



Exploring the Landscape of Communicable Diseases in Atlantic Canada

SUMMARY REPORT, April 2014

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A NOTE ABOUT THE COVER ART

Photo source: <http://thescentedhound.com/2013/11/11/finisterre-noir-tropical-by-maria-candida-gentile/>

Photo inspiration:

Quote from a participant: *“There is a need for the local groups... before moving forward with the deadline of 2017, there is a need for everybody to put their clothes on the line. Everybody, hang out what you are doing and let’s see what’s on the line...this is our opportunity to hang it all out. Let’s see what we’ve got.”*

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ACRONYMS AND ABBREVIATIONS

ACB	African, Caribbean and Black people
AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy
ASO	AIDS Service Organization
CBO	Community-Based Organization
ED	Executive Director
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer and/or Questioning
GIPA/MIPA	Greater/Meaningful Involvement of People with HIV/AIDS
HCV	Hepatitis C
HIV	Human Immunodeficiency Virus
IDU	Injection Drug User
NEP	Needle Exchange Program
PHA	People living with HIV/AIDS
PWID	People Who Inject Drugs ¹

1 BACKGROUND

Exploring the Landscape of Communicable Diseases in Atlantic Canada was a collaborative and consultative investigation into the current state of HIV/AIDS, HCV and other STBBIs, affected populations, and associated service delivery needs in Atlantic Canada from the perspective of community-based organizations and the people who access their programs, services and supports.

The purpose of this document is to provide a summary report of some of the key results of the *Exploring the Landscape of Communicable Diseases in Atlantic Canada* project. The full report can be found on the AIRN website (<http://www.med.mun.ca/airn2012/home>).

The objectives of the project were:

1. To identify the current and emerging needs, key issues, and gaps in the area of services provided to populations living with communicable diseases—specifically, HIV/AIDS, Hepatitis C, and other sexually transmitted and blood borne infections (STBBIs)—in Atlantic Canada.
2. To generate evidence to guide decision-making concerning how organizations serving these populations might position themselves to provide effective and efficient services to those most affected in the region into the future.

2 METHODOLOGY

This project was a community-based initiative led by the Atlantic Interdisciplinary Research Network for Social and Behavioural Issues in Hepatitis C and HIV (AIRN) with ongoing input and feedback from all partners via a Community Advisory Committee (CAC), who were also members of the research team. Community partners collaborated in all aspects of the project, from planning to implementation and analysis, and knowledge exchange.

We conducted 33 face-to-face interviews (13 Executive Directors or Project Leads of PHAC funded organizations, 8 staff members of organizations which partner with PHAC funded organizations, and 12 service users or project participants) and four focus groups (former and current sex workers; people who inject drugs; Aboriginal people living with HCV; and gay men living with HIV).

In addition to extensive consultation, we also undertook a thorough examination of regional surveillance data, prevention and support programming and research. The document review included the PHAC funded organizations/projects' required reporting tool (PERT) and publicly available surveillance reports. Additional selected sources included published academic and grey literature, including community-based publications from various partners across the Atlantic region and from national level organizations.

3 HISTORICAL CONTEXT

“In the beginning, it was such a powerful movement. Like it was started by PHAs, for PHAs, by PHAs. And it was such a powerful movement in a group of people that were shunned. And it could have a lot to do with just the gay rights movement. It came on at the same time. A lot of it did cycle together.”

Whereas HIV was once characterized as a catastrophic illness afflicting gay men, it is now considered to be a chronic, treatable condition occurring at increased incidence rates in a range of population subgroups: bisexual, two spirit, queer, and men who have sex with men, people who inject drugs, youth at risk, sex workers, Aboriginal peoples, women, people in prison, transgender people, and people from countries

where HIV is endemic. Hepatitis C first came to light among people infected through the blood supply, but now is increasingly prevalent among people who inject or smoke drugs or engage in high risk sexual activities such as sex with multiple partners.

AIDS service organizations have traditionally been the backbone of the front line response in the Atlantic region, both in terms of influencing the government response, and in implementing it. In the Atlantic region we are faced with unique challenges: four provinces; two languages (French and English); diverse ethno-cultural populations; geographically dispersed populations including aboriginal communities, francophone communities, and rural communities; socio-economic hardships such as high unemployment and poverty.

The early movement was led by the population most affected—gay men responding to the catastrophic illness of HIV/AIDS in the 1980's.² The response over time has been shaped by such positive forces as resilience, asset based strategies, and peer-based models of support. Guiding principles such as the Greater Involvement and Meaningful Involvement of People with HIV and AIDS (GIPA/MIPA) have supported the involvement of those living with HIV in decision making and policy making. In contrast, the response to HCV has not been as high profile, nor shared the same history of engagement. One of the ways that service delivery has changed within ASOs is personnel increasingly being comprised of paid employees, rather than mostly being comprised of PHA peers. This shift has been described as “professionalization” of the HIV sector.

4 HIV AND HCV EPIDEMIOLOGY

From 1985-2012, a cumulative total of 1509 positive HIV tests (all ages) were reported from the Atlantic region (NL: 273; PEI & NS: 817; NB: 419). Across all of the four Atlantic Provinces together, an annual total of 32 positive HIV tests (all ages) were reported during 2012, which is approximately a 10% increase from 2011 when an annual total of 29 positive HIV tests were reported in the region.³ That said, for the reporting period 2004-2012, the Atlantic Provinces' annual rates of positive HIV test reports (all ages) were the lowest of all the Canadian provinces.⁴

Using the Public Health Agency of Canada priority population classifications, people who have tested positive for HIV in the Atlantic region have predominantly identified as men who have sex with men (MSM; gay, bisexual, two spirit, transgender, queer), followed by people who have experience using injection drugs (PWID), and heterosexual sexual contact with a person from a country where HIV is endemic or sexual contact with a person at risk. Men who have sex with men (MSM: 79%) continues to be the dominant exposure risk category in the Atlantic provinces as reported in 2012,⁵ though it is believed that cases identifying injection drug use as the primary exposure risk have been under-reported in the literature.⁶

There has been no clear regional trend in the number of HCV cases reported in 2005 and again in 2009 (NL: + 7.1%; PEI: -18.6%; NS: + 12.0%; NB: - 27.9), with a cumulative total for the region of 648 cases reported in 2005 and 600 cases reported in 2009 (- 7.4% for the region). Though the HCV rates (per 100,000 population) were below the national average both in 2005 and 2009 for all Atlantic provinces,⁷ the HCV rate change (%) from 2005-2009 was above the national rate change (-16.6%) for NL (8.6%) and NS (+12.0%), and below the national rate change (-16.6%) for PEI (-20.3%) and NB (-28.0%).

5 STIGMA AND DISCRIMINATION

Stigma and discrimination weaken the ability of individuals and communities (particularly those from criminalized and marginalized populations) to protect themselves from HIV or HCV and to stay healthy if they are living with HIV or HCV. Although great gains have been made in reducing HIV-related stigma and discrimination, there is still lingering and entrenched social devaluing of people who are living with or

vulnerable to HIV and HCV. Throughout the interviews and focus groups, stigma and discrimination was a ubiquitous experience reported by people living with HIV and HCV. The people from most-affected populations explained that they are judged and mistreated by society on the basis of being gay, transgender, working in the sex trade, living with addictions, living with HIV, living with HCV, having involvement with the criminal justice system, living with poverty, and living with mental illness. Unfortunately, a common source of this stigma and discrimination is health care or social service providers.

5.1 GIPA/MIPA and Nothing About Us Without Us

As a response to the pervasive and ubiquitous stigma and discrimination experienced by people at risk of and living with HIV, clear principles grounded in human rights have been developed. GIPA stands for the Greater Involvement of People Living with HIV/AIDS and aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. Likewise, the principle of “Nothing About Us Without Us” calls for the greater, meaningful involvement of people who use illegal drugs as a public health, ethical, and human rights imperative.

The level of engagement of PHAs has changed as the HIV/AIDS movement has evolved. While PHAs were instrumental in starting up and running ASOs in the early days of the HIV epidemic, their involvement has dropped off as their ability to “get on with life” improved, and as HIV has come to be experienced more as a chronic manageable disease:

“I am thinking back 17-18 years ago, PHAs were very involved. They were the voice. They were our presidents, our treasurers, our secretaries...they were our ever-present volunteers. They were here and they are not here now. Sadly, we have lost some. But on a happy note, they have moved on with their lives.”

The challenge of engaging PHAs in the activities and governance of the ASOs is that some PHAs are either independent and not reliant on ASOs for support, or don’t have the capacity to volunteer with the ASOs. Some interview informants felt that GIPA principles are outdated and belong to the old reality of HIV/AIDS as a catastrophic illness with common abuses of human rights. Other critique regarding the current relevance of GIPA/MIPA principles in ASOs is that there is lack of engagement of “new PHAs” (newly diagnosed PHAs, younger PHAs), women, immigrants and ethnic minorities, and lack of meaningful volunteer opportunities.

6 WHAT IS THE LAY OF THE LAND?

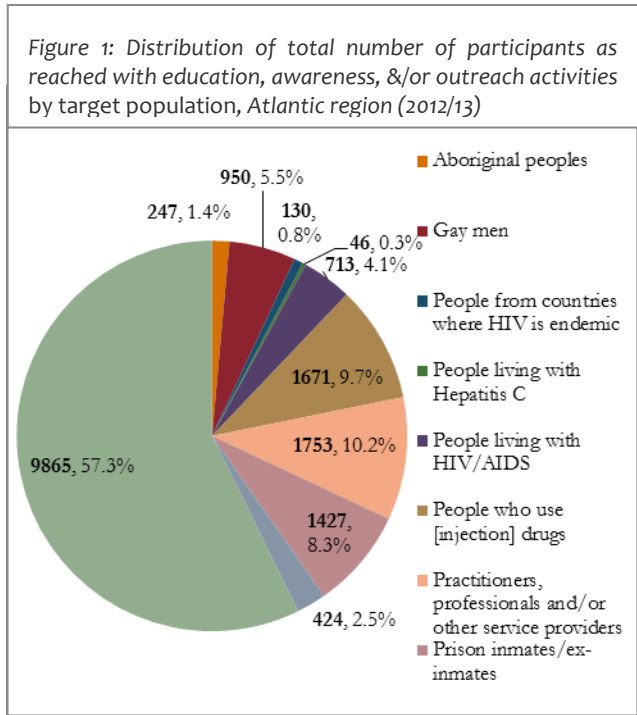
6.1 Service Delivery Models

The PHAC funded organizations and their partners described a wide variety of service delivery models that they have found to best meet the needs of their client populations. Inherent in these service delivery models are two value based approaches: a **client-centered** orientation and providing **culturally appropriate** supports and programs. Client-centered service provision is designed so that the person is at the center of the network of services that are set up to meet their broad range of individual needs. According to some of the interview informants, this means: providing an open door approach; being consistent and reliable to clients; building rapport and learning from clients about their concerns; creating a safe space; providing education through workshops and providing childcare. From the client perspective, a client centered approach is discreet and respects privacy; is easily accessible with appropriate hours; and provides a good support network of helpers. Informants also described Low Threshold Services as programs which remove barriers to clients, have tolerance around behaviours that might be deemed disruptive in other settings, and accept relapse as part of the recovery process.

In the context of HIV and HCV services, “culture” can include ethno-racial culture (e.g., Aboriginal people), sexual orientation (e.g., LGBTQ safe spaces), and drug addiction. Culturally appropriate services, as described by interview informants, are: open door policy that doesn't discriminate - *“Every door is the right door. No matter who you are, you come in”*; incorporating cultural ceremony; staff who have lived experience; and spaces which are respectful, non-discriminatory and free of judgment.

The array of services currently offered by PHAC-funded organizations include:

- **Access to Treatment and Primary Health Care:** relationship and trust building so that PHAs feel comfortable talking about their lives and HIV; providing support after diagnosis and maintaining contact with clients with frequent follow up visits; using collaborative and multidisciplinary teams; providing access to treatment in the community by health professionals to help facilitate adherence; helping clients navigate the system; crisis intervention and crisis counselling; referrals to other services.
- **Mental Health and Addiction Counselling:** helping clients cope with the anxiety, depression and in some cases, suicidal ideation that can come after an HIV or HCV diagnosis; helping clients with the mutually reinforcing challenges of mental illness, addictions and homelessness; provision of counseling, harm reduction and methadone services.
- **Case Management:** approaches where the community response focuses on individual needs, through mechanisms such as multi-disciplinary case management teams, giving individuals access to holistic services and supports that promote their general health, including reducing their vulnerability to HIV.
- **Drop-In:** creating friendly environments for clients to visit the agency whenever they want and for as long as they need to stay; a place to come in out of the cold, to eat, to shower, to get support free from judgment.
- **General Health Promotion:** focus is on meeting individual needs from a holistic perspective (addressing overall health and well-being), and assisting individuals with their needs across a range of determinants of health; collaborative and interdisciplinary teams working to address prevention (HIV and HCV) and building support for general health issues (e.g., sexual health, healthy sexuality, nutrition and diet).
- **One-Stop Shop:** integration of services that meet all of clients’ social and health needs under one roof, with a seamless referral process. Services are not HIV-specific, but focus on cross-cutting issues of poverty, income generation, housing, care and treatment needs.
- **Outreach:** seen as highly complementary to the one-stop shop model of services, particularly for clients who are vulnerable to triggers around addiction. Outreach, such as through home visits, expand services to individuals who may not be comfortable visiting the agency, but is resource-intensive.
- **Direct Services:** services provided to persons living with HIV/AIDS or Hepatitis C, such as case management, counselling, supportive practical assistance, harm reduction supplies and services (e.g., purchasing condoms, needles, needle exchange), HIV/HCV/STI testing or primary health care services; PHA retreats; nutritional programs; and daily living education.
- **Internet-Based Services:** organizations are increasingly turning to internet-based education outreach and support. Some examples of how organizations are exploring internet-based services are: providing targeted prevention education through online hookup or dating sites for MSM; promoting the organization’s projects through Facebook; creating a closed online support group to reduce the impacts of stigma for PHAs or



people living with HCV; and providing online support to individual clients.

- **Needle Exchange Programs:** offered in all of the large cities in the Atlantic region, plus informal, unofficial or remote needle exchange services in several of the smaller communities or through partner organizations that act as extra service points for PWID clients, such as through: satellite needle exchange locations; mobile outreach to outlying areas; small “informal” NEPs run by community-based organizations; needle distribution and disposal through natural helpers; delivering injection equipment via post in remote areas, and through local pharmacies
- **Natural Helpers:** volunteers who may be users themselves, dealers or people in recovery, and thus understand the social networks of PWIDs. Natural helpers are trained in safety and harm reduction, and help to increase the reach for needle exchange, providing PWIDs with health advice, wound care, conducting needle exchange, distributing condoms and information literature. They act as primary health care providers and are often the only trusted link to services for isolated PWIDs.
- **Methadone Maintenance Programs:** some regions have lengthy waitlists (e.g., Cape Breton and Truro, NS, PEI and NL), while others (e.g., Halifax, NS) have no significant wait time for methadone maintenance treatment for people struggling with opiate addiction. Some pharmacists and physicians prescribe and administer methadone for “stable clients” but there are large areas of Atlantic Canada without good access to methadone, creating onerous travel requirements and treatment adherence challenges for clients.
- **Overdose Prevention:** Naloxone (also known by its brand name, Narcan) is a safe, highly effective chemical compound that reverses the effects of opiates such as heroin, and prevents overdose. Several of the harm reduction organizations have started to provide Naloxone through natural helpers, or are working for policy change to allow them to do so. All of the clients in the IDU and HCV focus groups agreed that Naloxone availability was a high priority to improve harm reduction services.
- **Housing:** service providers facilitate housing supports for their PWID clients as an integral part of harm reduction and addiction services, such as working directly with housing services to set aside dedicated housing for their clients, liaising with landlords, providing trustee services, and helping clients find stable and affordable housing wherever possible. In alignment with the Housing First Model⁸, housing stability is a key prerequisite for overcoming mental illness and addiction issues, but more resources are needed to adequately provide the wrap-around services that are innate to the Housing First Model.
- **Education and Awareness Raising:** a staple of all of the PHAC funded organizations is education outreach. Figure 1Error! Bookmark not defined. summarizes the target populations for awareness and/or outreach activities by the 14 PHAC funded organizations. For the general population, HCV organizations or projects tend to do awareness-raising through venues that target a broad audience, such as through community health fairs, universities, and musical or cultural events. Many of the HCV education outreach programs focused on issues of tattooing and piercing.
- **HIV and Rapid Point-of-Care Testing:** new and expanded testing options for STBBIs, especially for individuals in small communities who may be uncomfortable going to their family doctors or where there is no anonymous testing (e.g., PEI). Promising approaches include a mobile testing unit that visits communities to provide HIV and HCV testing, and Rapid Point of Care (POC) HIV testing pilot projects.

6.2 Key Populations and Communities

The practical reach of the Atlantic region organizations is both extensive and diverse (see Figure 2).⁹ When asked which populations they worked most directly with, service providers listed the following:

- PHAs
- People living with HCV
- First Nations individuals
- People experiencing or at risk of homelessness
- People with addictions
- PWID
- Prisoners
- People who are co-infected
- LGBTQ
- ACB
- Women in crisis
- General public
- Youth

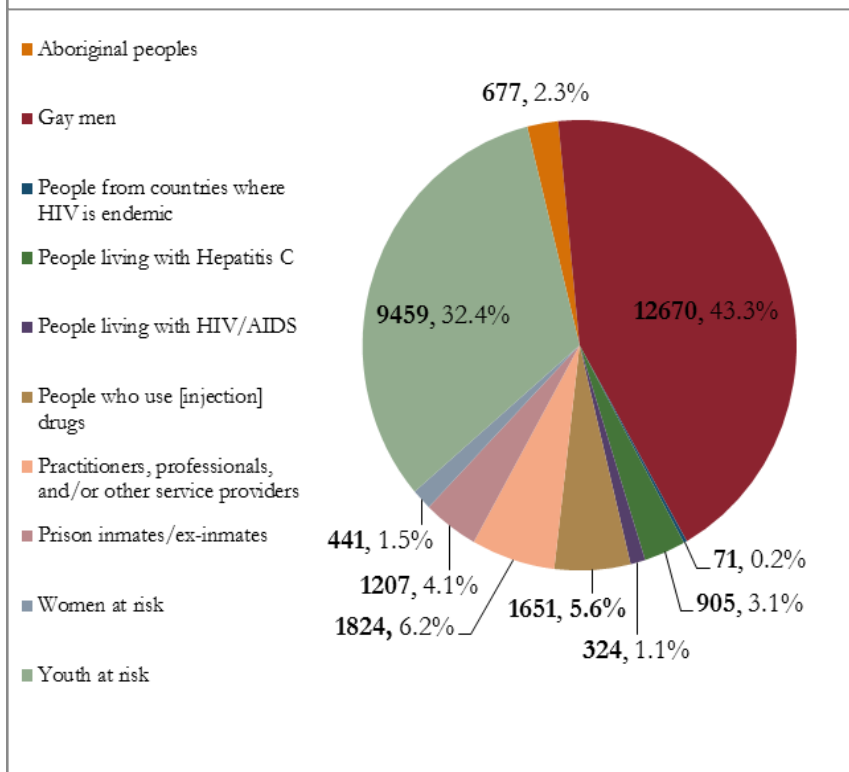
Most organizations have not had the capacity, or have intentionally

decided not, to organize their work by priority population. Many organizations have taken a more generalist approach in targeting “everyone” in order to avoid stigmatizing or “branding” certain groups as being associated with HIV. On the other hand, at least one organizations has established a gay men’s health coordinator role within their organization in order to better support the priority population most at risk for or living with HIV in our region, MSM. Integration may shift programming back to a population-specific approach. While an integrated approach would mean addressing a range of health issues and risk factors for any given subpopulation, the challenge is also in focusing health and prevention messages in ways that are meaningful, as noted by this ED:

“When it comes to integration, we are probably going to have to focus on priority populations that we deem at risk. But risk is a nebulous concept, because women are not always at risk. Which is a belief... just because you are a woman at risk of HIV, you are this a sex worker... and sex workers are not always at risk. In working with that population, we need to address a multitude of issues. And then once you identify who are our key priority populations, what are the priority factors of risk that influence their lives? Because you can’t give them 700 messages either. You have to choose. So what are the top 4 or 5 key risk areas, and address them in an effective way that meets their needs.”

PHAs have traditionally been the primary client population for ASOs, but the extent to which PHAs engage with ASOs, access support services and participate in peer events has changed over time. ASO programs have shifted over the decades from being primarily support-oriented with direct services to PHAs, to being more prevention focused. And for those PHAs who do still need support, their needs for services vary based on whether they have recently seroconverted, have lived with HIV for many years, or have been newly diagnosed late after HIV infection.

Figure 2 - Distribution of total number of individuals reached (through PHAC funded initiatives) by target population, Atlantic region (2012-2013)



People newly diagnosed with HIV, particularly those who are young, have a very different perception of their prognosis living with HIV than they would have 20 years ago:

“PHAs want to learn, not just about living wills and things like that, but about managing chronic illnesses and things like that...they want other things...They want to re-enter the workforce, so the education component for PHAs evolved into getting some capacity building and some self-esteem type motivations for people to live better. I think it has changed a lot. The community has changed. They don't need the same kind of support that they needed 20 or 15 years ago. I think that what they are looking for now, is more daily living type education... Living healthy, practicing prevention, positive prevention are what is needed now and what people want so that people can live a full life.”

While some PHAs want to learn how to pursue full and productive lives with HIV, others struggle with meeting basic needs or with adhering to treatment. One of the EDs felt that long-term survivors of HIV need fewer supports from ASOs, as compared to other clients who are dealing with issues of mental illness, poverty and homelessness.

Many of the PHAC funded organizations noted the new challenges in providing **aging PHAs** with support, particularly LGBTQ seniors. Given the successes of ART, PHAs are living longer and there are an increasing number of PHAs entering the senior years, experiencing health issues not only from HIV, but also from long-term use of ART, and from the aging process. They also noted that seniors are an important target group for HIV prevention education and are too often overlooked as a sexually active and at-risk population.

Several of the organizations noted that a significant (and growing) number of their clients are **Aboriginal people**. Despite Atlantic Canada having an Aboriginal-focused HIV organization (Healing Our Nations – HON), its catchment area is very large and it is a challenge to provide education outreach and support to on and off reserve populations in the Atlantic region.

While the proportion of **African, Caribbean and Black (ACB) people** living in Atlantic Canada is low compared to the rest of the country, some of the organizations have found that they are increasingly having to meet the needs of PHAs who have recently immigrated from sub-Saharan Africa, and in particular, women living with HIV. Confidentiality concerns are a deterrent for ACB PHAs to access supports from ASOs, especially for women.

Some of the interview informants indicated that there are an increasing number of **people who are co-infected with both HIV and HCV**, which presents clinical challenges for treatment coordination and timing. One partner noted that about 70-80% of PWID are living with HCV and that about 1/4 to 1/3 of people living with HIV are also living with HCV.

Gay men and other men who have sex with men continue to be a main focus for many of the ASOs in their community development and information outreach activities (e.g., Pride events and Gay Straight Alliance groups). As several of the ASO EDs noted, the gay men that they are serving are an aging cohort. A key challenge is providing education to men who do not identify as gay and thus are not likely to access LGBTQ services or information. On the other end of the age spectrum, some organizations are delivering targeted education outreach to LGBTQ youth, and working to create safe spaces in schools and the broader community through sensitivity training for teachers. Several of the interview and focus group informants also noted that there is a significant number of gay men and MSM with addiction issues. This is important to note in the context of integration; several informants made a point of noting that addictions is an issue for gay men living with HIV, and not only for PWIDs.

Conservative estimates are that approximately 7000 workers from Atlantic Canada commute to Alberta for employment in the oil sands¹⁰. This **migrant worker population** is a key concern for HIV and HCV organizations, as the high incomes from the oil sands is associated with drug use and purchasing of sex.

One of the challenges for tracking the HIV incidence in Atlantic Canada is that many of the people most vulnerable to HIV who migrate for work are tested for HIV outside of Atlantic Canada.

All of the PHAC funded organizations provide at least some services (direct or indirect) to **people who inject drugs**. Various parts of the addiction services continuum are provided by PHAC funded organizations and their partners, from early intervention and prevention, to harm reduction, to day programs for addiction counseling, to in-patient addiction treatment.

Many of the PHAC funded organizations work with **prisoners**, both while in prison as well as after release. Most of the work with prison populations is focused on education and support, including peer education training around HIV and HCV prevention, and one-on-one support for prisoners living with HIV or HCV. Several of the service providers felt that more harm reduction and prevention measures need to be available in prison because: *“injections, tattooing and unsafe sexual practices is all happening in prisons.”*

Some of the CBOs also provide prevention and support to **sex workers** such as: assistance with housing; street-based sex trade outreach worker; maintaining and distributing a “bad date report”; advocating on behalf of sex workers who are subjected to violence with the police; education for handling situations of violence, abuse or coercion; drop-in programs; advocacy and awareness messages to improve public perceptions of sex workers and reduce stigma; and HIV, STI and HCV prevention education.

The service providers most commonly reach **women-at-risk** through women’s shelters and through programs for vulnerable women. Some examples of issues faced by women: ACB women living with HIV are often very reluctant to visit the ASO in person and are very concerned about confidentiality; women who are victims of violence are vulnerable not only to HIV, STIs and HCV, but also to issues of poverty; and many women living with addiction or street-involvement struggle with child care and child custody issues.

The needs of **transgender and transsexual people** were discussed by only two interview informants. One ASO had a weekly transgender support group, with up to 23 individuals (15 female to male, and 8 male to female). An ASO ED noted that one of the education workers helps to deliver a workshop called “Bring Your Whole Self to Work” which includes a transgender youth to provide sensitivity training for teachers and to support local high schools in starting a gay-straight alliance.

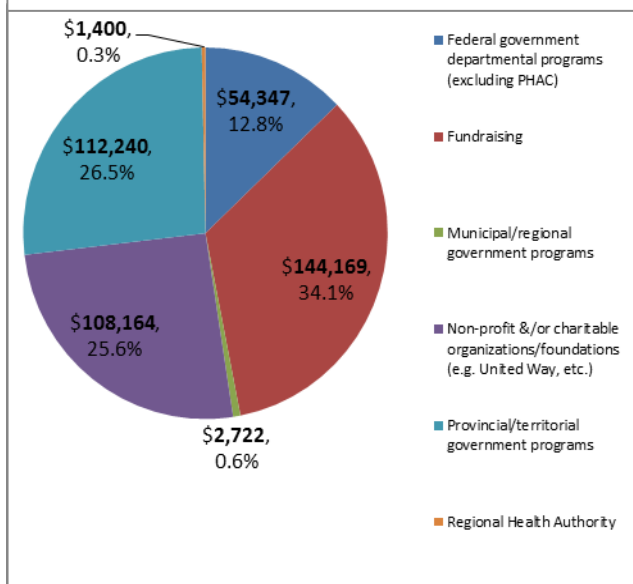
Youth across the Atlantic are also at risk for STIs and HCV and require specialized prevention interventions. A variety of methods are used by the CBOs to reach youth: workshops in classrooms; train the trainer peer education modules to teach youth the basics about HIV, Hepatitis C, STIs and life skills; STBBI awareness campaign (e.g., “Take Care Down There” Campaign in NL); GBLT inclusion programs (e.g., “Creating Safe Spaces Program” in NB); condom distribution in schools; and HIV and HCV tables set up at high school or teen health fairs.

6.3 Funding

Overall, the PHAC funded organizations and their partners felt that funding for HIV/AIDS has dwindled over the years, and has not kept pace with increasing operational expenses (e.g., staff salaries, rents, utilities).

While some of the organizations rely almost

Figure 3 Distribution of total amount of additional funding for projects by source, Atlantic region (2012/13)



exclusively on PHAC for funding, others have significantly diversified their funding with provincial and fundraised dollars. Some of the EDs were apprehensive about their ability to sustain community fundraising interest with integration and a dilution of focus and messages.

One of the frustrations for the CBOs is that project funding often is restricted to “innovative” projects and there is inadequate funding for simply continuing programs that are known to be effective, are responsive to client needs, or are based on the organizations’ own strategic directions, goals and mission. As can be seen in **Error! Reference source not found.**¹¹, PHAC funded organizations are acquiring additional funds from a variety of sources in order to meet the needs of their clients.

There are only a few organizations in the Atlantic region which receive funding from their provincial governments to provide direct services to PHAs (e.g., ACNS), although several receive funding to run harm reduction programs.

When funding is tight, one of the last priorities for organizations is to invest in their own organizational development. However, **capacity building** is going to need to be a more major focus for PHAC funded organizations as integration takes place. Many of the PHAC funded organizations wished that they had more resources to provide outreach services for purposes of education, harm reduction and support. All of the harm reduction programs reported marked increases in needle distribution over the years, some as high as ten-fold increases, without concomitant increases in funding.

One of the questions that arose in the discussions of funding is the level at which **funding allocations** should be decided and distributed. Funding levels for each region are determined based on an evidence-based formula developed in 2006¹². Some of the PHAC funded organizations would prefer that funding be allocated and administered at a provincial level, while others were proponents of a “zero-based budgeting” model¹³ that would not allocate funding to organizations based on historical levels or historical programming.

6.4 Gaps and Challenges

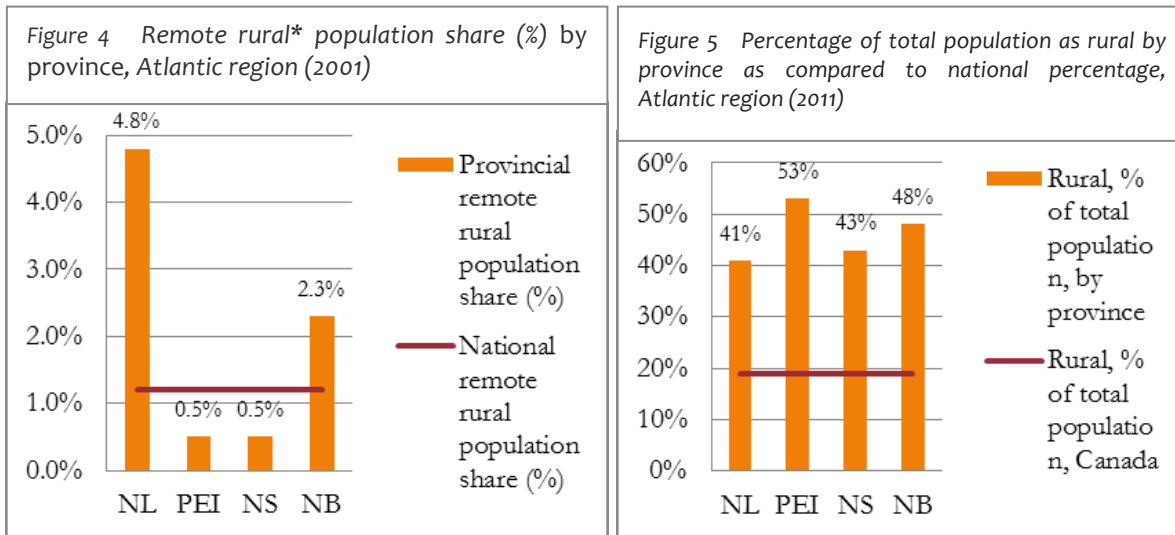
Some of the informants described how over-commitment to ASO work can result in exhaustion and diminished interest in the work, i.e., **burnout**. Interview informants noted that the sector is made up of very committed individuals who are passionate about their work, but are working with very limited resources. When people burnout and leave the sector, historical memory, expertise and experience is lost. The loss of service providers and resulting turnover is difficult for clients, particularly for those receiving counseling

One of the challenges facing understaffed CBOs is the meaningful engagement of **volunteers**. Although volunteers can provide valuable assistance and community development for organizations, many don’t have time for volunteer management.

There have been significant changes over the years in the composition of the ASOs’ **boards of directors**, particularly in terms of level of PHA involvement. It is increasingly difficult to find PHAs who are willing to sit on Boards because they either lack the capacity (due to issues such as poverty or addiction), or because they are not interested in the governance of an ASO. PHA inclusion on Boards has been an important component of enacting GIPA/MIPA, and this will likely have to broaden to include people living with HCV as integration unfolds.

Duplication of services only occurs when two agencies are providing the same services to the same constituency. As integration becomes more of a reality and a funder expectation, the potential for duplication of services may increase. In some jurisdictions and types of services, where there is a wealth of programs and organizations that overlap significantly, there needs to be better coordination of services, both to make better use of resources and for better clarity for service users.

As indicated by the **rurality** statistics in Figure 4¹⁴ and Figure 5¹⁵, the Atlantic is a highly rural jurisdiction. This high level of rurality means that it is difficult for CBOs, all based in the larger urban centers of the region, to reach all of the populations in need of services. Likewise, it can be difficult and costly for service users outside of these main urban centers to have adequate access to services (e.g., to counseling or support groups). Many of the PHAC funded organizations have large catchment areas, sometimes with 7-8 hour drives and ferry trips to reach the furthest parts of their constituencies, so they can only provide “piecemeal” services rather than consistent and regular contact with service users.



Service providers and some PWID talked about the challenges and frustrations in getting addictions treatment in remote areas and when on treatment, challenges in maintaining that treatment (e.g., having to travel to obtain methadone; abiding by the random urine tests that are required to be kept on methadone); and accessing support groups and needle exchange programs. Newfoundland only has one ASO and has found creative ways to increase its reach:

“For our province, geography is our greatest enemy in some respects. Newfoundland and Labrador, the geographic area, is three times greater than all of the Atlantic provinces combined. With a sparse population, it is very difficult, well it is impossible for us to be able to provide the services that are required throughout the province. So we are shipping needles to some of the isolated communities...shipping them by Canada Post. In those areas, the education piece is missing because you are not connecting with people face-to-face. You are simply sending needles. It is the lesser of the evils. If you don’t send the needles then people are reusing what they have. You are contributing to a higher risk of transmission of HIV and other HCV and whatever other illnesses can be transmitted through injection drug use. But sending just the needles without having the education piece, you are just feeding the lion.”

Many parts of the region **lack infectious disease specialists or sexual health clinics**, presenting barriers to people at risk of and living with HIV, HCV and STIs. This can create problems for patients, not only because of having to travel, but also in inconsistencies between coverage of certain ARVs under different provincial drug formularies. Many parts of the Atlantic region also lack a sexual health clinic, limiting testing options for people at risk of HIV or STIs. In terms of HCV, treatment is also limited for some parts of the region. Many people who are living with HCV face challenges with respect to poverty, and transportation to find specialized HCV treatment is a challenge.

Several of the EDs of ASOs felt that the HIV and HCV sector needs to be more closely guided by **evidence-based or informed practice** so that programming is cost effective while still effectively targeted to the greatest need so as to have the greatest impact. EDs expressed the desire to make better use of evaluation

data. While organizations are required by funders to collect a wide variety of data, the link is often not made to how that data should inform programming as opposed to more “bean counting” measures.

The interview informants provided their observations about what **populations are not being adequately reached** through current programs: people who smoke crack; women living with HIV; people aged 20-24; people living with HCV who are not accessing support programs; prisoners who use inject drugs; heterosexual; Francophone populations; and people who are living with HIV but are not diagnosed.¹⁶

One of the key challenges for HIV and HCV service provision and programming is that operational funding has been available only through year-to-year renewals (up until 2014-2017 contribution agreements) or through one-year project funding. Some of the organizations are not eligible for operational funding and must rely on project funding. Many of the CBOs feel frustrated by the **instability and insecurity in funding**, and this challenge did not escape notice by clients.

Interview informants observed that a key challenge for the process of integration is attitudes of **protectionism and territoriality** among CBOs providing various HIV, HCV and STI services. One of the EDs noted that protectionism over organizations will be a major impediment to the process of amalgamation and integration:

“I will give an analogy... a lot of churches are finding themselves in positions where they need to amalgamate because they just cannot sustain themselves. I have been part of these amalgamation discussions with these churches, and everything goes great until you are trying to decide on which building are we NOT using. Then it all falls apart. I think we can get ourselves, philosophically to an area where we are ready to do that, but then, who will we be? What name are we giving up? What does that giving up mean? Are we giving up territory? Are we giving up control? Are we giving up resources? In philosophy, yes it makes sense, in practicality it is going to take some time.”

There is also territoriality among service users about the divided focus of ASOs, such as between gay men and PWIDs. PHAs in the MSM focus group also expressed frustration with the geographic boundaries imposed by ASOs, and were proponents of having one provincial organization with chapters. Some of the PHAs perceive that there are challenges with territoriality and struggles between ASOs given the current organizational structures in place.

7 WHERE ARE WE WITH RESPECT TO INTEGRATION?

7.1 Financial Support for Integration

Most of the PHAC funded organizations were optimistic, or at least hopeful, that integration would bring more resources to expand services, or to better support services that are already integrated. Service providers want adequate resources for the expansion of their mandates. Additional resources would allow organizations to enhance programs for both HIV and HCV in ways that would be mutually beneficial.

Several of the ASO EDs were cynical about integration. They felt that integration was imposed upon them, and that it was being enforced in order to save money for PHAC, rather than for reasons of program effectiveness. One of the PHA clients feared that integration wouldn't necessarily be accompanied with additional funding, and was specifically concerned about how integration would impact support programming for PHAs.

7.2 Integration is Already Happening

Many of the interview informants noted that integration of STBBIs has already begun in their organizations, some for many years already. Some of the partner organizations (community-based organizations which focus on neither HIV nor HCV) felt that they were equally comfortable and well-versed in issues around HIV and HCV, and this is facilitated in part due to the availability of reliable information resources from CATIE (Canada's source for HIV and Hepatitis C information).

Some of the ASOs have been delivering HCV-focused services and projects for many years, and the reverse is also true – many of the HCV organizations also reported that they have been working from an integrated model. For example, an organization providing harm reduction services such as needle exchange, is already innately providing integrated services since promotion of safe injection prevents all blood-borne pathogens.

Many ASOs have already **modified their mission statements and strategic directions** to reflect integration where appropriate. One of the manifestations of integration and broadening mandates for ASOs has been a trend towards name changes.¹⁷ Many of the organizations have already begun discussions at board level about the possibilities for revitalization through **name and logo changes** to reflect their expansion into HCV and STIs. Name change is also a means for organizations to distance themselves from the stigma associated with HIV/AIDS that deters potential clients from accessing services. Regardless of the reasons for name changes, it is a sensitive issue, particularly for long-term survivors of HIV/AIDS who have a great deal of emotion invested in the ASOs that helped them through the HIV epidemic's early years.

7.3 What are the various perspectives on integration?

The overarching sentiment about integration among service providers is that “integration makes sense.” However, the advantages of integration are much easier to see from the perspective of prevention than from a care and support perspective. Clients living with HIV and HCV tended to be much more apprehensive about integration. In particular, the majority of PHAs expressed a strong desire to maintain HIV services and maintain ASOs as HIV-focused organizations, albeit with some notable exceptions.

Stigma and discrimination can be seen, on one hand, to be major impediments to integration, particularly in terms of one client population not wanting to be associated or blended with other client population(s). On the other hand, if integration meant combining several types of services and client groups within one organization, it could lend a sense of normalization, anonymity and make organizations more “generic” in the eyes of the public and their service users.

A key barrier to integration is the mutual feelings of stigma that some people living with HIV, people living with HCV, people living with addictions, or people belonging to the LGBTQ community feel for other client populations. HCV and injection drug use are strongly associated, as are HIV and being gay. And all four conditions are each stigmatized on their own.

“There's a lot of homophobia, and addictaphobia or IDU-phobia, from both sides.”

7.3.1 Client Perspective: People Living with HIV

People living with HIV are aware that integration is in progress, that it is an expectation of funders, and that it will likely involve some changes in the way that staff work and the programs that they deliver. Some PHAs are explicitly resistant to integration, and there is some backlash as they anticipate and lament the loss of HIV-specialized services (e.g., PHA retreats) and *“the way things have always been done.”*

Like service providers, clients also expressed concern about the need for organizations to *“do more with less”* in terms of funding levels. One PHA was hopeful that with integration would come additional funding that would be beneficial for both people living with HIV and people living with HCV. A client living with HIV

noted that integration is already happening at his home ASO and that despite his original misgivings about merging populations, it has turned out to work very well. Other PHAs recognized the logic in those ASOs incorporating other STIBBIs, although some applied the caveat that the ASO needs to find a way to separate the populations and services for people living with HIV versus those accessing needle exchange programs:

“When the needle exchange first started, I was definitely against it. I just didn't like the idea at all. It took away the comfort of the office. It took away I'm going into the office for whatever – to use the computer, to access services, and I'm going to a group of high, wasted people getting needles. Right? And for a long time, I was battling are we doing prevention work or are we enabling them? Because I had that conflict. But now I look at it as it is a prevention issue. And I think it's a good program but it sort has got to be separate from everyday office areas where people want to come in and access services. Like if a PHA wants to go in and speak to the executive director, he doesn't want to go through a whole line up of people waiting for needles, and arguing and fighting or whatever they do. So as long as it's separated.”

7.3.2 Client Perspective: People Living with or at Risk for Hepatitis C

Some of the clients in the PWID focus group expressed the barriers presented by an integrated model of service delivery. One key issue for them was having to access services from an organization/building with the word “AIDS” in its name, and in particular the stigma they feel from mainstream community members:

“It puts a big stigma on things too. Because you walk in the door, it says ‘AIDS.’ I had a big problem... they'll see me coming in here and they think, ‘Oh, did I see [participant] going in to the AIDS Coalition?’ and all this stuff. They just think that it's everybody with AIDS going in. Next thing you know: ‘[Participant] has got AIDS and HIV’ and all that shit. And I always say that, I don't think that the needle exchange should be in with the AIDS coalition. I really don't. I know lots of people that don't think that it should be with it. It's two separate things.”

In particular, people living with addictions and PWID feel reluctant to associate themselves with ASOs because of the stigma around HIV/AIDS and fears driven by ignorance around transmission. On the other hand, some people accessing harm reduction programs are focused on getting the services that they need, and don't pay much attention to the building or organization that it is housed within.

7.3.3 Service Provider Perspective - Optimism

There was almost universal agreement among service providers that integration makes logical sense from the perspectives of resource efficiency, common populations, common risk behaviours, and related education and prevention messages. From a clinical perspective, at the time of testing, it makes sense for service providers to offer “the whole gamut of STI and HCV testing” both on initial screening and with annual screening. One of the health system partners agreed that integration will be beneficial, particularly in shifting focus from disease-specific intervention to a focus on at-risk populations and behaviours.

Partner organizations (those who aren't ASOs) see integration as making sense from financial, management and service perspectives. Harm reduction service providers and health care providers, in particular, noted that integration would have no impact on their work; STIBBIs are already well-integrated at the level of public health, primary care and harm reduction. Some non-ASO service providers also noted that integration may provide greater educational opportunities for building frontline and primary care expertise across all STIBBIs.

7.3.4 Service Provider Perspective - Apprehension

Some organizations are embracing the change and are well on their way to integration, but one concern is that these changes are happening without adequate consultation and engagement of clients who will be

most affected by these changes. For other organizations, the shift to a truly integrated model will require significant change and they haven't seriously started adapting yet.

While links between HIV and HCV are easily apparent on the prevention side of the service continuum, more contentious is the support side of programming for people living with HIV or HCV. On this end of the service continuum, there is still some protectionism in holding on to specialized organizations for HIV and HCV. Some organizations which currently specialize in one or the other each firmly believe in their own indispensable niche, and each see themselves "surviving" integration (i.e., not being forced to amalgamate or shut down). Others are much more pragmatic, and recognize that the process of integration will likely mean that some organizations will become "folded into" other organizations. A common source of apprehension had to do with resources, and the expectation that organizations would be expected to "do more with less."

Several service providers called on the Public Health Agency of Canada to take more of a leadership role and were cynical about the burden put upon community-based organizations: "PHAC calls it integration. Sometimes we call it downloading."

7.4 Organizational Structures

While CBOs fill a vital niche in meeting the needs of vulnerable and marginalized individuals, there was mixed opinion on whether there should exist stand-alone organizations which are specialized and focused on HIV or HCV.

One model that was suggested for integration was to have one umbrella organization in each province, or even for the region, that would then have satellite offices, branches or chapters. They would be unified by a central organizing body that would take a lead on grant writing, capacity building, knowledge exchange, program development and program evaluation. Rather than build and sustain infrastructures of small organizations across the region, some felt that there could be a single organization in each province that runs satellite projects in both HIV and HCV, similar to the way that health authorities function. The local chapter offices could then be embedded with allied partners, such as in sexual health clinics, harm reduction programs, housing organizations and other CBOs, or public health authorities. This would also have the benefit of spreading expertise out across the provinces.

"I do think there needs to be less administration. We don't need nine organizations in every province... that is foolish. People won't like it, but what it will do is free up more program money and program people. So we don't need nine boards. We don't need nine Executive Directors, we don't need nine accountants... there is so much resources that we are ultimately wasting. But the question of who gets to maintain their infrastructure is challenging for the best of us. Because for whatever structure that comes out or whatever that might look like... all of that is up for grabs. So it is risky for people to say that, but we need to think broader, not about our own little box."

Many ASOs have a small and dwindling member base of people living with HIV. As one partner organization noted, if anything, based on the incidence and prevalence rates, there should be more Hepatitis C-focused organizations than HIV-focused organizations. Some informants felt that the AIDS organizations may no longer be necessary, and attributed the advancements in HIV treatment for rendering ASOs somewhat obsolete. Any organization could house the integrated services, but the "home" for integrated services should be based upon the extent of trust and quality of the relationships between the service organization and the most affected populations.

8 MOVING FORWARD

This document is the culmination of an extensive amount of work and inquiry in the Atlantic region in a relatively short period of time. While it expresses a range of diverse viewpoints and perspectives, it also is a reflection of considerable collective thought and convergent ideas. ASO and CBO participants were very candid in their responses during the focus group and interviews, and took the time to answer hard questions and pose potentially controversial positions. The richness of information (more completely reflected in the full report) is reflective of the many years of experience in both the service providers and the service users.

There are many strengths and successes to be celebrated in the Atlantic region. Members of ASOs and CBOs have worked tirelessly over the last three decades to keep the epidemic at manageable levels in this region of the country. It is also recognized that despite frequent changes and limited resources, community members have worked with steadfast dedication in order to meet the needs of those affected and infected by HIV/AIDS, HCV and other STBBIs. This work has not been easy—the intersections of various social, political, economic and cultural issues are complex. Going forward, we need to remember our organizational strengths and our relationships with our communities, holding these central as we continue to build new programs, projects and networks of support.

Building upon the results of this review, we make the following observations and provide directed questions left to be answered to inform future planning with respect to: the current state of communicable diseases and support services; challenges and successes of this work; and strategies to collaboratively work together to improve the lives of those living with communicable diseases in Atlantic Canada.

- 1) Currently, demand and supply are not in sync. The demand for services and basic resources (i.e. condoms, clean needles, methadone, counselling services, etc.) as well as infrastructural support (i.e. staff and training) steadily increases each year; however, available funds do not.
- 2) The burden of integration or any other change cannot rest on CBOs and ASOs alone. We cannot simply download tasks to ASOs and CBOs without equipping them with the skills and resources needed to complete these tasks successfully.
- 3) Stigma and discrimination (of both infected/affected populations and of the diseases themselves) are still prevalent, creating barriers to prevention and support for clients and challenges for CBO workers. Integration of services will bring together more affected populations creating potentials for even more conflict. How will we equip ourselves to deal with these challenges?
- 4) Historically there has been a strong sense of community amongst PHAs, creating a particular type of culture and political environment amongst ASOs that is not the same with other communicable diseases. How do we integrate services, diseases, and populations, without losing the sense of community identity that guided us (the HIV community in particular) until now?
- 5) Identity politics and classism is a big part of the challenge around integration – it is not solely a matter of adequate funding resources. Part of the root cause of protectionism over ASOs (by gay men living with HIV) is due to the need for a home for queer health issues.
- 6) GIPA and MIPA have been guiding principles in the HIV/AIDS movement. What role will they play in the context of integration? How and why are they still valuable within the context of our work? It is not enough to simply use GIPA/MIPA as a rhetorical strategy—the specifics need to be examined using evidence based practice.

- 7) We need to ensure that best practices are maintained and encouraged going forward. The organizations and their clients described service delivery models that will be conducive to an integrated model of programming: in particular, a combination of one-stop shop, plus drop-in, plus outreach services. How do we make sure that we maintain the integrity and support of these vital services? How do we share amongst ourselves which practices of ours are the most effective, and ensure that we reduce any duplication of efforts?
- 8) CBOs and ASOs are already integrated in some capacity, whether via addressing multiple diseases (especially HIV/AIDS and HCV), multiple affected/infected populations (gay/queer, aboriginal, sex workers, PWIDs) and multiple social determinants of health (poverty, homelessness). Lessons from trying to integrate HCV work into ASOs tell us that while such integration is necessary and useful, it is only effective when staff of ASOs receive the adequate training and resources to do this additional work.
- 9) Outreach capacities are a vital component of our work but is complicated by the geography of our region, the dispersal of affected populations and a lack of resources available to fund basic supplies. But distributing supplies (needles and condoms) without education or addiction recovery supports, is a limited approach.
- 10) It is necessary that we build our cultural competencies across our organizations. For example, we need to be familiar with the nuances of and historical context of racism and/or marginalization among Aboriginal cultures, ACB cultures, gay culture, drug using cultures, sex worker networks, aging PHAs, etc., as we integrate service needs. We cannot assume that ASOs and CBOs are equipped to automatically handle new affected populations, or that new populations can be adequately serviced and supported by a one size fits all approach.
- 11) As the Internet increasingly becomes the way for reach clients (especially youth) and affected populations across the region, training and support needs to be provided to ASOs and CBOs to help them effectively integrate such work into their organizations. How are our clients using the Internet to get their health information? Could we think of a collaborative integrated online presence for the region?
- 12) We need a consistent effective form of needle exchange as well as methadone programs. As it currently stands, resources for needle exchange programs are inadequate and methadone programs are oversaturated with long waitlists (with the recent exception of methadone provided by the BAILEY bus). Due to limited resources and an overall unclear direction in the region for these key services we are failing to address client needs and creating precarious conditions for affected populations.
- 13) Better testing systems, including point of care and awareness campaigns need to be devised regionally. These are foundations of all our work. Without effective (including increased access to anonymous) testing, we fail to reach individuals living with HIV who do not know their status, which is a key driver in this epidemic.
- 14) We need to have a consistent presence in the public and private school curriculum (up to and including high school), as reaching youth early on is important for keeping infection rates lower. Raising rates of STIs show that we are not doing enough here.
- 15) ASOs and CBOs need support from federal and provincial levels of government as well as clear direction from each. Right now there is some confusion over who is responsible for which aspect of

prevention and support, and what constitutes “direct services” and is thereby eligible for PHAC funding. The general impression is that there is an overall resource shortage.

- 16) We need to ensure a full circle of support. This takes active and ongoing coordination between organizations and requires stronger relationships between ASOs and health services. Mental health services are a key component of our work. Without effective connections between ASOs/CBOs, and these services we will not meet client needs. For example, ASOs/CBOs need to be closely aligned and operate seamlessly with mental health services and homeless support. Going forward, can we consider innovative liaison systems that could quickly link various organizations together to?
- 17) Harm reduction services are needed in prisons. Without them, we fail to reach a key population within our epidemic.
- 18) There is a concern with fundraising if we lose the HIV/AIDS focus to ASO work, since this works as a clear branding strategy of sorts (i.e. general ‘sexual health’ does not work). Training in fundraising methods could be very helpful, especially for very resources strapped organizations.
- 19) We need to focus on how to effectively implement evidence based practice. We know that new and innovative research is necessary to keep us effective, but putting evidence into daily practice is a challenge that needs to be addressed.
- 20) Some populations are being ignored or under examined, for example francophone populations, people who use drugs inside prisons, trans women and men, sex workers and people who smoke crack. These groups need to be incorporated into our work in order for us to be effective.
- 21) Clear direction and strong networks needs to be a priority going forward. Despite considerable goodwill, there is also a sense of protectionism in ASOs and CBOs across the region, with people working in silos. The most effective approach to addressing this epidemic will build upon all our strengths, and will have ASOs and CBOs working together in a strong clear direction. How can we work in the spirit of collaboration, transparency, and support going forward? How might defining and working toward agreed upon goals help to organize our work better and make us more effective?

In conclusion, this report presents the current state of community-based communicable disease initiatives and resources in Atlantic Canada; it identifies emerging trends, needs and gaps in these initiatives and resources; and it provides a future forecast of what is needed and ways of working collaboratively to meet the needs of those living with and those most affected by communicable diseases in the region. It is a document generated by the community for use by the community as the planning for integration of communicable disease services in the Atlantic region unfolds.

mental health, education, employment, substance abuse and community connections. Housing is not contingent upon readiness, or on 'compliance' (for instance, sobriety). Rather, it is a rights-based intervention rooted in the philosophy that all people deserve housing, and that adequate housing is a precondition for recovery. The Homeless Hub. (2014). Housing First. [On-line]. Available: <http://www.homelesshub.ca/housingfirst>. Access date: 15 May 2014.

⁹ PERT Questionnaire (2012/13): sec.5.1. The "population(s) targeted by the project" are given in a drop down menu on the PERT form. For each population reporters are asked to "identify the number of individuals reached" and may "only count individuals once." PHAC acknowledges that "often individuals fall under more than one category" but still asks reporters to "choose the category that best fits" (sec.5.1).

¹⁰ Ferguson, N. (2012). [From Coal Pits to Tar Sands: Labour Migration Between an Atlantic Canadian Region and the Athabasca Oil Sands](#). *Just Labour: A Canadian Journal of Work and Society*, 17/18, 106-118.

¹¹ PERT Questionnaire (2012/13): sec.1.1.

¹² Patten, S. (2006). AIDS Community Action Program (ACAP) grants and contribution allocation project 2005 | Final report prepared for Public Health Agency of Canada Regional Offices. San Patten and Associates - Health Research and Evaluation Consulting [On-line]. Available: <http://www.sanpatten.com/ACAP%20Final%20Report.pdf>

¹³ Zero-based budgeting is an approach to planning and decision-making which reverses the working process of traditional budgeting. In traditional incremental budgeting (Historic Budgeting), departmental managers justify only variances versus past years, based on the assumption that the "baseline" is automatically approved. By contrast, in zero-based budgeting, every line item of the budget must be approved, rather than only changes. During the review process, no reference is made to the previous level of expenditure. Zero-based budgeting requires the budget request be re-evaluated thoroughly, starting from the zero-base. This process is independent of whether the total budget or specific line items are increasing or decreasing. Sarant, P. (1978). *Zero-base Budgeting in the Public Sector, A Pragmatic Approach*. Addison-Wesley.

¹⁴ Beckstead, D. & Brown., W. M. (July 2005). [Provincial income disparities through an urban-rural lens: Evidence from 2001 Census](#). Ottawa: Statistics Canada, Micro-economic Analysis Division. Catalogue no. 11-624-MIE — No. 012. ISBN: 0-662-41052-1 : Table 2: p.4. [On-line]. Available: <http://www.publications.gc.ca/Collection/Statcan/11-624-M/11-624-MIE2005012.pdf>. Access date: 15 May 2014.

*"Remote rural: Rural census subdivision with no commuting flows to a CMA [Census Metropolitan Areas] or CA [Census Agglomerations]" (Table 1: p.3). Source: Special Tabulation, Census (2001).

¹⁵ Statistics Canada. (2011). 2011 Census of Population. [Population, urban and rural, by province and territory \(Canada\)](#). Last modified: 2011-02-04. [On-line]. Available: <http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo62a-eng.htm>. Access date: 15 May 2014.

¹⁶ It is estimated that about 18,000 people, or 25% of prevalent cases, were unaware of their HIV infection (PHAC, 2011). PHAC. (2011). [ARCHIVE – Summary: Estimates of HIV Prevalence and Incidence in Canada, 2011](#). [On-line]. Available: <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/estimat2011-eng.php>. Access date: 15 May 2014.

¹⁷ AIDS Calgary changed its name to HIV Community Link; AIDS Committee of Toronto increasingly is going only by its acronym ACT; CATIE is also tending towards the use of its acronym rather than its full name – the Canadian AIDS Treatment Information Exchange; the British Columbia Persons with AIDS Association (BCPWA) has changed to Positive Living BC; and there is a trend in Canada's big cities to develop gay men's health organizations to expand beyond HIV/AIDS work in gay populations – such as Health Initiative for Men in Vancouver, REZO in Montreal, and the Gay Men's Sexual Health Alliance in Toronto.