Perspectives on the Emerging Trends in Services and Funding: A facilitated dialogue

Afternoon session at the 2012 Pacific AIDS Network Fall Conference

September 25, 2012

Meeting notes

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1 PURPOSE OF OUR SESSION

The aim of this afternoon session, held during PAN's 2012 Fall Conference, was to open up a dialogue on the potential move of funders (federal, provincial, health authorities) towards models of service integration (i.e. a blood borne pathogens approach, communicable disease approach, and/or chronic disease approach), and the potential impact on the funding from the AIDS Community Action Program (ACAP), Hepatitis C (HCV) Prevention, and Support and Research Program that a number of Pacific AIDS Network (PAN) member organizations are now receiving. This potential move is a particularly "new" development for the Public Health Agency of Canada (PHAC).

During this session, we wanted to help participants gain a better understanding of this potential move, and share thoughts, experiences and ideas on opportunities and challenges related to this potential outcome. Together, we also hoped to identify information gaps in how AIDS Service Organizations (ASOs) have been responding to this potential move in order to inform future avenues for informal and formal research, and continued dialogue. PAN also hoped to hear from participants how it might best support this dialogue moving forward.

Meeting participants

The following is a list people who were registered for the event, and may not precisely match who participated in this discussion. Approximately 37 people participated in the session, composed of 21 members.

Name	**Position**	**Affiliation**
Lara Barker	Regional Health Education Coordinator, BC	CATIE
Andrew Beckerman	Board of Directors	PAN
Jessica Bridgeman	Street Nurse	North Okanagan Youth & Family Services Society
Jesse Brown	Executive Director	YouthCO
Ken Buchanan	Board of Directors	PAN
Claudette Cardinal	Board Member	Red Roads HIV/AIDS Network
Brian Chittock	Executive Director	AIDS Vancouver
Gay-Lene Collison	Peer Support Worker	Positive Living North
Craig Dales	Executive Director	Vancouver Island Persons Living with HIV/AIDS
Gary Dalton	Care Team	ANKORS
Karen Dennis	Executive Director	Victoria AIDS Resource & Community Service Society

Carlene Dingwall	Coordinator Mental Health, Substance and HIV/HCV	PAN and UBC
Monique Doolittle-Romas	CEO	Canadian AIDS Society
Thomas Egdorf	Regional Health Education Coordinator	CATIE
Michele Frensel	Board Member and Peer Support	ANKORS
Kira Gosselin	Health Navigation/Community Education	ASK Wellness Centre
Kari Hackett	Executive Director	Positive Living Fraser Valley
Ross Harvey	Executive Director	Positive Living BC
Mary Jackson	Executive Director	Northern HIV and Health Education Society
Barry James	Manager, Palm St.	Interior Indian Friendship Society
Ruth Jenkins	Board Member (Outreach)	Afro Canadian Positive Network of B.C
Katrina Jensen	Executive Director	AIDS Vancouver Island
Christie Johnston	Manager, Community Prevention Programs	CATIE
Elayne Vlahaki	Conference Presenter	Reciprocal Consulting
Andrea Langlois	Community Based Research Manage for BC (Acting)	PAN
Darren Lauscher	Board Co-Chair	PAN
Clare MacDonald	Executive Director	Living Positive Resource Centre
Melissa Medjuck	Support Worker and Retreat Coordinator	Positive Women's Network
Sam Milligan	Clinical Coordinator – MASP	Central Interior Native Health Society
Marilyn Morrison	Nurse Educator	Positive Living North BC
David Nixon	Reception Services/Resource Centre Facilitator	AIDS Vancouver
Patience Nyoni	Volunteer	Afro Canadian Positive Network of B.C
Christopher Phillips	Executive Director	Interior Indian Friendship Society

Steven Prentice	Program Coordinator	Positive Living Fraser Valley
Wayne Robert	Executive Director	Health Initiative for Men
Hesham Ali	Board of Directors	PAN
Tsitsi Watt	Manager, Program Delivery	CATIE

Session Agenda: Perspectives on the emerging trends in services and funding

Context and where we are now	
2:00pm	Stacy Leblanc, Director of Program Development, PAN
Experiences with and research on integration	
2:15	Katrina Jensen, Executive Director, AIDS Vancouver Island
	Cheryl Dowden, Executive Director, AIDS Network Kootenay Outreach and Support Society (ANKORS)
	Marcie Summers, Executive Director, Positive Women's Network
3:00	*Break*
Exploring the opportunities and challenges of a potential move towards models of service integration	
3:15	Facilitated small group dialogue
4:15	Sharing some discussion highlights
Wrap-up	
4:30	Closing remarks – Stacy Leblanc
4:45	Evaluation and networking
5:00	Close

2 CONTEXT AND WHERE WE ARE NOW

Stacy Leblanc, PAN's Director of Program Development

"As you have read in the agenda for this session, we want to open up a dialogue on the potential move of funders towards models of service integration. I fully realize that in some cases, primarily with some health authorities, that train left the station some time ago. But with other funders, primarily federal funding, that isn't the case, at least not yet. And while we may have heard some rumblings, we haven't really heard anything concrete at this time.

A year ago, at the request of the Executive Director Summit attendees, PAN conducted an e-survey with member organizations to get a basic snapshot of who was providing services for people living with Hepatitis C virus (HCV) or co-infected with HCV and HIV. We presented the findings at last year's conference. The survey highlighted that the majority of PAN member agencies were delivering services and programs to persons mono-infected with HCV and/or living with HIV/HCV co-infection. The survey did not ask what that level of service was, so in some

cases, it could have been quite minimal. The survey also noted that for many of those organizations delivering HCV service, Harm Reduction was the key focus.

The information from the e-survey wasn't particularly surprising because, over the last number of years at these gatherings, we've heard directly from members about a shift, mostly in regards to HIV and HCV, and less so toward complex models of service integration (e.g. a communicable disease or chronic disease approach), and how their work was changing.

Federally speaking, it's probably where we have the most uncertainty. It is clear that this current administration has a strong focus on "efficiency", and they have made overtures about HIV programming becoming "embedded" in the broader context of health promotion and the social determinants of health. And as recently as a few weeks ago, with the release of the Project Continuation Funding for Non-Reserve First Nations, Inuit and Metis Communities HIV/AIDS Project Fund, we understand that they started an information conference call by saying, "In 2014, we will be implementing an integrated communicable disease model."

So while we have concrete information on the direction of some agencies, for example, regions that have been mandated by their health authorities to do at least some form of HIV/HCV integrated work, for other agencies, it's not quite as clear.

Given the trend toward models of service integration, PAN's goal with our session this afternoon is get the conversation ball rolling. And this is by no means the be all and end all of our dialogue. While we recognize that face-to-face time is a challenge for all of us since we only meet in-person as a large group once a year, we're hoping to hear from you this afternoon about other opportunities for dialogue we could develop. And we have a few ideas knocking around in our heads, too.

At the end of our session today, we hope to have a wealth of information generated by our dialogues that we will take back to our office, spread out across the meeting room table, analyze, and then lay out a plan for the next several months. I'm looking forward to a very productive and lively afternoon, and really looking forward to bringing back this information to report back to PAN's Executive Director Evin Jones."

3 EXPERIENCES WITH AND RESEARCH ON INTEGRATION

Three PAN member organizations with experience in or research on service integration were invited to participate in a facilitated "coffee table" style discussion in front of the other session participants. The three organizations were AIDS Vancouver Island, AIDS Network Kootenay Outreach and Support Society, and the Positive Women's Network.

Below is information on the three organization's work related to service integration, followed by a record of the facilitated discussion.

3.1 Related work of the three organizations

Following is information on work related to service integration carried out by each of the three organizations invited to participate in the facilitated discussion.

AIDS Vancouver Island

Integrating HCV prevention and support into services at AIDS Vancouver Island

- The numbers of people living with HCV on Vancouver Island are far in excess of the numbers of people living with HIV.
- Aids Vancouver Island (AVI) had run the primary needle exchange service in Victoria since 1988, and so HCV was already a significant issue for many of our clients.
- We received funding from Health Canada around 2000 for a peer education project specifically targeting people at risk of, and living with HCV. We also received funding from the Ministry of the Attorney General to run HCV peer education in the provincial jail.
- The Vancouver Island Health Authority (VIHA) began consultations with community members in 2004 to develop a new island-wide HIV strategy. When it was released in 2006, VIHA asked HIV contracted agencies to add HCV services.
- In 2004, AVI was asked to assume responsibility for services in three communities in North Vancouver Island. Services in these communities were already integrated, and the majority of their work was HCV related.
- AVI developed a strategic plan in 2008/2009, which included changing our mission statement to include HCV prevention and support.
- We continue to have a PHAC-funded HCV project, but this is our only dedicated HCV funding.
- Our Education programs were already relatively integrated.
- Our Positive Wellness program for people living with HCV had been providing advocacy and support for people for several years, and over the last 2 years, we have integrated the programs further.
- Challenges we have faced with integration include having to provide HCV services with little or no increase in funding, while ensuring that people living with HIV don't lose access to services as a result. Many of our HIV clients were worried that they would lose services if they were extended to people living with HCV. Staggering integration and ensuring open and clear communication about changes helped mitigate this challenge.
- Opportunities in the move toward service integration include being able to provide dedicated services to a group of people who had not had access to appropriate services before. Many HCV organizations, where they do exist, were not set up to accommodate people who are using drugs by injection. AVI has had the chance to provide accessible and dedicated services.

AIDS Network Kootenay Outreach and Support Society (ANKORS)

AIDS Network Kootenay Outreach and Support Society's experience with the integration of HIV and Hepatitis C (HCV) programs

- AIDS Network Kootenay Outreach and Support Society (ANKORS) is a regional organization serving the East Kootenay, West Kootenay, and Boundary Region of BC. ANKORS has offices in both Nelson and Cranbrook.

- ANKORS mission is: a) to respond to the evolving needs of those living with and affected by HIV/AIDS, Hepatitis C (HCV) and other blood borne infections; and b) to foster healthy, informed communities.
- ANKORS has championed the cause of serving people infected with HCV since the 1990s. In 2000, we were successful at obtaining Health Canada funding to undertake a three year project that provided advocacy, education, outreach and prevention HCV programming. The coordinator, Ken Thomson, was hired, and the HCV project gained momentum and became successful. Unfortunately, in 2003, Heath Canada directed monies for HCV programs elsewhere, and the project at ANKORS ended.
- From 2003 to 2009, ANKORS struggled to meet a threefold demand for HCV services within existing resources. In 2005, ANKORS hired a consultant, Evelyn Riechert, to develop a strategic plan for ANKORS that addressed the role of the organization and approaches to be taken to best meet the needs and priorities of HCV in the region.
- In 2009, ANKORS received PHAC funding under the HCV Initiative, for a HCV Project in the East Kootenays.
- ANKORS currently holds a contract with PHAC to provide HCV Services in the East/West Kootenay and Boundary Region until March 31, 2013.
- In 2011, ANKORS changed its mission statement to include Hepatitis C.

Positive Women's Network

AIDS Service Organizations in BC: Still relevant? A small research project

In the spring of 2012, the Positive Women's Network (PWN) undertook a small research project funded by the Canadian Institutes of Health Research (CIHR) Centre for Research Evidence into Action for Community Health in HIV/AIDS (REACH). The goals of the research were to assess the climate of HIV services in BC and to look at the possible impact of a shift toward a communicable disease model.

The project coordinator attempted to interview seven ASOs, and successfully reached five organizations. Of those five organizations interviewed, some organizations cater exclusively to people living with HIV/AIDS (PHAs) and others provide services for those infected with HCV or who are co-infected. Either Executive Directors or Program Coordinators were interviewed. The participants were sent a series of questions beforehand.

<u>Summary of findings</u>

- Most ASOs serving wider populations did so due to service demands, rather than from pressure from funders. This was especially true in rural areas.
- Vancouver groups were more resistant to integrating HCV into their mandate: due to higher demand, HIV prevalence rates, and greater funding, urban organizations can provide more specificity in service delivery.
- The major concern is that there is insufficient funding to accommodate such a shift toward service integration.
- An opportunity pointed out was that expanding beyond HIV would provide more funding opportunities.

3.2 Discussion with the organizations

Following are highlights from the "coffee table" style discussion which took place in front of the session's participants. Taking part were Katrina Jensen from AVI, and Marcie Summers from the PWN. Cheryl Dowden from ANKORS was unable to attend. Peter Abrams facilitated the discussion.

Katrina: (providing an overview of AVI's integrated work) AVI ran a needle exchange program since 1988, and started an HCV peer education project with Health Canada funding in 2000. Later, after regionalization, the VIHA developed a plan that included HCV. While there was no additional funding provided for this, AVI developed a strategic plan that included integrating HCV into our services. For some areas it was straight forward, for example, our education services had long included HCV in workshops and other prevention activities. For our HIV positive client services, we used a more gradual approach.

Peter: What were some of the opportunities you took advantage of?

Katrina: There were a large number of clients who were living with HCV that we were already seeing. These were clients who were not getting their needs met. As well, in 2004, VIHA had asked us to take over the HIV organization in North Vancouver Island. Services ran out of these offices were already completely integrated. This provided a model for the South Island.

Peter: And what are some challenges you've been facing?

Katrina: There is not enough funding. Also, while there are some similar issues between HCV and HIV clients, there are also some differences. So, there was a concern that services would be taken away from others and we'd be overwhelmed. But that hasn't happened. However, a funding shortfall has not allowed us to provide similar services in some areas. We still don't have any additional funding. We did it because it was the right thing to do.

Peter: When you assumed services in North Vancouver Island, was there a challenge with joining organizations with different cultures?

Katrina: It's not a one-size-fits-all approach, and that's the main thing. We look to see if it serves us to work together.

Peter: What was the importance of your strategic planning process in your move to service integration?

Katrina: It gave us a structure for dialogue and a place to come back to, to report on what was accomplished and to identify gaps.

Peter: Thank you, Katrina. Marcie, tell us about PWN's research project.

Marcie: There has always been a great resistance to combining the services. We had a very small research project where we were to ask 7-10 ASOs about integrating services to get a sense of the climate around this shift. 5 interviews were completed. The summary of our findings are:

- The shift to integration was resulting from a demand for services from clients or members, rather than a demand from the funders;

- Vancouver groups were a bit more resistant to integrating HCV into their mandate: due to higher demand, HIV prevalence rates and greater funding, urban organizations can provide more specificity in service delivery;
- The communicable disease model had the most resistance;
- There is an increased client base;
- There is an increased need for more community networking

A key message from our research is that, if the shift is to take place, ASOs want to be included in the conversation.

There is an opportunity here in that stigma could decrease: HCV has a different kind of stigma than HIV, but it's there. There is an opportunity to discover their commonalities.

PWN has applied for more money to carry on more research.

Q & A with participants

Comment: My question is, with an integrated approach, where do we cut this off? This could mean looking beyond simply HCV, for example, TB or all Sexually Transmitted Infections (STIs)....should they be considered and included in our service mandate as well?

Question: Has AVI changed their Board composition or mandate?

Katrina: AVI has not sought to change our constitution or composition on the Board, but that is on the agenda. We've gone through many discussions around potentially changing our name. Our current name is staying for the time being, even though HCV folks are not included. Another concern is that some people don't want to come to an organization for services that has "AIDs" in the title.

Peter: How did you face the challenge of training your staff on HCV?

Katrina: We had a staff person who was an incredible resource in terms of HCV-specific training. In general, we need to find more funding and be creative about our use of funding. We have taken a gradual approach to integration. For example, recently we opened up our provision of hot meals to those with HCV, too. Models for communicable disease versus chronic disease are not necessarily set in stone.

4 EXPLORING THE OPPORTUNITIES AND CHALLENGES OF A POTENTIAL MOVE TOWARD MODELS OF SERVICE INTEGRATION

After the discussion with AVI and PWN, session participants formed 5 facilitated breakout groups to explore opportunities and challenges of a potential move towards models of service integration. Key ideas and comments – captured on flipcharts by group facilitators – are presented below according to each group, followed by some key opportunities and challenges as selected by each group.

4.1 Breakout group discussions

Each breakout group responded to the following question:

What are the opportunities and challenges of this potential move towards models of service integration for our agencies, and our communities?

Below are the responses by breakout group, captured as bullet points.

Group 1

Opportunities

- Reduce costs – building access to services
- Educate others on HIV so others can learn and reduce stigma
- Normalization
- Educate ourselves on another illness
- More dollars for sexual health and harm reduction education
- More opportunities for fundraising
- Utilize funding re: HIV and HCV
- More people engaged with the related topics
- Options for Sexual Health – Provincial Program
- Clients may be more comfortable around disclosure
- Opportunity for anonymity
- Safety for clients
- Importance is that we're doing something important with dollars despite funding mandate.

Challenges

- Time/quality/funding
- Accountability regarding deliverables
- Mission drift regarding support services
- Cure versus treatment
- HIV related social issues such as disclosure, dating, treatment/no cure, confidentiality, stigma
- Stigma: different challenges faced by HIV and HCV groups
- Doing HCV justice: people don't find it as interesting or care. HCV education is complex
- Neither group's individual needs will be met
- Tensions arising from long-time members who feel their services and safe zone are being encroached upon

- Too broad education scope instead or being kept up to date on HIV
- Additional need and resources for staff training on HCV
- Doing more with less because of government directive: where's the breaking point?
- Culture of fear because of pressure from funders
- Diluting the message and the AIDS movement
- Disconnect from the importance of the history.

Group 2

Opportunities

- Leadership and expertise
- Community development
- Community-based research
- Community expertise
- A unity of services with specific programs
- ASOs have significant expertise to share, especially in working with marginalized populations
- There are some commonalities, especially between HIV and HCV
- It may reduce HIV stigma in the minds of non-positive people who come into contact with positive people
- Stigma reduction in the long term
- Outreach support workers for individuals on HCV treatment who may be isolated
- Prevent HCV infections with specific programs, supports and education
- It will contribute to reduced health care expenditures, enabling a tax cut (to be enjoyed disproportionately by wealthy people).

Challenges

- Funding
- Integration of what?
- HIV needs to maintain its autonomy: 'fear' of losing HIV exceptionalism and focus:
  - Gay men
  - Criminalization
  - Grassroots involvement
  - History of the movement
- Grassroots philosophy and values at risk
- Legal implications, for example, for charitable organizations, bylaws, etc.

- People living with HIV face difficult and distinct challenges, for example, stigma
- Potential reduction in HIV+ members participating due to new non-HIV members accessing "their services"
- Integrating services and providing services across greater #'s of people means existing resources are spread even thinner resulting in reduction of services/resources presently available for HIV+ people (i.e. Positive Living's Complementary Health Fund, spaces at retreats, etc.)
- Reduction of "attractiveness" for HIV+ people concerned about confidentiality
- HIV is a social issue
- Bringing in education and skilled persons to deliver both HIV and HCV services
- Skills and staff support
- Value and commitment to all members equally by providing specific support and programs
- Rolling this out provincially: there are immense differences within the province with respect to geography and population.

Group 3

Opportunities

- Access to broader range of funding sources
- Opportunity to deliver multiple prevention messages (STIs/HIV)
- Increased skill sets of service providers might help HIV move into mainstream health services and out of the ghetto
- Increase confidentiality, because walking in through the door no longer means the individual is HIV+
- Increase knowledge
- Community building through a better understanding of the community needs
- More diverse membership = diverse funding opportunities.

Challenges

- Top down directive versus the grassroots history of the HIV movement
- Confidentiality issues
- Diluting the message
- Stretching resources
- Difficult for staff to know where to focus their limited time for learning
- Can alienate some clients who feel HIV+ persons deserve their own dedicated service
- Could overwhelm smaller organizations
- Resistance from clients.

Table 4

Opportunities

Clients

- More opportunity for care of patients
- Better Biomedical service
- One-stop services for people who are co-infected
- One-stop shop for multi-challenged clients
- Flexibility and adaptability.

Community

- Larger voice
- Greater understanding of the complex needs of clients
- More community relevance
- Better able to serve the needs of the community
- Ability for clients to network with peers.

Organization

- Minimize operational costs
- A chance to move from a 'disease perspective' to a 'marginalized/inclusive perspective', i.e. a whole person approach
- Sustainability as an organization.

Challenges

- Alienating /pissing off those who believe the agency is only for them
- Clients reluctant to be "lumped" together – may impede service delivery
- Integrating services with respect to virus-specific funding streams
- Complete revamp and renewal of funding streams
- Funding pots and dividing monies to different clients
- Mixed clientele with unequal prosecution under the law
- Inappropriate use of services by greedy clientele
- Keeping appropriate services with appropriate clients (service envy)
- Functional disparity for "disease specific" organizations
- Organizational management issues – serving different populations well
- Training infrastructure, leadership, smaller agencies absorbed by larger entities
- Losing sight of the mandate

- Educating Service Providers
- Having staff know how to deal with multiple problems, i.e. doctors, nurses, peer group.
- Broadening the knowledge, skills, networking, capacity
- Larger case load
- Burnout.

Table 5

Opportunities

- Meeting the needs of “at risk” populations
- Smoother continuum of care
- Address routes of problems, i.e. Harm reduction
- Dealing with newcomers, broadening base of support
- Opportunities to reduce stigma
- Opportunity for staff and clients to increase knowledge
- Potential increased funding opportunities
- Potential for restricted funding guidelines to expand
- Bigger voice at the table.

Challenges

- Funding
- Limited resource base, i.e. HCV donors
- Program integrity – general services versus specialized
- Spread too thin
- Silos
- Victim of our own success
- Losing the AIDS voice
- Discrimination
- Culture
- Language
- Disclosure
- Abuse and isolation, especially in women
- Criminalization
- Organizational capacity
- Physical space capacity: hitting limits due to client growth.

4.2 Some key opportunities and challenges from the breakout group discussions

At the end of the discussion period, breakout groups selected a few key opportunities and challenges to share in plenary. These have been combined and are listed below:

Key Opportunities

- Reduce stigma in the long term
- Build community expertise
- Access broader and more diverse funding opportunities
- Offer a more encompassing prevention program, i.e. includes STIs, HCV
- Address social determinants of health
- Offer more services under one umbrella for the client and the community
- Greater anonymity since there are more services under one umbrella
- Have a bigger voice at the table.

Key Challenges

- Sufficient funding and stretching of resources
- HIV disclosure
- Social issues such as dating
- HIV losing its autonomy, identity, and exceptionalism
- Losing sight of the mandate
- Losing the AIDS voice
- Rolling this out provincially: there are immense differences within the province with respect to geography and population.

5 SUGGESTIONS FOR HOW PAN CAN KEEP THIS DIALOGUE MOVING FORWARD

Each of the 5 facilitated breakout groups also generated suggestions for PAN as to how best to keep a dialogue on this topic moving forward. Following are the suggestions, combined and organized by key potential roles:

Advocate

- More advocacy for ALL people living with HIV. Launch an Anti-stigma campaign
- More advocacy on keeping ACAP or something similar
- More community work with ACAP
- Advocate to keep certain services HIV+ only so that some sense of identity is preserved
- Make our work visible – HIV is being addressed because of our work

- Community engagement and giving voice to the community
- Involvement of external partners in process (include their voice)
- Work with friends (champions) in the media and community to have community's voice heard
- Seek buy-in from grassroots, politicians, and bureaucrats.

Provide information and facilitate dialogue

- Share urgent information as it becomes available, including getting clarity on the issue of a move toward service integration from PHAC, ACAP, health authorities and the provincial Ministry of Health
- Keep members updated periodically, for example, a monthly executive update
- Keep current with what's happening in the province
- Provide opportunities for more informed dialogue
- Keep making this a topic at PAN events: keep this on the agenda for future discussions
- Create a continuum of strategies for ongoing dialogue (blogs, webinars, and discussion groups)
- Facilitate a discussion with HCV-specific organizations
- Educate both client types to be more informed
- Integrated communications: similarities of issues, how we are the same, cross over issues
- Maintain communication with natural partners to keep well informed
- Facilitate critical thinking
- Provide professionally development training on related issues
- Present counterarguments for membership
- Show that it is not in anyone's best interest
- Challenge the suggestion – Just say No
- Question the validity of combining services
- PAN has to buy-in first

Support research and development of tools

- Facilitate more research, e.g. a survey of ASOs
- Provide strategies and measures to assist with the transition
- Provide members with direction on how to change founding principles and manage practicalities.