RURAL AND REMOTE
NEEDS ASSESSMENT

CANADIAN AIDS SOCIETY
SOCIÉTÉ CANADIENNE DU SIDA

March 2014

Report prepared by Kim Thomas and Sue Scruton

DEDICATION

We would like to dedicate this to every volunteer, every person with HIV, and every worker in the Rural and Remote communities that we are talking about. Many a long night has been spent around kitchen tables, working on the unique, brilliant and special ways you have come to find services and deliver services in an often challenging environment. You have bravely become the "AIDS people" in your communities and you are our hope to break the stigma and discrimination that exists. We thank you, honour you and humbly hope this paper is of some support in understanding and responding to HIV and AIDS in Canada.

Published by the Canadian AIDS Society

For further information about this publication please contact:
Canadian AIDS Society, 190 O'Connor Street, Suite 100, Ottawa ON, K2P 2R3
www.cdnaids.ca

ISBN 978-0-9880504-2-6

Cover photograph compliments of Sue Thomas:
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Suggested citation: Thomas, K and Scruton, S. Rural and Remote Needs Assessment (2014)
Canadian AIDS Society, Ottawa, ON.

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6 NORTH
Ross River 226
WARNING!
NO SERVICES
NEXT 226 km

1: BACKGROUND

ACKNOWLEDGEMENTS

The Canadian AIDS Society wishes to acknowledge the direction and support of the Advisory Committee for this project: Tesfaledet Debesay Gebremedhin, Randy Near, John MacTavish, Carlen Costa, George Clark-Dunning, Simon Habegger, Julie Crouse, Heather David and Adrian Betts. The Advisory Committee has been instrumental in making a superb survey that encapsulates the reality faced by Rural and Remote communities in Canada facing AIDS. We also wish to acknowledge Sue Scruton for her stewarding of this project, working with the Advisory Committee, conducting interviews and generally collecting the information that is presented herein. Thanks to the Ontario HIV Treatment Network for their work on the rapid response literature review. The following individuals have also provided support in a number of ways, to bring you this report —Monique Doolittle-Romas, Patrick McIntyre, John Sharp, and Bernice Aye. And we wish to thank our transcription team, lead by Bernice Aye: Maddison Van Balkom, Uyen La, Duyen La, Nhi Dang and Zen Yuen Pang.

Finally, we wish to acknowledge the time and efforts of the following agencies who took the time to share information about their work, so we can learn and provide appropriate supports in our work:

AIDS Committee of Newfoundland and Labrador
AIDS Committee of Guelph and Wellington County
AIDS Saint John
AIDS Support Chatham Kent
Alberta Health Service, STI Services
All Nations Hope
ANKORS
Blood Ties Four Directions
Central Alberta AIDS Network Society
Centre des R.O.S.É.S. de l'Abitibi-Témiscamingue
Hazelton Community Health
HIV Network of Edmonton Society
HIV North Society
HIV/AIDS Regional Services
Huron County HIV/AIDS Network
Living Positive Resource Centre
Morning Sky Health and Wellness Center
Northern AIDS Connection Society
Portail VIH/sida du Québec
Positive Living North Society
Positive Living Resource Centre
Positive Living Society of BC
Positive Women's Network
Regina Qu'Appelle Health Region
Regional HIV/AIDS Connection
Réseau ACCESS Network
Saddle Lake Health Centre
The AIDS Coalition of Cape Breton
3 additional groups who wish to remain anonymous.

EXECUTIVE SUMMARY

The Canadian AIDS Society is a national coalition of community based AIDS organizations providing services at the front line of Canada's response to HIV and AIDS.

The overall findings of this survey indicate that the biggest priority to be addressed is Stigma and Discrimination.

There is another key finding in our report that we need to examine in greater detail as well, and that is the issue of funding. Funding is an issue of the same proportions as stigma and discrimination. Feeding into the funding conundrum is the increasing costs of travel, particularly in regions without stable public transportation — like the Rural and Remote communities surveyed here.

And finally we see increased demand for services in rural communities — many of the communities surveyed depend on urban service providers for programs in Rural and Remote communities, leaving many needs in the communities unmet as people living with and at risk for HIV travel for their services.

In order to understand the current state of the literature on this topic, the Canadian AIDS Society requested that the Ontario HIV Treatment Network (OHTN) conduct a rapid response review of the literature related to two questions: What are the challenges and barriers to providing HIV/AIDS services in Rural and Remote AIDS Service Organizations in Canada? And what are some of the best practices for serving Rural and Remote populations? The results of this literature review are available on the OHTN website at http://www.ohtn.on.ca/pages/Knowledge-Exchange/Rapid-Responses/RR73-2013-Rural-ASO.pdf.

In the fall of 2013 the Advisory Committee, working with staff from the Canadian AIDS Society developed the needs assessment survey, based on the priorities and challenges identified through the OHTN rapid response review and developed a means to confirm these findings, while expanding our knowledge about the areas identified in the literature review.

The survey was distributed in French and English to the members of the Canadian AIDS Society with a request to share the survey among relevant networks and beyond. The survey was developed using the Fluid Survey tool, in total we received 28 completed responses, plus 2 completed responses to our draft survey.

A series of six key informant interviews were also completed to help us further understand both the needs and responses being offered in rural settings.

Trends identified in the findings indicate that there are some common concerns in service delivery for Rural and Remote communities. What is also evident, is the fact that there is no one-size fits all solution. Common threads in the responses indicate that the service providers are all well-versed in the needs that their communities have. We have a glimpse at the diversity of services provided in urban settings and the gaps in Rural and Remote settings is significant. While efforts are in place to bring services to Rural and Remote service users, there is still a large number of agencies working to

bring service users to them - at no small cost for transportation in some cases. The complexity doesn't end there either, as service users are in need of supports and services from various providers, most of whom are not available in Rural and Remote settings. The results of this survey indicate that Rural and Remote populations of people living with and at risk for HIV/AIDS are severely limited to resources such as: HIV specialists, primary health care, support workers, peer networks, information, safer sex materials, harm reduction materials, mental health care and nutritious food.

To further complicate the situation, the staff at the agencies that do provide Rural and Remote supports are severely limited with the resources available to them. And many reflected on the fact that Rural and Remote work was done with project based funding, which meant that once the project was over, the services available, and more importantly, the connections and partnerships that were developed are lost.

Front-line staff are further challenged by the isolation of working in Rural and Remote settings, including isolation from peers, few opportunities for advancement and professional development, and low salaries.

SUMMARY OF RECOMMENDATIONS

STIGMA AND DISCRIMINATION

- Focus attention on Rural and Remote experiences in developing awareness campaigns.
- Build relationships and partnerships with diverse community groups, businesses and organizations to help build understanding of HIV/AIDS issues.
- Provide more opportunities for peer-based networking in Rural and Remote settings.
- Increase awareness among people living with HIV/AIDS and at risk for HIV of their rights and options.

FUNDING

- Flexibility and recognition that a variety of services are needed to address HIV/AIDS in rural settings.
- Support for long-term activities in Rural and Remote settings.
- All funders provide additional funding for evaluation requirements in their funding agreements.

TRANSPORTATION

- Flexible and accessible funding for Rural and Remote travel.
- Recognize and address the challenges of reaching communities for service provision.
- Support for infrastructure for travel.

SERVICES FOR PEOPLE WHO USE DRUGS

- Support for peer-based programs.
- Support for research in Rural and Remote communities to understand the role and impact of peer leadership and access to services.
- Education and awareness about the harm reduction approach to service delivery.

PARTNERSHIPS

- Longer-term funding models that allow for stable presence of AIDS Service Organizations in Rural and Remote communities to develop working relationships with other service providers.

INTRODUCTION

The Canadian AIDS Society is a national coalition of community based AIDS organizations providing services at the front line of Canada's response to HIV and AIDS. The Canadian AIDS Society came into being nearly 30 years ago, after a series of national consultations with front-line service providers. These consultations took place across Canada with an emphasis on the communities that were hardest hit by AIDS. Of the 16 founding members of the Canadian AIDS Society, the majority of them, while based in urban settings, were providing services to people living in or who came from rural communities. These issues are not new.

In preparing for this report, and in reviewing the issues affecting AIDS Service Organizations working in Rural and Remote settings the dominant experience shared was that of stigma and discrimination. Not surprisingly, then, the overall findings of this survey indicate that the biggest priority to be addressed is Stigma and Discrimination.

The Public Health Agency of Canada endeavoured to understand the attitudes of Canadians towards people living with HIV/AIDS in 2003 where they reported that "less than one in ten agree that they could not be friends with someone who has HIV/AIDS" and one in ten also believes that "people infected with HIV/AIDS through sex or drug use have gotten what they deserve." While these "one in ten" statistics are alarming, even more so is the fact that "a significant portion of the population… does not believe that people with HIV/AIDS should be allowed to serve the public in certain occupations like… dentists and cooks. In fact, almost half of Canadians (44 per cent) believe that they should not be allowed to serve the public in these capacities."[1] An update to that survey in 2012 revealed some changes in these attitudes: "thirty-two percent disagree that people with HIV/AIDS should be permitted to work in positions such as dentists."[2]

In 2011 the Social Research Centre in HIV Prevention and CANFAR engaged in a similar study, with the following findings: The number of people who felt they could not be friends with a person living with HIV/AIDS went from 9 to 8 percent. But wait, the number of people who are afraid of people living with HIV ***increased*** by three percentage points (from 13 to 16 percent) and the number of people who chose not to answer the question went up 6 percent (from 10 percent to 16 percent). The number of people who felt the people with HIV had themselves to blame stayed relatively the same, but once again, there was a significant increase in those who neither agreed or disagreed (up 8 percent). There is good news; Canadian's level of comfort seems to be improving across many scales (being friends with, buying groceries from a person with HIV), although there is also an increase in the level of discomfort of a friend dating a person with HIV[3] - perhaps due to the high visibility of HIV criminalization cases in the media.

While there is a positive change in what occupations are acceptable, there is still that underlying stigma. That feeling among a significant portion of the population that people living with HIV and AIDS are not deserving of the option to be a dentist, or a cook… it is not based on actual facts, it is based on the fear that hides behind the stigma and discrimination that is still being experienced by people living with HIV/AIDS.

1 Ekos. HIV/AIDS — An Attitudinal Survey FINAL REPORT (2003) accessed at http://pubs.cpha.ca/PDF/P15/21393.pdf, March 03, 2014.

2 Ekos. 2012 HIV/AIDS Attitudinal Tracking Survey Final Report (2012) accessed at http://www.ekos.com/admin/articles/038-12.pdf, March 24, 2014.

3 Calzavara, L et al. (June 2011) A National Research Report on Canadian Attitudes, Behaviours and Knowledge related to HIV/AIDS. SRC, CANFAR.

There is another key finding in our report that we need to examine in greater detail as well, and that is the issue of funding. Funding is a issue of the same proportions of stigma and discrimination. Health care costs being among the things cut when balancing provincial and regional budgets, the exploding costs of travel when we depend on fuel costs that keep going up and up, the need for population-specific resources in First Nation, Metis, Inuit, and African-Caribbean-Black communities and service for people who use drugs.

So, why then, is funding still an issue? According to our findings, it is a simple equation of need exceeding available resources. HIV has spread to become a disease affecting those most marginalized in our society and the needs have become more complex and more specific to the populations being served. This means no cookie cutter programs. One community may implement a naloxone program in an active peer-based, drug using community, while another may have problems even getting clean needles to the drug using community they know is there. And while money may not be the silver bullet in every case, the fact that there is a dearth of workers in Rural and Remote settings cannot be argued.

These two issues are high on the priorities of every rural worker we consulted, but there is more. We have amazing stories about peers based programming that is saving the lives of people using drugs, stories of strength and resilience of individuals and organizations and increasing understandings of need based on careful evaluation and consideration of the programs and services being offered in Rural and Remote settings. There is no one-stop solution, but the results of this work do show us what types of approaches are working in diverse communities.

BACKGROUND, GOAL AND OBJECTIVE

Approximately 20 percent of Canadians are living in rural communities[4] with rural being defined as communities with less than 10,000 people in its population. Remote is defined as being more than a 2-hour commute to the nearest rural community.

While HIV is often perceived as a predominantly urban issue, there is an increasing amount of qualitative and anecdotal evidence that demonstrates that HIV strongly affects Rural and Remote populations in Canada. Because "invisibility, isolation, and stigma are common in rural regions of Canada," people who are living with HIV in Rural and Remote regions often face important concerns when it comes to accessing confidential care and support[5]. Moreover, given the lack of basic and sexual health services in many Rural and Remote regions, let alone specialized HIV care, it is not uncommon for people who are living with HIV to have to leave their communities to access the services they require[6]. However, as a key informant who participated in a CAS-led project on HIV vaccine preparedness notes: "If I was out in the small community, where the heck am I going to go … if I'm poor and I'm not working, how am I going to get to town?"

Rural and Remote populations also face important issues in relation to HIV prevention. Misconceptions persist that HIV doesn't exist in Rural and Remote communities or that it only affects certain populations. A key

4 www.nationmaster.com/country-info/profiles/canada/people accessed March 4, 2014.

5 Groft, JN; Vollman, R. (2007). "Seeking serenity: living with HIV/AIDS in rural Western Canada." Rural and Remote Health, 7 (677), p.2.

6 Peters, D. (2011). "Small-Town Life." *The Positive Side*, 13(1).

informant in the aforementioned project reminds us that "people don't think that there's anyone with HIV here … they still think that HIV is a 'gay' disease." Similarly, a recent study published in the Journal of Rural Health showed that among a surveyed group of 1,777 rural Canadians, almost "25 percent thought that the disease was transmitted through casual contact."[7] Again, lack of access to confidential or anonymous services may limit people's ability to access HIV preventive information and tools, or to undergo HIV testing. As Orchard et al. state "Aboriginal people and others living in rural communities [are] less likely to [receive] HIV test when compared to those living in urban settings."[8]

This project was designed to be focussed on Rural and Remote service providers and the communities they serve. Our goal is to provide insight into the issues that are faced by Rural and Remote Service Providers.

Our objectives are to improve community-based prevention and support responses in Rural and Remote communities through the development of resources. And to increase the community's capacity to respond to needs related to HIV/AIDS through sharing knowledge, research and findings from the community-based experience.

METHODS

In order to understand the current state of the literature on this topic, the Canadian AIDS Society requested that the Ontario HIV Treatment Network (OHTN) conduct a rapid response review of the literature related to two questions: What are the challenges and barriers to providing HIV/AIDS services in Rural and Remote AIDS Service Organizations in Canada? And what are some of the best practices for serving Rural and Remote populations. The results of this literature review are available on the OHTN website at http://www.ohtn.on.ca/pages/Knowledge-Exchange/Rapid-Responses/RR73-2013-Rural-ASO.pdf.

In the fall of 2013 the Advisory Committee, working with staff from the Canadian AIDS Society developed the needs assessment survey, based on the priorities and challenges identified through the OHTN rapid response review and developed a means to confirm these findings, while expanding our knowledge about the areas identified in the literature review.

The survey was distributed in French and English to the members of the Canadian AIDS Society with a request to share the survey among relevant networks and beyond. The survey was developed using the Fluid Survey tool, In total we received 28 completed responses, plus 2 completed responses to our draft survey. There were 79 responses to the survey, of these 28 were complete and used in this analysis.

Representation from within the regions identified and used by the Canadian AIDS Society was well-divided, with the following breakdown of respondents.

Upon completion of collecting the surveys, we used the Fluid Survey tool to further analyze open-ended questions and present the findings here.

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7 ibid.

8 Orchard, T.R.; Druyts, E.; McInnes, C.W.; Clement, K.; Ding, E.; Fernandes, K.A.; Anema, A.; Lima, V.D.; Hogg, R.S. (2010). Factors behind HIV testing practices among Canadian Aboriginal peoples living off-reserve. AIDS Care, 22(3), pp.324-331.

Figure 1: Responses received by region.

Region	Number of responses
Atlantic	4
Quebec	2
Ontario	8
Prairies/NWT/Nunavut	7
Pacific (BC and Yukon)	7

A series of six key informant interviews were also completed to help us further understand both the needs and responses being offered in rural settings. Key informants were representatives of AIDS Service Organizations working with rural and remote communities and were selected to ensure national perspective. Representatives were from Yukon, British Columbia, Nova Scotia, Saskatchewan, Alberta and Quebec.

2: RESULTS

Thanks to the respondents of the survey, and of several key informant interviews, we are presented with a rich review of the services and programs, as well as the barriers to providing services in each area.

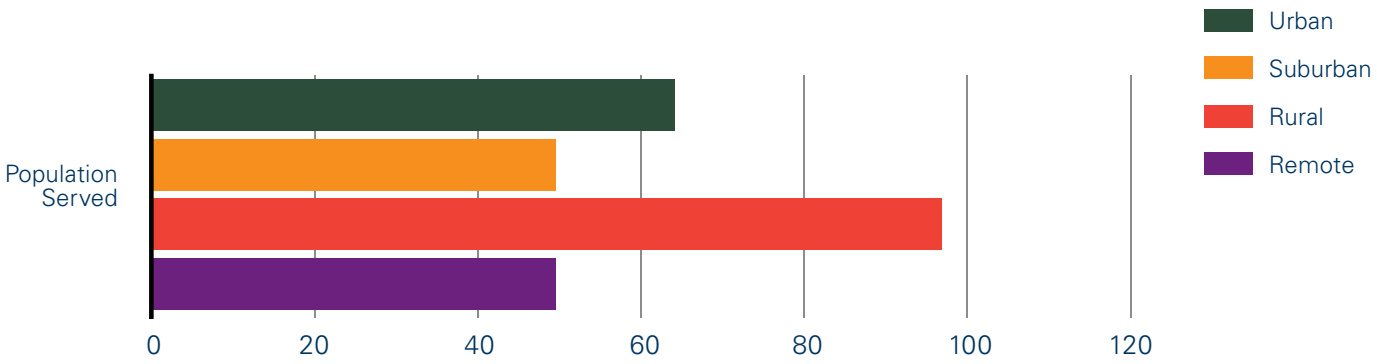
One of the most interesting findings observed in reviewing responses from different agencies is that different settings (and there are loads of them) need unique responses. There are pages and pages of unique responses described in this research, and that is what is important at the end of the day — understanding the threads of commonality that run through these unique responses. In the following review of the results, we will be focussing on those trends, in hope of identifying what needs to be considered in developing interventions that work in rural communities.

CHARACTERISTICS OF PARTICIPATING ORGANIZATIONS

The majority of respondents in this survey were front-line service providers (53.6 percent) with Executive Directors and Managers making up most of the balance (35.7 percent). Of those that completed the survey 82.1 percent were AIDS Service Organizations, with community health centres and regional health authorities making up the balance.

Even now, we are seeing agencies that are based in urban settings providing services to rural communities, with 64.3 percent of the organizations providing Urban and Rural/Remote services (see figure 2).

Figure 2: Which of the following populations does your agency/organization/program serve (select all that apply)?



When we reflect on the distances that service users have to travel, and the size of the jurisdiction, we begin to see some of the complexity of the challenges facing clients when it comes to accessing service providers. Almost two thirds (64.3 percent) of service providers have service users who live between 50 and 500 kilometres from their agency. An additional 10.7 percent have clients that are more that 500 kilometres away.

In our survey, 74.1 percent of respondents indicated that there are people who live outside of their jurisdiction who access services (we'll see the issue of jurisdictions come up again, particularly when dealing with on and off-reserve First Nations communities.)

About half of the agencies that completed the survey are providing services to between 0 and 500 individuals each year, and another 35.8 percent are serving in excess of 500 clients per year. Further analysis reveals that this is in part due to the number of urban based organizations providing services to rural communities.

People living with HIV/AIDS do make up a significant proportion of people seen — indicating that people living with HIV/AIDS are actively using the services. However, these organizations report relatively small numbers of people living with HIV/AIDS coming from rural settings. 42.9 percent of respondents indicated that less than 25% of the people living with HIV/AIDS live in Rural and Remote communities.

While AIDS Service Organizations provide the bulk of the supports for people living with and at risk of HIV/AIDS, the rural setting is not always their only region. As a matter of fact, the bulk of respondents (67.9 percent) indicated that less than a quarter of their resources were spent on Rural and Remote services. Only 10.7 percent of respondents indicated that 76-100 percent was spent Rural and Remote communities.

AIDS Service Organizations, which make up the bulk of respondents, range widely among the options for the number of people on staff. The median is in the 7-10 full time equivalents range, while community and regional health show no trends.

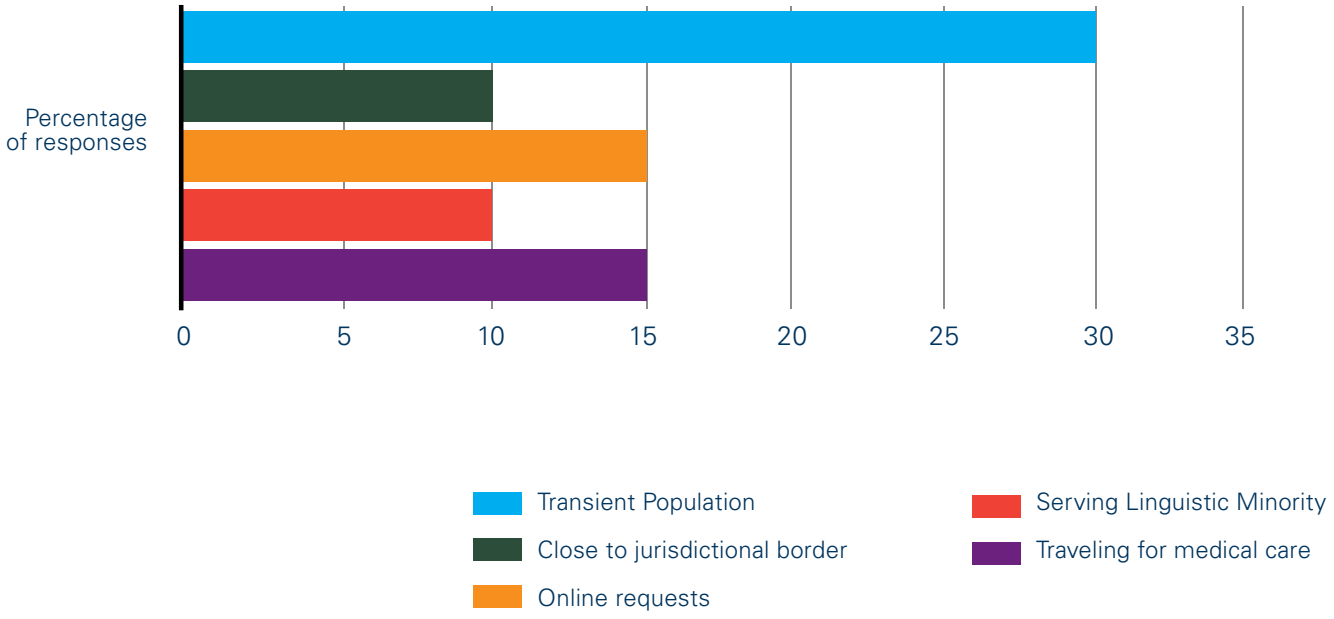
Figure 3: How many staff does your agency employ full time?

	1-3	4-6	7-10	11-15	16-20	More than 20
AIDS Service Organizations	5	3	7	3	1	3
Community and Regional Health	2	0	1	1	0	1

As with many community-based organizations, there is a dependancy on volunteers to guide and support the agency. 74 percent of respondents indicated that they had between 1 and 15 full time equivalent volunteers.

The challenge of regions and jurisdictions came up repeatedly in the results of this survey. Further exploration of the topic of who is served from outside a organization's jurisdiction revealed a number of reasons. See figure 4.

Figure 4: Please elaborate on people outside your jurisdiction who access services.



As one participant reported, it is difficult to determine what is within one's jurisdiction: "sometimes the only identifying information we have is a name and a phone number…sometimes people are from one of the communities I serve and they are away for work. In both situations I would be expected to contact these clients."

Word cloud: the above word cloud was created using an online tool[9] for text analysis. The text submitted for analysis consisted of the responses to the open-ended question: "What makes your community unique?" Both French and English language responses were included in the original submission. We have translated the results in order to give an accurate representation of the response rate. The cloud gives greater prominence to words that appear more frequently in the source text.

WHAT MAKES RURAL AND REMOTE COMMUNITIES UNIQUE?

Almost all organizations (96.4 percent) surveyed in this assessment reported that they were serving Aboriginal people, and 32 percent reported serving immigrant or refugee populations. Additional populations served include: Prisons/prisoners (67.9 percent), migrant work camps (21.4 percent), college or universities (75 percent) and seasonal populations (39.3 percent.)

There are several identifiable categories that come up when answering the question "what makes you unique". Recognizing that this question, will garner a variety of comments, the following represent some of the key themes identified.

9 http://www.wordle.net/ accessed March 22, 2014

STIGMA AND DISCRIMINATION

* "Isolation and fear of stigma in their own community."
* "Concerns around privacy while attending HIV/AIDS related appointments."
* "Worries about confidentiality."
* "Another huge barrier is stigma and discrimination which hinders individuals from coming into the office site for visits."

TRANSPORTATION ISSUES

* "There is a need for newly diagnosed HIV patients to travel to Vancouver 3 or 4 times to receive medical care."
* "Transportation between communities can be challenging/impossible for many, and accessing services like doctors, counselling, education, pharmacies, and amenities can be incredibly challenging."
* "There is also a lack of support in terms of transportation in rural communities, so we also provide assistance in this regard."
* "Our rural community has no public transit thereby making clients rely on volunteer drivers to get them to specialist appointments between 1 and 3 hours away."

DRUG USE

* "Homelessness and addictions are a strong factor in the lives of those we support."
* "Some reluctance to access harm reduction supplies, especially needle exchange."
* "The collaborative arrangement between the provincial needle exchange's outreach program, where *AIDS Service Organization* staff go out in the community with *Harm Reduction Organization* staff to promote prevention material and needles, etc."
* "Significant addictions issues, undercurrents of racism, discrimination and stigma related to addictions/HIV/poverty."

LARGE GEOGRAPHICAL AREA

* "In our health zone we have the 3rd largest population in the second largest zone. We also have 7 First Nations reserves."
* "This community includes two towns, one about 10,000 people and one 6,000 people, and an Aboriginal community of about 14,000 people. The aboriginal community is spread over 5 reserves and about 100 square miles."
* "Geographical distance and diversity add challenges to providing services as travel costs and expenses can be exorbitant in comparison to other provinces."

ABORIGINAL COMMUNITIES: NH (NORTHERN HEALTH)

This single quote captures the complexity that can be at play in providing services.

* "We have 7 different First Nation communities within our service area and 80% of our population is first nations. Each of the first nations communities has their own community health station staffed by at least a part time RN and others LPN's, HCA's, etc... We are a NH ***(Northern Health)*** facility and serve all the non aboriginal residents and any first nations persons that choose for any reason to come to us. We have developed long standing relationships with the 7 communities and share the care of the first nations residents well. A strong spirit of collaboration exists for doing this work. On the other hand the first nation health stations are not allowed to provide any care for non first nations residents so their care is solely our responsibility. Only ***one community's*** Health RN's have obtained certified practice in STI management so we share this care with three of the first nations communities and provide this care to the other 4 first nation communities ourselves. It is a very interesting community to live and practice in. Very unique."

LACK OF MEDICAL SERVICES

* "There is a lack of doctors, no drop in clinics in our region."
* "Many people do not have a family doctor. It is difficult and often impossible to find counselling or health care specifically around HIV/AIDS or LGBTQ issues."
* "Must access the urban centre for certain services, such as HIV care, access to Methadone etc. Inadequate primary health care in rural settings."

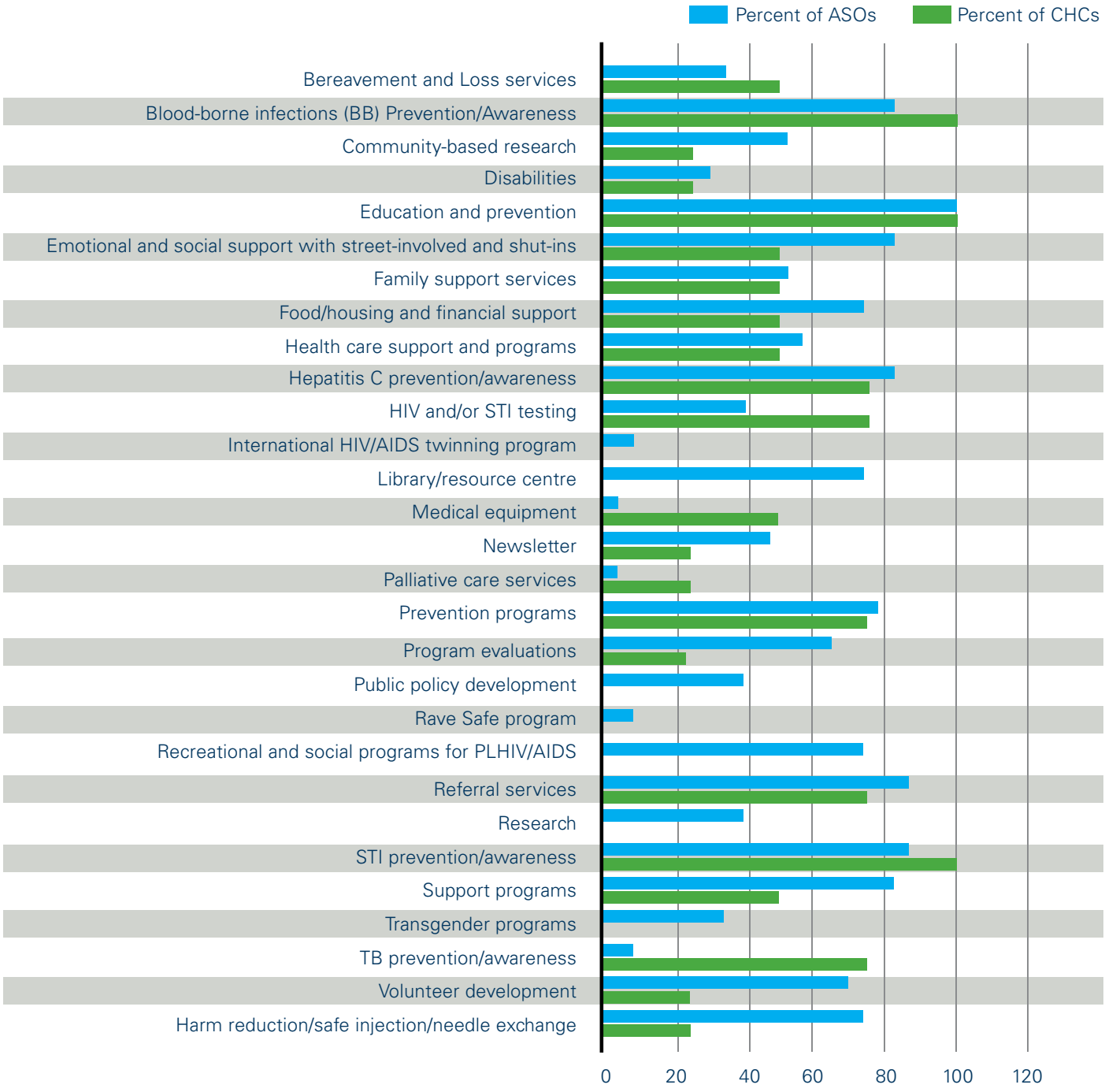
SOCIAL DETERMINANTS OF HEALTH

* "Challenges include poverty, addiction, homelessness, unemployment and street gang activity."
* "Lack of access to practical support in their own community (i.e. food banks), Poverty…"

SERVICES AND GAPS

Figure 5 shows the breadth of services being offered at each agency. What is lacking is an analysis of which of these services (if any) are available in Rural and Remote only settings. As has been noted earlier, the service organizations responding to this survey often serve both rural and urban populations. We will see later on in the data that there are issues related to access daily support services testing, care and support in rural areas.

Figure 5: Service offered by ASOs versus community health centres



While a relatively small sample of community health centres responded, the trend seems to be that more HIV/AIDS services are available through AIDS Service Organizations. This is to be expected, given the specialization of AIDS Service Organizations, however, the question of which of these services are available in Rural and Remote settings is not answered. This will tie in to the question of funding that is coming up.

Figure 6 outlines the variety of ways that service delivery can happen in a rural setting, with an emphasis on individual contact.

Figure 6: How people in rural/remote settings get access to service.

How we provide services to rural/remote service users.	Percentage
They come to us	92.9
We go to them	71.4
Phone	92.9
Email	75
Web-based services	64.3
We bring them to us	7.1
Regular mail	3.5
Outreach to community groups	7.1

When asked how much access people have to a series of services an alarming number of responses fell into the Limited to None range. The following results are ranked from highest to lowest in this range.

Figure 7: How much access do people living with HIV/AIDS in your rural/remote communities have to the following expertise, materials and service, ranked.

Service	None (%)	Limited (%)	Adequate (%)	Substantial (%)
HIV Specialist	17.9	67.9	14.3	0
Peer Engagement	7.4	77.8	14.8	0
Nutritious Food	0	82.1	17.9	0
Mental Health Care	0	78.6	21.4	0
Support workers	3.6	64.3	28.6	3.6
Harm Reduction Materials	7.4	66.7	22.2	3.7
Information	0	60.7	39.3	0
Safer Sex Materials	0	60.7	32.1	7.1
Primary Health Care	0	55.6	33.3	11.1
High speed Internet	0	52	44	4

Here we begin to see a bit more about the lack of access to services (some of which are provided by our AIDS Service Organizations in urban settings.) Health care services, however appear to be a priority, along with nutrition, ranking three out of the top five.

Overall there is a trend of ranking services to specific populations (women, youth, men, Aboriginal people) in rural settings as being met poorly compared to the general urban population served.

Figure 8: Relative to the general urban population that your agency serves, how well are the HIV-related needs of the following populations in your jurisdiction being met?

Population	Rural	Urban
Women	15	5
Youth	13	7
Men	13	5
Aboriginal people	11 - off reserve 14 - on reserve	7

ORGANIZATIONAL NEED

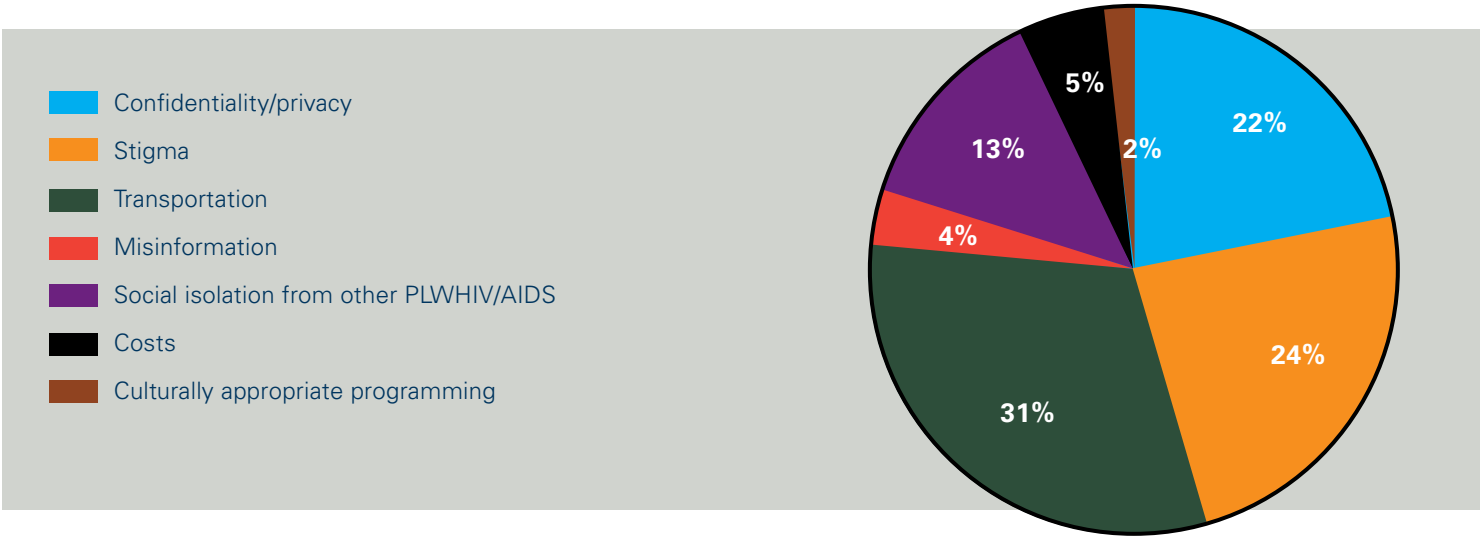
When asked what would most help their agency meet the needs of people living with HIV/AIDS in Rural and Remote setting, 18 out of 23 AIDS Service Organizations responding to this survey indicated that funding is their greatest need. When you add the number who ranked it second, that number increases by another 3 to a cumulative total of 91.3 percent of AIDS Service Organizations identifying funding as the most helpful. The next closest ranked item was partnerships with other agencies, but at close to fifty percent of the responses. The ranking revealed that the following priorities (starting with most helpful):

1. MORE FUNDING
2. More partnerships with other organizations
3. More peer mentoring
4. Better technology
5. More mentoring opportunities for staff
6. More professional development for staff
7. Better Policies and Procedures

BARRIERS AND CHALLENGES

Transportation is a significant issue when it comes to barriers for people accessing services in rural settings. As we have seen above, the most common means of accessing services is either attending the service agency (usually in an urban setting) or having the service brought to the service user. Some agencies report paying for travel for people living with HIV/AIDS or coordinating volunteer travel while others speak of the lack of public transit between towns as a barrier. It was rated 1st and 2nd most significant by 30.9 percent of survey respondents. See figure 9 for a complete breakdown of the top 2 most significant barriers for rural service users.

Figure 9: Barriers for rural service users



Respondents also identified lack of access to service providers as a significant barrier in providing services to Rural and Remote people living with and at risk for HIV/AIDS.

Unfortunately barriers exist for front-line staff in providing services. Here is where we learn more about the understaffing of workers in this field. Figure 10 shows the cumulative score over the top three (of eight) for each identified challenge. A follow-up question asked for any additional challenges to be identified. The most often noted response in that question was an observation that staff are overworked, the agencies are understaffed and left unstable due to high staff turnover.

Figure 10: The most (top 3 most significant) challenging issues front-line staff face

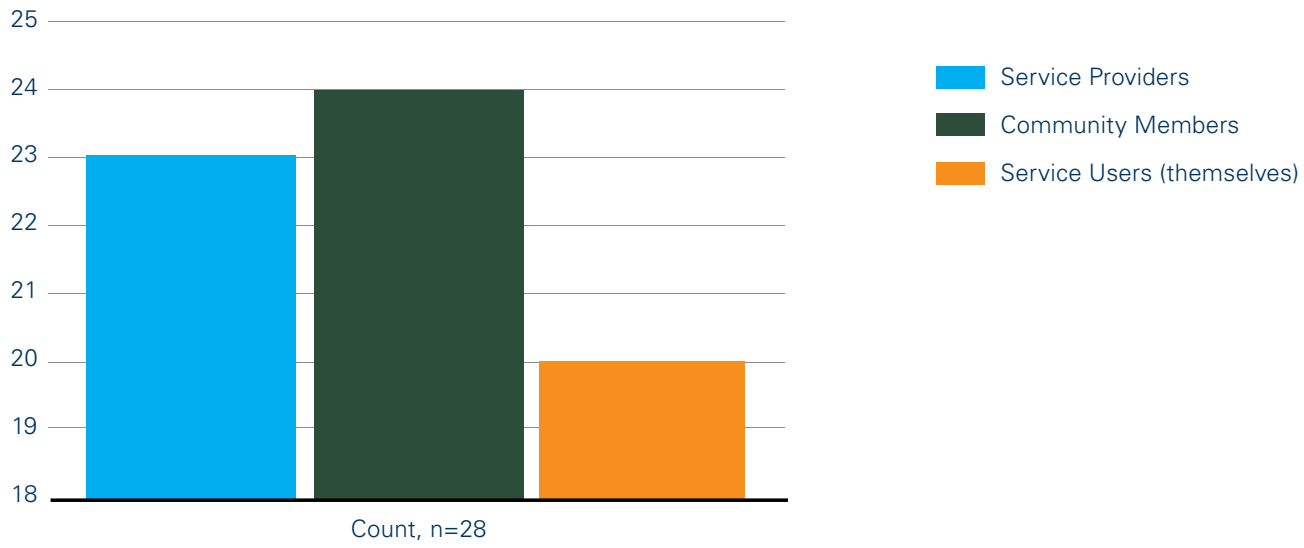
Challenge	Ranked significances
Pay	16
Travelling and transportation	14
Opportunities for professional development	13
Isolation from peers	13
Few opportunities for advancement	12
Morale	4
Appropriate policies/procedures	3
Technology (e.g. access to high speed internet)	2

Finally, we need to look at the challenges that the organizations themselves face in reaching out to rural communities, particularly since a significant number of organizations are serving both urban and rural communities. Once again, our top issues include community mindset (24.1 percent), transportation (27.8 percent), stigma (16.7 percent) and confidentiality/privacy concerns (14.8 percent) and a write-in for funding (44 percent). Additiional write-in responses included reserve boundaries and prohibitive policies regarding harm reduction in some communities,showing the breadth of challenges faced by organizations seeking to do HIV/AIDS work in rural communities.

STIGMA AND DISCRIMINATION

Here is where it gets hard.We need to look at stigma and discrimination, closely, and understand where it is coming from. When asked for the source of stigma and discrimination, the responses were all high — as in stigma and discrimination is coming from many sources. Figure 11 shows these alarming results.

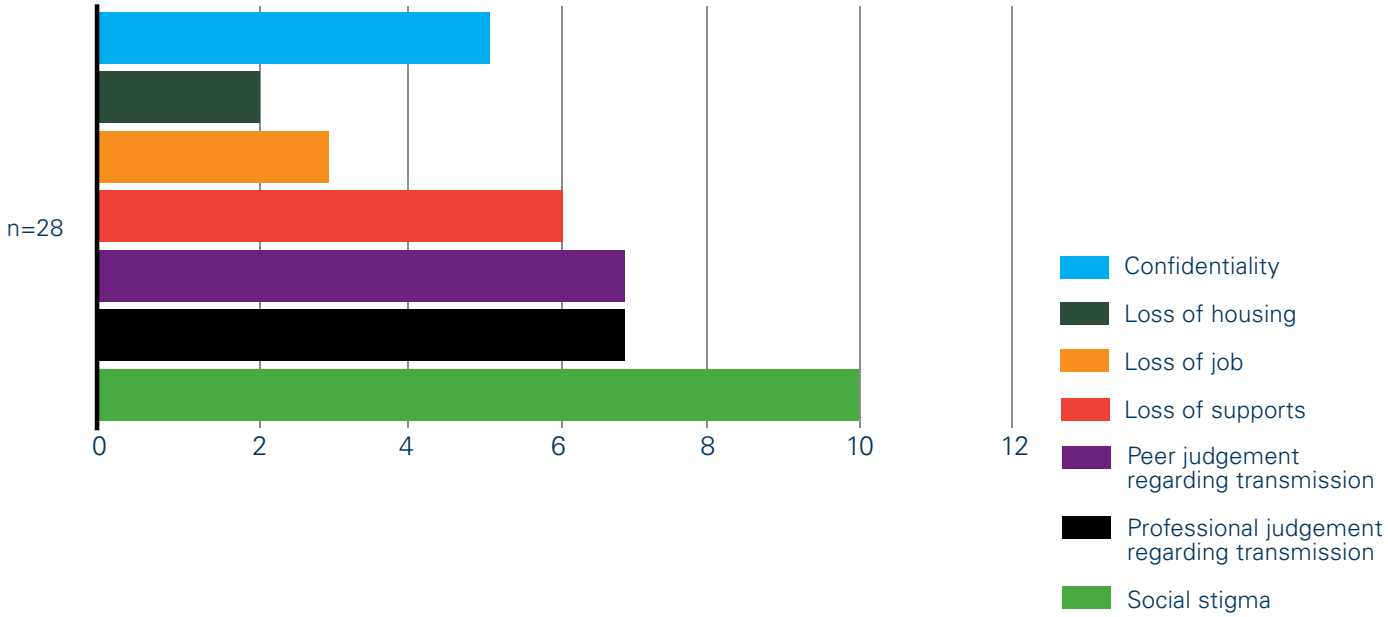
Figure 11: Have you seen any examples of HIV stigma coming from the following sources?



When asked to share specific examples there were several general areas that described these examples (see Figure 12).

- Confidentiality: "staff thinking that the bus driver for a facility NEEDS to know."
- Loss of housing and job: "people won't rent to HIV related people, won't give them jobs don't want to share space won't eat with them present."
- Loss of supports: "There is a specific dentist office in our Community that has refused to do dental work on a member of agency name due to their HIV Status."
- Peer judgement regarding transmission: "A PHA entered through our back entrance, a volunteer assumed this person was a Needle Exchange client; the PHA was offended and did not want to be associated with that population and asked if there was another door to use.
- Professional judgement regarding transmission: "staff in acute care do not know how to manage addictions - lots of blame and "they should just pull up their socks" attitude." "Service providers - different reactions to how PHA "got" HIV."
- Social Stigma: "community members fear our clients and see them as undeserving of help or causing the duress that they are in."

Figure 12: Specific Types of Stigma

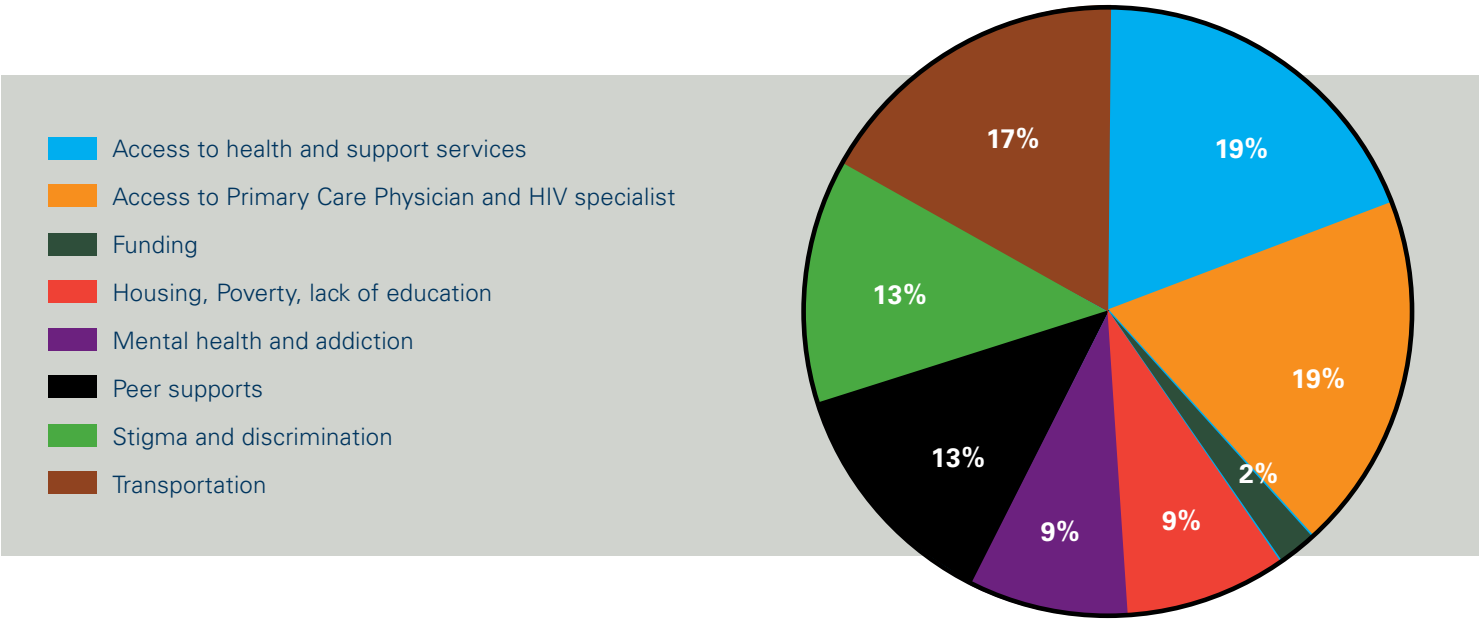


When asked what issues or specific populations warranted further study, the results showed overwhelming demand for research and further study on the needs of Aboriginal communities, harm reduction in rural areas and provisions of support in rural areas. Other topics included: stigma and discrimination, migrant workers, organizational supports and the social determinants of health. There was also the opinion that there has been a lot of research done with some of the communities and that it is now time for action.

UNMET NEEDS

An open-ended question invited survey participants to identify the most critical unmet needs among rural/remote people living with HIV/AIDS in your area. The results have been coded for similar issues and are presented in figure 13.

Figure 13: What are the most critical unmet needs of PLWHIV/AIDS in rural/remote settings?



Specific concerns raised reflect the diversity of needs in these communities:

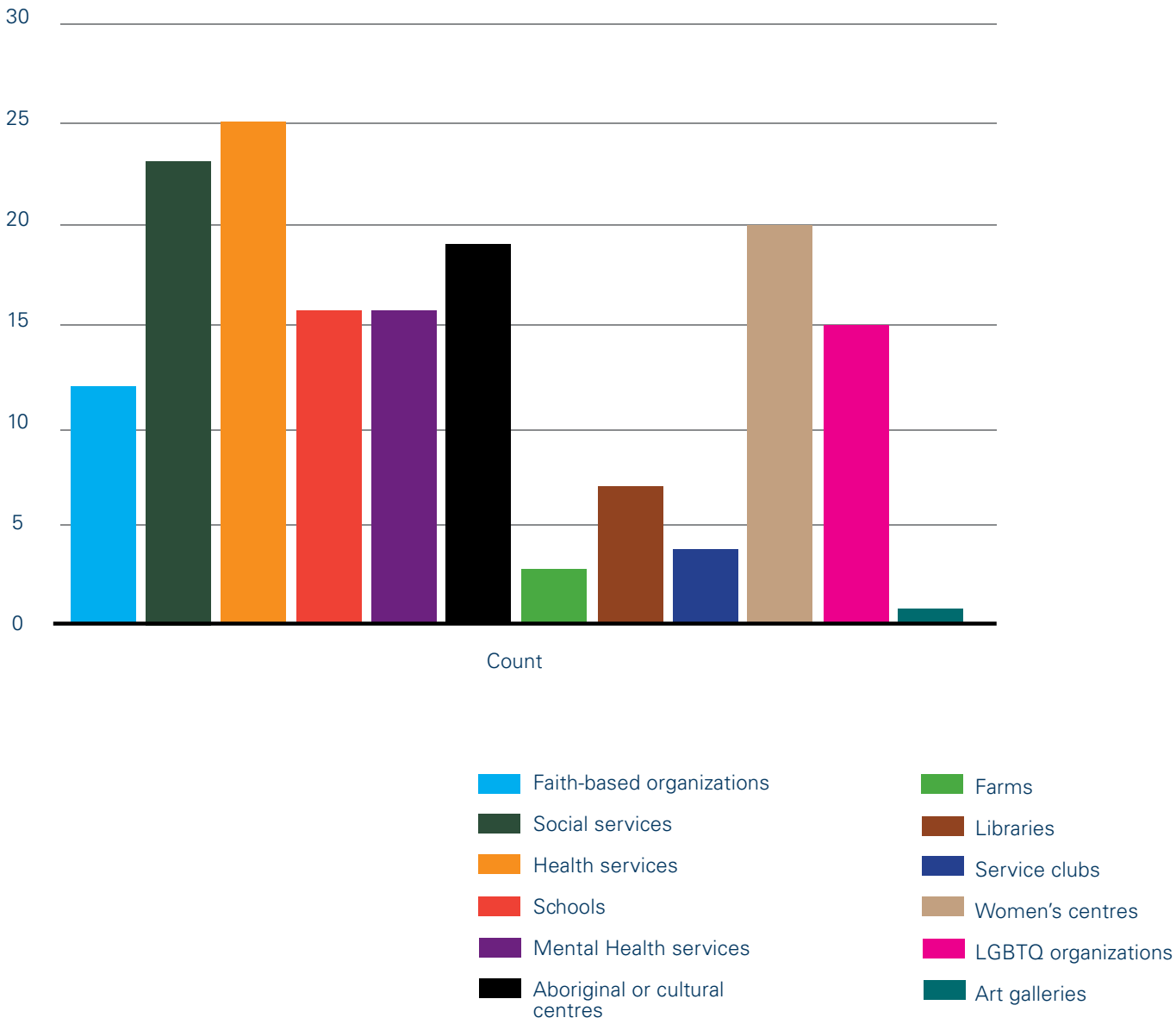
- "Having a safe needle exchange program and the stigma (related to confidentiality issues)."
- "Fear of stigma keeps most rural people living with HIV/AIDS in our area quiet about their diagnoses."
- "The biggest area of educational need is those in their early 20's who haven't been exposed to the current school curriculum and educational program. They are living with old information about HIV/AIDS and they are the ones we need to reach."
- "Low threshold medical services for folks who are actively using."
- "Challenges in getting on Hep C treatment."
- "Distance, time of year, condition of transportation systems, peer support."
- "Stigma and discrimination from community leaders."

When compared to urban needs, we see that there are similarities, particularly in the areas of stigma and discrimination and access to adequate support services. There is a demand being left unmet in both rural and urban communities.

PARTNERSHIPS

An important part of breaking down stigma is partnering with groups to provide education and awareness. In addition, it opens up awareness of needs from people living with HIV/AIDS and opens doors to services that are not HIV-specific.

Figure 14: Types of partnerships



Partnerships with each of the groups described in figure 14 tend to be reported as somewhat to very effective, with only 1 group reporting that it was not very effective. There is no trend in what type of partnership is considered more effective than others.

There are two trends when looking at what has worked in the past two years, and that is the benefits of building collaborative partnerships with community agencies and the importance of engaging people living with HIV/AIDS is providing services, particularly education and outreach.

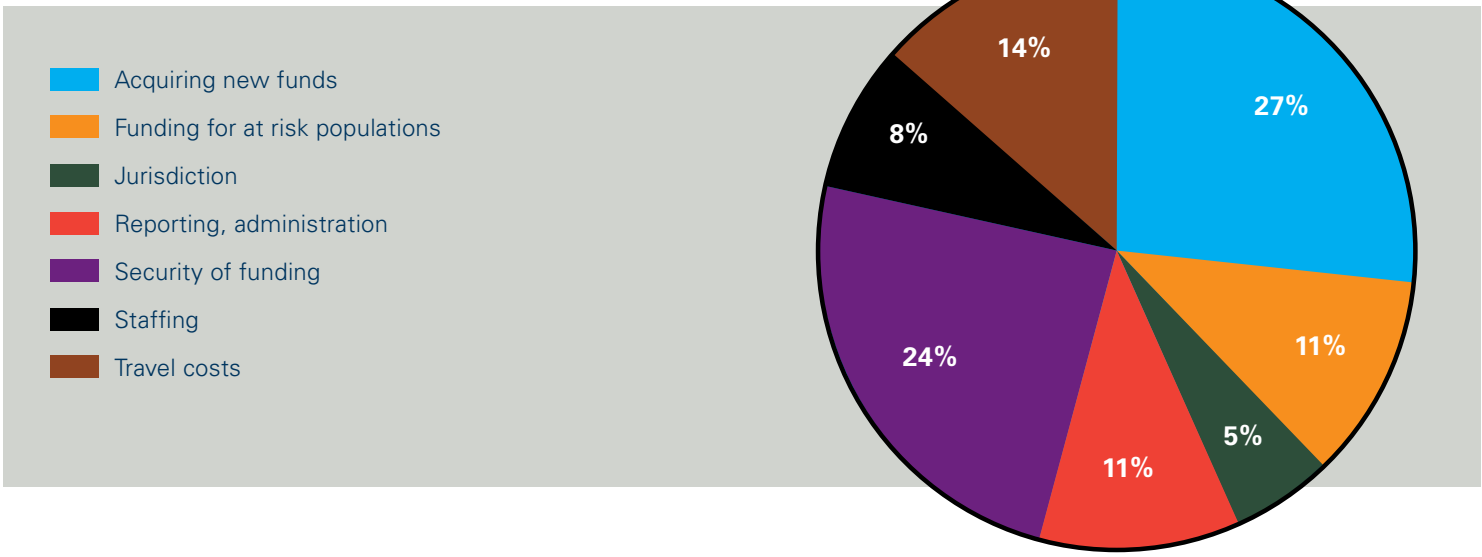
Respondents identified the following as having worked especially well with rural or remote populations:

- "Our Frontline Warriors are a group of members living with HIV/AIDS/HCV that attend education (presentations) with our Education Department to speak with a voice of someone living with the disease. It helps with stigma and discrimination."
- "We had funding for a six month rural communities project. Lots of great outcomes - connections with schools, service providers, health units, etc. - lots of presentations - building relationships." Unfortunately there was no ongoing support for the project, so the outcomes were lost.
- "Using individuals that hold some "power" in a rural area and get them on board."

FUNDING

Funding is a significant concern for the agencies surveyed, with acquisition of new funds and security of funding being the biggest concerns.

Figure 15: What are your greatest funding challenges?



3: DISCUSSION AND RECOMMENDATIONS

Trends identified in the findings indicate that there are some common concerns in service delivery for Rural and Remote communities. What is also evident, is the fact that there is no one-size fits all solution. While one organization has consulted and been told that they are needed as content experts who come into the community to provide services, another agency refers to this type of service provision as "seagulling" (swooping in from nowhere and depositing information, which may or may not be used).

Common threads in the responses indicate that the service providers are all well-versed in the needs that their communities have. We have a glimpse at the diversity of services provided in urban settings and the gaps in Rural and Remote settings is significant. While efforts are in place to bring services to Rural and Remote service users, there is still a large number of agencies working to bring service users to them - at no small cost for transportation in some cases. The complexity doesn't end there either, as service users are in need of supports and services from various providers, most of whom are not available in Rural and Remote settings. The results of this survey indicate that for Rural and Remote populations of people living with and at risk for HIV/AIDS are severely limited to resources such as: HIV specialists, primary health care, support workers, peer networks, information, safer sex materials, harm reduction materials, mental health care and nutritious food.

To further complicate the situation, the staff at the agencies that do provide Rural and Remote supports are severely limited with the resources available to them. One informant spoke about the need for flexibility in travel subsidies from funders — indicating how difficult it was to predict the number of times they would have to visit any one community, and asking how to provide services to someone in crisis when you have already made your annual allocation of visits to this site. And many reflected on the fact that Rural and Remote work was done with project based funding, which meant that once the project was over, the services available, and more importantly, the connections and partnerships that were developed are lost.

Front-line staff are further challenged by the isolation of working in Rural and Remote settings, including isolation from peers, few opportunities for advancement and professional development, and low salaries. Surprisingly, the issue of low morale was not seen as significant, perhaps indicating that there are additional, non-monetary benefits to working in this field. This may be mitigated by reports of high staff turn-over and burn-out however.

STIGMA AND DISCRIMINATION

"We continue to see some agencies that do not want to serve individuals living with HIV/AIDS. Often it is difficult to get homecare... (they have) staff who do not educate themselves around the universal precautions and often treat the individuals with below average service."

The number one concern identified in this analysis is the spectre like presence of Stigma and Discrimination. It exists everywhere and seemingly lingers in the most unexpected places. It has been reported among professionals (doctors, service providers, nurses), peers and in the public domain. So what do we do about it? Filing human rights complaints is one avenue, but will it put a person living with or at risk of HIV into secure housing. Eventually, perhaps… Education takes time and relationship building at many levels — an excellent approach for individuals seeking to do something, and likely the reason that there is not more discrimination.

One of the biggest challenges with the current "come-and-go" style of rural outreach is that it is difficult to develop and maintain working relationships with individuals. One group reported "We had funding for a six month rural communities project. Lots of great outcomes - connections with schools, service providers, health units, etc. - lots of presentations - building relationships. Did not receive funding to continue project." So over time these connections will be lost again.

Probably the most alarming report of stigma (if there were such a hierarchy) is that of stigma among clients and service users. This is clearly an example of how communities break down under financial pressure. With a limited amount of resources available, there is no way to meet everyone's needs, so it becomes a matter of economics and a bit of common sense that programs be developed for the highest risk groups in a community. But then, we are left with the situation of one group accessing services that may not be available to another group, which causes friction.

Stigma from service providers is an issue long-since identified as a concern in the HIV/AIDS movement. Recommendations of improved education may be reaching some providers, but there are still too many reports of stigma and discrimination with this group. While efforts are reaching service providers in urban settings, there seems to be a delay in this information reaching Rural and Remote settings, based on the concerns raised here. Additional challenges facing

A National Partnership in Fund and Awareness Raising

One thing that the Canadian AIDS Society does is support the Scotiabank AIDS Walk for Life in 16 Rural and Remote communities across Canada. This national event could not exist without the endorsement of some of the largest cities in Canada, but what is so unique about this event is that it is built to be both a fundraiser and an awareness raiser in all communities. Some of the best stories from the Scotiabank AIDS Walk for Life come from Rural and Remote communities.

...cont'd

service providers, such as high staff-turn-over and burn out indicate that there are issues that need to be addressed in the service providers' domain as well.

In 2006 the Canadian HIV/AIDS Legal Network came out with a comprehensive plan of action for Canada to reduce HIV/AIDS-related stigma and discrimination. This document included roles for all members of our communities — from elected leadership to individuals. It listed a number of actions to change public attitudes, including calling for support for "year-round campaigns with strong local community involvement to change negative attitudes toward people living with HIV/AIDS or vulnerable to HIV infection."[10]

This report, with 18 goals and 17 pages of recommended actions was published in 2004, a decade ago, yet it remains every bit as relevant today as it was then. It includes strategies for dealing with stigma and discrimination as a rights based issue, but also has concrete examples of steps that can be taken at a variety of levels to help mitigate the impact of Stigma and Discrimination.

RECOMMENDATIONS

- Focus attention on Rural and Remote experiences in developing awareness campaigns.
- Build relationships and partnerships with diverse community groups, businesses and organizations to help build understanding of HIV/AIDS issues.
- Provide more opportunities for peer-based networking in Rural and Remote settings.
- Increase awareness among people living with HIV/AIDS and at risk for HIV of their rights and options.

In the north, the Canadian Inuit HIV/AIDS Network hosted walks in all 53 Inuit communities. While the intent was to never raise a cent, the event brought people from the entire community together to learn about HIV and to show support for people living with HIV/AIDS. This helped to raise awareness of everything from transmission to knowledge of the social issues facing people living with HIV and helped address some of the stigma around HIV.

10 deBruyn, Theodore. (2004) *A Plan of Action for Canada to reduce HIV/AIDS-related stigma and discrimination.* Canadian HIV/AIDS Legal Network. Montreal.

FUNDING

"What I could really use is some core stabilized funding so that it allows me to do various activities in these communities, and to have presence in these communities on a more ongoing basis."

Perhaps one of the most oft-mentioned funding issues is that it is always time-limited. Because Rural and Remote communities were late to the funding table, by and large they missed out on the opportunity to qualify for core funding under the AIDS Community Action Program. This leave project-based funding as the main source of accessing funds for the majority of communities. This is problematic, as there are more limitations on it, and traditionally it has been very time-limited.

The Canadian AIDS Society has focussed its attention on the issue of funding at the federal level for a number of years now. In a time of extreme cuts to community-based organizations, funding for HIV/AIDS has remained stable. But as this report points out, there are severe gaps in delivery of the most basic services that tells us that status quo is not an option. Community needs are growing, and funding is not — this takes an already tight fit and makes it impossible to squeeze into.

There is hardly an issue that has been raised that cannot be helped by additional funding. Money cannot be seen as the silver bullet, there are issues of staffing, access and relevance to community need that must be addressed as well, however, stable, and secure funding would go a long way to addressing the other significant concern raised in this assessment — transportation.

RECOMMENDATIONS

- Flexibility and recognition that a variety of services are needed to address HIV/AIDS in rural settings.
- Support for long-term activities in Rural and Remote settings in the following areas:
- Increased education and awareness through targeted public campaigns.
- Increased access to daily living services and supports for people living with HIV/AIDS.
- Increased access to confidential testing and treatment.
- All funders provide additional funding for evaluation requirements in their funding agreements.

A Step in the Right Direction

In 2013-14 the federal government extended agreements with AIDS Service Organizations for a three year period. This included funding under the AIDS Community Action Program and the First Nations, Inuit and Metis Off-Reserve Fund. While many Rural and Remote activities are still being run as time-limited projects, the commitment for three years allows groups to plan longer-term partnerships and provide more of a presence in some communities.

TRANSPORTATION

"You can go from having someone quite stable to in total chaos within the space of a week ... when something fairly small like transportation changes," participant speaking of what happens when a person loses access to transportation in a rural/remote setting.

"Having to travel to a major city... to attend clinic. Lack of support groups because of numbers of PHAs staying in rural communities. They all seem to think they need to be in the city because of services, transportation, etc."

There are so many sub-issues in the area of transportation — costs of fuel, estimating travel costs for funders, accessing funding for transportation, public transit between communities and within communities, recruiting volunteers, dealing with confidentiality with medical drivers etc.

What to focus on? Within the parameters of this report, there seems to be an emphasis on the challenges of travelling to and between communities as a barrier to service delivery. This brings into consideration many things that we have no control over — weather, road conditions, the existence of roads and/or public transport. But perhaps one thing we do have control over is the flexibility in funding to allow organizations to visit communities when there is a crisis or immediate concern, and to recognize that it is worth the investment on behalf of the agency to spend a day, or even several days, in transit in order to provide services to a small number of people.

Many respondents noted that while their mandate was provincial, there were no additional resources provided for travel within the region. "Funding doesn't allow for realistic provincial outreach despite being designated as a provincial organization." "Even though we are funded to serve the entire territory/province, we are not appropriately funded to do so."

RECOMMENDATIONS

- Flexible and accessible funding for Rural and Remote travel.
- Recognize and address the challenges of reaching communities for service provision.
- Support for infrastructure for travel.

Provincial Women's Retreats

Positive Women's Network recognized the value and benefit to service users to be together at times, building personal relationships among a group of peers. Several times over the course of the year they offer the opportunity for women from across the province to come together on a weekend retreat. "Weekend retreats are a wonderful opportunity for HIV+ women from across BC to come together for peer support, fun, relaxation and sharing information. All costs are covered by PWN, including travel costs for women coming from across the province."[11]

11 http://pwn.bc.ca/programs/support-programs/ accessed March 17, 2014.

SERVICES FOR PEOPLE WHO USE DRUGS

*One trend that perhaps not all would expect is the prevalence of programs and services needed for people who use drugs. As one respondent noted "HIV and Hep C prevention is largely focussed on harm reduction around drug use. That is the main modality of infection in **territory/province** around Hep C and HIV is through risky drug use."*

Respondents in the survey spoke often how drug use in Rural and Remote settings is a significant challenge, and that the responses needed were inclusive of peers. "Homelessness and addictions are a strong factor in the lives of those we support." "A lot of rural communities have had to come and rely on us for HIV/hepC/IDU (i.e. … needle exchange programs) services as these services are not available."

One group spoke of a "reluctance to access harm reduction supplies, especially needle exchange" within Rural and Remote communities. This may be tied to concerns about confidentiality and to the need for more education with community leaders to help understand the objectives of harm reduction programs.

This is an area identified as one that requires additional research and planning according to the participants in our survey and our Key Informants.

RECOMMENDATIONS

- Support for peer-based programs.
- Support for research in Rural and Remote communities to understand the role and impact of peer leadership and access to services.
- Education and awareness about the harm reduction approach to service delivery.

Getting Together on Harm Reduction

A recent Canadian AIDS Society project on Harm Reduction in rural setting brought together service providers to learn about best practices in Rural and Remote settings. A series of webinars and networking teleconferences culminated in a Rural and Remote stream offered by the Canadian AIDS Society at the Alberta Harm Reduction Conference. Recommendations from this project clearly reflect the need for services for people who use drugs in Rural and Remote settings.

COLLABORATIVE MODELS

"We work very collaboratively with other organizations in town to make sure that we are not duplicating services, but we do a lot... Making sure that the basic social determinants of health are all sort of taken care of..."

There is a lot of work to be done to provide the services and supports needed by people living with HIV/AIDS and at risk of infection with HIV and all group interviewed agreed that collaborative community relationships are somewhat to very helpful in their communities. There is a consistent focus on not duplicating services within the communities surveyed and outreach to diverse groups is evident in the response to the types of organizations that partnerships are evident in.

Increasingly AIDS Service organizations are being asked to take on expanded mandates — including Hepatitis C, sexually transmitted infections and blood borne infections. This was repeatedly reported in the surveys and key informant interviews.

RECOMMENDATIONS

- Longer-term funding models that allow for stable presence of AIDS Service Organizations in Rural and Remote communities to develop working relationships with other service providers.

Partnerships Abound

Northern AIDS Connection Society prides itself on partnerships that have been created, enhancing capacity within the community. The Condom Co-op, allows members to access condoms at a reduced cost, sharing the benefits of bulk purchases. The collaborative arrangement between the Mainline, the provincial needle exchange's outreach program, allows NACS staff go out in the community with Mainline staff to promote prevention material and needles, etc. The Northern AIDS Connection Society has found ways to be innovative in partnering with community groups by sharing the resources from the AIDS walk, ensuring that education around HIV is provided by partner groups within their communities. They also work with the local Food Bank by putting prevention education material as well as condoms into each bag along with their contact information.