
Working Well

VOICES OF EXPERIENCE
From Community-Based Projects
Involving People Infected With,
Affected By And At Risk For
Hepatitis C in B.C.

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Contents

Acknowledgements 1

Introduction 3

1. Outreach 4

 Strategies for specific populations:

 Youth 9

 Street-involved 13

 People who use injection drugs (IDU) 16

 Marginalised 17

 Aboriginal 19

 Women 20

 Adults 20

 People infected through the blood system 21

 Co-infected 21

 Prison populations 22

 Public 24

 Health care providers 25

 Service providers 27

2. Client Empowerment 28

3. Prevention and Education 32

4. Harm Reduction 39

5. Partnership 43

6. Volunteers 49

7. Community Involvement 52

8. Support 58

9. Stigma 65

10. Geographical Consideration 70

11. Media 74

12. Fundraising 76

13. Evaluation 78

14. Organizational Capacity 82

Appendices

A. Project descriptions

B. Questionnaire

Introduction

Working Well: Voices of Experience from Community-Based Projects Involving Those Infected With, Affected By and At Risk For Hepatitis C (Working Well), is a reflection of the work, experience and wisdom of fifteen projects funded through the Health Canada, Population and Public Health Branch, Hepatitis C Community-Based Support Program, BC/Yukon Region between fiscal years 1999 and 2003.

In 1998, the Hepatitis C Division was created within Health Canada to respond to the challenges and needs around hepatitis C in Canada. Within this unit, the Hepatitis C Community-Based Support Program was initiated to support a strong community-based response to the needs of persons infected with, affected by or at risk of contracting hepatitis C and to develop mechanisms for effective input from community-based organizations. Community-based projects began receiving funding in B.C. in 1999 after initial consultations with groups throughout the province.

Community-based projects in B.C. have faced many challenges during their three year funding cycle. Some of these challenges include the diversity of the population infected with, affected by and at risk for hepatitis C; the lack of awareness around the medical and psycho social issues of hepatitis C among healthcare professionals as well as the general public; funding constraints; and the constantly changing medical treatment.

The purpose of this document is to share the learnings of community-based projects in B.C. so that other community-based organizations, public health agencies and healthcare and service providers may benefit from their experience working with those infected with, affected by and at risk for hepatitis C.

The fifteen community-based projects (project descriptions in Appendix A) responded to a questionnaire (Appendix B) in writing or through an interview process where they shared what worked well with their target populations and their communities. These responses are brought together under main categories (outlined in the table of contents). Key points are highlighted throughout the document with quotations and real life experiences.

1. Outreach

*What strategies are effective for reaching and working with people infected with, affected by, or at risk of contracting hepatitis C?
What strategies work well with specific populations?
How can organizations engage the public and health care and service providers in hepatitis C work in their communities?*

Actively involve the target population

- ◆ The target population needs to be involved from the start and in all stages of the program - e.g. in the organizational infrastructure, program/project design and development, implementation, and evaluation, and as members on an advisory committee.
- ◆ Peer involvement enables you to be accurate about what you're working on or where you're going with something.
- ◆ Involvement enhances self-esteem - people know that they're being heard and that their voice matters. It helps clients feel pride in what they're doing, and when their skills, abilities, and input are acknowledged, they're more open and responsive.
- ◆ Let people know how the program is run with peer involvement.

Experience: In one project, peer educators were credited when they came in to do pieces of the work or facilitation and were acknowledged in meetings. In a prison program, participants were informed that the first group named the program and that it has been adjusted on an ongoing basis according to participants' feedback.

- ◆ Accept that working with target populations may mean working in a different and necessarily flexible way.

"When you involve clients in the work in the way that we've been doing it, it's tough. It is way more work than not including them, but it's way more rewarding - for them and for us. So that's how we choose to do it. We choose to have them in on every single level."

Olive (Northern Interior Health Project)

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- ◆ Use community members' knowledge of local culture. They can reach the hidden populations - people at risk or infected but who have not come out - at reachable moments.

Meet people where they're at

- ◆ Accept that people's life situations are what they are. They don't need you to change them. Your role is to provide information, education, and support so they can make healthy choices.

- ◆ Listen. People will tell you what they need.

"Keep compassion in your hearts at all times and really listen. Sometimes people do not want a solution as much as they want to be heard."

Rae (HeCSC BC Chapter Network Project)

- ◆ Don't expect clients to come to you. Find out where they are, how you can reach them, and who can help you reach them.

- ◆ As hepatitis C progresses, people's experiences and needs change. The disease progresses very differently for different people.

"People infected with hepatitis C find themselves in a radically changed life and health situation. A wide range of assistance is necessary to support these individuals. In addition to formal health care, support is needed for social, psychological, and employment adjustment to address the consequences of this debilitating disease."

Rae (HeCSC BC Chapter Network Project)

- ◆ Recognize the diversity of populations in the hepatitis C community and the need for targeted services.

Experience: One group reflected that people who are currently using drugs may not feel comfortable around those who do not, and people who are no longer using drugs may not want to associate with current users. People living in poverty may find it difficult to understand the point of view of people who have jobs, supportive partners, insurance, or hepatitis C compensation. People who were infected through the blood system have different mental and emotional needs. And some people are unaware of their risk and where they fit.

Tailor your work to the needs of the population

- ◆ Take the time to find out what people need instead of making assumptions about it - e.g. through focus groups, advisory committees, pilot projects, conversations at drop-ins or support groups, audience reactions to presentations, and evaluations.
- ◆ Be able and willing to adapt to what people need. Begin with basic information or approaches, then ask for feedback from specific populations on how the message can be delivered in a way that they can learn it and pass it on.

“When we put the word out, we put it out in a way that people could hear it. The language changed slightly for each group. The information was put out in a way that was useful for each population, rather than a generic language that caused deafness. So really taking a look at what was needed for each group and reworking the message so that it targeted that particular need.”

Karen (ANKORS)

- ◆ Ensure your materials are appropriate for the audience. Consider literacy levels, graphic content, appropriate levels of medical information, and relevance to their lives. Determine if it is something they can take away and use.

“We fall too easily into the kind of situation where we try to provide information to people in the way we think they need it, as opposed to listening to what they want.”

Terry (Canadian Liver Foundation)

- ◆ Adjust the format, presentation style, or approach of your program to accommodate the people you’re trying to reach. Don’t force a set format on them - e.g. adjust the time of day, weekday or weekend, duration, structure, or content of a program to match people’s interests and day-to-day lives. Also take into account the resources, knowledge levels, and expertise available.

Build relationships and partnerships

- ◆ Work with other service organizations and programs that have mutual clients or potential clients. Bring them on board at the beginning of a project (e.g. public health nurses in rural areas, street nurses, doctors, hepatitis C service organizations, and AIDS service organizations).

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- ◆ Make referrals to other services and encourage referrals from them to your own services.
 - ◆ Coordinate services located at one site.
 - ◆ To cover a large area or to reach rural and isolated communities, find out who is doing the work in these communities and approach them to see how you can work together.
 - ◆ Bring together what can be seen as separate communities (e.g. different areas of public health, health care, and health institutions with community-based organizations) and identify how you can work together, what you can learn from each other, and how you can co-facilitate the process.

Keep in regular contact with communication

- ◆ Send out a short email, flyer, or newsletter on a regular basis to keep the program at the front of people's minds.

Experience: At the beginning of every year, one group did a mailout to 50-100 local doctors and agencies, reminding them of who the group was and what they did, what they could do for others working in the community, and how they could be reached.

- ◆ Contribute to a newsletter produced by another organization you work with.
- ◆ There can be a high turnover in community agencies. Renew and maintain contact consistently throughout the duration of the program, not just at the start.
- ◆ Participate in regular conference calls and meetings with other service providers and organizations (e.g. public health nurses' regional conference calls).
- ◆ Visit local agencies regularly. If feasible, every few months do a walk-about of the community-based organizations in your area to distribute information materials and to create opportunities for face-to-face discussion about hepatitis C and other issues.

Promote your program effectively

- ◆ Before a presentation or workshop in other communities, do some preliminary work with local contacts and people likely to attend. Since they know the community, they can help access populations and get the word out.

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- ◆ Posters, notices, press releases and other advertising for program events can open doors and raise community awareness around hepatitis C.
 - ◆ Use your organization's web site or a community web site to provide up-to-date information about your program. Get your organization included in lists of community resources in other agencies' newsletters and web sites.
 - ◆ The BC Hepatitis Community Group Directory (maintained by the BC Centre for Disease Control at www.bccdc.org/hepatitis/community) gives community groups an opportunity to either establish their own web pages or post their information on a province-wide web site that has the resources to be sustained.

Establish your organization's profile and credibility in the community

- ◆ Be a place people can turn to for accurate information, respectful and confidential service, and commitment to follow through. Provide confidential phone lines (e.g. no call display) and 1-800 numbers.
- ◆ Stay up-to-date; information is always changing.
- ◆ Continually self-educate and attend educational workshops and conferences.

“Even though I think sometimes that it's a waste of time for me to go to different conferences and training, because I'm thinking of all the work I've got left to do at the office, I always come back and find myself saying, 'I was just in Vancouver and I learned this.' And people go, 'Oh, cool, she's got something new.'

Sometimes you get ten good minutes out of three days, but further down the road, that ten minutes can turn out to really be something good.”

Kari (North Island AIDS Coalition)

Follow through

- ◆ Do what you say you're going to do.
- ◆ Be realistic about your organization's capacity and resources and what you can do with what you've got. For programs with a large geographical scope, focus on a part of the region that you can cover with the time and budget available.
- ◆ Be clear from the beginning about how much energy you have available to put in and at what point to stop.
- ◆ Manage your schedule so you don't have to turn down requests.

Follow up

- ◆ Be consistent and tenacious about maintaining contact despite staff turnover in organizations. Recognize that it takes time.
- ◆ Include some method for follow-up in every presentation or workshop - e.g. through phone calls or by asking participants for a commitment to use the information or to do some homework. When there is a series of meetings or visits, ask participants to report how they've been able to implement or share what they've been learning.

Be patient

- ◆ Outreach is a process - it takes time and it may mean doing the same things over and over again. Build on what has been done and involve people who have experience doing the work.
- ◆ Keep reaching out.

“It doesn't happen right away. You can ask 10 times and get no response, but the 11th time, they let you in.”

Kari (North Island AIDS Coalition)

Outreach strategies for specific populations

Youth

Get youth involved

- ◆ Trust that youth are going to do the work and support them to do it. It's not hard to get youth involved in what you already do.

“Anybody can do this. Really, any group can. It's just a matter of, if you're going to take on youth work around hep c, then let it be youth work around hep C. Provide the guidelines that you need to, know what your organization can do, and really build up that trust. All you need is one youth.”

Sheena (YouthCO)

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- ◆ What you do isn't going to be as effective as what youth do in reaching other youth.
 - ◆ Have meaningful youth involvement in projects, done by youth for youth.

Experience: One group piloted a project geared at youth outside the traditional school system. Two youths were hired for a six-week period to go out on the streets and into arcades and malls to recruit other youth to attend a one-day workshop. The two interviewed and screened the presenters, told the presenters what they wanted, and phoned around to get food donations from the community. The workshop became a good employment experience for the two organizers, as well as benefiting the youth who attended.

- ◆ In meetings, ask youth what they think and give them space to voice what they know, what they can do, and what they want to do.
- ◆ Build trust with youth through consistency, follow-through, and non-judgmental attitudes.

"It doesn't work to come in and give them the 'I'm the adult, listen to me' sort of deal. You have to have a relationship. I used to think that you had to hire young-looking youth outreach workers and educators, but that doesn't really seem to be the case. It seems to be more about the individual and how they present themselves and how they relate."

Kari (North Island AIDS Coalition)

Provide youth-specific services or locations

- ◆ Youth may be reluctant to access services along with adults because of power or authority issues, intimidation, fear, or lack of understanding.

"There's so much competition for services in the Downtown Eastside - not between services but between the consumers of the services - that it can be hard for youth to get access. When you're competing, for lack of a better term, with someone who's lived down there for 20 years, who knows the system and is much stronger and bigger, there's such a power differential. You can get pushed to the back of the food line or the needle exchange line."

Sheena (YouthCO)

Make your organization and materials youth-friendly and accessible

- ◆ Have an office where youth feel comfortable, and where they can come to just hang out or get information, condoms, or anything that they need.

“Many youth access our offices for free condoms. This provides us with the opportunity to educate them. The free condoms are kind of a carrot, because condoms are expensive and they’re embarrassed to go buy them. They know that they can come in here and nobody’s going to look at them funny or tease them. But it’s what happens during that whole interaction that’s invaluable.”

Kari (North Island AIDS Coalition)

- ◆ Develop resources appropriate for youth that suit their interests and use their language.
- ◆ Distribute your materials widely throughout the community at youth-friendly sites.

Work with other organizations providing services to youth

- ◆ Learn from the experience of organizations in the community in accessing youth and find ways of working together to reach youth.

“Just outreach in and of itself, just going to other community organizations’ drop-ins and events, may not be the most effective. There are only so many times that you can do that. What YouthCO would do differently is more of a goal-oriented partnership. That’s where we’re moving for outreach now, when working with community agencies, making sure that what we’re doing is going to be effective.”

Sheena (YouthCO)

Take part in youth events

- ◆ Organize, partner on, or participate in events oriented to youth - e.g. youth forums, raves, school events.

“We did partnering with a number of raves in the area, such as Shambhala, a three day rave out in the country attended by over 5000 people. ANKORS had a booth - I think something like over 2000 people visited - where we partnered with a community group that was testing what people thought was ecstasy. It brought a lot of curiosity to the booth, then people had an opportunity to engage and pick up resources. It was also a place for people to just sit and be. There were three youth outreach workers too. We provided a lot of different things that weren't just targeted at teaching.”

Ken & Karen (ANKORS)

- ◆ More youth will be able to come to you than you're able to go to.
- ◆ Bring in other organizations, health care providers, and service providers to share their learning and expertise.

“YouthCO's Shoot for Safety forum was hugely successful. It was an opportunity to take what we knew and our expertise about working with youth and to bring together other experts... So much care and attention went into making it accessible to youth and really taking their needs into account. We took information that was really lofty and made it really street level and hugely health promotion.”

Sheena (YouthCO)

- ◆ Incorporate different approaches to accommodate different learning styles - e.g. interactive workshops, video, panel discussion, web-based information, printed resource materials, opportunities to get together and talk.

Get hepatitis C information into schools and colleges through the appropriate channels

- ◆ Make students aware of the issues around hepatitis and HIV through presentations in schools.

Experience: One group found that student's evaluations all said they'd had lots of HIV education, and although they appreciated it, hepatitis C touched them closer to home. They knew someone who had it - a relative or a teacher. One young girl, crying because her mother had it, said "I shared my mom's razors! Nobody told me I shouldn't."

- ◆ Provide take-away packages for students that include pamphlets on hepatitis (e.g. the differences between A, B and C). Also include information for parents on how to talk to kids about difficult issues.
- ◆ Provide support and education for teachers.
- ◆ Talk to the administrators and counsellors in schools and provide educational materials as often as you can.

"Sometimes the administration, concerned about what parents are going to think, acts as a gatekeeper. Sometimes it's really helpful to meet with the local parent advisory committee and basically give them a mini-presentation. They get to see the value of it and have their fears addressed. Then what usually happens is that they become quite vocal advocates of having us in there. They see we're just talking about useful information and making good choices and things like that."

Ken (ANKORS)

Street involved

Work with people who are street involved at their level

- ◆ Learn the issues they are dealing with.
- ◆ There is a spectrum of street-involvement - from simply being connected with the street scene socially, to actively participating in the drug scene, to living on the street full time.
- ◆ Be sincere and non-judgmental.

-
- ◆ This population is often considered an impossible-to-reach group, and they are impossible to reach by conventional methods. They experience a whole range of barriers to accessing services: homelessness, not feeling comfortable with the system, not feeling like they belong, and getting barred from drop-in clinics and other agencies because of their behaviour.
 - ◆ Use your program to act a gateway into conventional health service provision that they wouldn't access otherwise.

Engage through peer outreach and education

- ◆ Utilize social networks to access the street-involved and IDU community. Without their voice, you won't get the message across.

“There is no more effective way to truly reach out to people who are street-involved than through the people they socialize with on a daily basis.”

Jill (VANDU)

- ◆ Peer involvement and peer support foster a sense of belonging in your program or organization.

Provide incentives to attend programs or meetings

- ◆ Food and honoraria are key for successful connection and outreach.
- ◆ Incentives can be a variety of things: money, gift certificates for grocery or drug stores or bus tickets.
- ◆ Buy or get donated more food than is needed so there will be leftovers for people to take home.
- ◆ Helping with survival issues is a way to reach people.

“Virtually anyone who is street-involved is living in a situation of perpetual poverty. In order to help them access our services and programming, we offer some sort of incentive that helps them with day-to-day survival. For example, small healthy snacks are distributed at all our Hep C Support Group meetings. This small gesture is enough to ensure that 50 or more people attend each weekly gathering.”

Jill (VANDU)

Provide a drop-in space with educational resources readily accessible

- ◆ Have a space in your organization where people feel comfortable about coming in and spending time. Have coffee and food available.
- ◆ Don't create an overly structured atmosphere. Have only a few basic rules (e.g. no violence, abuse or sleeping).

“You really get to know what’s going on in their lives and the opportunity to educate is huge. I can just wander in and say, ‘You guys look bored,’ and throw a video in, and they’ll watch it. Whereas, if I put a sign up saying I’m going to show a video on hepatitis C at 2:00 on Thursday, the place would be empty; they wouldn’t show up. But if you have them here already with coffee and doughnuts, they’re more willing. The big thing is they’re not feeling judged. They feel safe.”

Kari (North Island AIDS Coalition)

Work with other organizations or programs reaching this population

- ◆ Partner with needle exchange programs and street nurses.

“The more times you see someone and the more and different contexts you see them, the greater your opportunities to build trust. Then you can talk to them about hepatitis C and safer using, etc.”

Hermione (AIDS Vancouver Island)

- ◆ Build on relationships already developed with these clients through work in other programs (e.g. HIV).
- ◆ Offer support and education for physicians, nurses, and addiction services or detox agencies that are working with these clients.

People who use injection drugs (IDU)

Build trust and relationships

- ◆ Accept where they're at. You can't come across as trying to change them.

“As with street-involved, learn to understand the issues facing those that you are providing information. Harm reduction becomes a more prominent part of information giving. Also provide information on how to try and maintain wellness, and accept that change will not be obvious.”

Ken (HEPHIVE)

- ◆ You have to have sincere respect for people who are IDU. They can detect anything that's fake, and they won't participate.

Understand the context of addiction

- ◆ People using drugs have their priorities set through their addiction.

“Always consider that the drug problem is probably the main determinant of that person's health.”

Katerina (HeCSC Cranbrook Regional Chapter)

- ◆ When people are actively using, they forget things, or their addiction may win out over an appointment or meeting. There can be an attitudinal barrier among service providers, who see clients' behaviour as something directed at them and think the clients are behaving badly on purpose.

Have programs that are specific and sensitive to the IDU population

“The group that's been the most difficult and the group that's always the most difficult to get to come to meetings is, of course, the active users. I believe if you're going to target active users, you need to do it with them exclusively and you need to use particular strategies that work with them. If you think you're going to bring them to meetings and stuff like that with other people, it's probably not going to happen.”

Olive (Northern Interior Health Project)

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- ◆ Set up programs so the hours are reasonable for these participants - e.g. start training later in the morning and have short days.
 - ◆ Access this population through programs that encourage IDU involvement, such as needle exchange programs. Needle exchanges should be open every night of the week and on weekends, as well as daytime office hours.
 - ◆ Within the IDU population, there may be groups that need their own specific programs - e.g. youth.

Marginalised

Recognize the multiple ways people can be marginalised

- ◆ People face barriers from hepatitis C or HIV infection, other illness, poverty, drug use and addiction, street-involvement, or sex trade work.

“For me, it’s all about how well we take care of the vulnerable people in our society. There’s a whole group of people I know living with hepatitis C who maybe don’t see themselves as the most vulnerable in our society, or they didn’t before hepatitis C. But now suddenly they’ve become that. Suddenly they’re marginalised because they have hepatitis C. Society is not that accepting of them. They, too, are on the margins now.”

Olive (Northern Interior Health Project)

- ◆ Hepatitis C is about much more than the disease: it’s about access to services, education and awareness, stigma, being able to articulate needs, and being able to advocate for yourself.

“Just because you’re an intravenous drug user, does that equate with not being able to handle treatment or not being able to have access to something more?”

Gail (BC Centre for Disease Control)

Make your organization open and accessible

- ◆ Build people into the infrastructure instead of building the infrastructure around them.

- ◆ People need to be supported, and they need to feel like they're having input.

"There's an incredible amount to be learned from people about how you can access them. That sounds really obvious, but unfortunately it's not. There's a lot of talk about how to access these multiple-barrier people. Why don't we just ask them? Why don't we ask them how we can get them to come and sit for an hour and talk about something? It's not about data collection; it's not about shrinking their heads; it's just about getting them patched into some network of care."

Jill (VANDU)

- ◆ Make sure your organization isn't creating barriers through attitudes or judgements by staff. Be respectful, open, and helpful.

"You're not going to get anywhere telling them what to do. They have everybody telling them what to do. That's the problem. They're frowned on and judged everywhere they turn around. And the reason programs like ours work is that we don't do that. Ninety percent of the clients that we get in here refuse to go to some mainstream organizations. It's not because they don't want help. They do. But they don't like to be judged."

Kari (North Island AIDS Coalition)

- ◆ Have realistic time frames. Intake processes or multiple appointments with long waiting periods in between will fail clients. When people are willing to reach out and ask for help, you have to seize the chance.

- ◆ Offer different ways for marginalised people to be involved in your organization so they can access the services you provide and for connections to other services they may need.

"Offering membership, empowerment, education and a sense of community are only some of the ways that VANDU reaches out to marginalised people. Just having them as part of the organization in some capacity - whether as active volunteers or occasional visitors to different meetings - puts them in touch with a pool of information that is likely to be unavailable to them otherwise."

Jill (VANDU)

Aboriginal

Build relationships with Aboriginal communities

- ◆ Find someone in the community who can be the contact or entry point. Use an existing network to make connections - e.g. public health nurses and the people who are administering health services on reserves.
- ◆ Be persistent, patient, and consistent in making connections. Work with Aboriginal organizations and forms as many partnerships as possible.
- ◆ Be honest, respectful, and supportive.

“You have to approach Aboriginal populations with respect and enter into a relationship with them. You do not tell them that you’re going to come to teach them - you’re merely coming to exchange information and gain knowledge from both sides, to better serve everybody. The material that you create must be respectful of Aboriginal values and beliefs. You also have to realize things may be done differently in some communities.”

Kari (North Island AIDS Coalition)

- ◆ Involve Aboriginal people in your organization, programming and advisory committees.
- ◆ Be flexible about the time and structure of your program.
- ◆ Accept that people may arrive later and come in and out during a full day event. Start late in the day and have a short day.
- ◆ Have numerous breaks. A lot of the work happens where there is informal interaction.
- ◆ Try evening sessions. In some communities, there may not be a lot of other activities in the evenings.
- ◆ Use concepts that are familiar to Aboriginal people and materials appropriate to their learning style.

Women

Understand the specific needs of women around hepatitis C

- ◆ Provide information dealing with women's health issues and hepatitis C.
- ◆ Make referrals appropriately and educate other community service providers about the issues affecting women.

"We're talking about women who live marginalised lives, who may or may not be living with violence, addictions, poverty... The work that we engage with them is linking them with all the other service providers that they can get assistance from, and making sure that whoever is supporting these women is aware of how hepatitis C symptoms may affect service provision."

Karen (ANKORS)

- ◆ Provide training and presentations for women's agencies - e.g. with volunteers and staff at women's centres or transition houses.
- ◆ Be aware of special requirements - e.g. childcare.

Adults

Offer different types of services for different needs

- ◆ Adults who do not fit into the other populations just want facts. They want their questions answered, and they want their confidentiality maintained.
- ◆ Pay attention to where people are in their disease cycle.
- ◆ One-on-one support will always be highly needed, especially when people are newly diagnosed, seeking treatment, or in the last two years of their life.
- ◆ Group work (training, educational sessions, peer groups) can be effective and encourages sharing of the experiences and pain involved in being hepatitis C positive.

People infected through the blood system

Understand their context

- ◆ Be understanding of their anger and disappointment with government agencies.
- ◆ Many come for help in accessing compensation packages. The application process can be difficult; some doctors may be willing to help with it.
- ◆ Many people infected through the blood system are also experiencing marginalisation.

Co-infected

Be sensitive to both or all diagnoses

- ◆ People infected with both hepatitis C and HIV have different needs around medical support, care, quality of life, and financial support.

Work with other organizations and support groups to overcome isolation

- ◆ Co-infected people are afraid of being ostracized from either the HIV or hepatitis C community because of stigma and judgement.
- ◆ Find ways of collaboration among hepatitis C and AIDS organizations, programs or support groups to address co-infection in both communities.

Bring co-infected people into group work

- ◆ Draw on their experiences. Many will have been living with HIV for years but have only recently been diagnosed with hepatitis C.

Experience: People who are co-infected responded well to both group training and one-on-one office consultations. Having already been through so much, they have a great deal of experience and insight to share.

Prison populations

Be non-judgmental

- ◆ Ignore the crime and focus on the person and his/her health and well-being.
- ◆ Be clear about why you are there.

Be appropriate for the culture

“Recognize the culture in prisons and incorporate it into your approach and materials. It’s a very confined environment; literacy is generally low, though not always; there are emotional issues; there is injection drug use, tattooing, and sharing needles. Harm reduction is important. Focus on damage control. Look at what is going to work in a very specific, confined situation to prevent more infection.”

Terry (Canadian Liver Foundation)

- ◆ There is a strong need for confidentiality and anonymity. Inmates often do not report their positive status because they fear dealing with the health care system within institutions.
- ◆ Do not use scare tactics, sensationalising, or anything confrontational.
- ◆ Lecture-style presentations do not work.
- ◆ Successful materials incorporate plain language, graphics, and content that relates to the culture (e.g. body art and drug use). Aboriginal content is also appreciated.
- ◆ Only send trained volunteers who have strong facilitation skills and can deal with anger and anger management issues.
- ◆ Provide a variety of outreach opportunities.
- ◆ One-on-one or very small groups work, since each person’s story or needs are listened to.

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- ◆ Follow up through regular monthly outreach. Give inmates homework or projects to do with other inmates and the opportunity to report back on how they were able to use or share the information.

Experience: Following one group's prison program, inmates formed their own ad hoc groups and support system. They reported a decline in hepatitis C rates, and when they saw they would not be dealt with severely as feared, more inmates self-identified.

- ◆ Peer education is effective with inmates both in and out of prisons. If they are on remand and are going on to do time in a federal prison, they take the information with them. After release, they bring it back out on the street and back to their home communities.

Provide education for health care staff and front line workers

- ◆ Provide formal and informal education to staff about hepatitis C transmission and risks.

Experience: Because of one group's work in prisons with inmates, there was a lot of information getting out to the officers as well. The jail had its own tv station that scrolled information and staff had their own web site which included information about the project.

- ◆ Be aware of fear and lack of understanding of hepatitis C among prison guards and judgements they may have about prisoners.
- ◆ Partner with external health agencies and doctors to provide information on treatment to health care staff.

Public

Set up information booths at public events and places

- ◆ Participate in health fairs, wellness shows, and other community fairs (e.g. fall fairs, volunteer fairs). To learn about events, monitor the local media and contact the person in charge.
- ◆ By being at public events, you help raise awareness of hepatitis C and address stigma - i.e. anyone can have hepatitis C.
- ◆ Have a table in a shopping mall and provide information. A free draw is a big help in getting people to stop. Ask the merchants for donations.
- ◆ Tag onto other events or established campaigns (e.g. Drug and Alcohol Awareness Week, World AIDS Day) and include hepatitis C information in the activities.
- ◆ Be active in promoting May as Hepatitis C Awareness Month.

Consider your community

- ◆ Public awareness events around hepatitis C tend to have poor attendance in rural settings. Communities are too spread out, and there is still too much stigma for people to attend publicized events. Smaller, specific training may be more effective.
- ◆ Use a variety of methods to get hepatitis C information out into the community. Have information and education materials available in doctors' offices and medical clinics for people to pick up. Use newsletters, brochures, posters, presentations, information sessions and web sites.

Make the most of media opportunities

- ◆ Be available to talk to reporters about topical issues (e.g. injection drug use in the community) and get your organization or program identified.
- ◆ Submit articles to local newspapers and send out press releases.

Health care providers

Make direct and ongoing contact with health care providers in your community

- ◆ It is easier to get your foot in the door where there is overlap in service provision (e.g. street nurses).
- ◆ Put together an information resource binder for health care providers containing the latest clinical guidelines, protocols, and consensus reports. Send out regular updates with articles and abstracts. Be available to answer questions by phone or email.

Experience: One group reported that health care providers seemed to appreciate faxes and newsletters that they could read, absorb, and then call about if they had questions. The group also received many emails from local health care providers and questions about hepatitis C treatments, transmission, and workplace safety. Emailing was more immediate and easier for health care providers than finding time to attend training.

Partner with health service providers

- ◆ Work with community nutritionists, dental professionals, or pharmacists to put together presentations or information materials related to their areas of expertise, for use in the community or at conferences.
- ◆ Partner with different services and seek to establish comprehensive care for people infected with hepatitis C. Include all the stakeholders: representatives from the community, specialists, public health, health authority, alcohol and drug services, palliative care, and community service organizations.

Offer educational opportunities

“Consumers told us they want service providers to be educated about their needs so they will get accurate, up-to-date information when they go to health professionals. That starts right with the GP, who may never have had a person with hepatitis C in their practice. We developed three-day interdisciplinary workshops for physicians and nurses, because that’s who the consumers said should be the main target groups.”

Gail (BC Center for Disease Control)

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- ◆ Bring in hepatology and nursing specialists to do grand rounds, presentations, and educational updates.

Experience: One group in a rural region learned that nurses and health care professionals wanted to have consistent contact with someone who could answer their questions. Part of the information gap was filled by organizing presentations by specialists. Further ongoing consultation was made available through telehealth and videoconferencing in health units and hospitals.

- ◆ Build in continuing medical education credits whenever possible.
- ◆ Approach pharmaceutical companies to sponsor a forum for health care professionals and to cover the costs of the venue, speaker and/or dinner.

Connect with nursing and social work schools at local colleges

- ◆ Do presentations in nursing and social work classes. Contact the directors of the schools to have your presentation included as a component in the curriculum.
- ◆ Offer volunteer and practicum placements for students and assist them with information for their course work.

Service providers

Provide opportunities for education and training

- ◆ Where there are regular meetings for service providers, access those meetings to provide updates and information on hepatitis C and your program. Share with them any challenges clients are facing.
- ◆ Provide in-service training. Employers may be reluctant to send their staff to training, because it takes them away from their jobs, so it may be easier for you to go to them. Use time available during staff meetings or at lunchtime.

Work with body art establishments

- ◆ Offer educational workshops and information to tattooing and piercing artists and aestheticians.

Experience: One group collaborated on a show in a local tattoo shop. They had a DJ, food and prizes, and provided a whole evening on health and safety around HIV and hepatitis C.

- ◆ Work with tattoo and piercing artists on body art safety materials.

“Body artists have got a huge bad rap around HIV and hep C and hep B, but our experience working with them is that they know their stuff. They care very deeply for their craft and for their clients. They have always jumped at the chance to share their knowledge and create partnerships.”

Sheena (YouthCO)

2. Client Empowerment

What can community groups do to help clients become empowered, learn how to get their needs met, and get involved in peer-run initiatives?

Provide client-based service

“Remember why we’re here. We’re not here to write reports for the program or the province. We’re here because there’s a certain role we have in people’s lives. If we truly believe in client-based services, then my job is to make sure that the car has got gas, and it’s the staff’s job to drive that car wherever the person wants to go.”

Karen (ANKORS)

◆ Validate people for who they are.

“Just to go somewhere and be validated as a human being, as you are - as a user, as an addict, as somebody who has issues - may be the first empowering thing that has happened for somebody in a long time... When people have such a negative view of themselves that they can’t imagine themselves as human beings, the main thing is to restore a sense of humanity in people.”

Jill (VANDU)

- ◆ Provide information and help people identify the steps to get to where they want to go. Check with them if they’re comfortable doing these things and at what stage there might be some role for you to play.
- ◆ Accept when people say that they don’t want you to do something.
- ◆ Be able to say what you can do and what you can’t. It may be something the client needs to do or there may be somebody else who can help.

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- ◆ Use what you know about your population to figure out ways of working with them that fit having a chronic illness and ways they can access services.

“People know when they’re being respected. If I’m carrying a belief about somebody that because they’re hepatitis C positive they can’t look after themselves, that’s going to come through in how I talk to that person. It’s in our language and in our body language. Being able to accept a person where they’re at, without thinking that they should be in another place... Those kinds of things are empowering.”

Deb (Positive Living Northwest)

Cultivate peer involvement

- ◆ Create a sense of belonging.

“If you think about humanity and what makes us human beings, it’s our relations to each other. It’s about making contact and building relationships and becoming a member of something. Feeling that you can talk to people and they’re going to respect you as an equal. That’s the key of the peer-to-peer thing. You’re talking to an equal, not somebody’s who’s above you, who’s going to power trip you eventually.”

Jill (Vandu)

- ◆ Let people find their own comfort level around involvement - as members, as someone who comes to meetings regularly or not, as volunteers, or as board members.
- ◆ Incorporate peer-driven initiatives and/or structure in your organization. Involve peer members in all the work and decision-making.
- ◆ Include peers as representatives of the organization out in the community (as long as they feel safe doing this.)

Focus on people's similarities

- ◆ Engage people around the disease of hepatitis C, instead of around the transmission factor.

“We put very little emphasis on how people got infected. One epidemiological weakness is that when doctors are taking histories, they will stop at the first mention of any kind of intravenous drug use, no matter how infrequent or how long ago, when in fact there might have been other risk factors that played a much bigger part.”

Ken (ANKORS)

- ◆ Help people find strength in collaborating.

Use a wellness approach

- ◆ Look beyond the disease. To promote healthy lifestyles and wellness, consider all the aspects of a person's life.
- ◆ Encourage people to be active in their own health care, to educate themselves and their health care providers, and to take charge of their illness. Support them to make any necessary changes.

Help clients navigate the system

- ◆ Help people find information and the experts who will spend time with them, which can help them feel empowered - that there's someone on their side.

“By consulting with your client about what the next step should be in regards to medical treatment, it lifts a tremendous burden from them. It decreases fear, shame, and anxiety, and makes the person feel better emotionally and often times physically.”

Katerina (HeCSC Cranbrook Regional Chapter)

- ◆ Inform clients of the benefits and services they are eligible for and where to access them.
- ◆ The system is complex and the disease is complex. To cover all the different areas, consult other people and organizations who have the expertise.

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- ◆ Recognize that clients may believe they're not going to get helped. Some health and social service providers may discriminate because of a person's lifestyle or past lifestyle.
 - ◆ When appropriate, act as a go-between for clients with service providers. Clients may be confused or uncooperative or have histories of problem behaviour that have been flagged in the system.

"It helps improve the health of the person that you're dealing with, and it also helps educate and streamline the system of care..."

Kari (North Island AIDS Coalition)

Work on an individual and collective level

- ◆ Work with individuals around day-to-day survival things such as social services, disability forms, getting nutrition allowances, and housing issues.
- ◆ Many organizations don't have the time or capacity to do individual casework with people. As an alternative, teach people about the systems they are engaged in, so they can navigate them on their own.
- ◆ Collectively, raise the general awareness about issues like the prevalence of hepatitis C, harm reduction, housing, and upcoming changes in relevant legislation or regulations.

3. Prevention and Education

What works well when developing and delivering prevention and education messages?
What works with specific target populations?
What approaches are effective for sharing information and raising public awareness?

Consider the big picture when doing prevention and education work

- ◆ Whether you're doing prevention or harm reduction, you must have education.
- ◆ Look at both primary and secondary prevention (those living with hepatitis and those close to them).
- ◆ All populations need prevention work, and it has to be ongoing and long term.

"I think it's a mistake to say that because most IV drug users have hepatitis C anyway, don't focus any prevention or education on that population. Because there are some who don't have it yet, and there are youth coming into that population."

Kari (North Island AIDS Coalition)

- ◆ Poverty, social-economics, and reduced social and health supports have ramifications for hepatitis C work.

"Yesterday somebody came in, and it was the first time they had screwed up the courage to come in and talk to somebody about their diagnosis. Talking about how they got infected, it was likely in a relationship with another user and a situation came up where there was no clean equipment available. And you get into the whole thing of gender issues, power imbalance, ability to negotiate, refusal skills, poverty, low education... You could probably apply all the determinants of health."

Ken (ANKORS)

Actively involve your target population

- ◆ Work with your target population to find out what is needed and who will be attending workshops and using materials. Find out what was done in previous sessions, what materials were used, and how well they worked.
- ◆ Develop resources collaboratively. Work with an advisory committee and members of the community, and draw on their experiences and expertise.

“I’ve seen other hep C posters for youth and it’s so obvious they did not have youth involved. You need to work with youth if you want to do a youth poster; otherwise, don’t bother doing it. It’s such an easy rule: involve your community. Get youth you know to do the design. Don’t do it yourselves, because it will look like it came from you. It’s a longer process, but you can do it if you want to be effective.”

Sheena (YouthCO)

- ◆ Test the format and materials with the target population through piloting, focus groups, feedback, evaluations and audience reactions.
- ◆ Incorporate changes suggested by feedback and add material from the target population (e.g. poetry, artwork, and stories).
- ◆ Include members of your target population in educational workshops and conferences you attend. They will be able to contribute their perspective to the conference and disseminate information from the conference to their peers afterwards.

Use a peer-to-peer approach

- ◆ People engage more actively with peers. With service providers and staff, language, comfort level, and lack of shared experience can cause a gap.

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- ◆ Peer education can happen formally or informally through social networking within a population. Information that normally may not be accessible to marginalised populations can be obtained in familiar and safe settings.

“We’ve found that hep C information, as well as any other type of health information, is best communicated peer-to-peer. This happens not only in the formal settings of meetings or alley patrols, but also as people socialize and perhaps use together. One person may learn something about harm reduction and hepatitis C at a support group meeting one week and apply it later while partying with some friends. This becomes an example of peers not only exercising safer personal practices, but also modelling them for one another.”

Jill (VANDU)

Use positive peer pressure

“One side effect of peer-to-peer outreach and education is that people who otherwise wouldn’t use any of the drop-in clinics in the Downtown Eastside end up doing so because they are urged to by their friends. There is nothing more valuable in terms of reaching out to this target group than word of mouth publicity. Good reviews on the street will get people out to the services.”

Jill (VANDU)

Tailor strategies and resources to your target population

- ◆ Look for good tools and information materials that others have created. Adapt as needed.
- ◆ Provide information in a format and learning style that fits the specific population or audience. It’s more effective that way, since people know it’s for them, it relates to their life, and it’s very specific to what they’re doing in their life.

“Try and make learning fun. Relate personal experiences whenever possible. Give as much information as you can, but don’t give answers to things you don’t know. Watch the audience to ensure that they are understanding what you are talking about.”

Ken (HEPHIVE)

- ◆ Consider barriers around literacy and language and ability to understand medical information. Use graphics, and have written material said aloud so those who can’t read or can’t read well will still hear it.

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- ◆ Use culturally appropriate materials.
 - ◆ Find out as much as you can about your audience before you go in to do education or training. Don't assume that what works in one community will automatically work in another or for different Aboriginal bands.
 - ◆ Understand what the risks are for each specific population. Develop materials that address these risks.
 - ◆ Identify the most important information they should know - e.g. If you had only one minute with the person, what would the message be?

Adopt specific strategies for youth and schools

Experience: In the hope of reaching students before they might be exposed to injection drug use, one group provided sessions in schools for students in grades 6-10. They found that many students knew someone with hepatitis C and wanted to know more than their teachers understood and could teach them.

- ◆ Things that work well with youth: a non-formalized structure, responding to their needs and working with where they are at that moment, using the right tool at the right time - sometimes an active, structured exercise, sometimes a looser, facilitated conversation.

“This is not about delivering information, this is about facilitation and sharing knowledge. When you stand at the front of a classroom and say ‘Hepatitis C is ...’ you stop that. To work with youth in a much more effective way, ask ‘What is hepatitis C?’ It’s flipping it and saying ‘Oh, this is what hepatitis C is to you, and this is what hepatitis C is to me, and this is where we meet.’”

Sheena (YouthCO)

- ◆ Make presentations fun and interactive with opportunities to participate.
- ◆ Involve peers or someone close to the same age who can be available as a resource.
- ◆ Develop by-youth-for-youth hepatitis C messaging. Working with school drama classes to develop and produce skits containing prevention messages. These can also be used for public service announcements (e.g. on radio).
- ◆ Make materials more youth appropriate by working with youth organizations that are doing the work already (e.g. around HIV).

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- ◆ Work with prevention and education workers in schools - e.g. public health nurses giving talks on hepatitis C and HIV.
 - ◆ Go to where youth are, especially those not in traditional school systems - e.g. raves. Identify and reach out to at-risk youth.
 - ◆ Use incentives to bring youth in, so they can hear prevention and education messages - e.g. make free condoms available at your office.

Explore different ways of delivering prevention and education messages

- ◆ Provide information through a variety of ways - e.g. health fairs, community presentations, workshops, meetings, peer education, street support, a lending library, and throughout your organization.

“We’ve found the most effective way to get information out to our target population is to saturate our organization with as much information as possible... That way, even if someone stops for only 30 seconds at our needle distribution table to pick up some clean needles, it becomes an opportunity for new information about hep C to be disseminated.”

Jill (VANDU)

- ◆ Get information to people where they are. Distribute materials through locations frequented by your target populations - e.g. free clinics, needle exchanges, Alcohol and Drug Services, other community agencies. Regularly follow up with locations to make sure the materials are on display and in stock.

“You just have to get as much information out there, to as many places where your target audiences hang out as you possibly can.”

Kari (North Island AIDS Coalition)

- ◆ Use different kinds of media and materials - e.g. written, graphic, video, audio, web-based, public service announcements on radio or tv, telephone information lines, cards, stickers, and temporary tattoos.

“You can pack lots of information in other ways than text. People need to hear, see and do.”

Ken (ANKORS)

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- ◆ Put information on things people can use - e.g. matchbook covers, sewing kits, first aid kits. It's a non-threatening way to package information.

Experience: One group developed succinct messaging to put on matchbook covers for street-involved and IDU populations. Matches are something that people need and can easily pick up and take away with them. Along with the agency's phone number, the messaging contained three short points about not sharing needles: there's more than one strain of hepatitis, hepatitis C is blood-to-blood, and bleach may not kill it.

- ◆ Make information available in electronic format for easy access - e.g. as PDF files, on web sites, or compact disc.

Experience: One group made a CD containing the hepatitis C materials they developed. Copies were burned and distributed on demand at low cost, avoiding the large up-front costs associated with traditional print production.

- ◆ Provide materials at no charge. When there is a need for cost recovery because of the expense of producing a resource, use a sliding scale or institutional rates.
- ◆ Contribute to building a larger system for information and resource sharing (e.g. clearinghouse).

Ensure your information is accurate

- ◆ Changing and conflicting information and ongoing research on the hepatitis C virus make prevention and education work a challenge.
- ◆ Provide information that you can be certain about.

Experience: Groups expressed frustration about the lack of definitive or authoritative information on various aspects of hepatitis C - e.g. changing treatment options or the effectiveness of bleach for killing the virus. They advised being very selective about any information you put out. Do not put out anything as fact until it's corroborated by more studies.

- ◆ Provide people with information they can safely and realistically use - err on the side of caution. Promote the use of universal precautions.
- ◆ Keep updating and finding the most accurate sources.

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- ◆ Work with people who have expertise in the relevant areas to review information for accuracy and to ensure it is not inflammatory or reactionary.
 - ◆ Stay current or involved with institutions doing research.
 - ◆ Stay current on Internet resources and what is credible or not (especially information about remedies).

4. Harm Reduction

What approaches are successful in reducing the harms associated with drug use and in improving the health and quality of life of people who use drugs?

Incorporate harm reduction philosophy into your organization

“Harm reduction benefits everyone. People tend to think we’re giving special service to a particular population, but harm reduction serves everyone.”

Hermione (AIDS Vancouver Island)

- ◆ Adopt a policy around harm reduction for your organization.

“Harm reduction is in all the work we do. It isn’t just located in the needle exchange. It’s support services, it’s the front desk, it’s the writing of the grant proposal, it’s the board... Everybody works from the harm reduction model, regardless of what program they’re working on.”

Karen (ANKORS)

- ◆ There are a range of harm reduction approaches - e.g. promoting wellness and taking care of one’s body, needle exchanges or distribution, and alley patrols with street nurses.

“Embracing a harm reduction approach includes having low threshold services. Some groups ask that people not be using or be sober, but you need to have a whole range of services if you’re going to meet people where they’re at. Considering that the people who are mostly getting infected these days are the people who are injection drug users, we need to be adapting programming to suit their needs, not the other way around.”

Hermione (AIDS Vancouver Island)

- ◆ Harm reduction approaches, such as needle exchange programs, let you access many at-risk people. You don’t have to go find them.

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- ◆ By building trust and relationships with clients through harm reduction programs, you are able to bring them into contact with other services.

“All they think at the time is that they’re coming in to get some free needles. Little do they know they’re already going down that long road to recovery or responsibility. We also refer a lot of clients to detox and recovery. Harm reduction is cost effective and a needed link to the continuum of care.”

Kari (North Island AIDS Coalition)

Respect and accept what people are able to do

- ◆ Harm reduction works with populations like youth and IDU, who get told over and over again by everyone in authority what they should do, because it allows them to choose their own behaviour.

“No matter how chaotic or low on the social rung a person appears to be, they still do have some choices, especially if we help them and give them the tools to have those choices.”

Hermione (AIDS Vancouver Island)

- ◆ Don’t try to control the outcome or overlay your expectations on the process.

“I didn’t have any restrictions about people turning up stoned or drunk or people being on the nod during a meeting or training group. That wasn’t an issue. The issue was always about people being respectful to each other. It’s reminding people, these people in particular, that they have some very valuable skills. Find the positive aspect and build on it. They are who they are, and you can’t change them. All you can do is give them the information.”

Hermione (AIDS Vancouver Island)

Encourage self-responsibility and self-empowerment

- ◆ Give people tools to make better choices for themselves. Harm reduction can lead to behaviour change or not; it gives people an opportunity to do what they want to do and change their behaviour at the same time.

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- ◆ One example of a harm reduction tool is the “set setting dose”, a set of questions people can ask themselves before doing drugs. Set = where’s your head set at before you start doing any sort of drugs or alcohol? Setting - where are you? Dose= is this a drug you’ve done before? How much are you doing? Do you know what the source is?

“It’s very easy. It’s not saying, don’t do drugs. It’s saying, why don’t you ask yourselves these three questions before you go in. If you’re not happy with the answers, you can actually change the outcome of it.”

Sheena (YouthCO)

- ◆ Provide opportunities for people to take responsibility for the things they can - e.g. hold art sessions and supply materials for people who use injection drugs to make their own mats and spoons. It encourages people not to share and to take some ownership over their equipment and drug-using behaviours.

“It’s like an act of acceptance of them, saying, ‘OK, you are a user and this is where your life is at, but if you are going to use, then do it safely.’ People were surprised that anybody felt that they could feel proud of their spoon or mat or whatever. They felt good about it because they made it. While people are making them, you also have the opportunity to talk to them about why they’re making them: ‘These are what the risks are. This is why it’s a good idea to do this.’”

Hermione (AIDS Vancouver Island)

- ◆ Use peer outreach and education for harm reduction

Look at what harm reduction means for hepatitis C

- ◆ Build on what has been learned from harm reduction in HIV work, but recognize that there may be different things needed for hepatitis C.

“We now need to be worrying about spoons, cottons, water, and all of the other stuff. The whole harm reduction philosophy hasn’t caught up with hep C yet. If we were running our programs to use harm reduction in terms of hep C and preventing hep C, it would look quite different.”

Hermione (AIDS Vancouver Island)

- ◆ People may have a good understanding around HIV and injecting drugs, sharing needles, and safer sex, but they may not have made that translation for hepatitis C, which is also a blood-borne disease and hardier.

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- ◆ There is a need for widespread availability and easy access to harm reduction messages and harm reduction materials. As with needle exchanges, there are educational opportunities embedded in providing materials.

“If you can’t get clean filters, clean water, or a clean rig, all the education in the world is not going to do you a bit of good. If it’s not there when you need it, it’s not going to do you any good.”

Ken (ANKORS)

Educate the community about harm reduction

- ◆ There is a big need for public education around harm reduction. There are a lot of assumptions about it. Many people think harm reduction is going to mean increased drug use among young people.

“We deliberately put things out into the community to engage some sort of conversation, but we haven’t had a lot of explosions about the needle exchange or about condom distribution. I think it’s because we’ve done a level of community awareness that they know it’s necessary and that it lives here. All of those things live here.”

Karen (ANKORS)

5. Partnership

What do community organizations need to know about building and sustaining strong partnerships?
How can organizations overcome resistance or conflict in partnerships?

Identify potential partners

- ◆ Find agencies with common ground, common goals, common clients.

“Who deals with our target populations? Those are the partners we need, because we have a common interest. Who has what we need that we don’t have? What do we have that somebody else needs? We help each other out by sharing resources, infrastructure, and staff.”

Kari (North island AIDS Coalition)

- ◆ Develop partnerships at the beginning of your project. Include everyone that needs to be involved to do the work.
- ◆ Research organizations that are working effectively and approach them to identify ways of working together.
- ◆ Initiate contact through letters of introduction, poster campaigns, connections to people working in that field, and volunteers and clients who have told you about another agency’s work.
- ◆ Build on existing connections and relationships to develop working partnerships.
- ◆ Current contacts and partners can open doors to other possible partners.
- ◆ Expand partnerships to cover the geographical area and activities you want to cover. For a large region, you’ll need partners in many communities.

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- ◆ Look beyond your community or region. Support the development of coalitions or advisory groups of organizations already providing health services to communities.

“By bringing together programs and organizations, community by community, we can coordinate efforts, streamline communication, avoid duplicating services, and identify gaps in programs and services currently available. This group vehicle will also provide a voice for the diversity of experience within the hepatitis community.”

Rae (HeCSC BC Network Chapter Project)

- ◆ Look outside your sector. Partner with businesses such as pharmaceutical companies to bring in specialists to educate health care professionals in your community, or partner with a local body art shop on awareness raising events or developing materials.
- ◆ Be willing to grow and change in your organization and expand your partnerships accordingly.

Overcome resistance or differences among partners

- ◆ Right from the start, be clear about roles and responsibilities and how you’re going to work together. Be firm about your boundaries - specify what you can take on and what you can’t.
- ◆ Different agencies approach the work from different perspectives - i.e. community-based, public health, different levels of government, medical and non-medical models. Recognize that even so, you’re all doing similar work and share common goals.
- ◆ Respect the environment that you’re working in - e.g. in prisons, work within their rules and system; stay professional.
- ◆ Open up a conversation about what the work means, to get a better understanding of what you’re doing and how you’re doing it in different ways. Be able to think outside the box (or your particular box).

“You may not agree with others on how things should get done or even who should do them. However, having the conversations that lead to change is the first step toward a shared vision.”

Rae (HeCSC BC Network Chapter Project)

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- ◆ Be willing to say what you need or want.

“We persevered. One of the things that we have in common is that we're all really hard workers, we're all very professional, and being accountable is important to all of us. We stuck it out. I think that we're probably in a better place now than we were at the start of the hep C project, because we've confronted some of these issues, we've said some of this stuff to each other.”

Olive (Northern Interior Health Project)

- ◆ Question perceptions around working with specific target populations. For instance, the preconception that youth are too casual and too young to have the knowledge and skills to deliver programs, or the IDU populations are unreliable.
- ◆ Be aware of the reasons some population groups (e.g. marginalised or IDU) may be reluctant to enter into partnerships and address those concerns.

“There's an inherent defensiveness that comes with being downtrodden or oppressed for who you are for so long. You have a really self-protective thing that happens...”

Jill (VANDU)

- ◆ Remember that although there are challenges in partnering, it's worth it.

Experience: Despite the difficulties groups experienced in creating and sustaining partnerships, they reported that it was well worth the time and effort to see partnerships through. They said the ability to partner was necessary for their survival and that organizations which did not partner, did not progress.

Have a process for dealing with conflict

- ◆ Be able to confront issues and say what you are feeling.

“You have to have understanding of conflict resolution. Conflict is not necessarily a bad thing, and conflict doesn't necessarily destroy people. It can be respectful to make the choice to go through the conflict and to confront the conflict.”

Olive (Northern Interior Health Project)

- ◆ Recognize there may be cultural differences around conflict resolution.

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- ◆ Rise above the negative by not taking situations personally. Look at the broader picture about what you are trying to do for people with hepatitis C.
 - ◆ Be specific, professional, and accountable in partnership relationships.
 - ◆ Keep talking.

“The lines of communication must remain open at all times with your partners. If there is a problem in communication, it may be a misunderstanding that can be easily resolved by clarifying what it is that resulted in a conflict.”

Katerina (HeCSC Cranbrook Regional Chapter)

- ◆ Have a contingency plan or process for dealing with things when they go wrong.
- ◆ Try to resolve the conflict and accept it when you can't.

“Find ways to still work together in serving the community that was your common ground. Accept the more formal ties are lost and that is okay. Remember lots of marriages end in divorces... Realize when there is potential to resolve a conflict and then proceed.”

Ken (HEPHIVE)

Look at different ways partners can contribute

- ◆ Different types of organizations have different resources they can put into a partnership - e.g. health units have an infrastructure that can provide meeting rooms, vehicles, and staff who can consult or sit on committees; community organizations, in turn, can take some of the workload by assisting clients through their programs.
- ◆ Share physical resources whenever possible (e.g. office space, furniture, telephones, computers, supplies, and information materials).
- ◆ Share expertise on presentations, education and training, resource development, organizing events and conferences, and community-based research.
- ◆ Share administrative support, volunteers, and volunteer support.
- ◆ Share your passion for the work and your care and commitment to the clients.
- ◆ Recognize not all partnerships are equal. Though power and resources may be unequal, a partnership can still work as long as the partners are satisfied they're getting what they need.

Find an appropriate level of partnering

- ◆ There is a range of formal and informal partnerships - from sharing information and making referrals, to organizing events together, to entering into formal agreements to share resources and programs.
- ◆ Partnerships can be for a limited time or open-ended. Be aware that staff changes may affect partnerships and their viability over time, as can changes in your community.

“The community may want different information than the partnership ever intended. You must adapt to the needs of the community - they are truly your partners if you want your project to be a success.”

Ken (HEPHIVE)

- ◆ Determine whether a formal or informal partnership is suitable. Informal partnerships are more flexible; formal partnerships may have an effect on core programming.
- ◆ Develop goal-oriented partnerships where, at an agency level, there is the capacity to create and implement effective projects and services. Partnerships work when they are practical, project or issue specific, and have tangible goals.
- ◆ In small or rural communities where there may not be many partnering opportunities, look at mentor ship with a more experienced project elsewhere. The project coordinator can provide visits, ideas, or support by phone or email.

Recognize partnership and coalition building is a process

- ◆ Ensure good facilitation and leadership are in place when entering into collaborative relationships. Bridge building may be needed among people who come with diverse experiences and personalities.
- ◆ Select a skilled facilitator who will recognize all of the significant differences between the people sitting at the table, draw out their issues, emotions and experiences, and move things along. This may include helping individuals direct anger in positive, constructive ways.

◆ Recognize who the leaders are.

“Who puts the project forward isn’t necessarily the leader - there are people hidden in those groups who are leaders. And they may not have the confidence when they first come to the table, but you can find out pretty quickly who the players are and groom them along so they develop the confidence and esteem to become leaders.”

Stacy (BC Collaborative Circle)

◆ Find ways to sustain partnerships and coalitions.

“The Circle and other projects have succeeded tentatively in connecting with each other around the province. And that can still happen. Unfortunately though, and it isn’t just hep C, funding is uncertain. So building is a bit like building sand castles in the waves. You can’t think, I’m going to finish this castle when half of it’s being eroded by waves, and there’s no sense that there’s more funding. It’s unfortunate but it’s just a fact of life in funding.”

Eric (BC Collaborative Circle)

6. Volunteers

What strategies work well for recruiting, training and supporting volunteers?

Find creative ways of attracting volunteers

Experience: Some groups found that engaging volunteers in hepatitis C work differed from their previous experience with volunteers in other fields, including HIV work. Complicating factors include a lack of rallying around hepatitis C, stigma around who has it and how they were infected, the effects of hepatitis C on people's health and energy levels and their ability to volunteer, and the perception that volunteers who don't have hepatitis C don't know what it is like.

- ◆ Make your organization known in the community and let people know about opportunities for volunteering.
- ◆ Target your volunteer recruiting efforts. Look at people's motivations to volunteer and approach them that way. Engage them in your work in a way that is meaningful to them.
- ◆ Involve professionals from public health and similar services as volunteers.
- ◆ Expand volunteer work in the HIV area to include work around hepatitis C.
- ◆ Attend volunteer fairs (e.g. at libraries and universities). When your organization has a booth at community events or health fairs, use the opportunity to both educate and invite people to get involved in your organization.
- ◆ Advertise in different media.
- ◆ Use community work placements.

Experience: One group involved high-risk youth through court-ordered placements in assembling needle exchange packages and education packages and wrapping condoms. This was a population they were trying to reach, and there were opportunities for conversation and education during the work activities.

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- ◆ Use course requirements and practicums to involve students from nursing, social work, and other programs.

“We do an education piece with nursing students at Selkirk College. From that, there’s usually a couple of nurses who either want to do a project or work with us on something around HIV or hepatitis. We try to construct something for them so that we get an output and they get to do what they need to do.”

Karen (ANKORS)

- ◆ Ask to borrow volunteers from other agencies for a specific project and time.

“It’s ok to reach out and ask for help from other organizations. It’s not like you’re stealing their volunteers; you’re only borrowing them for a day.”

Kari (North Island AIDS Coalition)

Be ready for volunteers

- ◆ Determine what your organization has in terms of work to be done, ways for volunteers to be involved, and your capacity to support them.
- ◆ Develop policy and procedures for bringing volunteers into your organization - e.g. an intake process, a volunteer application form, and programs for orientation, training, support, and recognition.

“VANDU’s volunteer program is probably the most powerful part of the organization. A large part of the empowerment, peer outreach, and peer education takes place through our volunteer infrastructure. The training and orientation allows the volunteers to see how important the work they do is. Every time they reach out to someone on the street, visit someone in the hospital, or hand out clean needles, they are actively participating in saving the lives of their brothers and sisters.”

Jill (VANDU)

- ◆ Hire a volunteer coordinator. The work involved in running a volunteer program can be equivalent to a full-time position.
- ◆ Ensure you have the right person in place to coordinate volunteers, whether it’s someone you hire, someone on staff, or a volunteer doing it. If you don’t have a person with a positive attitude, it can turn off volunteers very quickly.

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- ◆ Give appropriate training to volunteers and support them in the work they are doing. Don't send volunteers out to workshops or other agencies without figuring out what information and support they're going to need first.
 - ◆ Incorporate fun into volunteer training, as well as information.

Find meaningful ways to engage volunteers

- ◆ Find the right fit for volunteers in your organization.

“We let volunteers find their level. We need volunteers to do what they need to do. We try to find ways to adjust the programs to let them be involved.”

Karen (ANKORS)

- ◆ Be realistic about what volunteers can do.
- ◆ Accept the workload volunteers can do, given their energy, capacity, and time.
- ◆ Involve people as board members or members of your advisory committee and have an active role for them. Include both health professionals and people who have experience living with hepatitis C.
- ◆ It's not necessary for volunteers to have knowledge about hepatitis C - you can educate them. Choose people for the active interest and skills they bring.

Acknowledge volunteers' contributions

- ◆ Let volunteers know how valuable they are to your organization, whether the rewards are tangible or not.
- ◆ Involve volunteers in developing and producing materials and include them in conferences and trips to other communities to showcase your program.

7. Community Involvement

What can organizations do to raise awareness of hepatitis C in the community and engage community members in hepatitis C work?

Understand your community

- ◆ Each community, whether urban or rural, has very different needs.
- ◆ People with hepatitis C bring their voices and lived experiences of hepatitis C to inform whatever process they're involved in.

"The local volunteers are best suited to understand the community's needs through their personal experience of the issues, challenges, and developed relationships with local service providers."

Rae (HeCSC BC Network Chapter Project)

- ◆ Learn from the community.

"I think that the only way you're going to develop guidelines for clinical practice, treatment, and support is by working with community. In a way it's like collecting their stories, trying to find out the themes and telling the stories so that people can use them."

Gail (BC Centre for Disease Control)

Use needs assessments to get direction from the community

- ◆ Use a participatory process to collect needs assessment information.

"Using a participatory strategy really worked. It worked this time, this well, for the same reasons that it always works - getting people involved right at the ground floor and people having ownership of the information and ownership of the project. They're invested. Plus, when peers are talking to peers, it makes for better and richer information."

Olive (Norther Interior Health Project)

- ◆ Use surveys and focus groups to gather data for needs assessments.

Work with a community advisory committee

- ◆ Make sure the membership of the committee represents the community, and includes people living with hepatitis C, as well as health care and service providers.

Experience: In one group's project, an initial needs assessment recommended the development of an advisory council. The same people who were trained as community researchers for the needs assessment were involved in developing the advisory council's terms of reference, ethical code of conduct, and social contract for appropriate behaviour at meetings. The terms of reference outline the targeted composition of the committee: out of 12 members, 50% plus 1 were to be people living with hepatitis C.

- ◆ Structure the committee operations and meetings so they encourage participation (e.g. include honoraria, regular scheduling, and flexible procedures).
- ◆ As more people go through your program and gain experience and training, there will be a different skill level and level of understanding and willingness to draw on.
- ◆ Ensure that your advisory group represents the scope of your program - i.e. a regional advisory group for a regional project.
- ◆ Involve the community through a review team for any written resources that go out to the public.

Experience: For a brochure on body art and hepatitis C, the review team for one community group included tattoo and piercing artists, a public health nurse, youth, and a person living with hepatitis. Another organization involved 12 different individuals/groups on their advisory committee to develop and vet written materials for youth, including youth living with or affected by hepatitis C, hepatologists, and community and street-level doctors. It was then passed on to a focus group for additional feedback.

Incorporate community development into your work

“Most of the project has been about community development and involving community... This is not something that happens quickly. We know that, but we tend to wonder if it ever will happen. It just takes time and patience and persistence. You can't push anything on anybody - building the relationships, respecting where people are at, providing opportunities, starting exactly where people are at, and moving forward at whatever speed they're comfortable with.”

Deb (Positive Living Northwest)

- ◆ Community development is a process. It's about building relationships and good communication.

“Community building has to go through growing pains or it lacks authenticity. Community development is peer-based and that's what lends it the credibility needed to do things that community-based movements need - like secure volunteers, passionate boards of directors, and the kinds of ideas that work in communities as opposed to top-down public health models that rely on mass vehicles like advertising and radio shows, which are fine, but they lack the authenticity that makes real education happen.”

Eric (BC Collaborative Circle)

- ◆ Work with people to identify what's really important to them and what can be done given the supports available.

Experience: One group's community development project began with advertising in each community (posters and press releases in local papers). This opened up a little awareness around hepatitis C. Public health nurses helped identify people who might want to attend a meeting to identify concerns and issues around hepatitis C. The meeting was an opportunity to air what was happening or not happening in the community and to get some information. A report documenting the results was sent back to those who attended. From that, a second, educational phase of the project was developed.

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- ◆ Make sure you have a manageable scope for your project.

“There’s a saying that has come out of some of the environmental work that’s been done up north: ‘It takes a thousand cups of coffee.’ And that’s how the work gets done. You go and have coffee in people’s homes and you talk about it and you talk about it and you talk about it. If you’re going to do ‘a thousand cups of coffee,’ then you really need to focus on the area you’re going to do it in. That’s a big learning. We were too broad geographically for what we wanted to do.”

Deb (Positive Living Northwest)

Build good relationships

- ◆ Focus on what you have in common. Connections are more readily made and sustained when you share a similar client base, philosophy, or priorities.
- ◆ Community connections may be difficult to make happen or maintain because each agency is focussing on its own clients or working in isolation and doesn’t have the ability to extend itself. Service providers may become disconnected from one another.

“At first I would get offended if people didn’t return my calls, or didn’t remember me, or didn’t know about the project, when I knew I sent them a package. What I realized is that my world is very narrow in some sense, that I serve the population that I serve with a passion, and that everyone else is out there doing the same thing.”

Hermione (AIDS Vancouver Island)

- ◆ Encourage a reciprocal relationship - e.g. “How can I make your job easier and vice versa?”

“You go where they are. You take your message and incorporate it into what they are doing. Don’t own it. Don’t be a gatekeeper. Give them the information and try to get them to partner with you on whatever level they can. Hopefully they’ll start taking the message, but recognize that very often, these are people who don’t have any more room in their day, so by default you become the person to go to.”

Karen (ANKORS)

- ◆ Good communication is vital. It includes simple things like answering messages as quickly as possible or admitting if you don’t know the answer.
- ◆ Expand and build on relationships that your organization has developed through other work in the community.

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- ◆ Organize or attend monthly meetings for community outreach and education workers, as a support network and to let one another know about current work.
 - ◆ Ensure that confidentiality is maintained when discussing clients.

Engage the community in your program

- ◆ Continually look for opportunities to engage and educate people about what you're doing.

“Don't be afraid of controversy. Crisis always makes people more receptive. Don't be afraid of crisis either. Watch for the teachable moments.”

Karen (ANKORS)

- ◆ Incorporate community involvement throughout your program.

“HIPPO attempted to involve the community at each level of the implementation. One of the starting activities was to involve the community in the advisory committee, guiding the project. Similarly, over the project period, individuals from the community have been trained to be volunteer speakers at various speaks and training sessions held by the project and by ARC.”

Navin (ARC)

- ◆ Involve other community agencies and their volunteers in a specific project.

Experience: One group involved 40-50 volunteers to do their needs assessment. They had “hep C blitzes” where volunteers were available all day to help people who came into the office to fill out the assessments. They also filled out assessments for people over the phone. It was a great success because the group didn't try to do it with just a few people. They borrowed volunteers for a day from a variety of community agencies and centres. Health units kept assessments for people to fill out, and doctors gave them to anyone who has hepatitis C positive who came into their offices.

Look at the barriers to community involvement

- ◆ There is a need to find a bigger public forum to challenge people's prejudice and stigma - e.g. community forums and posters with diverse representation. Posters need to be displayed in alternative locations, not just in community organizations where people are already familiar with hepatitis C material.
- ◆ Bring in experts to do presentations in communities where they do not usually have such events. Provide the opportunity for people to come and get trustworthy information.

8. Support

What approaches are effective for promoting, facilitating, and sustaining support groups?
What are some other ways of providing support outside of support groups?

Assess what kind of support is needed

“We have to understand how people that have a chronic disease like hepatitis C actually seek out information and support, so that we don’t go and invent something that they may not ever use. I’m talking about moving from a paternalistic, old-world view of putting stuff together - build it and they will come - to going to them and determining what they’ve already built and where the gaps are.”

Gail (BC Centre for Disease Control)

◆ Recognize the importance of emotional support for people living with hepatitis C.

“People dealing with emotional issues of hepatitis C... If you get them in a room together and they listen to each other for an hour, it’s incredible to see the difference. Some people really relax and think ‘Oh, it’s really not all in my head. These people are all feeling the same thing that I do’...”

Terry (Canadian Liver Foundation)

◆ People infected with hepatitis C may feel that effects like fatigue are not given adequate attention by physicians. Often they’re told there’s nothing wrong with them.

“One of the biggest issues is fatigue. It’s like for people in palliative care, the pain is what the person perceives it to be and tells you it is. People with hepatitis C become very defensive about the fact that when they talk about their fatigue, they get turned off or they get a cursory ‘Yes, now let’s move on,’ when they’re not ready to move on. They need some validation of their fatigue.”

Gail (BC Centre for Disease Control)

◆ Recognize the role of anger.

“There’s a level of anger that hasn’t been addressed. What does it really mean in your day-to-day life? What would it mean to continue carrying this level of anger at something that you may not ever be able to address? What does that mean to your health?”

Deb (Positive Living Northwest)

◆ In some communities and populations, support groups work well.

“That’s what people need at a support group - they need to talk to another person who’s in similar circumstance, who’s walked that road slightly ahead of them.”

Olive (Northern Interior Health Project)

◆ In some communities and populations, support groups are not effective or membership lapses after a time.

“If the group stops having good numbers you can try setting up information tables in busy areas. Offer similar types of information and offer private consultations for those with more complex issues than they are willing to talk about in public. Also have public forums and health fairs. They can reach far more people than a support group.”

Ken (HEPHIVE)

Ensure the elements for a successful support group are in place

- ◆ Support groups need to be facilitated.

Experience: Organizations agreed on the need for support groups to have a skilled facilitator - someone who has specific training and ability around communication, listening skills, and working with emotions, and who can prevent the group from getting stuck in a “pity party”, going off track, or being monopolized by one person.

- ◆ Encourage peer facilitation - if members have received peer support training and are ready for it.

Experience: In some organizations, the support group members were not yet ready to run the support group, but they started to take more ownership of it (e.g. phoning each other with reminders about meetings). They felt a professional or staff person still was needed to keep the group focussed and to provide information and stability (especially as members’ illness, attendance, and commitment fluctuated). In one organization, a steering committee for the support group was elected by the rest of the members, and with staff support, did much of the decision-making about how the support group was run and what happened at meetings.

- ◆ If you can’t provide ongoing facilitation for a support group, look for other organizations that are willing to share the role with you.

“If you partner with other agencies that have a like desire for some kind of support for people with hepatitis C, you can make it work. We’ve partnered with the Liver Clinic, Alcohol and Drug, Mental Health, and the hospital, and now we have a) the location to have support groups meet, b) a free facilitator, and c) the strategy. We’re going to do once a month education/support sessions. We’re all going to take turns, which will mean we’ll each only have to facilitate about three times a year each.”

Kari (North Island AIDS Coalition)

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- ◆ Be clear about the purpose of the support group.

“It’s a support group; they have the right to have a space where they can complain, and it’s ok, because they’re there with other people who understand where they’re coming from. Depression and sadness and pain and tiredness and all the other things that come with chronic illness have to be acknowledged. There’s a whole emotional component, and people have a right to feel upset and angry or whatever. You can’t just have a happy time every time.”

Hermione (AIDS Vancouver Island)

- ◆ Provide the support group with education and access to other resources (e.g. lending library, Internet connection).
- ◆ Include guest speakers with expertise in different areas (e.g. nutrition, dental care, alternative therapies). Focus on one topic per session.
- ◆ Have regularly scheduled meetings with a consistent time and meeting place.
- ◆ Recognize the commitment among members that is required to sustain a support group.

Experience: Organizations reported that often there was one person in the community who worked tirelessly to develop and keep a support group running. Typically it was a volunteer with hepatitis C, somebody who put out information about the group and meeting times, organized meetings, showed up every time, made changes as needed, and promoted the support group through local media.

- ◆ Make sure the support group is based on the local needs of the community, and be aware how those can vary from community to community.

“The telephone survey conducted as part of the interim project evaluation identified strong support for having a group, even by those who did not attend regularly. Half wanted more speakers; half wanted more meetings without speakers. At the last meeting, members discussed ways we could have speakers, with the understanding that the speakers would also be prepared to learn from group members what it is like to have this disease.”

Eleanor (Coast Garibaldi Health)

- ◆ Be willing and able to continually adapt.

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- ◆ Provide opportunities to meet at times that fit people's schedules.

Experience: In one community, the support group moved from having evening meetings to lunch-hour meetings. People were tired after work and wanted to go home; they often lived 10-20 miles out of town. In another community, the support group added a monthly morning get-together in a local café, called "Perk Up" coffee meetings. People interested in attending were told to look for the table with the daisy.

- ◆ Consider that attendance may be only one measure of success.

"If what you're trying to do is provide support then even if someone comes to one meeting and they go away feeling that they were heard and supported, then you've done your job."

Hermione (AIDS Vancouver Island)

- ◆ Continuity may be more important than consistency.

Experience: Some organizations found that continuity of the support group was more significant than consistent attendance by the same people, especially among more transient populations like IDU and street-involved. Some people came regularly for a while, then stopped, but if there was enough overlap, there could still be continuity.

- ◆ Recognize that support groups have their own life span.

Experience: Some organizations reported that support group members identified things they needed that evolved from the original purpose of the support group, including different activities and opportunities for socializing.

Effectively promote your support group

- ◆ Recognize how far word-of-mouth can go and tap into available networks.

Experience: Some agencies found that people heard about their support groups most often from other people (e.g. friend, family, nurse, doctor, or someone in the group), more than through all their other promotional activities combined.

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- ◆ Get information about your support group into as many places as possible - e.g. newsletters (both those produced inside your organization and by others), web sites, pamphlets, posters, information booths at community events or shopping malls, local newspapers, free community service bulletins on radio and cable tv.

- ◆ Be aware of concerns around confidentiality.

“In small communities, it is extremely difficult to ensure a person’s right to confidentiality. If you advertise your group in your local paper with specific times and locations, people will be afraid to come, because they may be seen entering the facility at that specific time. A better way to advertise is to state the existence of the group and a contact name and number of details.”

Katerina (HeCSC Cranbrook Regional Chapter)

- ◆ Encourage referrals from other agencies and promote support groups at professional group meetings and conferences.
- ◆ Include information about the support group in hepatitis C information packages given to everyone newly diagnosed at doctor’s offices or clinics.
- ◆ Provide incentives - e.g. healthy snacks, treats, bus fare for people who need it, milk thistle or vitamins at cost or low cost. These may get people to the meeting the first time, then the information and conversation will keep them coming back.

Support your support group

- ◆ Connect with other support groups in your area to exchange information, ideas, and resources.
- ◆ Connect with other support groups in the province through the BC Hepatitis C Collaborative Circle - for a sense of the bigger picture, contacts with groups in similar situations, and skills that you can put to use in your own communities.
- ◆ Involve support group members in the meetings and conferences attended by your organization.

“Members of the support group have accompanied hep C project staff to conferences on hep C on Vancouver Island since the project began. Project staff report that these conferences seem to have increased members’ interest in carrying on and strengthening their group.”

Eleanor (Coast Garibaldi Health)

Consider alternatives to support groups

- ◆ In both urban and rural areas, there may be reasons why people don't want to or can't attend support group meetings. Confidentiality and anonymity can be an issue in any setting.
- ◆ Set up an online peer support network. It overcomes rural and geographical barriers and ensures confidentiality and anonymity. Provide peer support training for volunteers to facilitate the network and computer training as needed.
- ◆ Develop a phone network for support - e.g. people agree to have their contact information on a list that is distributed among themselves in their communities.
- ◆ Provide one-on-one support.

Experience: Some groups found that more people started coming into their offices to talk about their experiences and to get support because of situations like the provincial disability review and reduction in frontline services.

- ◆ Facilitate ways for people to get support from one another. Provide peer support training and set up informal or formal peer support programs - e.g. a buddy system or a program that reimburses trained peer support counsellors.
- ◆ Include a place for support in your community advisory committee.

Experience: One group's advisory committee usually held its meetings over a meal, which gave them time to talk and do some networking before the business of the meeting.

- ◆ Call "support" something else, such as "information/education sessions".
- ◆ Where people are reluctant to attend a hepatitis C group, set it up as something more general.

"May be hepatitis C doesn't even come up for the first couple of months. Then, as trust is built up, try to focus on living with hepatitis C."

Sheena (YouthCO)

- ◆ A drop-in can amount to a support group that is not advertised or know as that (i.e. if you called it a support group, people wouldn't show up).

9. Stigma

What can organizations do to address stigma in their community and deal with the stigmatizing effects of hepatitis C, addiction, and poverty?

Understand how stigma affects people

“Perhaps the most destructive aspect of stigma is what it does to a person’s psyche when it is internalized. If the message that you are getting from the general public and the people close to you is that you are barely human, at some point, you may come to believe it. When this happens, people get locked into a cycle of self-loathing that contributes to their addiction and the level of safety they engage in while practicing their drug use.”

Jill (VANDU)

◆ Stigma creates barriers.

“It can happen with any group, including the supporters and the providers of services, as well as the people living in communities stigmatizing themselves, hiding with the disease.”

Gail (BC Centre for Disease Control)

◆ There is stigma around how someone got infected and around having the illness, as well as from health professionals towards people who are infected, and from drug companies, who determine who they will let into their drug trials.

◆ Recognize how stigma affects both people infected with hepatitis C and their families.

Experience: One organization member reported one of her children had been told that if their mother had hepatitis C, that meant she was a drug addict. One day the child blurted out, “Are you an addict?” She wasn’t sure how long her child had been carrying around this idea, but it was obvious they were deeply affected by it.

◆ Stigma around drug use compounds the risks around hepatitis C.

“If somebody is an injection drug user, they’re already going to be stigmatized. They’re already marginalised in the community. If they’re afraid they’re going to be further marginalised, are they going to go get tested? If they’re not going to be tested, if they can’t talk about it with anybody, what are the chances that they’re going to be practicing harm reduction? ... All of those things keep people from being able to keep themselves safe.”

Deb (Positive Living Northwest)

◆ People are further stigmatized by poverty.

“Poverty is something that we don’t name enough as something that’s stigmatized. There are so many people in this world who use drugs actively on a regular basis who aren’t poor. Yes, their drug use is totally stigmatized and they hide it, but there’s this whole added thing of living in the Downtown Eastside, living on welfare, using drugs... The stigma of being that poor and being a drug addict manifests in all these really awful ways. People feel they can get away with treating people in the Downtown Eastside really poorly.”

Jill (VANDU)

Address stigma with public education

◆ People experience stigma and labelling through assumptions about how they became infected with hepatitis C, assumptions surrounding both infection through the blood supply and infection through drug use.

“It’s a process of finding a balance between maintaining personal confidentiality and anonymity, while at the same time normalizing the experience of living with a chronic viral infection. It’s also a process of dealing with the general community, gently rooting out unconscious assumptions and fears, and replacing them with accurate information and empathy.”

Ken (ANKORS)

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- ◆ Address people's fears: educate about the risks, who is at risk and who is not, what hepatitis C is, how it's transmitted, and how you live with it. Deal with people's fear about being tested.

Experience: Many groups identified the need for an effective national campaign around hepatitis C with public service announcements directed to a general audience, and then more targeted campaigns for specific populations. There is also a need for a campaign directed towards health care providers, who are often the most overlooked and sometimes the least knowledgeable.

- ◆ Find a public forum to open up talk about what stigma looks like in communities. Talk about drug use and addiction, how people get addicted, and how stigmatizing drug use increases the harm. Overcome public resistance to talking about drugs in schools.
- ◆ When drugs are stigmatized, then people who use drugs are stigmatized, no matter what age. Young people can become addicts as teenagers, but they're afraid to ask for help because of the stigma at that point in their lives.

"Stigma can trigger lifelong addiction in some people. They can become deeply entrenched in their addiction by being unable to cope with what will happen if they come out about it, or by not having an adequate support network. They get further and further away from the point where they could possibly even come out of that addictive state."

Jill (VANDU)

- ◆ Continuously raise public awareness: put on community awareness events and workshops, make frequent public service announcements, advertise your program, do radio interviews, put up posters, and write newspaper articles.

"Reducing the stigma associated with hep C through community education is a slow process which is difficult to measure. However, it was not difficult to realize the enthusiasm generated at our major public forum for this year. Some 49 people attended the presentation on how to look after your liver. The topic attracted many people who would never have come to a talk about hep C, either because they do not have hep C, or they do and are afraid to be identified as having the disease."

Eleanor (Coast Garibaldi Health)

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- ◆ Educate health care and service providers when helping clients navigate the system.

“In the process of advocating for people, you’re also doing a tremendous amount of education, because a lot of times, whoever you’re trying to get help from does not understand the disease.”

Kari (North Island AIDS Coalition)

- ◆ Model accepting behaviour.

“I openly show other people that I’m not afraid of people with hepatitis C. I shake hands, I hug.”

Kari (North Island AIDS Coalition)

- ◆ Use films like the movie “Fix” (which profiled the issue of safe injection sites in Vancouver) to increase understanding around drug use and harm reduction.

“After seeing it, people came into our office. They felt some compulsion to engage. Seeing the layers peeled off the Downtown Eastside one by one helped people understand or sense that these people are human beings.”

Jill (VANDU)

- ◆ Speak on panels and at conferences and use your organization’s profile to educate the public.

“VANDU has also participated as guest speakers on panels and conferences such as ‘Saving Money Saving Lives,’ which carry the harm reduction message to places it may not normally reach (in this case, the private business community). There are many ways to convey the message that drug users are not evil and are human beings. We try to tailor that message for specific audiences to get through the socialized stigma on this issue.”

Jill (VANDU)

Provide safe ground

- ◆ Make your office and meeting spaces as generic as possible. People may fear being stigmatized by just walking in the door or being seen with a staff member.
- ◆ Don't have your organization's name openly or fully displayed if it can be readily identified as a hepatitis C or AIDS organization and it's a concern for people to be identified with it.
- ◆ Locate your office in a building with several other organizations or programs so people could be coming to use any kind of service.
- ◆ Don't locate near highly frequented areas in your community, like the main grocery store.
- ◆ Keep general programs accessible to anyone.

Experience: As an example of what doesn't work, one group told of another organization in their community that, with good intentions, tried to set up a community kitchen. Despite repeated advice not to, they made segregated groups for people with hepatitis C and HIV. No one showed up.

- ◆ A change in context can lead to a change in perspective - try taking people out of their usual setting.

Experience: One group provided retreats for their positive members. They went camping or to retreat centres, and strong and consistent facilitation was provided by someone who was able to let them go where they needed to go. People went from feeling they had nothing in common and divided about how they got infected to feeling like they belong to a community.

"The difference between a flower and a weed is a judgement."

Anonymous

10. Geographical Considerations

What do organizations need to consider when providing programs and services in rural and remote communities? What can be done to make programs and services more accessible?

Appreciate the differences when working in rural communities

“You have to engage in every community. One size does not fit all. You cannot come in like an expert and overlay your truth on a community. Whether we’re talking about a community defined as a town or a community defined as a population, you have to start wherever they are and go from there.”

Karen (ANKORS)

- ◆ Adapt programs and services to suit where people live and how. Recognize the different cultures - i.e. religion, level of conservatism, type of employment, ethnic makeup.

“What works really well for one community is absolutely the wrong approach for another community just a short distance down the road.”

Ken (ANKORS)

- ◆ Ensure that your messages reflect the community. Create materials and public service announcements with people in the community (by them for them).

“I think it’s great to empower rural youth to do this kind of messaging, because it’s all coming from cities.”

Deb (Positive Living Northwest)

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- ◆ Recognize how rural communities differ from urban centres.

“What does rural homelessness look like? What does rural marginalisation look like? Here, it’s pretty hard to be a traditional street person when the street is only 3 blocks long and it’s 20 below zero. It’s a lot more hidden, and it takes more time and trust-building to be able to access people who are at high risk and marginalised. They may be off in the bush, living in a shack somewhere; they may be couch surfing; they may be doing migrant labour and moving around a lot.”

Ken (ANKORS)

Adjust for impact of travel and distance in rural programs

- ◆ Distance, weather, and road conditions, plus available transportation affect clients’ ability to access services and programs.
- ◆ Recognize the impact on the people carrying out rural programs. There may be limited hours in the position, considerable travel between communities, and difficulty coordinating schedules for meetings among service providers.
- ◆ Ensure you have the resources for the area you undertake to cover.
- ◆ If you can’t cover the whole region, focus on one or more parts of the region or network with other organizations for regional coverage.

Look at different ways to connect people with services

“In rural areas, it is imperative that funding is secured for either travel to communities within the area or a collaborative network of individuals who are contact people for their community. A toll-free phone line may be secured for the community to connect with a support person.”

Katerina (HeCSC Cranbrook Regional Chapter)

- ◆ Use technology to overcome barriers like distance and stigma - e.g. telehealth, videoconferencing, web sites with links and resources, or online support systems. It increases clients’ access to services, and it provides opportunities for consultation and continuing education for health and service providers.
- ◆ Where there is a liver clinic or hepatitis C clinic established in a centralized location, ensure there is a “road show” component as well as a “virtual clinic”.

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- ◆ Partner with local community organizations. Let your community partners identify what is needed and work with them to ensure all the details are in place to deliver the workshop or training.

“Because we don’t have the core services that a larger community would be able to rely on, engaging all the service providers and community partners is absolutely necessary. You have to get a core level of knowledge built within the community structure so everyone has some idea of what you’re talking about.”

Karen (ANKORS)

Ensure confidentiality and anonymity

Experience: Groups described how difficult it can be for people accessing services in small communities. There are significant issues of confidentiality within social services, doctor’s offices, hospitals, and policing. For example, someone waiting at the lab in the local hospital likely knows the lab technician and most of the people sitting in the hallway with them, and the nurses walking down the hall discussing a case can be overheard.

- ◆ Educate health and service providers.

“If you have a service that either isn’t appropriate to what your needs are or there are issues like confidentiality, you’re in a very difficult position as a consumer or patient in taking your business down the street because there often is no ‘down the street’. You’re left with some really tough choices on how to deal with it. One of the things we’ve been working on with some limited success is sensitizing health care providers to some of these issues and also issues of working with people who use injection drugs.”

Ken (ANKORS)

- ◆ Be pragmatic. In a situation where making a complaint may result in a physician withdrawing services, and there aren’t other options, try a less direct approach. One way may be to go to lunch with the doctor to explain the program and engage him in it, and eventually address concerns clients have had with his behaviour or attitudes.
- ◆ Educate clients about their rights to confidential and respectful service and support them in carrying out complaints when they want to address them.

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- ◆ Tighten up confidentiality within your office. Use release forms and make sure your information and databases are secure.
 - ◆ Choose a neutral location for your office or meeting places. Be careful about signage - leave out words like “hepatitis C” or “AIDS” from the organization’s name on the sign or don’t put up a sign.

11. Media

What are effective strategies for working with the media to get your message out?

Develop good working relationships with the media

- ◆ Build relationships and network with people in the media.

“If you’re new to the community, call all the newspaper reporters who report on health. Introduce yourself to them and arrange to have a meeting. Create relationships. They’ll call when they hear something or need information. Radio stations, also. You need to become known in the community. You have to make that effort.”

Kari (North Island AIDS Coalition)

- ◆ Understand what reporters need and the pressures they’re working under, and try to be as helpful as you can.

“Let them have the controversy they want, so they can have the headline, and then educate within that particular article. Controversy is not necessarily a bad thing.”

Karen (ANKORS)

- ◆ Stress the importance of your story and share statistical data with reporters.
- ◆ Keep your media contact list up-to-date. Have the right names of the people doing the job and acknowledge whatever they do.

Use free advertising

- ◆ Through your media relationships, you may be able to get free coverage of events or publication of information you provide.
- ◆ Use the free public service announcements that radio and tv stations are required to provide.

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- ◆ Many newspapers have a section for non-profit organizations to advertise free of charge or will let you put a running notice in the upcoming events section.
 - ◆ Use press releases. They are often accepted and printed as submitted.
 - ◆ Tag onto other organizations' events to promote what you're doing.
 - ◆ Make use of national campaigns.

Experience: Groups spoke of the need for an effective national public awareness campaign. They suggested something on the level of what has been done with seatbelt ads, the kind of concentrated messaging that you see every day on tv and billboards and buses.

Know your audience and how to reach them

- ◆ Make messages that your target population will pay attention to.
- ◆ Determine the most effective media for reaching specific populations - e.g. high risk youth are unlikely to access mainstream media; rock stations may be interested in covering youth events.

Use advertising dollars wisely

- ◆ Paid advertising can be effective in reaching a wider audience, but weigh the benefits against the cost and determine whether you can get the word out for less (e.g. through volunteers putting up posters, fax-outs, etc).

12. Fundraising

What fundraising strategies work well for community-based organizations?

Contact community funding agencies and local service clubs

- ◆ Find out the guidelines for funding and fill out applications thoroughly, clearly, and realistically. Submit applications on time.
- ◆ Write request letters for donations for specific projects. Service clubs will often cover the cost of a specific item of equipment.

Put on events that are of interest to people in your community

“You have to look at your community to see what people like to do, what they’re really into. A lot of people will come, even if they’re not totally into what you’re fundraising for, and HIV and hepatitis C aren’t as warm and fuzzy as puppies and kittens. You have to come up with ideas that people enjoy doing anyway. People are going to golf anyway; people are going to bowl; people are going to go catch fish... You’ve got to be creative and you’ve got to know your community.”

Kari (North Island AIDS Coalition)

- ◆ Build on previous events or past successes - e.g. “Second Annual...”
- ◆ Apply to the Gaming Commission to participate in events like bingo and 50/50 draws.

Negotiate outside of dollars

- ◆ In exchange of graphic design work or printing costs for resource materials, offer to put the contact information for the artist or printer on the resource or indicate that it’s been “Sponsored by...”
- ◆ Tell potential sponsors that if they want to tap into a specific community (e.g. youth), your organization gives out hundreds or thousands of these resources

during the year. The material gets out there and it gets around.

- ◆ Collaborate with other agencies whenever possible.

Broaden your scope of opportunities

- ◆ Be aware of opportunities and be ready for them.

“If you see an opportunity, go for it. The fit does not have to be perfect to your program. It might actually help diversify your program and take you in directions you never envisioned in the beginning.”

Ken (HepHIVE)

- ◆ Apply to pharmaceutical companies for funding.

“Don’t be afraid to ask drug companies for support; they have a vested interest in your success. You are getting information out to the community which will lead to them getting more people involved in treatment, which helps their bottom line.”

Ken (HepHIVE)

- ◆ Become know in the community so that promoters needing to partner with a charitable organization to put on an event will choose you.

13. Evaluation

How can community groups measure and assess the work they're doing?
What evaluation tools are effective and easy to implement on an ongoing basis?
What are some success indicators groups can look for?

Incorporate evaluation into your program from the start

- ◆ Make evaluation a part of your work plan.
- ◆ Think out what things you really want to accomplish. Include your decisions about goals and objectives, activities, success indicators, data collection and analysis, and how to use and disseminate the information you collect.

“My idea of good evaluation is that you start in the beginning, at square one, and you think about how you are going to evaluate. Then it's simple. You count things. You talk to the people to whom you're providing service. You talk to them in focus groups, you have conversations, or written if that's appropriate. You collect information from people about how it's impacting their lives. You do that along the way. It's a participatory thing and it's not expensive.”

Olive (Northern Interior Health Project)

- ◆ Evaluation is for the benefit of clients in the program, as well as the organization delivering it. Involve your target populations in all aspects of evaluation and ensure that the benefit is obvious to them.
- ◆ Involve your advisory committee.
- ◆ Share evaluation results with clients, partners, other agencies, funding and potential funding.

Evaluate continuously

- ◆ Use evaluation data to get ongoing direction for your organization and to identify areas for change to meet current situations and needs.

-
- ◆ Make sure your evaluation matches your program. Keep data collection and evaluation questions relevant to your activities and priorities. Modify them as things change.
 - ◆ Implement feedback from a training or workshop immediately into the next training or workshop.
 - ◆ Look for themes in the evaluation information you collect and adapt your program and materials accordingly.

Choose appropriate evaluation methods and tools

- ◆ Make sure the method or tool you use is acceptable to clients and practical to implement.
- ◆ Make sure your data collection methods don't take the focus away from your core activities, disrupt services, or overburden staff.

Experience: Some organizations reported that they had trouble keeping up some of their evaluation activities. They were too complicated, too long, or took too much time. An in-depth questionnaire used by one group was discontinued because it was seen as invasive by the target population.

- ◆ Written methods include evaluation forms, questionnaires, and pre/post tests.

"I may not be able to tell from what's going on in the room, but then I read an evaluation form and it says how great it was or useful it was or wishes that we covered this or we had done more on that... It's so helpful. Then I know if I'm doing a good job or not, and I know what people need or wish for."

Hermione (AIDS Vancouver Island)

- ◆ Where low literacy issues are involved, try using diagrams, photographs, audio/video tape, or story boards.
- ◆ Other non-written methods include focus groups and one-on-one interviews, gauging audience reactions, conversations, and phone surveys.

-
- ◆ There are strengths in both qualitative and quantitative information. Clients get to tell their story and feel heard, and the organization gets information to develop programs and activities.

“People like to hear the story as well as the stats.”

Gail (BC Centre for Disease Control)

- ◆ If one thing doesn't work, try something else.

Experience: One agency distributed a follow-up questionnaire with their resource package, but very few questionnaires were returned. Project staff used phone surveys instead to collect data on the package and other aspects of the project.

- ◆ For evaluation feedback at workshops or presentations, use forms that can be filled out quickly. Try to have a discussion near the end of the workshop to brainstorm on what could be done to make it better and what participants think would work to get more people out in their community.
- ◆ At events like health fairs, to measure attendance, give out numbered tickets for a prize draw. To estimate how many people stopped to pick up information at your booth, count the number of information materials you have on hand before and after the event.
- ◆ Keep a database of the evaluation information and statistics collected.

Determine if external evaluation would be helpful

- ◆ There may be a role for an external evaluator: to provide objective feedback, to obtain responses from partners and clients, and to help come up with realistic work plans and time lines.
- ◆ An external evaluator may have more time to meet one-on-one with people and do more in-depth evaluation than program staff.
- ◆ Develop a relationship with your evaluator. Make sure it is someone you can work well with, someone who suits your organization and who isn't bringing biases with them.

Know what success looks like

- ◆ Determine what the success indicators are for your program and activities:

Presentations, workshops and training

- ◆ The way participants react, when they make decisions and changes in their lives, when you see their progression, or when they get involved in your program as volunteers.
- ◆ New participants repeat things they've heard from others who learned it at previous presentations, so you know that it's being talked about.

Community connections

- ◆ The number of referrals you get from other agencies or requests from more agencies wanting information, visits, training, or help.
- ◆ New projects or areas for collaboration and partnership that open up because of work you've already done.
- ◆ Increased networking of community organizations actively involved in hepatitis C work.

Awareness and education

- ◆ The number of calls and drop-ins to your organization.
- ◆ At the locations where your information is on display, it is accessible, easy to get at, and not stigmatizing for people to go in to pick up.
- ◆ Increased awareness of hepatitis C in the community, including the medical community - clients who come in seem much more knowledgeable after seeing their doctor or public health nurse.
- ◆ Increased demand for more complex information about hepatitis C. Decrease in the number of new/newly diagnosed infections.

Support

- ◆ Clients report that they do not feel as isolated.
- ◆ There is increased attendance at support group meetings.

14. Organizational Capacity

What can community groups do to make their organizations strong and supportive - organizations that work well?

Be realistic about what you can take on

- ◆ When you're in a situation where there is limited time, limited resources, and a big need, you need to focus your time and energy.
- ◆ Identify what you're going to need in order to do something, what you can do with the funding and personnel you have, and where to look in your community for additional support.

"This project and others were developed by listening to what people were asking for, then getting funding from available sources such as Health Canada... This does not mean that you are always able to do what you should, but that you do what you can given the limitations of funding and human resources."

Rae (HeCSC BC Chapter Network Project)

- ◆ Take it one step at a time. You can't create programming alone, overnight, but everything you contribute lays the foundation for future services and programs.
- ◆ Be willing to change and grow.

"It's been a really successful project because we responded to a need and then we were willing to evolve. If I think of the actual number of challenges we had along the way, it could have gone a much different way. I think it was not being afraid to overcome our challenges, not being afraid to think outside the box, not being afraid to eat humble pie, and not being afraid to be firm when we knew that we were doing something right."

Sheena (YouthCO)

Ensure you have the right staff and support them

- ◆ Hire people that fit in with your organization's philosophy and mandate and that will treat clients with respect and without judgement.
- ◆ Provide a supportive environment for staff.

Experience: One organization had high staff turnover in their work around hepatitis C. They realized that if they were going to hire someone living with hepatitis C, then they had to be prepared to put supports in place to make it possible for that individual to be able to do the work while living with this virus.

- ◆ Ensure that there is a supportive environment in your organization. This includes the board of directors who set policy, the executive director who meets with staff and helps them to implement policy, and staff who carry out the work.
- ◆ Provide opportunities for debriefing with other staff or with a professional counsellor.
- ◆ Provide flexibility of hours, especially for front line work and evening shifts.
- ◆ Ensure that everyone on staff is knowledgeable and aware of what each other is doing.

Provide training

- ◆ Give new staff orientation and training to your organization. Ensure there is time for transitional training when someone leaves.
- ◆ Provide ongoing training opportunities for staff to attend workshops, courses, and conferences.

Develop a strong organization

- ◆ Develop a strategic plan for your organization. Include your clients, members, advisory committee, board, and partners, and input from the community.

"Don't get tied into your 3-year goals. Be able to shift on a dime. At the same time, be doggedly determined. Sometimes it just requires a change in tactics and strategies, not necessarily a change in goal."

Karen and Ken (ANKORS)

◆ Foster good organizational leadership and participatory management.

“Understanding the intricacies of project management is important. One should not ignore the need for consistent monitoring, evaluations, and review of plans and strategies, involving all stakeholders as much as possible.”

Navin (ARC)

- ◆ Be clear about roles and responsibilities among your organization’s management, staff, advisory or steering committees, and board of directors.
- ◆ Encourage and value input from all persons involved in your organization.
- ◆ Take care of yourself.

Appendix A

Hepatitis C Community-Based Support Projects

AIDS Vancouver Island

Sponsor Name: AIDS Vancouver Island (AVI)
Project Title: Taking It To The Streets: HCV Guerilla Support and Education In The Trenches
Organization Contact: (250) 384-2366
Project duration: Fiscal years 2000 - 2003

This project worked to develop a network of peer educators who, with the help of a project worker, educated community health and service organizations about the reality of living with HCV and life as an injection drug user. Intended outcomes of this project included increasing the knowledge base of community organizations and assisting in the prevention of HCV infections and improving the quality of life for the IDU/HCV+ population and their ability to access services.

ANKORS

Sponsor Name: AIDS Network Outreach and Support Society (ANKORS) - West Kootenay Boundary
Project Title: The HepC Support and Education Project
Organization Contact: (250) 505-5506
Project duration: Fiscal years 2000 - 2003

The project endeavoured to increase community and individual awareness, to reduce vulnerability, to improve local and regional support and to increase service provider knowledge of treatment, options, support and care needs. This project worked with the Regional Health Authority and established partnerships to facilitate the development of a HCV management committee to determine the scope of the project and to ensure the needs of the HCV community were being met.

ARC

Sponsor Name: AIDS Resource Centre (ARC) Okanagan & Region
Project Title: Hepatitis Information Project Program of the Okanagan (HIPPO)
Organization Contact: (250) 862-2437
Project duration: Fiscal years 2000 - 2003

This project worked to provide the people living in the Okanagan region with a better understanding and appreciation of the nature and effects of HCV through awareness and prevention initiatives and by promoting community-based partnerships for the delivery of education and support initiatives. One of the intended outcomes of this project was to empower persons living with HCV and to improve the quality of life of persons living with or affected by HCV.

BC Centre for Disease Control

Sponsor Name: BC Centre for Disease Control
Project Title: Community Education Outreach Program
Organization Contact: (604) 790-3067
Project duration: Fiscal years 2000 - 2004

This project worked/works to support BCCDC's crucial role in refining and disseminating accurate information in accordance with policy, program and epidemiologic realities in British Columbia. By collaborating with a wide range of professional and public health agencies, a new Provincial Advisory committee and Health Canada's Regional Hepatitis C Reference Group, BCCDC will develop a multi-pronged strategy for public and professional education across the province. This initiative was/is intended to complement and collaborate with other projects that will be developing culturally appropriate educational strategies on hepatitis C for Aboriginal and ethnic minority communities in British Columbia.

BC Collaborative Circle

Sponsor Name: Hepatitis C Education and Prevention Society (HepCBC)
Project Title: The BC Hepatitis C Collaborative Circle
Organization Contact: (250) 595-3882
Project duration: Fiscal years 2001 - 2004

This project created a provincial network (BC Hepatitis C Collaborative Circle) of HCV partner organizations to support and inform individuals and groups throughout British Columbia who are dealing with the effects of HCV and to assist these groups to communicate and collaborate more effectively. HepCBC worked with individuals who contracted HCV through transfusions and intravenous drug use as well as with HIV/HCV co-infected individuals, healthcare professionals and community support workers, and the Aboriginal population.

Canadian Liver Foundation

Sponsor Name: Canadian Liver Foundation BC/Yukon Regional Office (CLF)
Project Title: Living With Liver Disease Program - Development and Promotion
Organization Contact: (604) 707-6430
Project duration: Fiscal years 1991 - 2003

This project augmented an existing CLF program, Living With Liver Disease (a series of educational seminars designed specifically for patients and family members). The project provided educational and resource tools and on-going training and support to CLF's help line volunteers and other volunteers to ensure an excellent understanding of HCV and related issues.

Coast Garibaldi Health

Sponsor Name: Coast Garibaldi Health Services Society
Project Title: Community Hepatitis C Support and Education Project
Organization Contact: (604) 485-8850
Project duration: Fiscal years 2000 - 2003

The project aimed to strengthen and expand the community's existing support and education structure through education of the general public, health care professionals, care givers, and HCV clients and their families, and by building capacity in the local HCV support group to offer more support to those infected, affected and at risk. The project steering committee had broad community-based representation which included Public Health, the Province, First Nations, Drug and Alcohol and the local HCV support group among others.

HeCSC BC Chapter Network Project

Sponsor Name: East Kootenay Chapter, Hepatitis C Society of Canada
(former sponsor: Chapter Hepatitis C Society of Canada)
Project Title: HeCSC BC Chapter Network Project
Organization Contact: (250) 334-2434
Project duration: Fiscal years 2001 - 2004

This project created a network of regional consortia with provincial HCV partner organizations focussing on the effective and efficient sharing of information, skills, support and joint actions to better serve individuals infected with or affected by HCV. This project intended/intends to facilitate training workshops and mentor programs as well as working to enhance communication networks so that the most current HCV information can more efficiently be collected, assessed and disseminated.

HeCSC Cranbrook Regional Chapter

Sponsor Name: East Kootenay Community Health Services Society

Project Title: The Hepatitis C Support, Education Prevention and Awareness Initiative for the East Kootenays

Organization Contact: (250) 417-2010

Project duration: Fiscal years 2000 - 2003

This project undertook a comprehensive range of activities including: public awareness and education about HCV; physician support and information seminars; community-based peer support; and volunteer training to build the capacity of the local chapter. A special feature of this project was the partnership between the Community Health Services Society (CHSS) and the grassroots support group.

HEPHIVE

Sponsor Name: Vancouver Native Health Society (NHS)

Project Title: Coinfection Outreach

Organization Contact: (604) 254-9949 ext 232

Project duration: Fiscal years 1999 - 2003

This project's goal was to increase the knowledge base of injection drug users (IDUs), the community and healthcare providers in the province of BC with respect to prevention, treatment information, and related issues pertaining to hepatitis C and HIV. These activities were intended to improve capacity by engaging professionals and consumers in crafting, delivering and evaluating support services, and give support to those infected with, affected by, or at risk of HCV infection through education and outreach.

North Island AIDS Coalition

Sponsor Name: North Island AIDS Coalition Society
Project Title: North Island Hepatitis C Community Support Project
Organization Contact: (250) 830-0787
Project duration: Fiscal years 2001 - 2004

This project has developed peer support training workshops and partnered with Aboriginal communities to provide culturally sensitive information and support to the Aboriginal population in their region. NIAC also recruited and coordinated volunteers to develop family and caregiver support and education workshops. They distributed summary documents of their needs assessment, peer support training program and other programs to community-based agencies, health care professionals and other primary stakeholders to both share knowledge and achieve sustainability for their project.

Northern Interior Health Project

Sponsor Name: Northern Interior Regional Health Board
Project Title: Northern Interior Health Region's Response to HepC
Organization Contact: (250) 565-7382
Project duration: Fiscal years 2000 - 2003

The goals of the project were to: contribute to the prevention of HCV infection in the Northern Interior Health Region; support those infected and affected by HCV through the identification of needs and the development and implementation of a care and support strategy that meets those needs; and raise the awareness in the community to build the capacity of the region to respond to HCV. This project worked with three partner agencies to conduct a needs assessment, develop an education and training program, and undertake capacity building of the existing HCV support group.

Positive Living Northwest

Sponsor Name: Positive Living Northwest (formerly Bulkley Valley AIDS Society)

Project Title: The North West Regional Hepatitis C Community-Based Support Project

Organization Contact: (250) 877-0042

Project duration: Fiscal years 2000 - 2003

This project worked with people throughout the northwest to develop a strategy to respond to HCV in their individual communities. Elements of this project included workshops, training sessions, and public awareness with the goal of ensuring an ongoing, sustainable response to HCV. Intended outcomes of this project were to contribute to the prevention of HCV infection in the northwest, support persons infected and affected by HCV, and strengthen the capacity of communities' response to the disease.

VANDU

Sponsor Name: Portland Hotel Society (Vancouver Area Network of Drug Users)

Project Title: Hypes for Healthy Living

Organization Contact: (604) 683-8595

Project duration: Fiscal years 2000 - 2003

Vancouver Area Network of Drug Users (VANDU) formed support groups for active injection drug users living with hepatitis C. In this project VANDU provided peer support and engaged in educational activities, skills training and advocacy.

YouthCO

Sponsor Name: Youth Community Outreach AIDS Society

Project Title: HCV Enhancement Project

Organization Contact: (604) 688-1441

Project duration: Fiscal years 2000 - 2003

The Youth Community Outreach AIDS Society (YouthCO) project provided outreach, support and advocacy in the Downtown Eastside for youth co-infected with HIV/HCV and youth at risk of co-infection with HIV and/or HCV. YouthCO also developed educational resources and offered training around HCV and co-infection to youth peers in the Lower Mainland and throughout B.C.

Appendix B

EXPERIENCES AND LEARNINGS DOCUMENT

Your work with those infected with, affected by and at risk for HCV in your communities is highly valued. The following questionnaire was developed with feedback we received from you about your successes and challenges.

Thank you in advance for your generosity in sharing your experiences and learnings.

This questionnaire appears lengthy but please do not feel that you need to answer each question. Please only focus on the questions that are pertinent to your project.

Please consider each of the guiding questions when reflecting on your experiences and learnings. Also identify the context in which you are working (e.g. rural or youth).

Guiding Questions

- ◆ **What did you learn?**
- ◆ **What do you think someone else can learn from your experience?**
- ◆ **What worked well?**
- ◆ **What did not work well?**
- ◆ **What would do differently if you could?**
- ◆ **How did you know it worked?**

Note that many of these questions appear in your final reporting template, i.e. 3.3 Outcomes - signs of progress, milestone accomplishments; 3.8 Lessons Learned. You can use your responses to these questions in this report.

1. OUTREACH

Please share strategies that have worked well with the specific target populations you are working with or trying to reach:

A. Clients:

Street-involved

Youth

Aboriginal

Adults

Marginalized

IDU

Women

HCV infected through the blood system

Coinfected

Corresponds to 3.5 Priority Populations in the final reporting template.

B. Public

e.g. awareness-raising events, health fairs

C. Healthcare Providers

e.g. presentations, educational updates

D. Service Providers

e.g. parole officers, tattoo and/or piercing artists, estheticians

For the following question categories, please refer to the “Guiding Questions” at the beginning of this questionnaire.

2. COMMUNITY INVOLVEMENT

e.g. needs assessment, community engagement, positive or negative responses from the community, participatory research.

Corresponds to 3.6 Partnership and Community Involvement in the final reporting template.

3. PREVENTION

e.g. providing information to specific target group/partners, most and least effective ways of getting the prevention message out, developing and sharing of prevention models.

4. EDUCATION

e.g. tools, peer education, culturally appropriate resources and strategies, sharing learnings/information from conferences and training.

5. HARM REDUCTION

e.g. specific work with clients and healthcare providers, community education.

6. SUPPORT GROUPS

e.g. effective marketing/advertising strategies, encouraging attendance, content, facilitation, other strategies to engage people outside of support groups.

7. STIGMA

e.g. community/public education, dealing with the stigmatizing effects of HCV, IDU etc.

8. ADVOCACY

e.g. empowering clients, navigating the system.

9. SHARING INFORMATION/ACCURACY OF INFORMATION

e.g. specific target populations receiving the information, dissemination, strategies to reach challenging populations.

Corresponds to 3.11 Sharing Knowledge in the final reporting template.

10. MEDIA

e.g. best advertising sources, strategies for working with reporters.

11. EVALUATION

e.g. effective evaluation tools and methods, extracting good information from community groups and clients.

12. PARTNERSHIP

e.g. how to identify partners, how to develop community partnerships and partnerships with funders, conflict resolution/problem solving strategies, overcoming resistance to partnering, advice to groups wanting to develop partnerships.

Corresponds to 3.6 Partnership and community Involvement in the final reporting template.

13. FUNDRAISING STRATEGIES

e.g. venue, time of year, publicity, event, advice for rural, urban or other populations.

14. ORGANIZATIONAL CAPACITY

e.g. hiring employees, training staff, strategic planning, office management.

15. VOLUNTEERS

e.g. recruiting strategies, supporting and sustaining volunteers, training volunteers.

16. GEOGRAPHICAL CONSIDERATIONS

e.g. reaching rural or urban populations, ensuring confidentiality and anonymity, coordinating services.

Final Reflections

- ◆ **What has been the best feedback you have received from a group/person?**
- ◆ **What has been the worst feedback you have received from a group/person?**
- ◆ **Drawing on your experience of things that did not work, what advice would you give to other groups?**
- ◆ **What words of wisdom would you like to share with other groups working with those infected with, affected by and at risk for contracting HCV?**
- ◆ **What stands out for you in your experience?**

THANK YOU!