Adult Working Group's Cross-National Consultations on Health and Learning Final Report on Adults Living in Rural and Remote Areas

Adult Working Group (AWG)
under the auspices of the
Health and Learning Knowledge Centre (HLKC)
and the
Canadian Council on Learning (CCL)

Sue Folinsbee and Wendy Kraglund-Gauthier
with Hélène Grégoire and Allan Quigley

August 2008

Table of Contents

Acknowledgments

We would first like to acknowledge the contributions of participants for engaging in the consultations held in Fort Liard, NWT, Seaforth, Ontario and Inverness, Nova Scotia. We thank them for their participation.

In Fort Liard, we would like to thank Rob Telford, Aurora College for planning and co-facilitating the consultations and Aurora College for hosting them.

In Seaforth, thanks and appreciation to Harold Flaming of The Ontario Rural Council (TORC) for hosting the consultations and for organizing the event together with Gwen Devereaux, Huron Perth Healthcare Alliance. Many thanks to Jim Whaley, Chair, TORC and Brian Innes, Chair, Rural Health Working Group for co-facilitating the session with community members. We would also like to thank Al Lauzon, AWG advisory group member for making the connection to TORC.

In Inverness, we would also like to thank Cathy MacMillan and Joanne Gillis, Inverness Family Place Resource Centre, of the Cape Breton Family Resource Coalition, for hosting the consultations and for organizing the event. Many thanks to Maria Coady, North Inverness Community Health Board, for contacting service providers, and to Jane MacDonald for co-facilitating the session with service providers.

We also want to thank and acknowledge the excellent work of Sue Folinsbee and Wendy Kraglund-Gauthier who wrote the final report.

We hope that this work will be useful to a wide range of audiences interested in research. This work was undertaken with support from the Canadian Council on Learning's Health and Learning Knowledge Centre and the National Collaborating Centre for Determinants of Health, which bear no responsibility for its content.

B. Allan Quigley
Co-Chair, Adult Working Group
Health and Learning Knowledge Centre
Canadian Council on Learning

Hélène Grégoire
Co-Chair, Adult Working Group
Health and Learning Knowledge Centre
Canadian Council on Learning

August 2008

I. Introduction

A. Background Information

In June 2005, the Canadian Council on Learning (CCL) held a Health and Learning Knowledge Centre (HLKC) consultation in Vancouver, British Columbia. At the consultation, participants agreed to establish various working groups to address the work of the HLKC. These working groups address life stages in health and learning and concentrate on settings, places, and communities where health and learning takes place. The HLKC coordinates and organizes its work according to both the life stages and settings. The Adult Working Group is now one of 15 working groups addressing learning across the life span. (See the CCL web site for further information at http://www.ccl-cca.ca/ccl)

The mandate of each working group is to build a knowledge agenda for the Canadian Council on Learning (CCL) under whose auspices the HLKC was established. Each working group is to focus its agenda on the three central themes of the HLKC. These themes are:

- health literacy (with a priority on access, equity, and achieving basic health literacy for all)
- developing and sustaining healthy communities of life-long and life-wide learning
- strengthening the capacity of communities, practitioners, and public agencies/systems to implement intertwined health and learning strategies in comprehensive, sustainable, effective ways

In addition, each working group also is expected to address the four primary functions of the CCL in the activities it recommends and undertakes. These four functions are:

1. research
2. data /monitoring/reporting
3. knowledge transfer
4. dissemination/communications

The AWG is developing a knowledge agenda for promoting the health and learning of adults:

- at the workplace
- in health care settings
- among families
- in communities

In 2006, the AWG identified the priority groups it would focus on at the outset[1] as follows:

- the health and learning of adults with low levels of literacy skills (2006–2007)
- the health and learning of adult immigrants and refugees (2006–2007)
- the health and learning of adults affected by HIV/AIDS (2007–2008)
- health and learning within regions and communities that fall well below national or regional health norms (2007–2008)

In the AWG's consultation plan, particular attention was paid to issues of gender and racialization[2] across the identified range of priority areas.

Over the past year, 2007–2008, the AWG priority groups have been: a) adults living in rural and remote areas and b) adults living with HIV/AIDS. This report addresses the priority group adults living in rural and remote areas. The AWG's work involved direct discussion with adults in the identified groups who could be directly helped through an effective knowledge exchange and translation with respect to health and learning.

B. Purpose of the Consultations

From the consultations focusing on adults living in rural and remote areas, the AWG sought to identify themes, gaps, and needs related to health and learning as experienced by these adults. The consultation outcomes will ultimately point to research priorities concerning the learning needed to improve the health of these groups and includes a plan to generate, mobilize, disseminate, and translate research-based knowledge into policy and practice change. This, we hope, will result in a greater understanding of the relationship between health and learning, and in initiatives to improve the health status of adults living in rural and remote areas across Canada.

The expressed views from the consultations are illustrative of the opinions of adults living in rural and remote areas. We hope their views will ultimately contribute to research, to policy, and to improved access and services for marginalized Canadians.

[1] The priority group of Aboriginal adults was removed from the AWG plan because the Aboriginal Learning Knowledge Centre was established by the CCL in 2006. See http://www.ccl-cca.ca/CCL/AboutCCL/KnowledgeCentres/AboriginalLearning/index.htm

[2] In this context, the terms "racialization" and "racialized" refers to a categorization or differentiation made of individuals based on race.

II. Consultation Methodology

A. Consultation Plan

The plan for the consultations was developed by the AWG with input from its national Advisory Committee as part of its planning work in 2005–2006 (see Appendix A). The AWG hired Lindsay Angelow, a health promotion student who worked out of Access Alliance Multicultural Community Health Centre in Toronto, to help develop the consultation plan. The methodology developed was based on the successful experience of Access Alliance in conducting other similar consultations.

i. Choosing communities for consultations

Consultations were held in Fort Liard, Northwest Territories; Seaforth, Ontario; and Inverness, Nova Scotia. In all cases, consultations with both community members and service providers began with both groups together. Then the whole group split off into two groups for most of the consultation process. Finally, the entire group came back together to further discuss and report on the issues raised and make recommendations.

Communities were chosen for the consultations based on the population's ability to represent a wide range of views in rural and remote areas. Fort Liard is a small, predominately Aboriginal community located approximately 240 km due north of Fort Nelson, British Columbia, with Yellowknife, Northwest Territories 544 km to the north-east. The community is governed by the Acho Dene Koe First Nation Band. The consultation in Seaforth represented four rural counties in Ontario: Huron, Perth, Bruce, and Grey. Inverness is on the northwest coast of Cape Breton, Nova Scotia. In the Inverness consultation, participants were from small villages and towns in Inverness County.

ii. Working with local partners

The AWG worked with local organizations to organize and conduct consultations. The tasks of AWG local partners included identifying and securing participants for the consultations, making all the logistical arrangements for the consultations, co-facilitating the consultations, reviewing consultation reports for accuracy, and disseminating consultation outcomes at the local level.

In all cases, we worked with a local contact person or organization to organize the consultations. Our goal was to attract the widest range of participants to the consultations by

advertising the sessions widely in the communities and surrounding areas. Our local partners used their community contacts and knowledge to advertise the consultations widely to organizations that work with adults in rural and remote areas in health and education and related areas.

In Fort Liard, our contact person from Aurora College worked in the community and was able to advertise the consultation to a wide range of community members and service providers. For the Seaforth consultation, we worked with The Ontario Rural Council (TORC). As a vital voice of rural Ontario, TORC used its well-established partners and networks to advertise the consultation in four rural Ontario counties. In Inverness, the Inverness Family Place Resource Centre, of the Cape Breton Family Resource Coalition, and members of the North Inverness Community Health Board were able to reach out to a wide range of community members and service providers in Inverness County.

B. Consultation Format and Questions

i. Consultation format

The standard format of the consultations was to hold a meeting with both community members and providers who work with them. Of the 20 participants we wanted to attract for each consultation, one-third (maximum) was intended to be providers and practitioners who worked with community members. Two-thirds were intended to be community members to hear their voice in particular. We wanted providers to participate in the consultations because of the useful information they could provide related to their experiences around health and learning in terms of the community members they worked with.

In each consultation, the plan was for both providers and community members to be together for introductions and a review of the consent practices. They were then to split into two groups —community members and providers—for the majority of the consultation discussions, coming back together at the end to report back and for further discussion. All three consultations conformed to the original plan.

Each consultation was approximately 3 to 4 hours long.

ii. Focus of the consultation questions

Following an explanation of ethics protocol (see Appendix B), participants responded to questions[3] in the following categories:

- what health means
- how community members keep in good health (including the impact of where one lives)
- how they learn about health and get information they need
- their experiences with the healthcare system
- who should learn what
- what else needs to be done

Community members were also asked to complete a one-page, anonymous background information sheet. Participants indicated details such as their gender, age range, employment status, and level of education.

An honorarium of $40 or more—depending on travel arrangements—was made available to all community members to compensate for their time and out-of-pocket costs. Participants also received lunch or dinner depending on the time of the consultation.

iii. Consultation Feedback

People participated in a short, oral evaluation of the consultation—what they liked about it, as well as how it could be improved—at the end of each meeting

iv. Consultation Reports

The AWG prepared detailed reports on the consultations in each community for a total of three separate reports. Each report was provided to the local partners for review and feedback before being finalized. The final community reports were sent to local partners so they could distribute them to consultation participants.

[3] Please see Appendix C for Consultation Questions.

C. Consultation Participants

The charts that follow outline the participation in AWG consultations. See Appendix D for participant profiles.

Consultations with Adults Living in Rural and Remote Areas

Location	Number of consultation participants
Fort Liard	6 community members 3 providers
Seaforth	13 community members 7 providers
Inverness	22 community members 7 providers
All locations **TOTAL**	41 community members 17 providers **58**

D. Limitations of the Consultations

There are several limitations of the consultation outcomes. The overall number of participants was small and they were selected based on the consultation facilitators and host organizations' ability to contact willing participants.

Based on the informal methods of choosing participants, we caution against generalizing the results of these consultations across contexts. While generalizations cannot be made from the consultation outcomes, the outcomes provide a good deal of insight with respect to areas of health and learning that need to be explored through systematic research related to adults living in rural and remote areas.

III. Consultation Outcomes

This overall report draws from the three individual reports that were prepared for each of the three locations in rural (Seaforth and Inverness) and remote (Fort Liard) areas. This section summarizes the outcomes from all three AWG consultations according to major themes.[4]

A. Concepts of Health and Being Healthy

> *"It's lonely when you aren't healthy. It is a feeling you have inside; you try to stay in your world. You lose friendships; you can't keep up, it's such an effort to do things. You are losing your courage."*
>
> **– Community member, Inverness Consultation**

i. Concepts of health

The most common theme from community members across locations was that they saw health as the ability to do the things that they want in life. This included having independence, a good quality of life, and the energy to do what one wants. Some community members across locations discussed the mental, spiritual, and social dimensions of health. Others saw being healthy as the absence of sickness—not being ill, not having a disease, or not being overweight.

Providers most commonly saw that their clients view health as the absence of disease. For example, providers reported that some clients want a quick fix through drugs when they are sick. However, in two locations, providers disagreed with this view, indicating that they thought their clients were beginning to see they could change their health and focus on wellness.

ii. Keeping in good health

In all locations, community members indicated that they were well aware of the activities they could do as individuals to keep healthy. These activities include exercising by walking, doing sports, walking, gardening and going to the gym. The issue of the need to stop buying processed food and to eat healthy food was addressed in two locations. Participants also mentioned the value of regular health check ups.

[4] For more details on each location, a summary report is available.

Maintaining good mental health was also mentioned by community members. For these participants, ways to maintain mental health focused on social relationships with family, friends, and community.

In Fort Liard, community members and providers described specific strategies for keeping good health that focused on traditional Aboriginal ways. These ways included going on the land, using traditional herbs, being involved in traditional arts and crafts, and using Elders as role models and mentors. Health care providers explained that families go out on the land in the summer and every fall for 2 weeks. According to providers, Fort Liard youth are also involved in sports and drumming. There are also traditional feasts organized for Elders and the community and Fort Liard health care providers indicated that these traditional activities contribute to overall good mental and spiritual health. Providers also noted the positive effect of their environment—no pollution, few traffic accidents, and an abundance of country food.

Specifically, participants in the Seaforth consultation discussed a shift in responsibility in that government is off-loading health to communities so individuals and communities have to look after themselves. Participants cited the need to lobby politicians for funding. They felt that communities need to take ownership of their own health and run their own health care.

iii. Factors that make it difficult to stay healthy in remote and rural areas

> *The cost of living makes it hard to buy healthy foods and it's expensive to travel for appointments.*
>
> **– Community member, Fort Liard**

Across locations, participants identified social determinants of health that make it difficult to stay healthy. Many determinants are particular to the rural or remote context of participants. The top factors that make it difficult to stay healthy are poverty, transportation issues, and isolation. Fort Liard participants also listed substandard housing.

Poverty

For example, poverty was cited as a determinant of health in all locations. A common theme reported was the high cost of living in rural and remote areas, where everyday necessities cost more. In addition, participants in Fort Liard noted that in the North, fresh fruits and vegetables were not easily accessible. In Inverness, community members reported they could not afford fresh fruit and vegetables in the winter. In these two locations, participants emphasized that junk food is more affordable than healthy fresh food.

In the Seaforth consultation, providers indicated that working on wellness is not a priority when people are concerned about putting food on the table and having a place to live. Similarly, in the Inverness consultation, participants identified lack of stable employment as a factor in affecting their ability to remain healthy. In the Inverness area, with incomes tied to fishing and forestry, incomes are decreasing and expenses are increasing. Providers reported that there is more use of food banks. One mother discussed how difficult it was to pack her children's lunches. She said, "I know what I am putting in there isn't as good as it should be, but I can't afford to do any better." Community members said that it was much easier to think about health and wellness when they are working.

In Fort Liard, participants indicated that although most people are working, the income level is low. Providers indicated that most jobs are in the oil and gas camps out of town which means that people are away from their families. Connected to the employment issue is a lack of childcare services in the community of Fort Liard. Literacy and language are also issues related to employment for community members in Fort Liard. Providers raised the fact that, in order to qualify for many available job postings in the skilled trades, people need certification and tickets. For many people in the community, Slavey is their first language. Providers identified literacy and language as barriers to working in these jobs.

Substandard housing

In Fort Liard, participants reported that the top issue was substandard housing with overcrowding, mould, poor ventilation, and no running water. They reported that mould causes asthma and breathing problems. They also indicated that overcrowding makes it difficult for people who want to stay sober when others are drinking. Cultural factors come into play as well; providers reported people have an "open" house and will not turn anyone away.

Transportation and travel

In the Inverness, Seaforth, and Fort Liard consultations, participants discussed the issue of transportation and travel. They said that the issue of transportation has a significant impact on staying healthy and accessing health services and appointments.

For example in the Seaforth consultation, participants identified the lack of public transportation as a problem. Furthermore, they indicated that there may not be taxies either. They acknowledged that even if there were taxies, the service may not be affordable or clients may have disability issues.

Similarly, in Inverness, there is no public transportation. Participants reported that they have to rely on friends and family and a local taxi service for rides. As in the Seaforth consultation, in Inverness there is the issue of access in terms of affordability of travel to larger centres for appointments. In addition, community members identified privacy issues around health when they had to get a ride from someone else. They said this made some people reluctant or embarrassed to ask for help. Community members also talked about limiting the travel they do and having to choose what they are travelling to because of affordability and access to a ride. These issues have a direct impact on health. One participant commented that she missed an appointment at the diabetic clinic because she could not arrange transportation.

In Fort Liard, participants said it is difficult for community members to travel to appointments because of long distances and the expense of travel.

Isolation

While issues of isolation affecting health were identified in each of the three locations, the specifics of the isolation issue were quite different in each location. In Seaforth, community members talked about the isolation of farmers working alone and how this affects their mental health. They also identified a lack of community places for people to come together.

In Inverness, isolation was discussed mainly in the context of seniors. When children move away to seek employment, seniors living alone may lose their family support. In addition, isolation was discussed in terms of activities in the winter months where "all there is is hockey at the rink. There is no gym and nothing else goes on either." Community members talked about their difficulties in staying active and "up-beat," especially during winter months. They noted that activities and special-interest groups and events were good to have, but "it is always the same people saying the same things."

Isolation was described in Fort Liard as tied in with a cultural shift away from a traditional life style. Community members thought it was difficult to stay in good health because life had shifted to being too easy with skidoos and other vehicles. They also felt that along with a lack of motivation, there was no support from peers and the community.

Drugs, alcohol and violence

In Fort Liard, providers cited drugs, alcohol, domestic violence, and sexual abuse as barriers to being in good health.

B. Learning and Getting Information about Health

"It is confusing 'cause you wonder 'where do I look for information?' "

– Community Member, Inverness

i. Most common ways of getting information about health

In all locations, participants said that people get their health information from a trusted source. This varies from individual to individual and from community to community. For example, in Fort Liard, the main sources of information about health are parents, grandparents, and teachers. Participants indicated that in Fort Liard, most health information is received orally, especially by the older generation because they do not read English. In Inverness, people get information from family, friends, public health agencies, and doctors. Across locations, participants indicated that people also get information from television, radio, books, and community notices.

The Internet and print materials were identified as the least effective ways to provide information on health. In terms of the Internet, computer literacy, access to computers, and reliability of Web sites were cited as issues.

ii. Barriers to accessing information about health

Across locations, the most common barriers identified by participants were:

- lack of knowledge about where to go or what to ask
- access to information
- literacy
- understandings of medication

In addition, there were issues specific to certain locations.

Lack of knowledge about where to go or what to ask

One common theme identified by participants in two locations was that they may not know where to get information because the information may not be in a centralized place, or people are not sure what information they should be asking about.

Knowing what questions to ask was cited as a barrier by participants. People might feel "stupid" asking questions, or they might not question their doctors. One community member in the Inverness consultation said, "We never question our doctors. Sometimes the doctors don't realize all the meds you are on." Similarly, in the Seaforth consultation, providers said patients tend to see doctors as god-like or as positioned in a patriarchal system. This may influence people not to question what their doctor says. A nurse in the Inverness consultation also noted that especially in emergency situations, people may not know the questions to ask and feel too intimidated to speak up.

In the Inverness consultation, community members and service providers talked about the need for patients to ask more questions about their health and to volunteer adequate information. They said that not doing this can compromise medical situations.

Access to information

In the Seaforth and Inverness consultations, participants talked about the challenges of accessing information. In Inverness, community members discussed the fact that they are expected to research information for themselves. They find that the information is not always available in libraries. If they have to ask for help around health issues, they may be concerned about confidentiality because everyone knows everyone else in a small community. In the words of one Inverness community member: "Now everyone will know I am sick." As well, participants reported that library service is provided on a rotating basis. They would like to see a multi-media approach to health care information.

In the Seaforth consultation, service providers said that they need access to information based on research to help their clients. They said they need access to library services and a centralized place to access information. They added that strategies for providing information to clients need to be tailored to different groups.

Literacy

Literacy issues were identified in all three locations. Low literacy and lack of clear language were identified as barriers to getting information from print in all consultations.

In Inverness, community members expressed frustration with trying to "read and understand those long and impossible directions [they] got from the pharmacy." They indicated that instead of reading them, they get their information verbally from health professionals. In addition, they indicated they relied on their memory for how they had taken that medication in the past, regardless of whether or not their health situation had changed. Those community

members who tried to get information from the Internet also said that the information was too difficult to understand. One provider also said that the volume of information can be overwhelming for clients, especially for elderly clients who have little or no education.

In the Seaforth consultation, health care providers related stories about patients who could not read print information and that they "pretended" to read the information they were given. A story was related about a doctor who did not realize for many years that his patients could not read. It was noted that, as a result, the patients did not know what they needed to do to be well. As in the Inverness consultation, providers identified the complexity of written instructions for medicine as an issue, explaining that people may not know how to follow the instructions for their medication as a result.

In Fort Liard, literacy was also an issue, especially for the "older generation" who never went to high school because high school education was not available in Fort Liard until the 1980s. Providers spoke about the papers related to health and health care that community members get. They said that people might throw a lot of these papers out. Fortunately, the health centre also gets a copy of the papers and follows up with people, especially around how they are taking their medication. Providers noted that there are a lot of misunderstandings around people knowing how to take their medication.

Understandings of medication

In all three locations, understanding of medication was cited as a problem area linked closely to literacy barriers. A common theme was that clients do not take medication as prescribed. For example, in the Seaforth consultation, providers indicated that clients do not understand what will happen if they stop their medication—especially when they start feeling better. Similarly, in the Inverness consultation, providers reported that people do not understand the implications of not taking medications as prescribed or the dangers of sharing them with others.

C. Experiences with Health Services

> [There have been] *deaths due to poor doctor service.*
>
> **—Community member, Seaforth consultation**

i. What is working well

Overall, what is working well across locations is a community-based approach to health care that does not rely solely on doctors. This includes Family Health Teams (Seaforth), the

community health centre (Fort Liard) and district health authorities (Inverness). Features that are working well are advanced nursing practice and good coordination and partnerships.

In Fort Liard, participants agreed that there is high quality health care available through the community health centre. Providers said that there are shorter wait times for general care than "down south"[5] and relatively shorter wait times to see a specialist (less than a month). Providers related that advanced nursing practice works really well at the health centre—"the nurses do 70% of what a GP does and doctors are just a call away." Community members said they had positive experiences with nurses and that there was a high quality of care. "Doctors come into the community every 2 weeks and a dentist also comes to the community," reported providers. Providers indicated these visits are promoted through word of mouth and on the radio.

Differently from the Seaforth and Inverness consultations, providers said that another positive feature of health care in Fort Liard is that dental care and most prescriptions are free for those community members who are covered by the band treaty.

In the Inverness and Seaforth consultations, providers rated the services provided by nurse practitioners very highly. They said that although there was initial reluctance to working with them from doctors, it has dissipated. They noted that nurse practitioners are filling an important gap in the provision of health care. This is similar to the advanced nursing practice used in Fort Liard. In the Inverness consultation, participants felt that nurses were better trained than in the past to deal with more medically-related questions. They noted that hospital staff are being educated on issues of discrimination, gender, and age, and issues of confidentiality and sensitivity. They felt there was good care in Inverness and that community-based help organizations work well.

In the Seaforth consultation, participants reported that Family Health Teams are the way of the future and provide access to information as well as integrated health services that can help compensate for the lack of doctors in the region. Family Health Teams are a key component of the provincial government's plan to improve health care in the province. There are 150 Family Health Teams in Ontario. These teams may consist of doctors, nurse practitioners, nurses, social workers and dieticians. Providers also noted there is better collaboration among and within agencies in terms of information sharing and service provision.

[5] Refers to areas located geographically south of regions in the north. For example, Edmonton and Calgary, Alberta. Would be considered down south for those in Fort Liard.

ii. Barriers

This section describes the most common barriers to health care services across the three locations.

These barriers were:

- lack of overall health care services
- access to specialists
- access to mental health services
- costs of health care services
- cultural barriers

Lack of health care services

In both the Seaforth and Inverness consultations, participants described an overall lack of health care professionals in their rural communities. In the Seaforth consultation, participants spoke about the many people in the region who did not have a family doctor even though they have lived in the region a long time. They explained that people cannot access other doctors and health care services in the community's Family Health Team[6] unless they have a family doctor. They also reported that it was difficult to attract health care professionals to come and work in rural areas. Furthermore, they said that even those who come to work may need training on how to work in rural areas.

In the Inverness consultation, participants reflected that health care services are being removed from local hospitals and care facilities because of decreased government funding and population decreases.

In Fort Liard, providers reported there was no youth treatment centre. They said it is difficult to send youth out of the community right away because of the paperwork. Sending people out for treatment is twice as expensive as having a local treatment centre.

[6] According to the Ontario Ministry of Long Term Care, a Family Health Team (FHT) is an approach to primary health care that brings together different health care providers to co-ordinate the highest possible quality of care for the patient. FHTs are designed to give doctors support from other complementary professionals such as nurses, nurse practitioners and other health care professionals who work collaboratively. FHTs are intended to bring better health care services to Ontarians. There are 150 teams altogether across Ontario.

Access to specialists

Access to specialists was cited as challenging in all three locations in different ways.

In both the Inverness and Seaforth consultations, participants talked about long wait times for specialists. In Inverness, one community member signed up for a medical study to bypass the long wait times. However, even though he received specialized treatment faster, the money he had to pay associated with travel for appointments was a hardship. The community member noted he got "Cadillac treatment because it goes in the news, you get called all the times for scans, etc. But they never ask for the cost to get to those places." In addition, community members might have to travel to several different communities to see different doctors and have tests.

In Fort Liard, travelling to see specialists is challenging. The territorial government wants community members from Fort Liard to go to Yellowknife for specialized treatment even though it is cheaper and closer to go to Fort Nelson, British Columbia. There is even an agreement between the NWT and BC governments that would allow people to see a doctor in Fort Nelson. Community members, especially Elders, do not want to go to Yellowknife because it is too far away from their families.

Providers also indicated that there are several barriers to specialized treatment for problems such as Foetal Alcohol Syndrome. They explained that the length of time to get an assessment and treatment, the cost, and the amount of paperwork to be completed before leaving the community were all barriers to accessing treatment.

Access to mental health services

Mental health services were identified as an issue in all three locations. The major theme was that people are reluctant to seek help in a small community where everyone knows each other and they feel shame about their illness. In one example from the Seaforth consultation, a woman told her husband not to go for an appointment during certain hours because he would be seen. Moreover, participants in the consultation said there are few supports to address mental health issues. In the Seaforth consultation, service providers said that because there are such long waiting lists for mental health services, children and families in crisis have to be referred to emergency departments in cities. In Fort Liard, service providers would like to see improved protocols for mental health services referrals.

Cost of health care services

Participants in the Seaforth and Inverness consultations indicated that there are costs associated with health care, such as the cost of prescriptions and dental care. According to providers in both consultations, most rural clients do not have drug benefits. This means that when doctors prescribe drugs, people do not have the money to follow through and fill the drug prescription. One community member in the Inverness session explained that because she did not have medical coverage, the doctor prescribed a less expensive 5-day treatment for her daughter's ear infection rather than a one-day branded treatment. Dental care was also identified as a cost issue. In the Seaforth consultation, one service provider related how a client had to have all her teeth pulled out, but could not afford dentures.

In all locations, transportation was identified as a cost factor in terms of getting to health care facilities.

Cultural barriers to accessing health services were mentioned in two locations: Fort Liard and Seaforth. In the Seaforth consultation, providers said that some Amish and Mennonite communities may not have health cards and may not access health services because they may believe that things happen because it is "God's will."

In Fort Liard, community members explained that men may be reluctant to tell their problems to a female nurse or to have regular check ups. In addition, they said that a traditional barrier for Elders is that they may not admit they are not well for privacy reasons, or because they do not want to be a burden.

IV. Participants' Recommendations for Strategies to Address Identified Barriers

Participants' recommendations have been organized according to the three priorities of the HLKC, which are:

- health literacy (with a priority on access, equity, and achieving basic health literacy for all)
- developing and sustaining healthy communities of life-long and life-wide learning
- strengthening the capacity of communities, practitioners, and public agencies/systems to implement intertwined health and learning strategies in comprehensive, sustainable, effective ways

A. Health literacy

i. Literacy and learning needs and supports for rural areas

In the Inverness consultation, participants agreed that everyone needs to learn when it comes to health and health literacy. They suggested health workshops with materials appropriate for people with low to no literacy. They also urged that more work be done on plain language writing for health-related information and medication instructions.

ii. Improved access to health-related information

In the Seaforth and Inverness consultations, participants recommended new ways of getting health-related information out to the community to address different learning styles.

In Inverness, community members recommended continued advertising of health-related information in local papers, community boards, and Web sites. They also recommended more advertising in heavy-traffic areas such as grocery stores, banks, and with employers. They felt that health-related promotional materials need to be in more locations than just a doctor's office. Community members also recommended better regulation on food labels, including the Heart and Stroke Foundation's "Health Check" designation on food.

Community members in the Seaforth consultation indicated that Family Health Team members should provide health-related information.

Providers in the Seaforth consultation recommended a multi-media approach to providing current, consistent, health-related information to people by phone, hard copy, Web sites, and television. They also recommended having a central place to access health information and that places to access health information should be close by for community members.

B. Developing and Sustaining Healthy Communities

i. Social factors affecting health

In all locations, participants want to see social factors related to poverty, employment, food security, and housing addressed.

In the Inverness consultation, participants recommended better social assistance and employment insurance rates, more resources for poverty coalitions, and more support for food banks. They indicated that school lunch programs also need more fresh fruits and milk products.

Similarly, in the Seaforth consultation, providers would like to see improved, more affordable housing, better welfare rates, and food security addressed. They would also like to see more resources for poverty coalitions that address these issues.

In Fort Liard, housing was the main social factor identified with recommendations given to improve the situation. Providers would like to see single-family dwellings where there are no more than five people to a dwelling. Providers would like to see adequate housing with no mould, and amenities such as running water and a sewer system.

ii. Health promotion and primary prevention

Health promotion and prevention strategies were common topics of discussions across the three locations. In the Seaforth and Inverness consultations, participants recommended more primary prevention programs, models, and a focus on wellness in rural areas. They would like to see more focus on staying healthy than on treating an illness. For participants in the Inverness consultations, a prevention model includes the recognition of the need for yearly check-ups, being able to identify and describe symptoms, knowing what medications one is on, along with knowing one's family medical history.

In Fort Liard, community members want to see more information sessions and public forums on health-related issues. They would like to see more programs that focus on prevention as a

way of maintaining health along with the formation of more support groups. They also suggested health and cooking programs and more recreational programs for young males.

iii. Local leadership

In Fort Liard, community members recommended that leadership needs to be promoted from within the community. They would like to see more healthy leaders as role models. They felt that too many leaders are "expatriates" who come in for the work and end up taking positions of influence because of a lack of local involvement. They felt that leadership is needed at all levels of the community.

C. Strengthening the Capacity of Communities, Practitioners, and Public Agencies/Systems

i. Improved access to quality health care in rural and remote areas

All locations would like to see improved access to health care services in their rural or remote areas. The main theme across locations was the need for better access and improvement to health care in terms of:

- more health care workers and incentives to keep them
- more options from health care providers
- more local services and coordination of these services
- improved transportation

More health care workers and incentives to attract and keep them

In all locations, participants want to see more health care workers in their region, along with strategies to attract and retain them.

In Fort Liard, participants want to see more male nurses and strategies to address the high turnover of health care providers. They believe that a high turnover of health care providers affects the quality of the service.

In the Seaforth consultation, a major recommendation from participants was to find ways to promote health care careers with youth so they will come back to rural communities. One way is to have medical students come to rural areas for internships and another is for camps like MedQuest that help young people consider careers in Grades 10 and 11 when they have to start

making decisions about current and future education. Seaforth participants also suggested paying for a person's education in health care with the stipulation that they will come back and work in a local area for a required amount of time.

In the Inverness and Seaforth consultations, participants also agreed that there needs to be a more welcoming environment and assurance of full time work for nurses. In Inverness, participants were pleased with the provincial government's strategy to actively recruit and encourage doctors to work and live in rural areas. Participants recommended that this strategy be used with nurses as well.

In Fort Liard, participants would like to see more specialists coming into remote areas.

More options from health care providers

In both the Inverness and Seaforth consultations, participants called for more options from health care providers over the medical model or the way they have always operated. These options include home care, nurse practitioners, midwives, and alternative treatments.

More local services and coordination of services

In both Fort Liard and Seaforth, participants focused on local capacity for health care services.

In Fort Liard, providers would like to see a local adolescent treatment unit and improved protocols for mental health services referrals. They suggested that communication about protocols for referrals with some groups needs to be ongoing because of high turnover in those organizations.

In the Seaforth consultation, participants emphasized the need for community innovation for solutions in health care. They indicated that over time, the Family Health Team could compensate for the lack of doctors. They reported on the importance of multi-professional health care teams and of community ownership when developing programs and policies.

Improved transportation and travel options

Participants from Inverness and Seaforth suggested having some kind of shuttle service to take people to appointments, thus improving their access to health care service. Inverness participants also suggested having a courier service for delivery of groceries and prescriptions for those who need it.

In Fort Liard, participants want funded options for travel out of the community to other jurisdictions for health care.

ii. Best practices and models

Participants in both the Inverness and Seaforth consultations recommended that best practices and new models need to be shared within communities on community wellness initiatives. Sharing best practices allows health care providers to learn from each other and makes sure the right people get the information.

iii. Research the needs of rural areas

Providers in the Seaforth consultation recommended more qualitative research on the health care needs of the community so these needs can be addressed in a relevant way. They also recommended that more research money be put towards local issues. They would like to see a research agenda on rural issues and health. This would include prevention research as opposed to the primary research conducted by drug companies.

V. Adult Working Group Recommendations for Setting a Knowledge Agenda

The recommendations that follow are based on the results of the AWG's cross-national consultations. The recommendations are directed to the Health and Learning Knowledge Centre to terms of supporting: 1) a research agenda that addresses key areas from the consultations, and 2) knowledge dissemination and mobilization. As such, the recommendations have been organized according to these two categories.

A. Supporting Research:

The AWG recommends that HLKC support research by:

- providing funding for the areas listed below
- including the research topics listed as priorities for HLKC Request for Funding Proposals (RFPs)
- raising awareness that the research priorities are important

- providing opportunities for researchers to meet to collaborate on the types of questions the research provokes

The AWG recommends that the HLKC specifically support:

- community-based participatory research on the interventions that could contribute to improving the access of adults living in rural and remote areas to the health services and health information they need, particularly the kinds of community-based approaches that participants across consultation locations say are working.

- a research agenda for rural and remote areas that focuses on local issues, specifically the health and health care needs of community members living in these areas. Include a focus on how location impacts health and health care in rural and remote areas.

- the evaluation of policy interventions designed to address poverty, housing, literacy, and other social determinants of health in rural and remote areas.

- research on lack of health care professionals which affects the health of all community members, but especially marginalized groups in rural and remote areas.

- research that focuses on both the unique barriers and effective interventions faced by marginalized communities in accessing health and health information in rural and remote areas as discussed in this report.

B. Knowledge Mobilization

- Ensure that that this consultation report is disseminated to a wide range of stakeholders including policymakers, researchers, and practitioners who can act on the recommendations made by those adults who participated in the consultations.

- Ensure that a wide range of stakeholders have access to the findings of the consultation report through plain language fact sheets, briefs, newsletters, etc.

- Support action on the findings of this consultation report with respect to the social determinants of health. The AWG completed a state of the field report on health and

learning[7] that shows there is a great deal of research on the determinants already and a need for action is now required.

VI. Summary Statement

There are some consistent outcomes across the two rural and the one remote location where consultations were held.

The consultations illustrate the critical impact that a rural or remote location has on the health and access to quality health care of the adults who live in these communities, especially those from marginalized groups. The consultations also identify the positive, community-based solutions to health care that have emerged and are in operation across locations.

Participants' recommendations indicate that it is critical to address the larger social determinants of health in the context of rural and remote areas. Social determinants of health such as poverty, lack of employment opportunities, high cost of living, substandard housing, different cultural assumptions, and access to health services, including mental health services are all shaped by the particular local context. In addition, transportation and travel issues within the context of health and health care are significant barriers to health and accessing health care in rural and remote areas.

Literacy and/or language are barriers to getting health-related information in all locations. In terms of health literacy, the outcomes of the consultations suggest that multi-faceted strategies are needed to present information about health to adults living in these communities. For community members, print materials on health issues and accessing information on the Internet are the least preferred strategies. Opportunities for adults to upgrade their literacy skills along with clear language strategies for presenting plain language information are needed. Learning needs to be two-way. Health literacy is a priority issue raised across locations, especially as it relates to understanding and taking one's medication. One particular issue related to health literacy is the need for community members to be able to ask questions of their health care provider—especially doctors—and provide the relevant information needed for the provider to assess their situation.

[7] Folinsbee, S., Kraglund-Gauthier, W. (with A. Quigley, H. Grégoire, & The Adult Working Group, HLKC). (2007). *State of the field report for health and adult learning: Updated 2007 Summary*. Victoria, BC: Canadian Council on Learning, Health and Learning Knowledge Centre.

Equitable and accessible health care services for community members are related to where they live. From the consultations, the most notable barrier is the lack of access to a range of health care providers in rural and remote communities. There are two issues contributing to this barrier. One is that it is difficult to attract and retain health care providers in these locations. The second issue is that the communities are not large enough to support a range of specialized health care providers. This means that community members have to travel outside their community to receive health care services. Transportation and the related issues of confidentiality and affordability are barriers to accessing these health care services.
On a positive note, communities are relying more on advanced nursing practices and health care teams with good results to address the lack of doctor in these communities.

Appendix A: Adult Working Group Members:

Name	Institution/ Affiliation	Location	Area of Work or Interest
Helen Balanoff	NWT Literacy		
Wendy DesBrisay	Movement for Canadian Literacy	Ottawa , ON	Canadian literacy
Sue Folinsbee (Support and coordination to AWG)	Tri En Communications	Toronto, ON	Adult literacy as a social practice; union and worker-centred-literacy; clear language and literacy integration
Doris Gillis	St. Francis Xavier University & University of Nottingham (PhD Candidate, CIHR Fellow)	Antigonish, NS & Nottingham, UK	Health literacy; maternal and child nutrition; food security; community development and participatory research.
Hélène Grégoire (Co-Chair)	Public Health Sciences Department, University of Toronto	Toronto, ON	Social determinants of health for immigrants & refugees; community development and capacity-building; parent engagement in education, school-community partnerships.
Budd Hall	University of Victoria	Victoria, BC	Participatory action research; social movement learning; and the links between learning and health

Name	Institution/ Affiliation	Location	Area of Work or Interest
Lilian H. Hill	College of Education and Psychology, University of Southern Mississippi	Hattiesburg, MS	Patient education & health professions education; professional practice; environmental adult education
Shelley Hourston	BC Coalition of People with Disabilities /AIDS & Disability Action Program/ Wellness & Disability Initiative/ Health Literacy Network	Vancouver, BC	Health and wellness for people with disabilities
Wendy Kraglund-Gauthier (Support and coordination to AWG)	St. Francis Xavier University	Antigonish, NS	Adult learning and literacy, skills development and recognition, distance and on-line learning
Al Lauzon	School of Environmental Design and Rural Development, University of Guelph	Guelph, ON	Foundations of adult learning and education; community capacity development; & rural health
Mahassen Mahmoud	St. Christopher House	Toronto, ON	Immigrants and refugees
Bosire Monari Mwebi	School of Education, St. Francis Xavier University	Antigonish, NS	HIV/AIDS and health education; curriculum development
Susan Nielsen	Toronto Adult Student Association	Toronto, ON	Adult Learners/students representation and participation; ESL; Literacy and upgrading

Name	Institution/ Affiliation	Location	Area of Work or Interest
Marina Niks	Institute of Health Promotion Research University of British Columbia Research in Practice in Adult Literacy (RiPAL-BC)	Vancouver, BC	Non traditional approaches to research; adult literacy; health literacy
Ningwakwe /E. Priscilla George	National Indigenous Literacy Association	Toronto, ON	Aboriginal health & literacy
Allan Quigley (Co-Chair)	St. Francis Xavier University	Antigonish, NS	Adult literacy and education; research & international linkages
Marg Rose	St. Francis Xavier University graduate student in Master's of Adult Ed (health literacy study) & Movement for Canadian Literacy member	Victoria, BC	Factors that hinder and enhance collaboration between community literacy practitioners and health educators
Rima Rudd	Harvard University	Boston, MA	Health disparities and literacy related barriers to health activities, programs, services, and care; & design and evaluation of public health community-based programs
Louise Sauvé	Téluq (Télé-université)	Montreal, PQ	Life-long learning
Linda Shohet	The Centre for Literacy of Quebec	Montreal, PQ	Adult literacy policy and practice; literacy and health; literacy and community arts

Name	Institution/ Affiliation	Location	Area of Work or Interest
Cate Sills	NWT Literacy Council	Yellowknife, NT	Aboriginal literacy; community literacy; community capacity building; literacy policy.
Nadine Sookermany	Parkdale Project Read	Toronto, ON	Community literacy; social justice; violence against women; ESL
David Stott	Capital Families	Victoria, BC	Community development, food security, and homeless shelters
Kate Swales	Yukon College	Whitehorse, YK	Early childhood education & development; parent and community support
Kim Thomas	Canadian AIDS Society	Ottawa, ON	HIV/AIDS prevention and education; voluntary sector engagement; and social justice

Appendix B: Sample Consent Practices

Community Consultation on Health and Learning in Rural and Remote Areas Sponsored by the Adult Working Group of the Health and Learning Knowledge Centre, Canadian Council on Learning

What are the community consultations about?

The Adult Working Group (AWG) of the Health and Learning Knowledge Centre (HLKC), Canadian Council on Learning is sponsoring the consultations. We follow all standard procedures with respect to research ethics and confidentiality. The purpose of the consultations is to find out adults in rural and remote areas experience health, learn about health information, and access health care services. We want to find out from you what the barriers are and what is working well. What changes would you like to see to make things better? Who needs to learn what to make the situation better?

What will I do at the consultation?

Community members and service providers will attend the consultation for a total of about 20–25 people. We will ask questions about health, getting information about health, and your ability to access health care services. Community members and providers will work in two separate groups. Everyone will come together at the end to share highlights of their discussion.

How much time will it take?

The consultation will take about 4 hours. Lunch will be provided.

What if I want to stop my participation?

Participation is voluntary. You can leave the meeting at any time.

Will anyone know what I said?

We will not use your name or anything that can identify you in the report on the consultations.

What are the possible outcomes if I participate in the consultation?

The long-term benefits are that there may be some improvements in accessing information about health and health care services for you, your families and other people who have had similar experiences to yours.

Where do I get questions answered?

You can contact XX at XX.

Appendix C: Consultation Questions

Questions for Consultations on Health and Learning in Rural Areas

Community members	Providers, Practitioners
1. What does health mean to you? • *Can you describe what it is like to be healthy?* • *What does it mean to be in poor health?* • *Why does this happen?*	**1. From your experience, what does health mean to your students/clients?**
2. What do you do to get or keep in good health? • *What do you need to get or keep good health?* • *Where do you get it?* • *What makes it difficult?* • *How does where you live affect your health?*	**2. What do they do to get or keep in good health?** • *What do they need to get or keep good health?* • *Where do they get it?* • *What makes it difficult?* • *How does where you live affect your clients' health?*
3. How do you learn about health in for you and your family? How do you get the information you need to be healthy? • *Where do you find this information?* • *How do you get it?* • *Do you talk to people or do you read information or do you use the Internet?* • *If you use the Internet, where do you get access to a computer?* • *What problems do you have using this and how do you overcome them?* • *What health information have you found so far?* • *Would you use a HELP Web site to find the health –related information you need?* • *What works well for you to get the information you need?* • *What kind of information or health topics is most important for you to get?*	**3. What are your clients' experiences with health and health services**? • *What makes it difficult to have the kind of health your clients and their families want?* • *What's it like when your clients have to go to the doctor, the hospital, or a community health centre.* • *What works well?* • *What was difficult?* • *How does where you live affect what kind of health services you get?* • *What are some of the different cultural assumptions?* • *What could these organizations do differently to make it easier for their clients?* • *What could your clients do?* • *What else would help them access health services better?*

Community members	Providers, Practitioners
• *What's hard?* • *What would make it easier to get the health information you need?* • *What suggestions do you have for the health field?* • *How does where you live affect what kind of information you get about health?*	
4. **What are your experiences with health and health services** • *What makes it difficult to have the kind of health you want for you and your family?* • *What's it like when you have to go to the doctor, the hospital, or a community health centre?* • *How does where you live affect what kind of health services you get?* • *What works well?* • *What was difficult?* • *What could these organizations do differently to make it easier for you?* • *What can you and others do?* • *What else would help you get health services easier?*	**4. How do you get information for your clients so they can learn about health for themselves and their family? How do they get information they need to be healthy?** • *Where do you find this information?* • *Do you use the Internet to get health-related information?* • *What information have you found that is useful? Please give examples.* • *Would you use a HELP web site to find the health –related information you need?* • *What works well for your clients to get the information they need?* • *What's hard?* • *How does where you live affect what kind of information clients get about health?* • *What kind of information or health topics is the most important for your clients?* • *What would make it easier for you to get the health information they need?* • *What suggestions do you have for the health field to do to improve the situation?* • *What kind of informal or formal learning would help? Who needs to learn?* • *How could this learning happen?*
5. What types of learning can help address these barriers? **6. Who should do the learning?** **7. What else needs to be done?**	**5. What types of learning can help address these barriers?** **6. Who should do the learning?** **7. What else needs to be done?**

Appendix D: Participant Profiles

Community Member Participant Characteristics Fort Liard, Northwest Territories	
• Education	
Less than high school	2
High school diploma	4
• Language	
Slavey as first language	3
English as first language	3
• Age	
18 – 30	4
51– 60	1
Over 60	1
• Gender	
Female	3
Male	3
Employed	3
Unemployed	3

Table 1: Fort Liard community member participant characteristics

Community Member Participant Characteristics Seaforth, Ontario	
• Employment Status	
Employed	10
Retired	3
• Education	
Less than high school	1
High school diploma	4
College diploma	2
University degree	5
• Age	
51 -60	10
Over 60	3
• Gender	
Female	5
Male	8

Table 2: Seaforth community member participant characteristics

Community Member Participant Characteristics Inverness, Nova Scotia	
• Employment Status	
Employed	10
Unemployed	7
Retired	5
• Education	
Less than grade 9	1
Less than high school	5
High school diploma	6
GED	2
College diploma	6
University degree	2
• Age	
20–30	3
31–40	4
41–50	3
51– 60	4
Over 60	8
• Gender	
Female	6
Male	16

Table 3: Inverness community member participant characteristics