons was managed by volunteers and required few resources.

Hepatitis C Moncton Inc Budget Sources	
■ Health Canada’s Hepatitis C Prevention, Support and Research Program, Prevention and Community-based support Regional Project Funding	85%
■ United Way & door-to-door fundraising	15%

Typical activities included the following:

- Providing telephone support and information;
- Providing individual consultations;
- Producing and distributing various information and awareness materials;
- Offering peer support/self-help group meetings;
- Conducting a needs assessment;

- Making referrals to other services available in the community;
- Networking and holding meetings with key stakeholders to identify and reduce/eliminate gaps in services;
- Conducting media and public events; and
- Making presentations to community groups and organizations.¹⁶

Hepatitis C Moncton Project Accomplishments

1. Use of Hepatitis C Information

Hepatitis C Moncton was not only getting information out to at-risk groups and service providers; there was also evidence that the information was being used. Among the pamphlets and brochures that the agency had co-developed were the *Hepatitis C Handbook for Injectors*, which was disseminated nationally by the HIV/AIDS Clearinghouse and has already been reprinted. Their *Living with Hepatitis C* booklet, and *Someone you know has, or could get, Hepatitis C* pamphlet were widely distributed in the region in both French and English. Also available is the brochure, *Are You Thinking About Being Tested for Hepatitis C?*, also in both languages.

In a typical three-month period, 30 information packages were mailed out, including a number to family physicians.¹⁷ The agency reported that over 50 physicians across New Brunswick were providing their pamphlets as handouts for their patients and approximately 25 local pharmacies were also distributing the materials. Evidence of their utility came from the project:

These brochures are obviously being widely circulated as evidenced by the number of requests we have for restocking. Many of the

calls we receive come from people who have found our number on pamphlets received at pharmacies or doctors' offices.¹⁸

It also came from client comments, such as the following:

Lately, it has been quite easy to get information. Most doctors have a little brochure. There is also a little advertisement on the local radio station.

Generally the clients we interviewed were more likely to receive the information they needed from Hepatitis C Moncton than from either their family doctors or other sources, as the following comments suggest:

My life has changed for the better. This way I have the chance to educate my kids. When they will be older, I will be more involved in hep C.

When I go to my family doctor and tell him how I feel he'll say "Oh yeah" and prescribe me some more pills—Tylenol 3s, Tylenol 4s, codeine and then send me home. I get a lot more value talking to someone who understands what it's like to have the aches and pains. That's what I get from Hep C Moncton. They take the time to explain it; they have more information on the interferon, Rebetrone and treatment than the doctors do! They're prescribing all this stuff and they don't even know what it will do to you. The doctors do not have the information they should. Even the specialists don't know as much as they should.¹⁹

If I want information I will call the Hep C Moncton Coordinator. She gives me the information I need about hep C. My doctor wanted me to take Interferon. I was very sick at that time. I said no to the treatment. I prefer dying than going through the treatment.

The agency also held a day-long workshop at the Moncton Hospital in the spring of 2001. More than 100 frontline workers, hepatitis C infected/affected persons and members of the community attended and heard from specialists in the field of hepatitis C.

Another important accomplishment was to make information about hepatitis C more accessible to the inmate population. The contribution of the Coordinator of Hepatitis C Moncton to the SHARP project (Surviving Hepatitis C and Risks in Prison), sponsored by the John Howard Society (and also funded by the Hepatitis C Prevention, Support and Research Program's Prevention and Community-based Support Regional Project Funding) was so significant that she received special mention in the project materials "for always going that extra mile and being an incredible source of inspiration."²⁰ The educational materials included a deck of playing cards, a pocket book on hepatitis C, and a poster, developed at a literacy level of Grade 6. With the help of additional funding, these tools were being distributed throughout Canada's prisons. The Coordinator was also involved in developing a questionnaire to evaluate the pocketbook. As the Education Coordinator at the John Howard Society of Moncton commented:

In the context of the prison population, my experience has been really positive. The inmates are very keen on getting information and want to be helpful but there is still a lot of stigma among the prison population... This issue is close to the heart of a lot of inmates.

The agency's toll-free telephone number was expanded beyond New Brunswick, thanks to the contribution of a private donor, and information was widely distributed using this medium throughout the Atlantic Provinces. The toll-free line was

also made directly accessible to inmates of the correctional facilities of Westmorland and Dorchester. In a typical three-month period in 2001, the agency received approximately 60 calls for information that may be broken down as follows:²¹

**Call Record for Information Requests
Typical Three-month Period in 2001**

- 14 general information
- 13 calls from inmates
- 8 transmission
- 8 compensation
- 8 treatment
- 5 general support
- 2 liver biopsy
- 1 herbal remedies
- 1 vaccination
- 1 viral clearance

By the first quarter of 2002, demand had grown to over 100 calls in three months.

2. Development of Effective Partnerships and Collaborations

There was a lot of evidence to suggest that Hepatitis C Moncton was able to develop many strong, effective and creative partnerships. They could be divided into three different partnership types.

a) Significant Exchange, Mutual Benefit

The first type involved a significant exchange of knowledge and services for the benefit of both partners. These included:

- **John Howard Society of Moncton**
The Coordinator worked collaboratively to develop and distribute information about hepatitis C to offenders, ex-offenders and high-risk youth. As a member of this agency's SHARP Advisory Committee (Hepatitis C Education for Inmates and their Families), she worked closely with them to develop educational tools. In return, the agency was able to access these hard-to-reach target groups.
- **Canadian Nurses Association**
The Coordinator was a member of the Steering Committee for the Canadian Nurses Association's Health Canada-funded project entitled, *Increasing Awareness and Competencies in Hepatitis C Among Nurses*; and had input into the content of the Association's Nursing Guide for Hepatitis C. Her personal story, "Living with Hepatitis C as a Nurse" which was published in the hepatitis C supplement to the *Canadian Journal of Public Health* in August 2000, was included in the Guide along with the story of one infected member from Hepatitis C Moncton. She was involved in reviewing the Guide and planning its distribution. By sharing her expertise and personal experience, the agency received two benefits: both an opportunity to build capacity among health care professionals and a chance to increase its visibility on a national level.

- **Greater Moncton Harm Reduction Steering Committee**

The Coordinator was a member of a multi-stakeholder committee whose primary target group was people who inject drugs. At the time of our visit, the Committee was working on the establishment of a mobile needle distribution van. If the funding was received, Hepatitis C Moncton would provide staff and volunteer training and could disseminate agency materials. Through working towards a common goal, the agency was going to be able to reach out to a high number of at-risk/infected people.

- **First Canadian Conference on Hepatitis C Organizing Committee**

The Coordinator co-chaired the Community and Social Sciences Track of the 1st Canadian Conference on Hepatitis C. She also presented two speeches at the conference. Proceedings were distributed throughout the Atlantic region by the agency. In exchange for providing first-hand experience and community expertise, the agency received networking opportunities, most importantly inclusion in the Atlantic Hepatitis C Connection, a network of hepatitis C group leaders inaugurated at the conference.

b) Shared Target Groups and Community Objectives

The second type of partnership evolved due to shared target groups and shared community objectives. Their collaboration involved general information-sharing,

dissemination of materials, referral of clients and general support. As the Project Coordinator commented:

We have established excellent working relationships with other key stakeholders and community groups in the region. These partners share resources and provide us with a wide range of in-kind services. This keeps our costs down and allows us to achieve a great deal more than if we were trying to do everything ourselves.

These partners included:

- **New Brunswick Department of Family and Community Services**

The Department delegated a public health nurse to sit on the Steering Committee, provided meeting space and disseminated project materials.

- **New Brunswick Department of Health and Wellness**

As of March 2002, the Department announced that Hepatitis C Moncton was considered to be a partner. The Coordinator was invited to speak to the Department's Addiction Services about the implications of having hepatitis C testing in all Addictions Services facilities.

- **Addictions Services Methadone Clinic Steering Committee**

The Hepatitis C Moncton Coordinator was a member of this Committee that was exploring the possibility of providing a clinic with supervised urine sampling, drug testing and counselling.

■ **Public Health Region 1**

The Region referred clients to Hepatitis C Moncton and disseminated project materials.

c) **Credibility Lent through Status**

The third type of partnership lent credibility to Hepatitis C Moncton due to the partner's status or visibility in the community and their strong commitment to agency goals in their own circle. These included:

■ **High Profile Family Physician/Researcher**

The only licensed physician in the province who prescribed methadone recently joined the Project Steering Committee. From his perspective as a physician he would be able to offer assistance in developing a strategy to build capacity among family physicians. He was conducting a study examining the relationship between methadone and hepatitis C and would inform the agency of his findings.

■ **Local MP and MLAs**

The local Member of Parliament and the local Member of the Legislative Assembly (who was also the Minister of Family and Community Services) participated in the unveiling of the agency's logo and first Annual General Meeting. They provided support and guidance regarding provincial and federal health priorities. The previous New Brunswick Minister of Health sent a special communiqué to all family physicians in the province to make them aware that Hepatitis A and B vac-

cines were available free of charge for hepatitis C infected patients, included a copy of Hepatitis C Moncton's French and English pamphlets and encouraged them to contact the agency for further information or materials.

The agency was well aware of the value of these many partnerships. The following comment appeared in the agency's Progress Report:

During the first year of our project, a great deal of our time was spent developing services, building partnerships and establishing ourselves in the community. However, as time has gone on the project has become better known and an increasing number of stakeholders are calling upon us for participation in their activities.... We plan to continue our involvement and co-operation with our current partners and believe the sustainability of the project will be greatly enhanced through these collaborative efforts.²²

3. Improved Care and Treatment Support

There were many indications that Hepatitis C Moncton was improving support services for victims of hepatitis C to help them deal with their anxiety and stress. In a typical three-month period, the Coordinator held eight face-to-face education and support consultations, predominantly for the newly diagnosed but some were about transmission or treatment.²³

A peer support self-help group was held each month and approximately eight infected or affected people typically attended.²⁴ However, at one meeting a breach of confidentiality occurred

which led to the design of a Support Group Confidentiality Agreement that each individual had to sign in order to become a participant. Confidentiality was indeed an issue in this small city. As one client commented in her interview:

I don't want to go to the support group because people know me. They will think I have Hep C or the father of my kids will know my partner has hep C.

When we asked clients what was best about Hepatitis C Moncton, they all agreed that the support they received was the main benefit:²⁵

Since we found out about Hep C Moncton last summer, we had some support. I phone her [the Coordinator] for information. She is giving us a lot of support. She is a friend. I called the national hot line (we found that phone number in the directory) and they gave me [Hepatitis C Moncton's] phone number.

The support. Any time of day she [the Coordinator] will be there for me.

Number one is the support group. There is also a ton of information, mostly on prevention.

Having hep C crushed me. My life has totally changed since I have known I have hep C. I lost a relationship. After losing my job, I was depressed and was contemplating suicide. Hep C Moncton's Coordinator talked me out of doing anything bad to myself. Now I don't want to apply for another job before my psychiatric problems are resolved. Having hep C affects my social life, but now I am less isolated.

The day that my doctor told me I had hepatitis C I went in a daze. When I got home, there was a friend there who gave me the number for Moncton Hep C. I called right away and I was crying and hysterical. The Coordinator calmed me down and kept reassuring me that I wasn't

going to die the next week. If it hadn't been for them, I would have been on my own with no one to turn to. It was majorly important that somebody tell me something about what to expect.²⁶

The project also provided us with comments from people affected by the disease, as follows:

My husband would go to the doctor and when he got home I would ask him all these questions but he didn't have the answers. He's not the kind of person that really questions a doctor—me, I want to know. But because of patient-doctor privilege, I can't call his doctor and my family doctor doesn't know much about it either. Once I found out about Hep C Moncton, I started asking for information from them and they seem to have all the answers I need.

I didn't ask my husband certain questions because I knew he was already feeling ashamed of his disease. But I was worried about how to protect our children and myself and couldn't seem to get many answers. Finally, I got a hold of Hepatitis C Moncton and they had loads of information for me.²⁷

Challenges faced by Hepatitis C Moncton

1. Awareness Still Needed in Specific Target Groups

Despite the headway made by Hepatitis C Moncton in a relatively short period of time, everyone we interviewed agreed that developing awareness about hepatitis C was still a significant issue in the Moncton area. As a representative from the New Brunswick Department of Health and Wellness, Public Health Division commented:

No, there is not enough information on hepatitis C. More information is required on

the following topics: prevention in at-risk populations (e.g. injection drug users), risk factors (e.g. needle sharing), disease transmission, support groups and other types of support and information on care and treatment. The majority of people do not know what is hepatitis C. There should be information adapted for persons with lower levels of literacy and education. Even physicians know little about hepatitis C.

In particular, several target groups were repeatedly identified as needing information about hepatitis C.

a) Employers

The need for employer awareness was mentioned to us a number of times by agency clients as they recounted their negative experiences in the workplace. Several had lost their jobs once their employer learned they had hepatitis C. Hepatitis C Moncton reported on the serious impact that a lack of appropriate information had in the workplace:

An issue that has repeatedly come to our attention over the past year is the high level of stigmatization around hepatitis C that currently exists in the community and particularly amongst employers. It appears that many people in the community have the impression that HIV AIDS and Hepatitis C are basically the same thing.

Having experienced this negative response in the workplace, infected individuals stopped informing employers or co-workers about their disease. However, feelings of guilt, depression and anxiety could then result. But as a recent agency document commented:

While they admit that some of these feelings may be their own paranoia, there is adequate evidence to suggest that people infected with hepatitis C do indeed face discrimination as a result of their disease.

The document went on to provide clients' examples:

A couple months after I found out I had hepatitis C, my doctor started doing a lot of tests and stuff and I had a number of appointments to attend. So I went to my boss and told him "I just found out about this, you don't have to worry about anything, I'm not contagious to other workers" and tried to explain to him the information that I had. Four hours later I was laid off! That was really devastating for me because I had been assured that my job was permanent and we had just bought a new house. I had been doing really well at my job, never any complaints, lots of compliments. My boss said "This isn't because you have the disease or anything" but I was never called back. This was a real lesson for me — I've never told another employer since.

I lost two jobs after telling my employers I had hep C and since then, no way. I went to one employer, and tried to explain to him how careful I am and told him that I carry my own kit with me to clean up after myself if I happen to cut myself — nobody else cleans up after me. But my employer thought it was going to turn into AIDS and other employees would just avoid me. Things got so uncomfortable; I ended up quitting myself because I couldn't take the stares and everybody looking at me. They

*stayed away from me and wouldn't talk to me. I was a big taboo.*²⁸

Hepatitis C Moncton was requested to work with the New Brunswick Human Rights Commission regarding the case of one such individual who was fired once the employer discovered that the individual had hepatitis C.

b) Family Physicians

In conjunction with the Moncton Chapter of the Canadian Liver Foundation and Schering Inc., the agency had planned a hepatitis C information dinner and had invited 100 family physicians in the Greater Moncton area to attend. A presentation entitled "Treatment of Chronic Hepatitis C" by a well-known Moncton gastroenterologist was planned. Unfortunately, only four physicians replied and the dinner was cancelled. This experience demonstrated how difficult it is to reach this target group. The agency decided that the next time they tried to offer an event like this, they would include continuing medical education credits as an incentive.

When the agency conducted a needs assessment, which involved interviews with 40 infected or affected adults or teens, the main theme that emerged was the lack of hepatitis C knowledge among family physicians.²⁹ Several of the clients we interviewed recounted negative experiences with their family physicians or health care workers due to their lack of adequate information about the disease:

I've had hep C for 20 years. Maybe it is too late for me to get treatment. I don't

believe there are enough support services at the hospital or at the doctor's office. They treat us just like an ordinary patient. It was OK the first time I called an ambulance, but the fourth time I called they said: "It's just [client's name], he can walk".

We need more specialists, doctors. They make us feel that it is our fault if we have hep C.

My doctor asks me questions on hep C because he doesn't know much.

As a board member commented:

Some people call on the hot line—they want to commit suicide because they didn't get the right information from their doctor.

Again, the agency was able to recount infected clients' experiences:

I called my doctor about half an hour after I got the letter from Red Cross and got in right away but I couldn't see my regular family doctor and had to see someone else that was on call. He made it sound like I had AIDS or something. He told me I couldn't have sex with my common-law wife, he told me I had to quit smoking and drinking and taking my Diazepam which I've been on for 12 years. He said it was like AIDS. I honest to God thought I was going to die.

Doctors need to be better informed. When you're telling a single parent "you're dying" and you have small children at home, what are you supposed to think? My doctor had nothing to give me, not a pamphlet or any information

*at all. He gave me no indication if I would live 10 weeks or 10 years, nothing. I just went home knowing I was dying.*³⁰

c) Youth

The clients we interviewed indicated that young people should have more information about hepatitis C and that education should be provided for them both in schools and in the community. As one client commented:

The young people should have their own place to go to for support and services.

While the risk factors associated with injection drug use needed to be addressed with this population, there was also a growing concern about the number of young people being tattooed or having body parts pierced with unsafe equipment.

In the opinion of the Coordinator and board members at Hepatitis C Moncton, there was only one possible solution to these awareness needs:

*We believe that the best approach to dealing with this issue is to educate, educate, and then, educate some more.*³¹

2. Growing Prevention Needs

Although hepatitis C information was being disseminated where there had been none before, the agency found that the need for prevention was actually growing. In particular, two at-risk groups were mentioned repeatedly as being at greater risk as time went by.

a) People who Inject Drugs

According to a recent report prepared by Hepatitis C Moncton, not only were more youth injecting drugs, but drug use was also increasing in frequency among people over the age of 25.

*Consultation with front-line workers from the Regional Addictions Services Treatment Centre confirmed that there is a phenomenal increase in the use of injection drugs in this Region and that they deal regularly with people of all ages who have opiate and cocaine addictions. Ten years ago, the Addictions Centre in this region didn't even have one "opiate-addicted" client and yet today it is one of the most common reasons for admission.... In 1999, of all the persons admitted for drug addiction, 26.5% were IDU's. By the end of 2001, this figure had increased to 65.9%.*³²

While efforts were being made by the Greater Moncton Harm Reduction Steering Committee (of which Hepatitis C Moncton was a member) to establish a Needle Distribution Program, no funding for this critical service had been secured. The agency's partnering physician had long been an advocate for the development of a provincial methadone treatment program but there had been no developments on this front.

Looking at the growth in the number of people who inject drugs, it seemed clear to the Coordinator that hepatitis C funding would have to be continuing rather than project-based because of the growing threat in this population and the low priority of IDU on the public agenda.³³

b) Prison Populations

Despite the excellent work done by the SHARP project, the representative from the John Howard Society indicated that there were still not enough services offered to the prison population. The SHARP handbook suggests that 30-40% of all Canadian inmates were infected with hepatitis C, as did 9 out of 10 inmates who had ever injected drugs.³⁴ As a result, more harm reduction programs, including access to clean needles, more peer education and support, and more effective addictions programming are required. In particular, she indicated that more information was still required on the following topics:

...prevention for special populations (e.g., injection drug users), risk factors (e.g., sharing of needles), disease transmission, support groups/other sources of support (there is a real sense of isolation in the prisons), harm reduction strategies, and care and treatment information. Inmates don't realize the risk of sharing needles and inks in tattooing. They also share personal items such as shaving blades.

3. Agency Growth Required

The third challenge faced by Hepatitis C Moncton was the need for more funding to address the growing demand for service. All the stakeholders we interviewed agreed that the agency provided a much-needed service but that it needed to be expanded. A number suggested the need for a counselling or therapy component. They pointed out that some support staff were

needed to help field the many calls received. As the Coordinator saw it:

If Hep C Moncton had more staff, we could do a lot more.

Above all, however, the agency needed accessible and public office space with enough room for meetings and private consultations. The lack of regular office space had a negative impact on public perception. The Coordinator commented:

Fundraising is hard and practically impossible when you're operating from your home. Some people think that the organization pays for a part of my rent!

She elaborated by saying:

We need operational funding, please. It would make such a difference if we only had an office, somewhere to get started.

To this end, the agency was developing a fundraising strategy and planned to hold a door-to-door awareness and fundraising campaign. The board was in the process of developing their bylaws and once this was done they would apply for a charitable registration number so that they would be able to offer tax receipts to donors. They were also looking at ways to secure funding from foundations and other municipal, provincial and federal government agencies and was preparing some research and programming proposals. They believed that their continued involvement with their current partners would greatly enhance their chances of sustainability. Judging from the number of strong community links they had forged so far, it was easy to believe that they would be successful.

The following types of documents were reviewed in the preparation of this case study:

- Project documents from Health Canada
- Original Project Proposal Submitted to Health Canada on June 9, 2000
- Project Proposal Submitted to Health Canada on April 17, 2002
- Project Progress Report Submitted to Health Canada on December 20, 2001
- Quarterly Reports (October 2000 – December 2001)
- Job descriptions: Project Coordinator, Executive Director
- *Hep C News*, Newsletters (3 issues: June, September and December 2000)
- Power Point Presentation:
 - *Hepatitis C 101*
 - *Hepatitis C Cases Compared to AIDS Cases Reported in New Brunswick*
- Hepatitis C Moncton resources including information sheet (Hepatitis C Facts), brochures (Drugs and Alcohol, Diet and Hepatitis C, The Proper Use of Drugs and Medications, How can I Protect Myself? What are the Routes of Transmission?), booklet (Living with Hepatitis C – A Support Guide/ Vivre avec l'hépatite C – Un guide d'appui)
- Letters of support for Hepatitis C Moncton's 2002 funding proposal to Health Canada
- *Surviving Hepatitis C And Risks in Prison (SHARP)* pocket book and Playing Card Mock-Ups (produced by the John Howard Society of Greater Moncton)

Case Study Information:

The case study was conducted between May 1 to May 3, 2002. The case study research team included Chantal Cholette and Sylvie Rossignol. The case study analysis was conducted by Chantal Cholette. The case study was prepared by Dr. Gail Barrington. It was approved for distribution by the Project Coordinator of Hepatitis C Moncton Inc. on December 4, 2002.

In total, 8 interviews and focus groups were conducted and 11 individuals took part in the case study in Moncton. Below is a breakdown of the number and types of interviews/focus groups conducted and of the number of individuals that took part in the case study:

	# Interviews/ Focus groups	# Participants
Advisory Group Members:	0	0
Board Members:	1	2
Primary Clients:	3	4
Project Coordinator:	1	1
Secondary clients:	3	4

- Executive Director, SIDA/AIDS Moncton, Chairperson of Moncton Harm Reduction Steering Committee
- Education Coordinator, Surviving Hepatitis C and Risks in Prison (SHARP), John Howard Society of Greater Moncton
- Nurse hygienists, Département de la Santé et du Mieux-Être, Division de la Santé Publique du Nouveau-Brunswick

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4. The Environmental Scan on Prevention Infrastructure and Capacity in Atlantic Canada. Health Canada. February 4, 2000.
5. Profile of Injection Drug Use in Atlantic Canada, Caroline Ploem, PPHB Atlantic Regional Office, October 12, 2000.
6. Profile of Injection Drug Use in Atlantic Canada, Caroline Ploem, PPHB Atlantic Regional Office, October 12, 2000.
7. As reported in Project Proposal Submitted to Health Canada on April 17, 2002, pp. 2-4.
8. Project Proposal Submitted to Health Canada on April 17, 2002, pp. 2-4.
9. Project Proposal Submitted to Health Canada on June 9, 2000.
10. Project Proposal Submitted to Health Canada on June 9, 2000.
11. Project Proposal Submitted to Health Canada on June 9, 2001.
12. Project Proposal Submitted to Health Canada on June 9, 2000. p. 10.
13. Project Progress Report Submitted to Health Canada on December 20, 2001.
14. Project Progress Report Submitted to Health Canada on December 20, 2001.
15. Personal communication. September 18, 2002.
16. Quarterly Report, October 1st thru December 31st, 2001, Project Proposal Submitted to Health Canada on April 17, 2002.
17. Quarterly Report. The Greater Moncton Chapter of the Hepatitis C Society of Canada. April 1–June 30, 2001.
18. Project Proposal Submitted to Health Canada on April 17, 2002, p. 7.
19. Project Proposal Submitted to Health Canada on April 17, 2002, p. 6-7.
20. *Surviving Hepatitis C and Risks in Prison...the Facts*. The John Howard Society of Greater Moncton. April 2002.
21. Quarterly Report. The Greater Moncton Chapter of the Hepatitis C Society of Canada. April 1–June 30, 2001.
22. Project Progress Report Submitted to Health Canada on December 20, 2001.
23. Quarterly Report. The Greater Moncton Chapter of the Hepatitis C Society of Canada. April 1–June 30, 2001.
24. Quarterly Report. The Greater Moncton Chapter of the Hepatitis C Society of Canada. January 1–March 31, 2002.
25. The first four quotations are from the case study interviews; the final comment provided by the project.
26. Project Proposal Submitted to Health Canada on April 17, 2002, pp. 6-7.
27. Project Proposal Submitted to Health Canada on April 17, 2002, pp. 6-7.
28. Project Proposal Submitted to Health Canada on April 17, 2002, pp. 8-9.
29. Quarterly Report. The Greater Moncton Chapter of the Hepatitis C Society of Canada. January 1–March 31, 2002.
30. Upcoming Project Proposal Submitted to Health Canada on April 17, 2002, pp. 8-9.
31. Project Progress Report Submitted to Health Canada on December 20, 2001.
32. Project Proposal Submitted to Health Canada on April 17, 2002, pp. 2-4.
33. Quarterly Report. The Greater Moncton Chapter of the Hepatitis C Society of Canada. January 1– March 31, 2002.
34. *Surviving Hepatitis C and Risks in Prison...the Facts*. The John Howard Society of Greater Moncton, April 2002.

Case Study:

Hepatitis C Foundation of Quebec (Verdun)/ Fondation de l'hépatite C du Québec

Montreal, Quebec

The Hepatitis C Support Group of Greater Montreal

In the summer of 1998, a rally was held for the victims of hepatitis C in Shawinigan, Quebec. Two women met there, one infected with hepatitis C, the other affected by it, and began to discuss their needs. Soon after the march, they got together in the Montreal suburb of Verdun. Sitting at the kitchen table, they decided to start a support group. As one of them commented:

We based the project on our personal experiences. In 1991, the doctors said to me that nothing could be done. I tried to find some answers, and I was frustrated when I was trying to find some information.

They called the support group the Hepatitis C Support Group of Greater Montreal and operated it out of the home of the Executive Director.

In a short period of time, the group caught the interest of many people dealing with hepatitis C and began to grow, as they recalled later, “like a mushroom.” As a Board member commented:

It is hard to communicate with people who have hepatitis C. They feel they have nobody to talk to, nobody to share their problems with. A lot of people will only talk to somebody who also has hep C. They think that only people with hep C will understand and will know what it's like to have it.

Realizing the increased need for support, as well as lack of information available about the disease, they considered the possibility of starting a chapter of the Hepatitis C Society of Canada because they knew someone in that organization. However, at the last minute, they decided to create their own organization. As the Executive Director explained:

The Hepatitis C Support group organized a meeting with the Hepatitis C Society of Canada's representative who was to come to Verdun to meet the Board and approximately 20 people to teach us how to start a Chapter of the Society. However, two hours prior to the scheduled meeting, the Society cancelled. That is why we decided to create our own organization, and any monies we obtained from memberships would stay within our own group.

Context

In 2001, Quebec had a population of slightly over 7.4 million, with nearly half of those residents living in the Montreal metropolitan area. In 1999, Quebec had a rate of newly reported cases of hepatitis C of 46.2 per 100,000 population which is lower than the national rate of 63.6 per 100,000 population.¹ Quebec residents who were infected with HCV by a blood transfusion between 1986 and 1990 are entitled to compensation through the national settlement. For individuals infected before 1986 and after 1990, the federal government provided a

transfer of funds to the Province of Quebec for infected individuals' clinically indicated medical care, regardless of the date of their infection. On May 6, 1998, the Province announced a \$75 million compensation package for victims of the blood system who were ineligible for the national settlement.² The Quebec Government also provides brochures in both French and English about hepatitis C and provides comprehensive information on treatment, prevention, transmission and compensation on its web page.³

In January 2000 in Quebec, Health Canada conducted an environmental scan to determine the community response to hepatitis C.⁴ Only half of the 35 community-based agencies polled mentioned that HCV was part of their agenda for 1999-2000. Half of the agencies worked on issues associated with HIV/AIDS; the rest provided help to high risk populations such as street-involved youth or youth in general, hemophiliacs or those receiving transfusions, the homeless, drug users, or Aboriginal people. Only three organizations made HCV the focus of their work and specifically offered activities and services for people living with HCV—and one of those agencies is the subject of this case study.

In 2001, the Montreal metropolitan area had 3.4 million inhabitants; 1.8 million of them were served by the central health region known as the Région de Montréal-Centre—outlying suburbs are served by different health regions. Hepatitis C rates for Montreal were not available but the city has a large population of people who inject drugs and other at-risk populations.

South of downtown and on the St. Lawrence River, the Arrondissement de Verdun consists mainly of working-class families, although the Ile des Soeurs area is home to several large service sector industries and desirable river-view townhouses and apartments. In 2001, the population was 60,564; 70% spoke French and 24% spoke English as their preferred language. About 11% of the population were immigrants. Of families with children, 42% were single parent families, and of these, 86% were headed by women.⁵ A staff member at the nearby Dawson Community Centre suggested that a significant number of these young mothers were using drugs and having unprotected sexual relations.

The Development of the Hepatitis C Foundation of Quebec (HCFQ)

On November 5, 1999, the Hepatitis C Support Group of Greater Montréal became incorporated as a non-profit organization, The Hepatitis C Foundation of Quebec (HCFQ)/Fondation de l'hépatite C du Québec. It was the first organization of its kind in Quebec devoted solely to those infected with or affected by the HCV virus.

While the HCFQ did not conduct a needs assessment, they estimated the extent of need based on the calls they received from what they termed “very sick people”, their family and friends who were looking for support, advice, information or just to be able to talk to someone who understood the problems associated with hepatitis C. They received approximately 20 calls a month from new individuals. About one-third of these were newly diagnosed cases.

HCFQ Mission

- To provide compassion, comfort and support to those affected by the hepatitis C virus and their family members;
- To increase awareness for the disease and its complications;
- To recognize all people with hepatitis C, no matter how the disease was contracted;
- To ensure that patients have access to the best care available;
- To share an equal interest in providing a better quality of life for those who are no longer able to provide for themselves or their families;
- To work in collaboration with researchers to improve diagnosis, treatment and prevention of hepatitis C; and
- We are people helping people.⁶

Agency staff and other stakeholders we interviewed identified other programs and organizations in the community that provided support for victims of hepatitis C or offered prevention information. These included:

- **Santé publique de Montréal**
Offered an integrated prevention program for STDs, AIDS and hepatitis C as well as a university course on the biological aspects of these diseases;
- **Schering Canada**
Provided free interferon and Rebetron® treatment to patients who could not afford it and provided physicians with information;
- **Ruban en route**
An HIV/AIDS public awareness program in secondary schools and help line that added hepatitis C information to their program in 2000; and

- **Travail de rue/Action communautaire**

A non-profit working with street-involved youth which is offered on site in bars, alleys, the Metro and other locations where they congregated.

When we asked HCFQ clients if there were other services for individuals infected with or affected by hepatitis C, they were only aware of a few other services. One mentioned the Canadian Liver Foundation as a resource. Another had been recommended to a hospital psychiatrist or psychologist; however, when he actually asked for service, he never received a reply. One had been to see a social worker at the CLSC but commented that the social worker knew very little.

Generally, the Foundation was their main source of information and for them it filled a serious gap in local services. As one client commented:

The Foundation is the only organization around. And it is bilingual.

Strengthening the Hepatitis C Foundation of Quebec Project

In the same month that it was incorporated, the HCFQ submitted a proposal to Health Canada's Hepatitis C Prevention, Support and Research Program for Prevention and Community-based Support Regional Project Funding for a project entitled Strengthening the Hepatitis C Foundation of Quebec. As the proposal fit with the region's plans to target prevention and awareness of HCV in street populations, incarcerated individuals and people who inject drugs, the proposal was approved. Funding of \$118,000 was received for the period from January 14, 2000 to March 31, 2002, as follows:

1999-2000: \$25,000

2000-2001: \$53,000⁷

2001-2002: \$40,000

The goal of the project was to develop further the Foundation's activities and structures, thus aiding it to fulfill its mission. Four main project objectives were formulated:

1. Structuring the organization (membership development; diversifying and increasing funding);
2. [Providing] education and awareness-raising about hepatitis C (production of communication tools, distribution of educational and promotional materials, media campaign, ensuring collaboration and representation);
3. Offering capacity-building and training (ensuring the development of a better understanding of HCV among health care workers); and
4. Developing the team (staff training; setting up and training a team of volunteers).

A fifth objective was later added:

5. [Providing] support and mutual self-help for people infected and affected (organizing support groups and offering telephone support).⁸

In their application, the Foundation indicated that it would address identified needs in the following manner:

- We will promote wellness by encouraging people to live a healthy lifestyle; for example avoiding alcohol and illicit drugs, maintaining a nutritional balanced diet. We will highlight the importance of reducing stress in the lives of hepatitis C infected and the necessity of keeping a healthy mental attitude.

- We will address personal health practices by supplying literature, holding information meetings and speaking to those infected with or affected by hepatitis C.
- We will direct them (HCV infected people who lack personal income to sustain themselves in regards to medication, housing, food, etc.) to the proper social services that can be of benefit to them. We would like to work with other charitable organizations to address these problems, i.e., social services, CLSCs, food banks, etc.
- [We will offer] support meetings as an outlet for those who are ostracized to become involved and support others that are infected with or affected by HCV.
- A therapist will be able to assess the needs of the individuals and guide them through their problems (by instilling various) coping skills.⁹

The Foundation's energies were completely focused on hepatitis C issues. They offered counselling, a support group, and awareness and prevention information and targeted a broad range of clients on all issues associated with hepatitis C, including:

- Infected/affected and co-infected individuals;
- Transplant patients and those awaiting transplantation;
- Prisoners and ex-prisoners;
- Youth and street-involved youth;
- Young mothers;
- People who use drugs;
- Professionals, including physicians, pharmacists, health care workers and community workers; and
- Linguistic groups (English and French), Aboriginal people and ethnic minorities.

As the project's Progress Report commented:

People infected with HCV have a feeling of hopelessness because they are suffering from a chronic illness and have no idea what lies ahead in their lives, or if they will have a life. The Foundation's support for infected people advocates that they are not going to die tomorrow, that treatment options are available and [it] also gives people encouragement not to give up.

The Foundation developed a very supportive atmosphere. Infected and affected individuals were invited to attend meetings to acquire the knowledge needed to cope with the illness. The interaction between infected individuals often developed into friendships and buddy systems. Affected individuals gained a better understanding of the problems of the infected person and this created a more comfortable home or work environment. The Foundation allowed for drop-in or scheduled visits where an infected/affected person could receive individual support and information.

Some HCV infected people needed help at home to perform daily tasks such as food preparation, shopping and cleaning. The Foundation addressed this issue by directing them to the appropriate community resource, such as the CLSC. The Foundation's president, who was a registered nurse, made home visits to teach patients how to take their medications properly. She often took on the role of a social worker and assessed the situation and capabilities of the individual, referring them to the correct organization to have their needs met.

Some patients awaiting transplantation needed information about what to expect after receiving their organ and the Foundation sent them information. Those who had received a transplant

often needed support. As the project's Progress Report explained:

Some are fearful that HCV will again raise its ugly head and attack their new liver. Some are unaware that treatment options for HCV exist after receiving their donated organ. We try to encourage transplant HCV carriers to take one day at a time, avoid stress, and to get involved in the support of others, especially those awaiting transplantation.¹⁰

In March 2001, the Foundation moved to its new location, a double storefront office a few blocks from Verdun's main street in an old, working class neighbourhood. The space was divided in two, lengthwise, with two large store windows in front and two front doors. The long narrow area on the right hand side had a table for meetings, a small area to display brochures, the Counsellor's desk and a kitchenette, all lined up behind each other. At the back was a very small washroom. Near the front was an opening into the other side of the office. This area had the Administrative Assistant's desk, filing cabinet and fax machine, behind it the Executive Director's desk and at the back a table used to prepare mail-outs. Although the staff were happy to have a public space at last, they were well aware of the space's limitations, including a lack of privacy for support groups and counselling.

The Executive Director, as one of the two founders, had been with HCFQ since the beginning but she was now a salaried employee and worked full time. Her primary role was to make sure that infected and affected clients received the services they needed. She supervised staff; worked with the Board and partners; provided individual support (particularly to English-speaking clients); wrote proposals and reports;

did the accounting; and looked for funding. The Counsellor was also full time and had been with the Foundation since February 2001. She facilitated and coordinated support meetings, provided individual support (particularly to French-speaking clients), and recruited volunteers. During our visit, we noted the many calls she received for information and support. The part-time Administrative Assistant, hired in April 2001, looked after the clerical work, coordinated materials and supplies, maintained the files, membership lists, partner and physician lists, and volunteer roster, and also looked after mailings.

There were four members on the Board, including the President who was the other agency founder. They were elected at the annual general meeting for a two-year term. Rather than representing a specific stakeholder group, Board members were volunteers who got involved because of their interests, availability and time. Their role was to ensure that the administration of the Foundation was carried out and that the needs of people with hepatitis C were met. There were two sub-committees, the Fundraising Committee and the Information Support Committee, in charge of awareness, conferences, and support groups.

The Foundation had 28 volunteers. In the 2001-2002 year, they contributed 450 volunteer hours visiting shut-in members at their homes, driving members to medical appointments, providing translation, selling tickets, distributing brochures, answering phones and helping out with clerical duties. They were recruited primarily by word of mouth and training was provided informally as needed.

Through extensive fundraising activity, the Foundation was able to augment its resources by over \$50,000 as shown below:

HCFQ Budget Sources and Funding¹¹	
■ Health Canada, Hepatitis C Prevention, Support and Research Program, Prevention and Community-based Support Regional Project Funding . .	\$118,000
■ Heritage Canada	\$25,000
■ Schering Canada	\$17,346
■ GlaxoSmithKline	\$500
■ Fundraising (various)	\$8,351

As the Foundation's project evaluation report stated:

This is a significant accomplishment for the organization, especially considering that it had raised only \$1,500 prior to the commencement of the project.¹²

In addition, a number of significant in-kind donations were obtained as well, including a computer, meeting space, educational videos, a bilingual dictionary, radio announcements, website support, at-cost printing and translation services, valued together at over \$9,700.

Strengthening the Hepatitis C Foundation of Quebec: Project Accomplishments

1. Improved community access to care and treatment support

One of the main accomplishments of the Foundation was the improved access to care and treatment support for those infected by hepatitis C in the community it served. Over the funding period, the Foundation worked hard to increase its membership which grew from 57 to 129.¹³

The needs of members were severe indeed; the Project Coordinator commented:

People need a supportive environment.... The people on treatment need a lot of help. There is a greater chance of suicide if they are alone.

This sense of isolation was supported by the comments of Foundation clients. When they were asked how hepatitis C had affected their lives, typical responses included:

Hepatitis C created havoc in my life. I use to work in construction. Now I live on social welfare and I am infected. I feel very anxious and I don't know what to expect next.
(our translation)

I thought I was going to die. This is why I decided to go on treatment. I had limited chances of success because I had cirrhosis of the liver. Treatment has been successful but I still have cirrhosis. It's like life has come to a halt and taken another direction.

Death ... not being able to complete my life. I have no wonderful outlook on life. I will soon need a liver transplant but I have a rare blood type. Therefore, my chances of finding an organ are even smaller. I constantly have to live with doctors and hospitals. That's not a life.

They repeatedly mentioned the support they had received from the Foundation and how it had helped to break their sense of isolation, particularly in dealing with the issues associated with treatment. They were eloquent in describing how their needs had been met:

I have been attending the support group meetings on Wednesdays for the last 3 to 4 months. It really helps me. It is essential for me. Without these meetings, I would feel very much alone. (our translation)

The first time I came, I had been on treatment for one year. I regularly attend the meetings. I was alone, isolated and treatment was hard on me. (our translation)

When I'm feeling down and low, I can always talk to someone at the Hepatitis C Foundation.... Sometimes, I can't go to the group session because I'm too tired and they accommodate me on the phone instead. I appreciate almost everything the Foundation offers. If I call and ask for something, they are always ready to help. I am also a cancer patient and they have been very supportive. They sometimes mail things to me.

The Executive Director expressed her satisfaction with the way that the Foundation had been able to provide this needed support:

I know we saved lives—we've received suicide calls. We help them and they feel they are not alone. We allow people to share their experience, to help each other.

In addition, the Foundation also provided support to those affected by hepatitis C. As the Project Coordinator explained:

The caregivers need help. It is very difficult to take care of people with hepatitis C. The caregivers need to take time for themselves.

Typical comments included:

For my friend it helped to demystify a lot of things. (our translation)

My family benefited from the services provided. Here there is a lot of information on the disease – but 90% of physicians are not aware of it. (our translation)

2. Improved access to information about hepatitis C

As well as being their main source of support, the Foundation was often their only source of information:

There is no other place to go. It is a wonderful group. I get information and help from the Hepatitis C Foundation of Quebec. This project improves the life of people.

This mainly francophone, mainly working class population had additional problems accessing information about hepatitis C. Most information was only available in English, and much of it was only on the Internet. As one client commented:

On the internet, there is a lot of information. If you don't have internet your access to information is limited. However, the internet is not always the best – companies try to sell you things and a lot of material is in English or American in content. (our translation)

The Foundation was able to prepare a detailed information guide for those infected with hepatitis C which was available in both French and English. The Executive Director explained:

The documentation in our pamphlets is based on our own knowledge and reviewed by nurses and Schering. We also had good information from BC and the USA. Health Canada and the provincial health department provide us with information. The types of information we primarily use are the basic facts about hep C, how the disease is spread.

Over 20,000 copies were distributed across the province to approximately 500 CLSCs and clinics, six hospitals, 13 community organizations and a few correctional facilities. As well, 30 copies were provided to Health Canada.

HCFQ also established a bilingual website in September 2000 and, as of April 2002, it had received 2,155 hits.¹⁴ As one client observed:

At the Foundation, it is easy to get information. If the Foundation does not have the information I need, they find it. (our translation)

While this support was definitely an improvement, Foundation staff saw how much more there was to be done. As one commented:

People are glad when they have answers. It is like a light at the end of the tunnel. They don't feel lonely anymore. They'll say something like: "Now I know what it is," but they want more than what they have. Information is missing everywhere.

Other communication tools were targeted at public awareness. These included:

- Posters—approximately 90 posters distributed to the cities of Verdun, Quebec, Lévis, and Valleyfield as well as to the Laval penitentiary; also distributed at the First Canadian Hepatitis C Conference.
- Four pamphlets (available in English only) on HCV and drugs, HCV and pregnancy, HCV and Sexually Transmitted Diseases (STDs), and HCV and the beauty myth, produced in collaboration with a Vancouver group.
- A bilingual Foundation bookmark—4000 distributed to HCFQ members, contacts and various organizations; and
- A new corporate logo, letterhead paper and business cards.

In addition, the Foundation advertised in the local newspaper, as well as on TV and radio. Three interviews with Foundation staff were aired on the Mohawk radio station. The Execu-

tive Director made several speeches, including one at the First Canadian Conference on Hepatitis C where the Foundation also provided an exhibit. As a result of all this publicity, the Foundation received many phone calls asking questions and requesting further information.¹⁵

3. Building capacity for local support groups

Another major accomplishment for this small agency related to building capacity, particularly by fostering the development of local HCV support groups. The Foundation worked with local CLSCs, clinics and community organizations to identify individuals who might be interested in starting a group. Once identified, the Foundation provided advice and encouragement and when the new group was ready to hold its first meeting, staff members co-facilitated the meeting and trained the local leaders. Then they remained available for consultation, information, and support. The Foundation produced a manual, called *How to Start a Support Group*. As well as providing the manual to interested individuals, 30 manuals were distributed at a Health Canada meeting.

By the fall of 2001, two new support groups had been established. In Hull, there are a large number of people who use intravenous drugs. Libération II, a drug abuse prevention and intervention centre in the Outaouais area, contacted the Foundation for help in the development of a support group. The group was pleased to know that the Foundation worked with all people no matter how the disease had been contracted. A FHCQ staff member attended a Libération II Board of Directors' meeting to explain how the Foundation addressed the needs of infected/affected people. A support

group was established and began to meet on a bi-monthly basis.

The Foundation also was contacted by a Sherbrooke area social worker who took great interest in providing social support for hepatitis C patients. That meeting gave the Foundation the opportunity to assist in the development of a support group in Sherbrooke, known as Les Grands Coeurs d'Artichauds. Staff worked closely with this group by sharing literature, information and educational videos. This group met monthly.¹⁶

At the time of our visit, the Foundation had begun to work with two additional groups, Le Mouvement d'information, d'éducation et d'entraide dans la lutte contre le sida (MIENS) in the Saguenay-Lac St-Jean area, and a fourth group in St-Jerome [no name provided], giving them information about how to set up a HCV support group.

The Foundation also targeted professional development. It provided 100 educational packages on hepatitis C for physician training at the Régie régionale de la santé et des services sociaux de Montréal-Centre. It also offered training sessions at several hospitals including two sessions offered for physicians at Ste-Justine's Hospital, one for medical staff at the Verdun General Hospital, and three for emergency nursing staff at the Montreal General Hospital. The Foundation also provided information kiosks at professional conferences to further health care workers' knowledge of hepatitis C.¹⁷ Staff also provided training to workers at the Dawson Community Centre on tattoos, safe sex and other harm reduction topics so that they could provide information to their clients.

4. Supporting partnerships

The Foundation had also worked very hard to support partnership and collaboration on hepatitis C issues in the community. A Board member commented on the importance of partnerships as follows:

We definitely have partnerships—otherwise, we wouldn't be able to reach as many people.

Key partners included:

- **Dawson Community Centre**

Provided free meeting space. Encouraged continued education to young people about the dangers of tattooing, body piercing, safe sex, and drug usage. Invited the Foundation to give a workshop to young mothers on hepatitis A, B, and C.

- **Régie régionale de la santé et des services sociaux de Montréal-Centre**

A physician worked with the Foundation to identify an infected mother to sit on the advisory board of the Society of Obstetricians and Gynaecologists of Canada (SOGC) to aid with the writing of the national guidelines for obstetricians and gynaecologists. He also operated a kiosk at the Régie's medical staff training; and found volunteers infected with HCV who were interested in being involved in the production of an awareness video about the disease.

- **Travail de rue/Action communautaire (TRAC)**

The Foundation worked closely with this group to teach street workers who work with street-involved youth and people who use IV drugs about HCV and its complications. TRAC disbursed Foundation literature and specific joint publications for their clientele

were planned. They also planned to collaborate on workshops for the workers.

- **Quebec Transplant Association**

In collaboration with the Canadian Kidney Foundation, invited HCFQ as a consulting partner by operating a kiosk in the Organ and Tissue Donation Awareness Campaign in April 2002. As hepatitis C is the main reason for liver transplantation, the Foundation supports their efforts toward organ donation.

- **The Montreal General Hospital**

Presented Foundation literature to patients and often referred them to HCFQ. Donated meeting space.

- **LaSalle Education Board, Adult Education**

The Foundation was developing a partnership to allow adult students to work on job training in the HCFQ office, giving students the opportunity for skill development in a community setting to prepare them to return to the workforce.¹⁸

Many other community partners disseminated information produced by the Foundation, referred clients or exchanged information. These included:

- **Ruban en route**

Included literature in their school-based safe sex workshops;

- **Hospitals in the Montreal area**

Presented literature to patients and often refer them to the Foundation;

- **Commissaire au développement local**

A business development association that introduced the Foundation to the local business community. Arranged to have articles about the Foundation written in the local newspaper;

- **Centre de ressources et intervention santé et sexualité (CRISS)**
Mutual information sharing and referral;
- **Fybromyalgia Support Group, LaSalle**
Mutual information sharing; provided a guest speaker for the Foundation's support group;
- **Fondation Farha**
Provided information on co-infected;
- **Fondation Laurent Pontbriand**
Mutual support and campaign planning;
- **L'Organisation d'entraide et d'information sur l'hépatite C (OEIH "C" Québec)**
Mutual support and campaign planning;
- **Spectre de rue Montréal**
Street workers disseminated Foundation materials;
- **Montreal General Blood Bank**
Information exchange; and
- **Canadian Association of Hepatology Nurses**
Membership through the Foundation president.

Challenges

In their interviews, clients, staff and stakeholders identified the many challenges which still surrounded a response to HCV. Three themes emerged from their comments.

1. Stigma associated with the lack of awareness about hepatitis C

Foundation clients mentioned many times the problems they had encountered with discrimination, fear, shame and rejection. As one community stakeholder commented:

The psychological challenge is an important barrier. Several people are in shock when they find out they have hepatitis C.

The anxiety is the worst. There is also shame because hepatitis is associated with use of drugs. (our translation)

Individuals encountered stigma at work:

It has been very bad. You don't have the energy to go out. If employers know that you have it, you can't work. You don't have much of a life.

They also encountered problems at home:

My relationship with my partner is difficult. (our translation)

They saw the stigma as being tied to a lack of awareness or understanding about hepatitis C on the part of the public. All of the groups interviewed had suggestions about who needed greater awareness; from the general public, to high school students, to special populations such as tattoo artists and street workers.

2. The need for more services

Clients had experienced a lack of support in many areas. One mentioned several times was Social Services. As one client described his experience:

During treatment, social assistance asked me to work. I had a lot of problems with social assistance. (our translation)

The Executive Director suggested:

People with hepatitis C should be recognized by Social Services as having a disability. They would then receive more money when they are on welfare.

One of the community stakeholders explained that there was a need, not only for specialists, such as hepatologists, but

also for more global support from general practitioners and other service providers:

One of the biggest challenges faced by a person infected with hepatitis C is to find someone who will address the infection in a global way: absenteeism, death, fatigue are examples of issues which come up. It should be the role of family physicians.

In a lot of cases, 90% of the life of the infected person is spent outside of medical treatment – but other services are required to cope. (our translation)

The Executive Director added Home Support Services to the list of needs:

We need home care for people who live alone and have problems with daily activities such as doing the groceries, cooking, etc.

3. The need for program sustainability and development

HCFQ had accomplished so much in a short time. As a Board member commented:

We have a sense of self-satisfaction when we help people. We are a small team and we're proud of where we are now. We still have a long way to go. When we look back, it's amazing how far we've come. We started with holding meetings in a kitchen, and four years later we have an office and some staff. I realized that when we really believe in what we do and when we see a need, we get somewhere with a tight group.... There are still a lot of people who need help.

The Foundation had many plans for development; however, at the time of our visit in April 2002, the last cheque from

Health Canada had been received and there was no new funding on the horizon. As the Executive Director explained:

Presently, there is no paid staff because we ran out of funds. We are all working on a volunteer basis.

Two and a half years previously, the Foundation had submitted an application for accreditation to the Ministère de la Santé et des Services Sociaux du Québec. Until it had a charity registration number it could not solicit donations from corporations that required a tax receipt. A new pamphlet and a tax receipt form had been prepared but were on hold until the registration number was received. Fundraising ground to a halt. By April 2002, the situation was very grave. The Executive Director explained:

It's been a constant struggle for the past two years even though we have a lawyer helping us. Without this number, we may very well have to close our doors because it is practically impossible to do significant fundraising.

Finally, on May 18, 2002, the Foundation received its registration number so that it was at last able to produce federal tax receipts—only to discover that they also needed a similar number from the provincial government and that they would have to go through another application process. By September, it seemed certain that the Foundation would lose their office. However, despite her intense frustration, the Executive Director was still able to laugh, if a little bitterly:

I can only tell you that I never had a job with so much satisfaction [and] gratification from people, even if it is the lowest paying job I ever had!

The following documents were reviewed in the preparation of this case study:

- Project documents from Health Canada
- Hepatitis C Community-Based Support Project Funding Application to Health Canada submitted in November 1999, pp. 9-10
- Hepatitis C Prevention and Community-Based Support Project Progress Report Submitted to Health Canada in September 2001
- Quarterly Activity Report from January 1st, 2001 to March 31st, 2001
- Hepatitis C Foundation of Quebec Mid-Project Evaluation, February 2001
- Hepatitis C Foundation of Quebec Final Project Evaluation, April 2002
- Job descriptions
- The Hepatitis C Foundation of Quebec resources including pamphlets, bookmark, ribbon and pin
- Letters of support for the Hepatitis C Foundation of Quebec's funding proposal to Health Canada
- Hepatitis C Foundation of Quebec Information Guide (both English and French versions)
- Hepatitis C Foundation of Quebec Starting a Support Group Guide (both English and French versions)
- Employment Agreement
- Confidentiality Agreement
- Program Implementation and Outcome Achievement Survey

Case Study Information:

The case study was conducted April 17 to April 19, 2002. The case study research team included Chantal Cholette and Sylvie Rossignol. The analysis was conducted by Chantal Cholette. The case study was prepared by Dr. Gail Barrington. It was approved for distribution by the Foundation's Project Coordinator on September 4, 2002.

In total, 10 interviews and focus groups were conducted and 17 individuals took part in the case study. Below is a breakdown of the number of individuals that took part:

- Board members: 2
- Primary Clients: 6
- Project Coordinator: 1
- Staff: 2
- Secondary Clients:
 - Moms & Tots Program, Dawson Community Centre
 - Dr. Marc Steben, Consultant physician and general practitioners, Santé publique de Montréal Centre
 - Dr. Raouf Saballil, Shering Canada Inc.
 - Funding Officer and Street Worker, Travail de rue et action communautaire (TRAC)
 - Coordinator, Hepatitis C Project, Ruban en route

References

1. Health Canada Notifiable Diseases Annual Summary 1999. Canada Communicable Diseases Report, 2001.
2. HepNet, Press Release, May 6 1998, Bouchard offers more for blood victims. <http://www.hepnet.com/hepc/news50698.html>
3. Government of Quebec Website, Ministry of Health and Social Services, 2000 <http://www.msss.gouv.qc.ca/f/sujets/hepatitec.htm>
4. Situation Report: Hepatitis C in the Province of Quebec. Yves Jalbert. Health Canada, Health Promotion and Programs Branch. Quebec Region. Hepatitis C Division. January 2000.
5. Profil socio-économique de l'arrondissement Verdun. November 2001.
6. Hepatitis C Community-based Support Project Funding Application Form, March 2000. p. 3. NB. One objective was removed in order to get charitable status, "To serve as an advocacy group on behalf of patients and their families."
7. This amount was originally \$40,000 but was augmented by \$13,000 to create two manuals: How to Start a Support Group and Information Guide on Hepatitis C.
8. Hepatitis C Foundation of Quebec. Mid-project Evaluation. February 2001. p. 2.
9. Hepatitis C Community-Based Support Project Funding Application to Health Canada submitted in November 1999. pp. 9-10.
10. Hepatitis C Prevention and Community-Based Support – Project Progress Report, September 2001.
11. Hepatitis C Foundation of Quebec. Final Project Evaluation. April 2002. p. 5.
12. Hepatitis C Foundation of Quebec. Final Project Evaluation. April 2002. p. 5.
13. Hepatitis C Foundation of Quebec Final Project Evaluation, April 2002, p.4.
14. Hepatitis C foundation of Quebec Final Project Evaluation. April 2002. pp. 7-8.
15. Hepatitis C Foundation of Quebec Final Project Evaluation, April 2002, pp. 7-8.
16. Hepatitis C Foundation of Quebec Final Project Evaluation, April 2002, pp. 11.
17. Hepatitis C Foundation of Quebec Final Project Evaluation, April 2002, pp. 10.
18. Hepatitis C Prevention and Community-Based Support – Project Progress Report, September 2001.

Case Study:

Winnipeg Hepatitis C Resource Centre

Winnipeg, Manitoba

The Development of the Hepatitis C Resource Centre

entreAcross the street from Winnipeg's Health Sciences Centre, home of the hepatitis C clinic, is a building known as the Manitoba Self-Help Clearinghouse Concerning Disabilities. It is owned by the Society for Manitobans with Disabilities and houses a number of small not-for-profit agencies. In a tiny office on the second floor, the Hepatitis C Resource Centre (HCRC) offers support and information to those infected with or affected by hepatitis C. The space is crammed with desks, a bookcase, a filing cabinet, piles of papers and files, and boxes of resources; not to mention two or more staff and volunteers. It is hard to find a place to sit down, but for the Executive Director, this situation is a huge improvement over the old days when she worked out of her home.

In 1991, her husband contracted hepatitis C. It took a while for the disease to be diagnosed and when a positive test result was finally found, it was devastating for them both. She recalled:

I was very, very scared for him. I remember for months going to work and just crying and crying.¹

Eventually, she realized the futility of this and began to learn all she could about hepatitis C. By 1996, she was so knowledgeable about both the disease and compensation for victims that she was invited to speak on a radio talk show. There she met another woman, recently moved

from Ontario, whose husband was also infected with hepatitis C. Out of their desire to help others and to spare them the anguish that they had been through, the two women formed the Manitoba Chapter of the Hepatitis C Society of Canada. As the Executive Director remembered:

We were concerned about prevention, education and compensation. Ontario had received compensation and we were trying to achieve the same thing.

Starting with five members, the Chapter grew to 250 members by the summer of 2000 and was receiving up to 40 calls a day.

Context

In Manitoba those who were infected with HCV between 1986 and 1990 through the blood supply, were entitled to compensation from the national settlement; those infected either before 1986 or after 1990 received a one-time payment of \$10,000 from the Province.² The announcement of provincial support was delivered to the public through a press release on January 18, 2001. "We're really proud of the work of [the Co-chairs] and the Manitoba Chapter members," said the Hepatitis C Society of Canada Chairman of the Board. Manitoba also made efforts to identify and inform all people potentially infected by the blood system³ and was one of the few provinces that covered the cost of Rebetron®, a medication used in the treatment of hepatitis C.⁴

On November 3, 1999, Health Canada invited representatives of interested community organizations to meet to identify priority strategies for the Provincial Hepatitis C Program. Consensus priorities for the Manitoba Hepatitis C Prevention and Community Support Program included:

- Harm reduction;
- Community support;
- Education;
- Determinants of health focus.⁵

In March 2000, an environmental scan conducted by Health Canada⁶ found that most organizations or agencies working in the area of hepatitis C devoted only a small percentage of their time to this health issue, compared to other health concerns. Further, the hepatitis C programming that did exist was mainly provided in the context of HIV/AIDS, substance abuse, or sexually transmitted diseases (STDs). The environmental scan listed a number of barriers related to addressing this health issue in Manitoba, including:

- A low knowledge level;
- Lack of resources;
- Attitudinal barriers;
- Lack of coordination;
- Barriers related to poverty and lack of housing; and
- Geographical barriers

By 2000, the rate of newly diagnosed cases of hepatitis C in Manitoba was 43.9 per 100,000, somewhat below the national rate (63.6 per 100,000 in 1999)⁷ and the province's population was approximately 1.1 million. Over half of its residents (56%) lived in Winnipeg which had a population of 619,544 in 2001. The Winnipeg

Health Region served 653,728 as of June 2001⁸ both in the city and the nearby rural areas. As the main urban setting in the province, it was not surprising that Winnipeg had the highest hepatitis C rate, at 61.4 newly diagnosed cases per 100,000.⁹ The city's Aboriginal population has increased over the years due to a high birth rate, decreasing mortality rates, increasing Aboriginal self-identification and in-migration from rural areas. By 1996, 45,740 Winnipeg residents identified themselves as North American Indian, Métis or Inuit.¹⁰

In 1998, the Winnipeg Injection Drug Epidemiology (WIDE) Study was conducted by the Epidemiology Unit of Manitoba Health. Findings for people who injected drugs included:

- HIV prevalence in Winnipeg in 1998 was approximately 12.6%;
- Injection drug use (IDU) was well established in Winnipeg, with the median year of first injection being 1987;
- There were nearly as many women intravenous drug users identified as men. The female users tended to be younger and had initiated injecting more recently;
- A disproportionately high number of the users who were surveyed identified themselves as Aboriginal. The male-to-female ratio among this population was approximately equal compared to the approximately 2:1 ratio among non-Aboriginal users;
- Overall low education levels, low income, high unemployment, and unstable housing characterized the Winnipeg IDU population;
- 60% reported that more than half of the time they obtained new needles prior to obtaining drugs. However, a significant number of individuals also reported risky injecting

behaviour in the last year including: binge injecting, injecting with a needle used by someone else, and using water to clean needles;

- Approximately 30% reported having difficulty obtaining needles at least some of the time.¹¹

By 2000, 40% of the 505 individuals diagnosed with hepatitis C that year in Manitoba reported that they injected drugs. Most new infections were among males, and most tended to be between the ages of 30 and 49; 18% of new cases were Aboriginal. In that year, there were 41 new cases reported at the Stony Mountain and Headingly Correctional Institutions, both on the outskirts of the city of Winnipeg.

In recent years, Winnipeg has become a research centre for hepatitis C. In 2000, the federal government, through Health Canada's Hepatitis C Prevention Support and Research Program, announced that it would contribute \$350,000 to the position of a Chair of Hepatitis C and Liver Research in partnership with the University of Manitoba and the Health Sciences Centre. The federal government, through strengthening Canada's research capacity, hopes to improve the health of all Canadians.¹²

At the moment, however, there are few treatment, care and support options for hepatitis C victims in Winnipeg. When we asked clients of the HCRC what other services were offered to individuals infected with or affected by hepatitis C, their unanimous response was that services were severely limited. They identified the following supports in the community:

- **Sage House**

An inner city project for street-involved women, which provides peer support/counselling, prevention information,

education and training on hepatitis C and related issues.

- **Mount Carmel Clinic**

A community health clinic which offers hepatitis C testing and provides condoms, counselling and a needle exchange.

- **Main Street Project**

An emergency shelter for the homeless which provides detox and referral services and has a follow-up hostel on site.

- **John Howard Society, Manitoba Chapter**

Implements a prevention peer education and harm reduction program aimed at reducing hepatitis C infection and co-infection for inmates and their families using a holistic approach, incorporating traditional teachings and Aboriginal spirituality.

- **Hepatitis C Clinic**

The University of Manitoba and Health Sciences Centre provides care directly to patients.

- **Sunshine Initiative**

Works in partnership with drug users infected with or at risk of co-infection with hepatitis C and HIV/AIDS, individuals who are leaving jail and those involved in or leaving treatment programs. Has a focus on youth.

- **Winnipeg Regional Health Authority (WRHA)**

To meet the immediate need of people infected with hepatitis C, the WRHA provided physicians at twelve different health centres in the region who had been trained on issues associated with hepatitis C at a basic level. Issues of availability of and access to family physicians with this training were being explored.

There were two hepatologists in Winnipeg; care and treatment for patients with hepatitis C was mainly provided by gastroenterologists. As one

HCRC board member with hepatitis C described his medical experience:

The general practitioners were not very knowledgeable. [The hepatologist] is very over-worked— they need more staff and funding at the hepatology clinic. Initially I had an 18-month waiting period before I could get in to see him and then I had to wait another year before I could have a biopsy done.... You don't have to wait that long to see a specialist for any other disease. I was not offered any other support in the time I had to wait. It took four weeks for them to get my official blood work back; then when I went for the biopsy I had to wait again.

Project History and Implementation

The transition of the small, home-based Manitoba Chapter of the Hepatitis C Society to the incorporated, independent and centrally located Hepatitis C Resource Centre is an interesting story.

a) Hepatitis C Society of Canada — Manitoba Chapter Booklet Project

The Manitoba Chapter of the Hepatitis C Society of Canada was an unincorporated affiliate of the national organization whose mission and vision are as follows:

The Hepatitis C Society of Canada (HeCSC) is a non-profit, national voluntary health organization. Our mission is to fight hepatitis C through prevention, early detection, support, appropriate treatment and comfort. Our vision for the future is that:

- The spread of hepatitis C is dramatically reduced;
- All people of Canada understand the risk activities for hepatitis C;

- All people of Canada have equitable access to testing for hepatitis C;
- A comprehensive hepatitis C research program is established; and,
- All people of Canada have equitable access to resources to address hepatitis C.¹³

From 1996 to 2000, the two women who founded the Chapter worked from their homes. Two programs increasingly stretched their personal resources as the number of callers increased: the Blood Notification program, and the Manitoba Look Back–Trace Back Initiative, which is a program to identify the donors who were the source of infected blood for individuals with transfusion-related infections (“trace back”), and to identify which patients received blood from an infected donor (“look back”). As one of them explained:

We provide them with information and let them know they are not alone. When the blood notification program came along we were there to support and reassure people. We were a vessel for their anger and we played a huge part. We joined up with other groups and gained a broad understanding of all groups affected. We shared our knowledge. We get a lot of calls about information about the disease.

Even the Chapter newsletter was produced in the Executive Director's basement. It was her dream to strengthen the structure of the organization and to establish an office and drop-in centre for people with hepatitis C.

The provincial Viral Steering Committee (VSC) was organized by the province to respond to the emergency and the Blood Notification Announcement. The committee was looking for a better-coordinated response to the emergency. It was comprised of medical experts and

provincial and federal government representatives. Pressure from community-based groups, including HCRC, facilitated the creation of this committee.

The Chapter was able to provide some support during the waiting period. As the Executive Director explained:

It's hard on people to wait that long. We have a "buddy" system. If newly diagnosed people are really anxious, they will be paired up with someone who has gone through treatment while they are waiting to see a specialist.

Based on the Executive Director's personal struggle to find appropriate information on hepatitis C, the Chapter decided to create a useful resource booklet, *What to do if you are hepatitis C positive*.¹⁴ In January 2000, it received funding of \$34,000 from Health Canada's Hepatitis C Prevention, Support and Research Program, Prevention and Community-Based Support Regional Project Funding to:

*increase awareness of hepatitis C-related programs and services available in Winnipeg ... [and to] develop and distribute a comprehensive, user-friendly booklet to assist people to make decisions regarding treatment, housing, employment issues and related issues.*¹⁵

The process involved the formation of a Community Advisory Committee consisting of a nurse representing the WRHA, a hepatologist, a representative from Manitoba Health, a representative from Health Canada, a graphic artist, a professional writer, and some individuals infected with or affected by hepatitis C. This committee made recommendations on format, content and design. Writing the booklet proved to be a challenge and it was re-written a number of times.

Topics in the booklet, entitled *Manitoba's Hepatitis C Support Guide*, included:

- What is Hepatitis C?
- How it is Spread
- Risk Categories
- How it Affects the Body
- What Happens After I'm Diagnosed?
- Coping with the Diagnosis
- Telling Friends and Family
- Resources
- Appendices
 - A. Glossary
 - B. Liver Function Tests
 - C. What is Cirrhosis?
 - D. Universal Precautions

Members of the Chapter were not satisfied with the final product as they felt it would have been more helpful if it had been worded from an infected person's point of view. They also felt that coping strategies were not well enough addressed. However, feedback about the booklet was generally positive and Manitoba Health provided additional funding, first to translate it into French and then in 2001 to revise and reprint it.

b) Hepatitis C Resource Centre–HCRC Needs Assessment Project

A number of factors influenced the Chapter to consider requesting funding to conduct a needs assessment. These included:

1. The increasing number of requests for information received;
2. The increasing hepatitis C infection rate in Manitoba;

3. A growing understanding of the potential needs of people living with or affected by hepatitis C;
4. The awareness that these needs should be better addressed;¹⁶ and
5. A need to build on the Environmental Scan of 2000 conducted by Health Canada.¹⁷

In July 2000, the Manitoba Chapter received \$50,000 of funding over 21 months (2000-2002) from Health Canada's Hepatitis C Prevention, Support and Research Program, Prevention and Community-Based Support Regional Project Funding. The main project goals were to conduct a needs assessment and to disseminate the findings. Part of the funding (\$10,000) was earmarked as transitional funding to be used for organizational development.

1. The Needs Assessment

The objectives for the needs assessment were described as follows:

1. To clearly identify the needs of persons infected with and affected by HCV in Manitoba, so that service providers can clearly respond with appropriate information, support, educational opportunities and direction. It will also determine the needs of service providers and how service providers will ascertain the needs of infected and affected persons.
2. To develop partnerships with other community based service providers by increasing awareness of the needs of persons living with hepatitis C and their families, and through these partnerships, better respond to those needs.¹⁸

In the project performance report (for the period of June 2000 to April 2001), the project's

intended outputs and outcomes were defined as follows:

Conduct a needs assessment for the province of Manitoba:

- Establish priorities in service development and programming for Manitoba;
- Determine the type of educational resources needed and by whom;
- Augment knowledge among the infected, affected and health care providers;
- Explore the needs related to co-ordination and partnerships with existing organizations.

Disseminate needs assessment:

- Make the assessment available to all service providers and community-based health care organizations;
- Further develop and strengthen relationships amongst concerned parties;
- Develop a strategy based on the results.

The needs assessment was conducted between August and December 2000 by a contracted researcher. The study included a literature review, focus groups with both infected or affected people and service providers (conducted in six locations around the province including three in Winnipeg and one each in Portage La Prairie, Brandon and Thompson), and key informant interviews (conducted in-person, by telephone and on the Internet). In all, 102 individuals were involved in the study. The priority areas of need identified included.¹⁹

1. Consistent, accurate information about hepatitis C and the liver in user friendly formats;
2. Liaison and coordination among service providers and levels of service provision;

3. Education for general practitioners, health care providers and the general public;
4. Counselling for victims and family members;
5. Strategies to meet the needs of injection drug users;
6. Programs, resources and support for incarcerated people, particularly women;
7. Research on and support for cross-infected individuals;
8. Research on and support for women with HCV as well as other social issues;
9. Information and counselling for caregivers;
10. Staffing, resources and space for both community- and hospital-based programs;
11. Research on transmission, treatment and a cure; and
12. More hepatologists and supports for transplant programs.

The needs assessment concluded that the needs in Manitoba also reflected the needs across Canada for:

1. Information and counselling;
2. Research, treatment and cure;
3. More trained health care service providers;
4. Resources, funding and compensation;
5. Education to increase public awareness; and
6. Core funding and support for grass roots organizations.²⁰

Conducting the needs assessment did meet with some opposition, however, and it was described in the report as follows:²¹

A number of people want to know why a needs assessment was being done so soon after the

environmental scan and saw this as repetitious as the environmental scan had taken a long time to complete. [Comments included]:

- a) *The suggestion has been made that the Winnipeg community has completed enough needs assessments;*
- b) *What is going to happen to this information?*
- c) *How is it going to be used to help HCV infected/affected and service providers?*
- d) *The same community-based service providers are approached for all infectious, communicable and STD issues.*

Despite the perceived overlap between these research activities, the outcome of both these investigative activities was positive. In response to their findings, the Winnipeg Regional Health Authority developed a training module for primary care physicians and nurses on Hepatitis C. The training was accredited by the College of Family Practice Physicians and it will become the national standard for training of family physicians. Also, WRHA developed “Information Guidelines for HCV Testing for Health Professionals” which were also adopted nationally.

2. Infrastructure and organizational development

The second part of the funding provided by Prevention and Community-Based Support Regional Project Funding was to be used for infrastructure and organizational development. The objective for the transitional funding was as follows:

To help the organization strengthen to efficiently respond to the hepatitis C community needs.²²

The intended outputs and outcomes for this objective included:

Transitional funding:

- [The] Chapter will increase the capacity to respond to the needs, caring about hepatitis C as a part of the community;
- Care and treatment to be accessible, provided without discrimination or stigma;
- Strengthen the organization;
- Establish an office;
- Enhance profile in the community;
- Hire a volunteer coordinator;
- Establish outreach in northern areas; and
- Recruit, train and coordinate volunteers.

In January 2001, a small office space in the Self-Help Clearinghouse was established. Patients attending the hepatitis C clinic at the Health Sciences Centre could easily drop in and access resources or support. For the Executive Director, her dream of increased visibility and professionalism was achieved; however, uncertain funding sources would continue to focus her attention on fund raising. There was no adequate parking available and she still had to move her car every two hours or pay \$7.00 per day, a not insignificant out-of-pocket expense for a full-time volunteer. However, even the cramped space was preferable to operating out of her home.

For some time, the needs of the Manitoba Chapter had been diverging from those of the national organization. With the leadership of the Executive Director, the Hepatitis C Resource Centre, Inc. (HCRC) became an independent, non-profit, incorporated body in September 2001. As one board member commented:

We decided we could serve Manitobans better if we were based here.

As a Hepatitis C Society Chapter, there was an informal steering committee. With independence, an eight-member board was formalized and yearly nominations and elections were planned. As one client/board member explained:

Originally there were no criteria for being on the Board—it was just a matter of being concerned and wanting to get involved. However, they are now trying to structure the board so that it will be more useful.

While at the time of our visit in April 2002 the Board tended to consist of infected individuals, in the fall of 2002, the membership of the board was enhanced to increase the scope of experience, knowledge and contacts. It now includes an HCV research nurse, a hepatologist, a counselor, a lawyer, a social worker and an accountant, as well as several members with HCV.²³

The Board's role is to determine the policies and procedures of the HCRC. It shares the responsibility of running the organization with the Executive Director who has the mandate to be the only public spokesperson for the agency. However, in this tiny organization, it was also a working board. As a client/board member commented:

We have control over the office, we decide what happens at ... meetings, what goes out to the public, fundraising efforts and getting speakers in.

The Board meets at least once a month and any member can attend. Several committees have been developed including a fundraising committee and a nominating committee. Decisions are generally made by consensus.

The staff included the full-time but volunteer Executive Director and a part-time employed Volunteer Coordinator who put in additional hours in a volunteer capacity. She was responsible for enlisting volunteers and developing policies and procedures and training programs. At the time of our visit, there were about ten volunteers actively working with the HCRC doing research, answering calls, working on the web page or newsletter, and generally helping out in the office.

Through a community partnership with Reaching E-Quality, an employment organization working with people with disabilities, a volunteer placement at HCRC was established. The Volunteer Coordinator assessed the individual's special needs and work ethic while the individual provided support for the Centre. As a Reaching E-Quality representative commented:

This is a win-win situation for everyone involved. The volunteer gets good job experience and a reference....It is a good fit and gave our clients a good outcome. We highly value this partnership. The positive self-esteem building and the positive work experience is great.

The HCRC planned to increase the number of volunteers through a volunteer recruitment drive at the University of Manitoba in the fall of 2002 and through a student volunteer program organized by the Department of Education, Youth and Training. New volunteer positions were being developed to provide direct service support, compensation information and to drive clients to their appointments. The Executive Director was able to report that:

Volunteer support for our various displays and other one-day activities has been plentiful and successful.²⁴

Although the board had no money for advertising, information spread by word of mouth due to their advocacy work, networking, information sessions and their booklet which had been distributed throughout the province. One board member described their communication strategy as follows:

We produce a quarterly newsletter that keeps growing; anything important that comes up in between newsletters gets mailed out to all members. New members get sent a starter pack, and the newsletter contains information on upcoming events, new research and stories from members and whatever is happening in the organization, recipes and how members can contribute.

The communication strategies appeared to be successful. Organizations often approached the HCRC to do presentations. The Centre received a lot of walk-in clients who were referred by the nearby clinic and many calls for information and support were received. As a board member commented:

The amount of work we do has grown in leaps and bounds. A walk-in can take quite a bit of time (2 or 3 hours), messages build up on the phone and e-mail during that time. We would like another space, other than the one office we have, to deal with these walk-ins.

The Centre also held monthly group support meetings. Sometimes a speaker was invited to make a presentation. The Executive Director also co-facilitated a support group at Sage House, a street-based agency, and was setting up a harm reduction group.

Clients who were interviewed during our visit identified accessibility, accurate information and

support as the key benefits of the HCRC. Sample comments include:

She is a phone call away I receive emotional support, literature and guidance.

[Her] information is very current. They are very accessible. You can call and leave a message on their machine. They send out newsletters. [She] is knowledgeable on drugs and diet updates.

...a support group for those who are infected/affected. It is a great resource for those people who are struggling and need help. And once again the information that is provided is very helpful and up to date.

The best thing has been getting acquainted with other people who have hepatitis C. Once I started attending I felt less stigmatized and realized that I could deal with his illness as others there were doing relatively well.

It was evident that one person could not continue to play the multiple roles fulfilled by the Executive Director and that additional staffing was required. To begin to address this staffing issue, HCRC was looking into the feasibility of providing a counsellor on a fee-for-service basis, based upon clients' ability to pay.

HCRC Accomplishments

1. HCRC has developed community capacity to address hepatitis C issues

The role of HCRC in developing community capacity to address issues associated with hepatitis C in Manitoba has been significant. Not only have individuals infected with or affected by the disease been supported and informed, but in addition, advocacy work by HCRC in the community has resulted in observable change.

For example, the Viral Steering Committee, established as a result of their advocacy work has had an impact on decreasing wait times for treatment. More recently, the Executive Director was instrumental in establishing a provincial Hepatitis C Coalition. Its mandate, adopted in April 2002, is as follows:

Manitoba Hepatitis C Coalition Mandate

The Hepatitis C Coalition shall be a forum to support individuals and organizations in their efforts to educate Manitobans about Hepatitis C prevention and eradicate discrimination and stigmatization associated with this disease. The Coalition will support the development and implementation of harm reduction strategies and other initiatives to assist those who are infected or affected by Hepatitis C and advocate for improved access to hepatitis C education, treatment and support.

The Coalition included a wide range of community partners, including:

The Hemophilia Society	A support organization for persons infected with or affected by hemophilia and other bleeding disorders
John Howard Society	An organization which works with people who have come into conflict with the law
Street Connections	A needle exchange which has a harm reduction focus
Kali Shiva	An HIV/AIDS organization
Mount Carmel Clinic	A community clinic with a focus on hepatitis C and HIV/AIDS
Sagkeeng Health Centre	An on-reserve health centre serving the Sagkeeng First Nation, 145 km NE of Winnipeg

First Nations and Inuit Health Branch, Health Canada	Provides services to on-reserve and northern Aboriginal people
Canadian Liver Foundation	An organization that supports research and education on liver disease
New Directions for Children, Youth and Families	Works with children, youth and families at risk and mainly serves Aboriginal people
Anishinabee Mino-Ayaawin	Works with Aboriginal people on reserve regarding hepatitis C and HIV/AIDS
Stony Mountain Institution	A federal corrections institution

The new Coalition planned to meet on a monthly basis and had already begun to develop proposals for funding from the Province of Manitoba. A public awareness campaign was also planned and the Coalition was looking into emerging needs both in the North and in isolated communities.²⁵

This significant achievement went a long way to change the perception in the community that the HCRC focused mainly on issues concerning the population that contracted HCV through the blood system, as had been suggested by the agency's recent evaluation report.²⁶ By September 2002, the Executive Director was able to report:

We are now seen as providing education, support and information to anyone infected with or affected by HCV. There is a greater awareness about the work we do at Sage House ... and the resources and services we have for marginalized population (pamphlets on tattooing and body art).²⁷

2. The HCRC has developed a broad community role

The transition from the small, home-based Manitoba Chapter of the Hepatitis C Society which served the needs of individuals infected through the blood system to the incorporated, independent and centrally located Hepatitis C Resource Centre is also a significant accomplishment. A look at agency plans for the fall of 2002 gives an indication of its broadening community role for such activities as offering support off-site, and serving identified target groups such as Aboriginal people and corrections groups:

- Plans to provide education, information and support to clients at the new Mount Carmel Hepatitis Clinic;
- Offering a workshop to the Community Health Representatives (CHR) General Assembly;
- Offering a one-day presentation to introduce the Hepatitis C Coalition to the CHR president and the West Region Tribal Council Health Department;
- Working with Health Canada and Corrections Canada to plan a harm reduction conference entitled Partners in Caring in Winnipeg, February 5-6, 2003.

Challenges

1. Sustainability

Our visit to the HCRC left us with two vivid impressions: the challenge of sustainability for this grassroots organization, and the need for more services in Winnipeg. HCRC has built capacity in a number of different areas including membership, outreach, volunteer training, governance, fund raising and networking and yet

the challenge for this little agency is its sustainability because of unpredictable funding. As one client commented:

They need core funding. With core funding they could get a full time person answering the phone so that when people call they will be able to get the help they need. They also need a counsellor to work with people who have been diagnosed. It would also be helpful if they could expand the Resource Centre as presently it only consists of one small office. It just isn't big enough to be able to really do the job of a resource centre well.

A board member supported this view:

The project needs core funding. How are they supposed to help people if they are not given any money to create the infrastructure necessary for this type of work? ... [W]e are just beginning to explore ... getting access to monies from bingos, lotteries etc. We are also currently working on developing strategies for proposals that will give us access to local monies.

Funding from Health Canada was running out at the time of our visit in April 2002—the agency had just received its final cheque. A proposal for additional funding had been turned down. They planned to submit another proposal to ACAP (AIDS Community Action Program) in the fall of 2002, but until then, the prospects looked bleak. As the Executive Director commented:

Somehow, we must use as little money as possible until October.

2. Lack of access to treatment and support

At the end of our visit, our other vivid impression was the extent of the need for access to treatment and the provision of care and treatment support in this major Canadian city, as well as in the rural area it serves. As the Executive Director commented:

I feel that care and treatment is improving but it's not where it should be. It's not gold standard treatment. There's a long way to go.... Everyone around comes to Winnipeg for care and treatment. They do some testing up North but not a great deal. It will put a great burden on the health care system in 10 years.

All of the primary clients we interviewed commented extensively on three inter-related needs:

1. Access to hepatologists and treatment;
2. Education for physicians; and
3. On-going support to live with this disease.

As one client summed it up:

Access is not easy enough, the time it takes to get diagnosed is too long, and then once you have the diagnosis and you start suffering from the symptoms, doctors just are not able to help.

Concluding Remarks

There is significant evidence in Manitoba that a number of community partners are beginning to come together to address the issue of hepatitis C. However, despite the capacity that has been built to date, there still appears to be a serious gap in service provision. The HCRC is one small but important player in this mix but its reliance on its volunteer base and its uncertain funding environment draw its sustainability into question. Should the HCRC have to close its doors, who would act as a community catalyst and

advocate for the needs of those infected with or affected by hepatitis C in Manitoba?

The following types of documents were reviewed in the preparation of this case study:

- Project documents from Health Canada
- Newsletters
- Copy of resource HCRC developed – *Manitoba’s Hepatitis C Support Guide*
- Listing of the training workshops completed by staff and volunteers
- Inventory of the resources HCRC has available for individuals
- Summary of newspaper clippings where the HCRC is mentioned
- Notes from the Hep C coalition meeting (April 9, 2002)
- Documentation on the number of walk-ins, and incoming calls to the HCRC
- Documentation on the number of paid members and the number on their mailing list
- Project evaluation
- Project needs assessment

Most of the primary client interviews were done over the phone while the research team was in Winnipeg. The staff, volunteer, board and secondary client interviews were, for the most part, done in-person. This case study proved to be challenging to conduct because the funded activities for the project were complete. Primarily volunteers run the HCRC and their main focus at the time of the case study was securing funding to continue to operate in some capacity. The main activities they engaged in were meeting with potential funders and writing proposals.

Case Study Information

The case study visit was conducted April 22 to April 24, 2002. The case study research team included: Casey Boodt, Laura L’Heureux and Joyce Pearson. Analysis was conducted by Joyce Pearson. The case study was prepared by Dr. Gail Barrington. It was approved for distribution by HCRC on November 13, 2002.

In total 13 interviews were completed:

- Staff and volunteers: 3
- Board members: 1
(2 primary clients were also board members)
- Primary clients: 5
- Secondary client interviews: 4
 - Health Nurse – Stony Mountain Penitentiary
 - Gastroenterologist treatment nurse – Winnipeg Clinic
 - Sagehouse – nurse practitioner
 - Reaching e-Quality – placement counsellor

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Case Study:

YouthCO AIDS Society

Vancouver, British Columbia

YouthCO's Neighbourhood

The Youth Community Outreach AIDS Society, known as YouthCO, is located on West Pender Street in Vancouver's Downtown Eastside in a walk-up building that also houses a dance studio, a music studio and a small store. As you enter YouthCO's office and drop-in centre on the second floor, you get a sense of openness and space. It is a youth-friendly environment with music and incense in the air. If you are lucky, Jake, the Executive Director's little dog, will welcome you—he seems to know everyone. The area is divided into an office with computers (including one for clients' use), a kitchen with coffee pot and pop machine, a lounge with comfortable couches and a pool table, and a library—which can be closed off for private conversations. Clients drop in and out during the day and on the evenings when an event, such as a dinner or a support group, is taking place.

This comfortable oasis contrasts with the grim reality of the neighbouring area outside, described as among the poorest in Canada:

Overdose deaths and other health complications of drug use have been observed in this neighborhood since the 1970s. Despite the presence of a needle exchange program that provided access to sterile syringes through several means of exchange, an explosive HIV epidemic, that remains among the highest ever observed in the developed world, was documented among the neighborhood's injection drug users in 1997. Specific local factors, such as the prevalence of

cocaine injection, which may involve as many as 30 injections per day, and the lack of additional prevention measures such as safe injecting sites and accessible drug treatment programs, have been suggested as contributing to the epidemic.¹

The Context of Hepatitis C

Reporting of hepatitis C started in 1992 across British Columbia by its 18 (now reduced to 6) Health Authorities. The Province has rates of newly reported cases of hepatitis C infection that are twice the national average, with the highest rates occurring in Vancouver and the adjacent Fraser Valley. The rate of newly reported cases of hepatitis C was 124.7 per 100,000 in 1999, as compared with a national rate of 63.6 per 100,000.² It has been estimated that there are 40,000 cases of chronic hepatitis C in BC.³ In 1999, two-thirds of newly reported cases were in males, a reflection of the higher number of males engaging in injection drug use which is associated with approximately 60% of newly reported hepatitis C infections in BC. The highest rate of newly reported cases of hepatitis C infection was among males aged 40-59, with a rate of 271.1 per 100,000, more than four times the overall national rate. The greatest number of infections among women was reported in the 30-39 age group. Males of all ages had higher infection rates than females.⁴

The Province of British Columbia negotiated a compensation package for those individuals

infected through the blood system before 1986 and after 1990, who would otherwise not be compensated through the national settlement. In 1999, the Vancouver Richmond Health Board developed a proposal for a provincial hepatitis strategy in response to high hepatitis rates in the area. The BC Centre of Disease Control (BCCDC) received funding from the Provincial Government to establish the BC Hepatitis Services. This division of BCCDC provides an integrated response to prevention and care management of hepatitis. Programs developed by BC Hepatitis Services are based on prevention and care management, education, community participation, information management, lab services, and research.⁵ The Provincial Hepatitis Advisory Committee was established as part of this initiative.

Vancouver is the largest city in British Columbia and the third largest city in Canada with a population of 545,000 in 2001 and a surrounding metropolitan area of nearly two million people. Vancouver is one of Canada's most ethnically diverse cities with immigrants from Asia accounting for a substantial proportion of its population. There is also a significant Aboriginal population in Vancouver.⁶ In 1997, it was estimated that the Vancouver Health Region served just over 556,000 people.⁷ The Vancouver region has the highest number (1,374) and rate (186.1 per 100,000 population) of newly reported cases of hepatitis C infection in BC.⁸ Further, it is believed that hepatitis C has spread rapidly:

More than 90% of persons who inject drugs in Vancouver are believed to be infected. Since the early 1990s the Vancouver region has also experienced alarming rates of illicit drug-

related overdose fatalities, averaging more than 300 per year since 1996.⁹

The Development of YouthCO

In April 1993, a meeting of over 30 BC community organizations was held to discuss issues related to youth and HIV/AIDS. The need for youth-specific services was clearly identified and in February 1994, the Youth Community Outreach AIDS Society was formed to provide education, support and advocacy for youth between the ages of 15 and 29 on issues associated with HIV/AIDS. Later that year, in July, it was incorporated as a non-profit society and eventually became a registered charity.¹⁰

Known as YouthCO, it is a non-profit agency run by and for youth, providing outreach, education, training and support to youth infected with, at risk for, and affected by HIV and is the only agency of this kind in Canada that is peer-driven. All of YouthCO's programming involves youth providing support and prevention/education services to other youth. The agency also has a philosophy of harm reduction, confronting the realities faced by youth in a non-judgmental manner and providing the information needed to make safer choices. Using youth themselves to provide support and prevention education services to their peers has been an effective strategy. YouthCO is known for its innovative training workshops and resources, developed by and for its young target group.

Any youth between the ages of 15 and 29 can access YouthCO's services or get involved as a volunteer. Originally the agency was entirely volunteer-driven but over time staff members were added and Board membership became more clearly defined. All Board members have to be under the age of 30 at the beginning of

their two-year term; two positions are open to individuals who are HIV positive and two are for individuals under the age of 19. The Executive Director is an ex officio member of the Board which meets every two weeks. The duties of the Chair rotate among Board members. As time has passed, the Board's role has changed from that of a working board to that of a policy board. Several committees have been established including Finance, Human Resources, Fund-raising and Policy/Governance. Working with a young target group has its own particular challenges. As one member described the Board experience:

You have to be committed to the work. It is a challenge to work on the board of a youth organization. There is a lot of turnover.... They have a lot going on in their lives. We don't have any real strict criteria, it is more passion driven, and the people on the Board really just love it. People are gaining skills.... The Board looks at the long-term determinants of health and the youth population. We look at projects staff propose and either yea or nay the ideas.

Many YouthCO initiatives are primarily volunteer driven. For youth to get involved, they just have to contact YouthCO, complete an application form and have an informal interview to determine their interest area. All volunteers attend core training and then are trained in their area of interest. At the time of our visit there were 76 active volunteers at YouthCO. They had contributed a total of 364.5 volunteer hours during 2001-2002 on hepatitis C-related programming.

The agency has three main programs. The first is a support program known as the Positive-youth Outreach Program (POP). It supports youth living with HIV so that they can work

with other HIV-infected youth by offering psycho-social support, advocacy, referrals and education. Activities include a monthly free dinner/discussion group, a drop-in support group, social events, advocacy training, and outreach. YouthCO also offers monthly workshops, called FIRESYDE Chats, which are delivered by members of the local sexual health community on issues related to youth, health, sexuality and harm reduction. Youth clients who receive YouthCO's support services go through an intensive orientation process including a preliminary interview and three meetings focusing on referral to related agencies, follow-up and placement. Typically, YouthCO adds between two and four new clients a month.¹¹

A second main program area is volunteer education and training. YouthCO provides a variety of training programs to meet the needs of youth volunteers to prepare them to carry harm reduction messages to youth and community audiences. Programs include Core Training (an interactive forum usually held on a weekend which explores the basics of HIV/AIDS and risk reduction); Speaker's Bureau Training (which focuses on public speaking and group facilitation skills); Outreach Training (which prepares volunteers for outreach education) and Theatre Training (which uses a popular theatre format). Other training opportunities are provided in such areas as office support, resource development, newsletter production and fund development.

The third program area is prevention/education. Through the Speakers' Bureau, YouthCO peers provide innovative, accessible education both to students, youth groups, and street-involved youth on the one hand, and to youth service providers, outreach workers and agencies with youth in their mandate on the other. Their

Theatre Project offers an innovative, interactive method to get people thinking and talking about the issues around youth sexual health, self-esteem and related issues such as drug use, racism, homophobia and assertiveness. The C.H.O.I.C.E.S. Program provides training on peer education to schools and groups in remote or rural BC so that youth outside of the Lower Mainland can be empowered to create self-sustaining groups of peer educators to address HIV and sexual health issues in their own communities. YouthCO also provides outreach services to disseminate educational resources at youth cultural events such as concerts, festivals, fund raisers and performances. In order to capture the attention of their target group, many youth-friendly, accessible educational resources, such as videos, brochures, posters and stickers, have been developed by YouthCO staff and volunteers. They also publish a quarterly newsletter for members, volunteers and donors called SPICY, and manage a website at www.youthco.org.

The YouthCO HepCATS Project

Proposal Development

In 1998, YouthCO staff had identified hepatitis C as an area of concern for an increasing number of clients and while there had been no formal needs assessment, they estimated that 90% of their support clients in the Downtown Eastside were co-infected.¹² In addition, many clients not currently co-infected were at risk because of drug use and such factors as poverty, homelessness, addiction and ignorance.

Staff conducted a literature review and found that co-infection with HCV and HIV was on the rise, especially for people who use intravenous drugs or those involved on the street. Thus they

saw their street-involved target population as being at risk and, further, for those whose immune systems were already compromised through HIV infection, co-infection with HCV was likely to magnify the threat. They conducted some focus groups and consulted with individuals who were either infected with or affected by hepatitis C. In November 1999, they prepared a proposal for Health Canada's Hepatitis C Prevention, Support and Research Program, Prevention and Community-based Support Regional Project Funding for the HCV Enhancement Project (as it was originally called). The funding requested was \$50,000 per year for a three-year period. Most of the budget was for the salary of the HCV Enhancement Project Coordinator, but some resources and leased equipment were also included.

Around the same time, Health Canada also received a proposal from the Portland Hotel Society, an organization that managed the funds for the Vancouver Area Network of Drug Users (VANDU), an agency working in the same neighbourhood. Although their target groups were different—people who use illicit drugs at VANDU and youth co-infected/at risk of co-infection of HIV/HCV at YouthCO—Health Canada funded the two agencies for a joint project, each to receive \$22,500 per year for three years. Their funding approval forms stated that:

Together, these two organizations will collaborate with others to develop a multi-agency approach to community development related to Hepatitis C in Vancouver. ... Target populations will include members of both organizations, staff, volunteers, and broader at-risk populations in Vancouver.¹³

Joint collaboration was mandated in several areas, including:

- Inter-agency referrals where appropriate;
- Outreach by the YouthCO HCV Project Coordinator at VANDU and among VANDU user groups where appropriate;
- Sharing training activities (YouthCO to share expertise on issues related to sexual health and HIV, VANDU to share expertise on attracting the participation of drug users as volunteers); and
- Cross-agency resource and materials distribution.¹⁴

In practice, however, the interaction between the two agencies was limited to the distribution of brochures and information sharing about activities. As the Executive Director of YouthCO commented:

VANDU does not have a lot of youth clients and it has been a strange marriage that never really happened. We keep VANDU updated, but we don't really involve each other.

Project Administration

Originally known as the HCV Enhancement Project, the project's name was changed to HCV Advocacy, Training and Support, or "HepCATS". Its goal and objectives were as follows:

HepCATS Project Goal and Objectives (revised in 2001-2002)¹⁵

GOAL:

HepCATS provides support services as well as prevention and education information to youth infected with, affected by or "at risk" of HCV infection as well as to the community-at-large. Through these efforts, it is anticipated that there will be a reduced vulnerability for populations at risk.

OBJECTIVES:

- To facilitate consumer involvement and direction in the Project
- To provide psychosocial peer-based support, information and advocacy to HCV+, co-infected and "at-risk" youth, facilitating an improvement in their quality of life
- To provide prevention and education information and support to the youth and broader communities about HCV, HIV/HCV and related issues.

YouthCO's annual operating budget is approximately \$360,000, the majority of which is funded by Health Canada's Aids Community Action Program (ACAP). HepCATS project funding accounts for approximately 6% of the total agency budget. However, the project has had a pervasive effect throughout the organization.

As soon as funding were received in the late fall of 2000, the YouthCO Board expanded its mission statement to address issues relating to hepatitis C and co-infection.

YouthCO Mission Statement

YouthCO is a non-profit organization working to involve youth ages 15-29 from all communities in addressing HIV/AIDS and related issues. We provide educational initiatives and support services to youth infected with or affected by HIV/AIDS and HIV/Hepatitis C (HCV). As a youth-driven agency, we provide outreach, prevention education, training, volunteer opportunities, advocacy and support to our peers.

According to YouthCO staff members who were interviewed during our visit, the mandate change did not happen without some controversy but as the Executive Director explained, YouthCO was better positioned than most agencies to deal with the shift in focus:

A lot of AIDS service organizations have been struggling with the shift from AIDS being a disease that affects the gay community to one that affects the drug using community. We have been in a better position to handle this shift since our focus is on youth (gay or drug using).

A half-time HIV/HCV Outreach and Support Coordinator was hired to provide outreach, support and advocacy services. Later, the position was augmented for one year to a .75 position. Staffing at YouthCO was as follows:

Staffing

At the time of our case study visit, there were five paid staff members at YouthCO:

- Executive Director (full time)
- Volunteer and Training Coordinator (full time)
- Educational Programs Coordinator (full time)
- Support Programs Coordinator (.75 full time equivalent)
- HIV/HCV Outreach and Support Coordinator and Prevention + Project Coordinator (.75 full time equivalent, .5 of which was funded by the HepCATS Project)
- Fund Development and Special Events Coordinator (.5 full time equivalent)

During the first year of the project, retaining staff in the HCV Outreach and Support Coordinator's position was a problem, particularly due to issues associated with addiction. As the Executive Director explained:

Our support is peer based. For hep C, the staff leading the support needed to be HIV/hep C positive. A challenge is that we need to provide support to the person in the position [to] deal with these realities....A couple of the support group leaders relapsed back to using drugs. Exposure to the drug-using community again through their work as a support group leader is a risk factor— the drug-using community is a powerful trigger for these people. Youth are vulnerable as it is; maybe it is not appropriate to put them in these situations.

Subsequently, YouthCO widened its eligibility criteria for this position to include non-co-infected youth.¹⁶ Despite this issue, it was apparent to us during our visit that the comfort and familiarity between YouthCO staff and clients was partly due to the fact that some staff

members were also struggling with their own positive status, demonstrating the strength of the peer-based model. They could relate to clients because in some cases they had been there themselves. The staff was young, hard-working and passionate about their role. They believed that YouthCO was making a difference and cared deeply for their clients.

Key Project Activities

Volunteer Training

As the main tenet of YouthCO is by youth for youth, the peer-driven model was central to program delivery. With the addition of hepatitis C prevention, awareness and support to their mandate, training activities and materials were adapted or developed to include the relevant information. In the fall of 2000, peer educators and other volunteers received training on HCV as well as HIV for the first time. In addition to basic HCV prevention education, offered in Core Training, all volunteers were also required to attend the Hepatitis: Beyond the Basics workshop, offered by the physician from the Three Bridges Community Health Services, a key YouthCO partner. Another partner for training was HEP/HIVE (a HIV/AIDS service organization).

In 2001-2002, YouthCO offered three core training sessions and four HCV-related workshops for staff and volunteers. Five new HCV-positive peer educators and 35 volunteers were trained on such topics as:

- Hep's A/B/C: Beyond the Basics
- Youth and Addictions
- Health Interventions that Matter with Youth
- Epidemiology of HIV/HCV among Lower Mainland Youth

YouthCO staff continually try to improve their peer education training methods and formats through research and through the use of feedback received from participant evaluations. Behavioural change is a key focus. As one staff member commented on the training process:

The number of youth who come to us after taking Core Training and say, "WOW! I feel excited about what I've learned and I want to share this." Having youth come back and report a behaviour change is really exciting. In working with youth there is not the kind of top down approach—there is a lot of respect for youth delivering prevention messages to other youth. Working with and collaborating with youth is very exciting, frustrating and inspiring.

After two years of integrating HCV information into YouthCO's programming, the 2001-2002 Project Progress Report was able to state that "all staff and volunteers are now fully trained on HCV transmission, prevention and viral progression."¹⁷

Peer-based Support

To provide in-house psychosocial peer-based support, the HIV/HCV Outreach and Support Coordinator established a regular fixed time that youth could come to the YouthCO office for peer counselling by providing a safe environment for youth to come together to talk about personal issues and provide or receive support. The support group was called Hep CATS Chat. Key activities included one-on-one support sessions, advocacy and group dinners. As the Executive Director commented:

We provide an opportunity for people to come and talk about the issues, it is invaluable to

provide a space for people to come and share information.

The twice-monthly support dinners were the peer-based support component's most successful activity and became one of the main ways of connecting HIV positive and HIV/HCV co-infected youth. A total of 58 youth attended these nourishing dinners during 2001-2002. Once a month, a professional from the community was invited to attend the dinner and answer questions in an informal way.

Advocacy services were also provided to help co-infected youth complete their applications for income assistance and disability benefits. One-on-one advocacy appointments were conducted with 10 HCV+ or co-infected youth during 2001-2002.

However, staff turnover had made it difficult to attract attendance in a consistent way. As the Executive Director commented:

An important consideration when working with vulnerable youth populations such as street-involved and HIV+ youth, as well as young IDUs, is the notion of trust. Feedback from these youth populations has repeatedly revealed to us the importance of staff consistency in order to develop and maintain trust with youth whose lives have been marked by instability and feelings of betrayal—by birth parents, foster parents, communities and “The System” in general. As a result, in the Spring/Summer season, we noticed a sharp decline in attendance at activities like support drop-ins and discussion groups, as well as a decrease in the number of one-on-one support services we were able to provide.¹⁸

Even after staffing had stabilized, they found that attendance at the support group was still low—only 3 HCV positive or co-infected youth

joined the group in 2001-2002. YouthCO staff reported that after talking with other HCV and HIV support groups in Vancouver that there seemed to be a trend towards decreased participation in this type of activity. Instead, staff were considering canceling it and focusing instead on other more successful strategies such as a needle exchange.

Outreach

Prior to the inception of the HepCATS project, most of YouthCO's education programs were targeted at youth already accessing school systems and youth groups. With the inclusion of HCV in their mandate, it became a priority to actively reach out to “disenfranchised” youth, especially those living on the streets of Vancouver's Downtown Eastside/Downtown South.¹⁹ Several target sites, already long-term partners of YouthCO, were identified to receive HCV outreach services and resource materials. These included:

- Boys-R-Us (male youth sex-trade workers)
- Pride Health Services (gay, bisexual, transgender and lesbian youth)
- BC People With AIDS (BCPWA) Lounge (HIV and HCV positive youth)
- Average Joes (gay men living with HIV/AIDS—all ages)

Another outreach activity was Street Sweep which was initiated in January 2001 in conjunction with other agencies in the Downtown Eastside. The purpose of the sweep was to reach street-involved youth in their own environment rather than waiting for them to come to YouthCO. Once a week, two staff members walked a three-by-ten-block area around Hastings Street in the Downtown Eastside. They visited all the organizations along the way that provide services to

people who use intravenous drugs in order to refill their supply of YouthCO resources. These included such agencies as the Youth Activity Centre (YAC), the Downtown Eastside Youth Action Site (DEYAS), Aboriginal agencies, a women's shelter and drop-in centre, health clinics, and a housing project.

On the afternoon that our researcher accompanied the street team, there were uniformed security guards in front of stores in the area. Many police were visible, as were a number of outreach personnel from other agencies. As the team moved up and down the streets, they handed out lollipops, condoms, and resource materials, primarily to women and youth whom they felt to be most at risk. In one area, in front of two large hotels, a crowd had congregated. Approximately 200 people were milling around, openly shooting drugs, making deals or soliciting. There was a smell of urine and garbage emanating from some of the alleys; however, no needles were evident in the litter along the curbs, likely due to frequent clean-up activities. Some people ignored the offer of a lollipop, some smiled and thanked the team members, and some asked for more information about the resources or about YouthCO.

The enormous social problems evident during this short walk were daunting, but, as the staff members reflected:

The sweeps are small steps and make a small difference.

It was obvious that any positive change, however small, was absolutely critical. During 2001-2002, 24 street sweeps were conducted and 1,202 HCV prevention resources were distributed.

Community-based Prevention Education

YouthCO began to incorporate HCV prevention education into community-based activities in 2000. Peer educators from the Speakers' Bureau took the message to youth in schools, youth detention centres, youth transition houses, youth groups, street-involved youth and service providers. They reached over 2000 youth in 2001-2002 throughout the Lower Mainland through the delivery of 78 presentations.

The Sexual Health Game was a popular training tool developed by YouthCO to present HIV information to school and community groups. It was modified to include HCV questions as well. Sample questions included:

- What area of the body does hepatitis affect?
- Which two hep viruses have preventative vaccines?
- How is hep C transmitted?
- How long does it take for a body piercing to heal completely?
- Name one place you can go to get clean needles.

However, the agency had found that the most powerful training tool was the personal experience of the peer educators. As the 2001-2002 Project Progress Report commented:

Due to their recent experience on the issues under discussion, peer educators such as those involved in YouthCO's Speakers' Bureau are often perceived by their audiences to add credibility to their messages. As "positive role models", peer educators also work to contribute to the social and group norms favouring HCV risk reduction behaviours among youth.²⁰

After two years of working to integrate hepatitis C information into their presentations, it now comprised 50% of their message, the rest focusing on HIV and harm reduction.

The Theatre Troupe also began to use HCV-related information in their presentations. In 2001-2002, approximately 200 youth attended their performances on harm reduction. They used the popular theatre philosophy of working from the inside to educate youth on HCV-related issues. As the project's recent Progress Report explained:

When the Theatre Troupe offers youth audience members the chance to make an "intervention", they may also be offering youth the opportunity to change the role of drug-related "gatekeepers" in their own communities. In this manner, YouthCO's HCV prevention programs work to alter the "norms" in the many high risk situations that youth face.²¹

YouthCO anticipated a significant increase in the number of performances requested over the summer of 2002 due to a project planned on theatre promotion.

Shoot for Safety: Conference on Youth and Hepatitis C

Another key activity was the Shoot for Safety conference held in March 2002. The purpose of the conference was to foster understanding and networking among a diverse range of groups in the community including youth infected with/affected by HCV, health care providers, youth workers, Aboriginal youth and Aboriginal youth workers. It provided prevention education, on-site support, referrals, networking and testing/clinical services.²²

As one Board member explained:

We were reaching out to communities who aren't normally included in conferences...it was a good and interesting range—a cool mix of people.

While about 70 to 80 people were expected at the conference, nearly 110 individuals from all over the province attended. More than 50% of those attending were youth, including many who self-identified as street-involved, HCV positive and/or Aboriginal.²³ As another Board member commented:

I had an overwhelmingly positive experience with the conference. It is important for people to come together and share their experiences. People infected have an enormous amount to say about prevention (because it didn't work for them).

Resource Development

Several years previously, YouthCO had used youth focus groups and worked with a designer to develop a line of HIV/AIDS-related materials with a youth-specific image. In 2000, staff began to identify HCV information needs and gaps in resources and in 2001 they established a Resource Development Advisory Committee, comprised of over 30 individuals from a variety of community agencies.

It was this committee that changed the project name from The HCV Enhancement Project to YouthCO Hepatitis C Advocacy, Training & Support (HepCATS). With the same designer, a "jazzy, youth-friendly, 'street-smart' image"²⁴ was created—the HepCAT.

Several new resources were developed and circulated as follows (2001-2002 circulation figures provided in parentheses):

- *YouthCO HepCATS* brochure—provides youth-friendly information on HCV transmission, risk reduction, disease progression, symptoms and HCV/HIV co-infection (2,150 brochures);
- *Hepatitis C: Shoot for Safety—Know your Risks* poster and sticker (134 posters and 1,199 stickers);
- Hepatitis C-specific club cards (1" x 1"), trading cards and temporary tattoos to be used at raves and during street sweep activities (1,357 cards and 1,521 tattoos);
- *Body Art Body Smart* series of cards on tattooing, piercing and branding (423 sets);
- *The Facts* brochure for service providers; and
- *Calling All Volunteers* brochure for volunteer marketing.

In addition, older materials were updated to include HCV information. These included:

- *YouthCO: The Complete Story* brochure;
- Agency stickers and postcards;
- *Safer Sex Tips and much, much more—from the files of Dr. Willy*, a risk reduction brochure;
- *The Sexual Health Game*;
- Training resources for peer educators; and
- The agency website.

The resource order form was updated and circulated to over 200 service providers in the BC Lower Mainland and throughout Canada. The agency newsletter was restyled for a more cutting-edge image. It was written, edited and produced by youth on topics related to HIV/AIDS, Hepatitis C, sexual health, drug use and upcoming YouthCO events. New submissions of editorials, poetry, artwork and rants were welcomed.

Resources produced by YouthCO were also distributed at all workshops, training events and theatre performances. Outreach volunteers also provided materials at community events such as concerts, festivals, fairs, raves and demonstrations. Requests for brochures, posters and stickers has grown significantly as awareness of YouthCO's HCV programs and services have expanded. The print materials and resources have been promoted and distributed to agencies not only throughout the Lower Mainland but also across both British Columbia and Canada as well.

YouthCO HepCATS Project Accomplishments

1. Development of a peer-driven support service model

YouthCO's greatest accomplishment is clearly the development of an innovative, peer-driven support service model which works with this young, at-risk population. When clients were asked what they liked best about YouthCO, their comments indicated how they valued the focus on youth:

The approach is very positive in a youth's life. The support is really helpful. They are there for you.

I like best that I feel good when I come here. I like coming here, I don't like places that feel like a clinic atmosphere. It is a place to relax.

YouthCO is youth-driven. The people that are here have the disease. They are really caring, gentle and open people. It's fun to come here. It is also very educational.

Staff agreed that the youth-centered approach was effective:

Having the support from someone your own age makes a world of difference. Isolation is common, so it is great to do anything to break that isolation. YouthCO is thought of as a leading organization for youth in the community. Our focus is HIV/hep C, but it is thought of by the community as [being] much broader.

Respect for youth was the cornerstone of the approach. Even the conference steering committee had HCV positive youth, as well as other youth volunteers, as members. One conference participant commented:

We need to engage youth and listen to them. It's tiresome listening to adults and professionals who always impose their knowledge/information.

The peer-driven model allows staff and volunteers to work with co-infected and at-risk youth in a positive way. One client's comments pointed to the value of involvement:

They are always calling and asking if I want to be involved in activities. I have been [HIV] positive for eight years now. I learn more by being involved.

And staff also saw the benefit of youth involvement in terms of growth:

The very small things—watching people rebuild and gain confidence, watching them deal with the realities of living with this disease is pretty huge.

2. Development of youth-friendly information on hepatitis C

YouthCO staff and volunteers had worked hard to make information on HCV more accessible, through the development of innovative and engaging youth-friendly materials and resources. These have been designed to appeal

to a variety of learning styles, abilities and literacy levels. In addition, significant youth input has increased their utility as they suit young lifestyles (e.g., club cards and temporary tattoos) and use humour. As one client commented:

The information at YouthCO is good and it is presented in a real basic way. It is made for people to understand—it's not for doctors. If you want more information, you can get it as you need it. There is no dumping of too much information all at once. I don't see anywhere else than YouthCO where we can get this kind of information in Vancouver.

As one volunteer commented about the resources:

These brochures are great. I get the kids to take brochures and encourage them to give to their friends, etc. The whole goal is to create awareness. Because of the logos, etcetera, everything is viewed as "cool". They can read it and understand it. They have a question and they can find the answers here. The brochures are cool. They get passed on from youth to youth.

The fact that YouthCO materials were being widely disseminated demonstrated their utility with this target group.

3. Development of partnerships

Promoting community partnerships has been an important focus for YouthCO and staff members have been active in this regard. The Shoot for Safety conference was a catalyst for partnership development and by organizing it, YouthCO had the opportunity to develop closer ties with other agencies interested in HCV, including:

- Chee Mamuk (an Aboriginal education program of the BC Centre for Disease Control)

- AIDS Vancouver Island
- YM/YWCA Street Outreach
- Providence HealthCare
- Vancouver Street Nurses
- Dusk to Dawn

The conference helped to build links to the community. As one staff member commented:

We are also talking to teachers, street workers, nurses and doctors. We bring people together to work on hep C. We are re-energizing people to get active in their own community.

Other recent activities which promoted partnerships include attendance at a meeting of the Hepatitis C Collaborative Circle in Nanaimo, presentation of a workshop on youth and hepatitis C at the Canadian AIDS Society (CAS) Skills-building Conference in Montreal and attendance at two Health Canada Community-based Support Program meetings. At the most recent Program meeting, YouthCO staff members were able to develop other community partnerships, particularly with rural HCV projects in the province and gained an opportunity to work with the BC Centre for Disease Control to promote YouthCO's HCV services on the BC CDC website.

Challenges

When asked what challenges or obstacles were faced by youth infected with or affected by HCV, staff, clients, peer educators, volunteers and community stakeholders had much to say. There was a lot of agreement among their views and the three challenges they identified, while not specific to YouthCO, reflected more overarching issues confronting youth and the community in relation to hepatitis C.

1. Stigma

While public awareness for youth about hepatitis C has been increased by the many presentations made by YouthCO staff and volunteers at schools and other youth agencies in Vancouver and the Lower Mainland, there was still a lot to be done to combat attitudes about hepatitis C. As a staff member commented:

It is still hard to talk about needle drug use in schools. Teachers and administrators don't want us to mention that at all. It makes it hard for us to tell youth how to protect themselves. Youth don't know that sharing needles for tattoos or steroids or cutting can put them at risk.

A peer educator described the attitudes she had encountered in schools:

It is automatically hard for me to go into the high schools and provide education because I am female and talking about sex... [We] need more open-minded people out there doing this and it is needed at younger ages... into the elementary schools because they are sexually active but no one wants to admit it.

2. Lack of physician information and training

Appropriate information for physicians' use was often mentioned as a gap. As one client commented:

Unless you have a doctor who wants to go deeper on hep C, all you get is a single one-pager pamphlet that explains hep C in very general terms. There is no information on medication, on how to eat and on how to live with hep C.

A YouthCO staff member supported this view:

Generally, general practitioners don't have enough information/training on hep C. If the

doctor can't give out the appropriate information, who can youth contact if they have hep C, who can they talk to?

A physician at the Three Bridges Community Health Centre stressed the need for physician training and associated research:

For individual practitioners, hep C is one of five other things they do. It requires CIHR funding to attract physicians to become academic specialists in hep C and out of that a hep C clinic occurs that also does research. Until the centre exists, other GP's have less to work with.

3. Access to treatment in the context of addiction

Another serious obstacle was the lack of access to treatment for people who use intravenous drugs. Respondents commented on the community's resistance to the addictive behaviours of this target group. As the physician at Three Bridges commented:

The biggest barrier is access to treatment for people with addictions. They are not wanted in the clinics and support groups, etc. They have a whole load of maladaptive behaviours.... We need to support people with addictions.

A client shared a personal perspective:

They just push IDUs into the cracks and forget about them. The hospitals ignore hep C as well. When someone comes in with hep C and a cough, they tell them to get some cough medicine

As a community stakeholder explained:

The biggest challenge people face is treatment. Will they qualify and will they be able to handle the treatments? The criteria in BC are very rigid and a lot of our clients don't meet these criteria so treatment is denied.

For the Executive Director, the barriers faced by the target group were many:

It is hard to distinguish the barriers they face because they have hep C and the barriers they face from the activities and the lifestyle that led them to becoming infected with hep C (drug use, social barriers, poverty, addiction, and lack of education on a variety of health issues). [They face] barriers on how to take care of themselves; these individuals don't have access to a lot of healthy things in general—safe home, healthy food, support. Life in general can be a barrier.

Concluding Remarks

YouthCO has been able to make contact with this isolated target group and has begun to provide HCV education and support in a way that has gained respect on all sides. Its peer-driven programming has resulted in creative responses to this serious health and social issue. As one staff member commented:

We filled a gap. There was nothing around youth and hep C going on in Vancouver before. It was a big glaring gap. It has done a lot for the idea of blood borne diseases in general. I get the idea that youth are talking a lot more about blood borne diseases in general.

When staff members were asked to comment on the difference which the HepCATS project has made, they stated clearly that the project had a benefit on the agency as a whole.

The hep C project has opened up our agency. We are accessing so many other youth since the hep C project started. We are able to bring in youth [who are] using [drugs] into the agency. Our services respond better to youth because a lot of our volunteers are under 21 years of age and I think that makes our services richer.

Youth have access to more information and opportunities to really talk about things that preoccupy them.

As the project continues to move ahead, the next challenge staff have set for themselves is to develop a needle exchange to provide yet another way to build rapport with youth and support harm reduction. Judging from their record to date, this effort is likely to meet with success as well.

The following types of documents were reviewed in the preparation of this case study:

- Program documents from Health Canada
- HepCATS Shoot for Safety Conference package
- Proposal for needle distribution
- Newsletters (*Spicy*)
- YouthCO resources including pamphlets, stickers, temporary tattoos, trading cards and posters
- Job descriptions
- Scene from theatre troupe
- Background information: history and mission statement

Case Study Information

The case study visit was conducted April 9 to April 11, 2002.

The case study research team included: Barb Briggs, Chantal Cholette and Joyce Pearson. The case study was prepared by Dr. Gail Barrington. It was approved for distribution by YouthCO on Nov 29, 2002.

In total 18 interviews were completed as well as four observational activities:

- Staff and volunteers: 8
- Board member: 1
- Primary Clients: 4
- Secondary Clients: 5
 - Coordinator – Boys R Us
 - Educator – Cheema Muk
 - Dr. Trevor Corneil – Three Bridges Community HealthCentre
 - Project Manager – Canadian Liver Foundation
 - Coordinator – HepHIVE
- Observation of Boys R Us drop in
- Observation of YouthCO theatre troupe
- Observation of Street Sweep (outreach)
- Observation of HepCATS Advisory Group Committee meeting

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