



Staying the Course

*Literacy and Health
in the First Decade*

SECOND CANADIAN CONFERENCE
ON LITERACY AND HEALTH
October 17-19, 2004
Crowne Plaza Hotel
Ottawa, Ontario

Summary Report

*Working together to improve the
literacy and health of Canadians*



Human Resources and
Skills Development Canada

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Section 1

Introduction

1.1 Acknowledgements

Our National Literacy and Health Program would like to thank:

- The National Literacy Secretariat for providing the major funding for the conference.
- The members of the Program Committee for their practical assistance, thoughtful advice, and helpful guidance in planning the conference.
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- The speakers, session chairpersons, and workshop presenters for sharing their expertise and opening up useful discussion about what needs to happen in the future.
- The many literacy organizations that helped to promote the conference within literacy communities.
- The partners of the National Literacy and Health Program who helped to publicize the conference to their members.
- The conference participants who came from across Canada, the United States, and overseas to take part in the conference.
- The authors who wrote articles for the literacy and health supplement to the *Canadian Journal of Public Health*, published in September 2005. Some of the content for this report was drawn from their work:
 - Learners' Foreword – Fiona Murray, Margo Fauchon and Learner Advisory Networks of Movement for Canadian Literacy and la Fédération canadienne de l'alphabétisation en français
 - Introduction: The Captain's Log Continues – Deborah Gordon El-Bihbety and Irving Rootman
 - Best Practices in Literacy and Health – Linda Shohet and Lise Renaud

- Aboriginal Focus – Nancy Cooper, Janet Smylie, Lewis Williams
- Francophones Focus – Louise Bouchard, Kenneth Deveau, Rodrigue Landry
- Ethnocultural Focus – Iraj Pourselami, Margareth Zanchetta
- Building Knowledge, and Lisa Langille – Heather Hemming
- Building Healthy Public Policy – Lynn Chiarelli and Peggy Edwards
- Conclusion: Peggy Edwards and Irving Rootman

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1.2 Conference Summary

The Canadian Public Health Association (referred to as “we” throughout this report) hosted the Second Canadian Conference on Literacy and Health in Ottawa from October 17 to 19, 2004. This conference was called “Staying the Course: Literacy and Health in the First Decade.” It offered more than 100 presentations, workshops, and discussions to over 300 participants from across Canada. This conference built on 10 years of study and work in literacy and health that has been done by us and our 27 national health partners of the National Literacy and Health Program.

The goals of the conference were to give participants the opportunity to:
build new partnerships in literacy and health;

- share knowledge, skills, and practical tools; and
- identify future action in practice, policy, and research.

Workshops and discussions were grouped into four theme areas:

- building best practices;
- focusing on language and culture;
- building knowledge; and
- building healthy public policy.

Health literacy is a new concept. It links our level of literacy with our ability to act upon health information and, ultimately, take control of our health. Health literacy is defined as the degree to which a person has the capacity to get, process, and understand basic health information and services needed to make appropriate health decisions. Almost half of Canadians have low literacy skills. These Canadians are more likely to have poorer health than those with higher levels of literacy. They are more likely to be living with chronic diseases such as diabetes, heart disease, and cancer. They are also more likely to have an early death. Literacy also affects other factors that determine health, such as:

- income; and
- access to jobs, education, and social supports.

Addressing health literacy means breaking down the barriers to health that low literacy creates. Keynote speaker Dyanne Affonso said that health literacy is affected by individual factors as well as by the context in which people experience health. Health services are part of these health contexts. Therefore, they have as much or more responsibility for addressing health literacy as the person who is affected. Affonso and other speakers said that language and culture impact on health literacy. These factors need to be considered when developing policies and programs. Speaker Ilona Kickbusch emphasized that health is a human right. She said that health literacy is necessary for equitable access to health and health services.

In Canada, there are limited program in place in health care settings to improve clear communication and sensitivity. Presenters and participants noted that there is a major gap in knowledge and awareness among health professionals about how literacy affects health. While there are excellent resources to help literacy practitioners and health care

professionals work with people with low literacy skills, there is nothing in place to share best practices.

One conference theme was about how language and culture affect literacy and health for Aboriginal peoples, Francophones, and other ethnocultural groups. There was discussion about health literacy being more than reading and writing. People, families, and communities have belief systems, religious and cultural values, and group identities that give meaning to health information and messages. Cultural health beliefs affect:

- how people think and feel about their health and health problems;
- when and where they go for health care; and
- how they take advice about prevention and treatment.

Participants recommended that new literacy and health research focus on language, culture, health, and learning. Partnerships between communities and researchers in the literacy and health field are needed to support community-based programs that improve literacy and health outcomes to reduce health disparities.

The complex relationship between literacy and health was recognized as one that needs to be acknowledged by policy makers and practitioners. Recognizing the relationship would end myths, reduce stigma attached to low literacy, and empower disadvantaged groups. Participants said that new studies are needed to find more effective ways to communicate health information and give people with low literacy the support, tools, and skills that will lead to better health.

Policies in literacy and health need to address two perspectives:

- how basic literacy skills influence people's health; and
- the degree to which people are able to get, process, and understand basic health information and services needed to make appropriate health decisions.

Three potential areas for action were identified:

- the health system;
- the education system; and
- culture and society.

Adult learners made a meaningful contribution to the conference by sharing their experiences and perspectives as people with literacy challenges. A pre-conference session was held where these learners chose their workshops and discussed how to have their voices heard during the conference. There was a learners' gallery featuring stories, art, and poetry created by learners before and during the conference. Learners developed a list of key messages for health care professionals, the health system, people with literacy challenges, and literacy workers. The messages shared ways to improve access to health services for people with low literacy.

Based on evaluations of the conference, networks of practice and research in literacy and health were expanded and new partnerships are developing. Detailed recommendations

were brought forward, along with the request that our Association and its Program Committee develop a plan to put them in place. Recommendations addressed:

- raising awareness and improving access to resources and training for literacy practitioners and health professionals working in the area;
- developing a strategic program to build capacity in literacy and health research;
- supporting and engaging partners from Aboriginal, Francophone, and other ethnocultural networks to address health literacy in their communities; and
- further engaging policy makers on the impact of low literacy on health and access to health services.

Great momentum was created through the activities before and during this second conference. The conference proceedings are being published in November 2005 as a supplement to the *Canadian Journal of Public Health*. Our National Literacy and Health Program plans to create a secretariat to support the conference recommendations. We have created an Interim Advisory Committee. It has leaders in literacy and health to guide the process. A website and other communication tools for exchanging knowledge are planned. To raise the profile of the issue on the national agenda, a research study on literacy and health in Canada is proposed to build our knowledge base, to help identify issues, and to more fully engage the health sector on this issue.

For more information about the conference and follow-up activities of the National Literacy and Health Program, visit www.cpha.ca/literacyandhealth on the Internet.

1.3 Recommendations Summary

Theme 1: Building Best Practices

- 1.1 Champion an inter-disciplinary approach to health and literacy programs that integrate parenting, nutrition, literacy, and developing community (example: the Healthy Living Manitoba model).
Who: The Council of Ministers of Education and the Deputy Ministers of Health Joint Committee on Education and Health
- 1.2 Link the literacy coalitions in every province and territory with the health literacy programs that are now underway.
Who: Our Association and the 27 partners of the National Literacy and Health Program and provincial and territorial agents
- 1.3 Develop and carry out a strategy to increase awareness and strengthen the capacity of health professionals to serve people with low literacy, and develop and carry out a strategy that supports collaborative approaches to providing service.
Who: Our Association in collaboration with the partners of the National Literacy and Health Program
- 1.4 Build on strategies that encourage using plain language in health settings. Focus on health environments such as hospitals, clinics, and public health and community-based health programs to improve access, help consumers to navigate the health system, and to understand and act on health information.
Who: Our Association in collaboration with the partners in the National Literacy and Health Program (engaging health professional regulatory bodies and training institutions)
- 1.5 Help programs share knowledge and resources with literacy and health workers (for example, the lessons learned and bibliographies from the Centre for Literacy in Québec's Phase 2 Program).
Who: The National Literacy Secretariat and Health Canada
- 1.6 Seek funding to safeguard/host the National Institute for Literacy LINCS health special collection and share and promote these materials to literacy and health workers in Canada.
Who: The National Adult Literacy Database

Theme 2: Focusing on Language and Culture

- 2.1 Address health literacy among Aboriginal peoples in Canada by identifying key people and ways to build on cultural practices, traditions, and strengths.

Who: The National Indigenous Literacy Association approach the First Nations and Inuit Health Branch of Health Canada, the National Aboriginal Health Organization, and the Indigenous People's Health Research Centre

- 2.2 Continue to build partnerships with leaders and institutions working in the areas of public health, social services, and promotion of French language and culture to develop collaborative research and practice models for Francophones in Quebec and other parts of Canada.

Who: Fédération Canadienne de l'alphabétisation en français

- 2.3 Identify funding support for outreach programs that engage ethnocultural partners working in literacy and health, and to identify opportunities for partnership.

Who: Our Association, partners of the National Literacy and Health Program, and the Canadian Ethnocultural Council

Theme 3: Building Knowledge in Literacy and Health

- 3.1 Seek funding from government and other sources to commission the Royal Society of Canada to study literacy and health research in Canada. This study should follow the model of the Institute of Medicine's reports on health literacy. They included a testimony from community groups and key informants in the field.

Who: Our Association and our National Literacy and Health Program

- 3.2 Adopt a funding model that builds capacity for evaluation so that evidence derived from practice can be developed and used as a driver for developing policy. This could be designed like Health Canada's fund for Population Health. It includes building capacity in evaluation (for example, two-day training sessions on using logic models in evaluation, mentorships with trained evaluators and time to do evaluation).

Who: National Literacy Secretariat

- 3.4 Undertake a joint strategic project on literacy and health research. This project would include funding for projects and developing capacity and infrastructure with the following priorities: culture, literacy and health; evaluation; cost benefits of literacy and health efforts; and the role of technology in literacy and health.

Who: Our Association, the National Literacy and Health Program, Canadian Institutes of Health Research, and the Social Sciences and Humanities Research Council

Theme 4: Building Healthy Public Policy

- 4.1 Initiate a meeting to discuss creating an interdepartmental program to support literacy and health practice.

Who: Minister of State for Public Health, Health Canada, and Human Resources and Skills Development Canada

- 4.2 Review these and other recommendations put forward at the conference, develop a strategy for putting them in place, and monitor the outcomes.

Who: Our National Literacy and Health Program and the Program Committee for the Second Canadian Conference on Literacy and Health

- 4.3 Seek funds from the National Literacy Secretariat and other partners to monitor, assist, and put these recommendations in place. Report by November 2005 with a “Literacy and Health Report Card.”

Who: Our National Literacy and Health Program

Recommendations from Adult Learners

- Speakers should use more plain language when speaking, and should speak more slowly.
- Learners should be more involved in planning the conference. They could help to simplify the program guide.
- Adult learners need to be part of the solution. They could speak to graduating classes of health care workers.
- Adult learners could be part of the public awareness campaign needed to connect literacy and health.
- The issue needs more media attention—for example, a panel discussion on television.
- Investing in literacy will reduce health care costs. Literacy is not getting enough funding. Successful programs are too often being cut.
- Health care professionals should use plain language, review brochures, and check that patients understand information. They should not assume that everyone can read.
- It is important to continue raising awareness, including talking to governments about the links between health and literacy.
- People who have a hard time reading and writing should receive help when they need it.
- Women’s health was heavily discussed at this conference; the next conference should have more information on the situation among men.

Section 2

Background

2.1 About the Second Canadian Conference on Literacy and Health

“Staying the Course: Literacy and Health in the First Decade” was the Second Canadian Conference on Literacy and Health. It was held in Ottawa from October 17 to 19, 2004. We hosted more than 300 participants from across Canada and elsewhere. They took part in over 100 presentations, workshops, and discussions about literacy and health in Canada.

The goal of the conference was to provide a national forum to discuss what is being done to improve the health of Canadians with low literacy skills. This forum aimed to give participants the opportunity to:

- build new partnerships in literacy and health;
- share knowledge, skills, and practical tools; and
- identify future actions for all participants, in practice, policy, and research.

Topics for workshops and discussions were grouped into four theme areas:

- Building best practices in literacy and health
- Focusing on language and culture
- Building knowledge in literacy and health
- Building healthy public policy

The theme areas were set to help participants identify what needs to be done over the next 10 years to build a:

- stronger social foundation where Canadians are literate, healthy, and able to reach their full potential in our economy;
- healthier population with fewer people living with avoidable diseases;
- more sustainable health system where all Canadians can access services and get quality care that is sensitive to language and culture; and
- culture of life-long learning where children arrive at school ready to learn and where youth and adults can access education and training.

2.2 How this Report is Organized

There was much activity leading up to and during the conference. Participants came together and attended over 100 sessions, presentations, workshops, discussions, and poster sessions.

Info Link recorded our conference with the help of graduate students. They prepared a brief report on each session that took place. This full-length conference report is on the Internet at www.cpha.ca/literacyandhealth.

In this report, there is:

- Information about literacy and health in Canada
- Information about health literacy
- A short summary for each theme that provides:
 - the main points of discussion at the conference
 - a list of the sessions that took place
 - the recommendations
- Appendices with literacy and health resources

This report has been written in plain language and put in clear design to ensure that it is accessible to everyone.

Supplement to the *Canadian Journal of Public Health*

Articles about the conference themes are being published as a special supplement to the *Canadian Journal of Public Health* in November 2005.

Thank you to Pfizer Canada for their financial support of this journal publication.

Visit www.cpha.ca/literacyandhealth on the Internet to see the supplement.

2.3 What We Know About Literacy and the Health of Canadians

The study of literacy and health in Canada began about 15 years ago. In 1989, the Ontario Public Health Association and Frontier College worked together on a project to learn how reading and health were connected.

Together, they produced two reports:

- *Making the World Healthier and Safer for People Who Can't Read*; and
- *Partners in Practice*.

The reports gave examples of how literacy workers, health workers, and learners worked together to improve health information for people who did not read well.

From these reports, and from other studies since 1989, we know that:

- Literacy is an important determinant of health. Literacy also affects other factors that determine health, such as income and access to jobs, education, and social supports.
- Almost half of Canadians have low literacy skills.
- There has been little change in literacy levels since 1994, with one in seven Canadians at the lowest level of literacy. A person at this level is unable to look at a bottle of medicine and determine the correct amount to give a child. Canadians who have low literacy skills are more likely to have poor health, compared to those with higher levels of literacy. They are more likely to be living with chronic diseases such as diabetes, heart disease, and cancer. They are also more likely to have an early death.

In 1994, we began the National Literacy and Health Program. The program is a partnership of 27 national health organizations that work together to:

- make people more aware of how literacy affects health; and
- improve the health of people with low literacy.

In 2000, we hosted the first national conference on literacy and health in Canada. We produced the report "The Captain's Log." This first conference:

- set a solid foundation for future research in literacy and health;
- raised the profile of many health literacy projects across the country;
- advocated for the rights of health consumers with low literacy skills; and
- furthered discussion on policy by placing literacy as a social determinant of health linked to other factors such as income and work.

Since that time, work in literacy and health has grown. There is still exciting work to be done to:

- capture and share best practices; and
- build evidence-based programs and policies that will improve the health of Canadians with low literacy skills.

Literacy and health care workers are seeking out and finding new ways to work with people with literacy challenges. New areas for literacy and health research have been identified and supported through the efforts of the Canadian Literacy and Health Research Project. The project is funded through the Social Sciences and Humanities Research Council.

There are new trends linked to literacy and health:

- **More jobs need higher literacy skills.** Workers need better reading skills for their changing jobs and for new jobs.
- **The use of computers is growing.** Many people use computers for work and to learn about their health. People who don't read well often find it difficult to use computers.
- **Immigration.** Newcomers to Canada have special needs because of culture and language. The ability to read, write, speak, and listen in English or French is important to get information about health and to know where to go to get help.
- **The Canadian population is aging.** There are more older people now. There will be even more in the future. Older people are more likely to have reading problems. Older people take more medication and need more health information.
- **Home health care.** There are more people being cared for in the home instead of in the hospital. Good, clear information is needed to provide health care for people at home.

To move forward, our National Literacy and Health Program worked with national partners to host this second conference. The conference brought together a diverse group of practitioners, researchers, policy makers, and adult learners who are active and interested in literacy and health in Canada.

Report on Literacy and Health in Canada

All conference participants received a background paper to help open discussion on what can be done for literacy and health in Canada. Barbara Ronson and Elsie Petch wrote this report on clear language called, "Literacy and Health in Canada: What We Have Learned and What Can Help in the Future." It is on the Internet at <http://www.cpha.ca/literacyandhealth>.

The report was based on a full research report with references by Irving Rootman and Barbara Ronson. It is on the website of the Canadian Institutes of Health Research at <http://www.igh.ualberta.ca/RHD/Synthesis/Literacy.htm>.

2.4 What is Health Literacy?

At the conference, participants discussed the meaning of the term “health literacy.” This discussion was based on thinking about health literacy taking shape around the world. Health literacy is a new concept. It links our level of literacy with our ability to act upon health information and take control of our health. Low literacy can create barriers to good health. Addressing health literacy means breaking down these barriers.

A new definition of health literacy used by the World Health Organization says:

- A person must be able to get health information.
- A person must be able to understand the information.
- A person must be able to use it to improve their health or the health of their family or community.
- A person does not always have to read or write to get health information and use it.

The Institute of Medicine (IOM) in the United States produced a major study on health literacy in May 2004. Conference participants discussed what the study means for Canada. This included discussions about the new definition of health literacy presented in the IOM report described below.

Health Literacy

Health literacy is the degree to which people are able to get, process, and understand basic health information and services needed to make appropriate health decisions.

The US Institute of Medicine report¹ adds to our understanding of health literacy:

- It identifies three potential areas for action to improve health literacy: the health system, the education system, and culture and society.
- It proposes that health literacy is affected by individual factors as well as by the context in which people experience health.
- It suggests that health services are part of these health contexts, and therefore have as much or more responsibility for addressing health literacy as the people who are affected.

³ Nielsen-Bohlman, L., Panzer, A., Kindig, D.A. (eds.), 2004. “Health Literacy: A Prescription to End Confusion.” Report of the Institute of Medicine Committee on Health Literacy, Washington: National Academy Press pp101-102.

2.5 Language, Culture, and Health Literacy

English is the main language of communication in daily life in many parts of Canada. It is most commonly used when people access health information and services outside of Quebec. At the same time, people in Canada speak many different languages and have diverse cultural backgrounds. This may create more barriers to health and access to health services for people whose first language is not English, or French inside Quebec. To better understand this reality, one theme of the conference focused on how language and culture affect literacy, health, and health literacy for Aboriginal peoples, Francophones, and other ethnocultural groups.

People, families, and communities have belief systems, religious and cultural values, and group identities. These factors give meaning to health information and messages. Cultural health beliefs affect:

- how people think and feel about their health and health problems;
- when and where they go for health care; and
- how they take advice about prevention and treatment.

There is a need to understand and respect the relationship between literacy and culture in Aboriginal communities. Aboriginal peoples value language and control of education. They see literacy programs as a way to become empowered and self-governing. At the same time, Aboriginal peoples see health and healing as holistic. Community-based Aboriginal literacy programs are integrated into all community work, including healing.

Francophones, like Aboriginal peoples, see language as an important part of their identity. At the same time, language and cultural identity are linked to the health of people and communities. Literacy and learning in French, both inside and outside of Quebec, are important.

People who immigrate to Canada often have lower levels of literacy in English. Newcomers who read and write well in their mother tongues often need lessons in English or French to get jobs and carry out day-to-day activities. To improve health literacy of immigrants and new Canadians, health services need to be sensitive to language and culture.

Section 3

Workshops and Presentations

3.1 Focus on Learners

Adult learners made a meaningful contribution to the conference. Based on their personal experiences, much expertise was shared about how low literacy has affected their health and the challenges they face when finding, understanding, and using health services.

Carole Blouin and Marie David worked with us and our Program Committee to plan the conference. They are members of the Learners' Advisory Networks of our national literacy coalitions, the Movement for Canadian Literacy and la Fédération canadienne de l'alphabétisation en français.

A Learners' Forum took place before the conference. Adult learners from across the country met, chose their workshops, and discussed how to raise the voice of learners at the conference. Learners were briefed about literacy and health in Canada using a report about clear language. The report was prepared by Elsie Petch and Barbara Ronson.

The Learning from Learners Gallery displayed the stories, art, and poetry created by adult learners. This material was sent in by adult learners from across Canada before the conference. They also created art at the Learners' Forum. Many adult learners took the time to share their experiences with health and the challenges that they face when they use the health system. Material from the Learners' Gallery is posted on our website at www.cpha.ca/literacyandhealth.

Speaker Ellen Szita talked about her personal struggles and achievements resulting from problems with reading and writing. Her main message was that the adult learning system is in great need of repair. A better learning system would help people like Szita look forward to the future without fear. It would allow people to give their children the legacy of freedom that education can bring.

Workshops took place in English and French on the topic "What would make it easier for you when you visit the doctor, clinic or hospital?" Participants talked about the rights of health consumers in the health system. Based on the discussions, participants listed key messages for health care professionals, the health system, people with literacy challenges, and literacy workers. Raymond Roy, the spokesperson for the learners, presented these key messages at a lunch.

Key messages from Adult Learners:

Messages to health care professionals:

- Take sensitivity training. Invite learners to speak to groups of medical students (doctors, nurse, therapists, lab technicians, etc.) before they graduate.
- Use visual props, models, and pictures to explain things.
- Use tools like the “Literacy Audit Toolkit” from Literacy Alberta to evaluate your services, offices, and waiting rooms.
- Give information on video screens in the waiting room—especially to explain routine questions and procedures.
- Take the time to listen. Your patience and empathy are just as important to *our* health as your knowledge and skills.

Messages for the “system:”

- We need to slow things down so patients and medical staff have time to build trust and exchange information.
- Hire staff to do follow-up when people have questions after their appointment. That’s when the questions usually pop up.
- We need to work together to develop positive questions that will be asked to everyone so no one feels singled out. For example, “Do you need help?” Or better yet, “We have extra help available if you’d like it...”
- Involve adult learners in any work that needs to be done to make improvements. They can teach people about the realities for less literate patients.
- Simplify written health information with pictures, symbols, and diagrams.
- The system needs to provide sensitivity and accommodations for those with special needs, such as interpreters, ramps, etc.

Messages to people with literacy challenges:

- Ask for help! Don’t be afraid to say that you’re unclear—health workers need to know this! It is your right to understand.

Messages for literacy workers:

- Work with health workers to help them figure out how to provide services to people with literacy challenges (especially appropriate “screening” questions).
- Encourage learners to bring a support person to medical appointments.
- Help make everyone more aware of learning difficulties.

The Canadian Health Network (CHN) held a workshop to teach learners the skills they need to find information on the CHN website. Learners gave feedback about how to make the website easier to use for people with literacy barriers.

Learners took part in other sessions at the conference. They developed a set of final recommendations. They were presented by Ellen Szita and Raymond Roy at the closing session. Szita and Roy stressed that low literacy has a real impact on health. They said that learners, educators, health care workers, and decision makers all have a role in finding solutions.

Resources for Adult Learners and Students of English as a Second Language

Information is available in plain language about health literacy and common health problems at these websites:

- 1. California Health Literacy Initiative**
This website has information about health problems and diseases.
http://www.cahealthliteracy.org/hlrc_plainlan.html#gpl
- 2. Ask Me 3**
This website has good questions to ask when you visit your doctor, nurse, or other health care worker. <http://www.askme3.org/>
- 3. LINCS Health and Literacy Collection**
This website has health information and a dictionary where you can look up words about health, disease, or medicine. It also has stories and health projects by adult learners.
<http://www.worlded.org/us/health/lincs/learner.htm>

3.2 Building Best Practices in Literacy and Health

Best practices in literacy and health are programs, projects, and policies that aim to improve the health of Canadians with low literacy skills. Best practices succeed by helping people to:

- know where to go for help;
- understand their health problems;
- have information about the best treatments and how to use them;
- know about how to live a healthy life; and
- have resources to take care of their health.

Best practices may also focus on the link between literacy and other factors that affect health, such as:

- income;
- social support;
- access to jobs; and
- self-esteem.

Participants shared what they have learned through their own experiences in literacy and health in places such as:

- communities;
- schools;
- public health institutions;
- hospitals and other health institutions;
- public libraries; and
- the workplace.

Topic areas included best practices in:

- sharing health information for preventing disease and promoting health and treatment (through plain language, verbal communication, video, theater, computers, and other approaches);
- building the skills of learners and health consumers to know how to find and use health information;
- building the skills of health professionals to know how to effectively give information about health;
- providing programs in family literacy to parents with low literacy skills and their young children;
- working with youth who drop out of high school;
- working with seniors who have low literacy;
- building partnerships that combine adult literacy and health;
- planning and providing services through developing community and using participatory approaches (involving learners, health consumers, and practitioners); and
- improving the health of people with low literacy skills from distinct population groups, such as people living with a common disease (for example, diabetes, cancer, or heart disease) or people of the same background or culture (for example, Aboriginal peoples, Francophones, immigrants/new Canadians, and other ethnocultural groups).

**Health Conscious Societies in the 21st Century –
Implications for Health Literacy in Canada**



Dr. Kickbusch is a professor for global health at Yale University's department of epidemiology and public health. She initiated the Ottawa Charter for Health Promotion. In her speech, she explained why literacy is so important in our society. She said that health has become the main theme and driving force of modern society.

Health and health literacy are basic rights. They are an essential part of politics.

Health is a social, political, and economic driving force. Political platforms are built and elections are won and lost based on people's expectations of health care. Kickbusch outlined six factors that health-conscious societies have in common:

- A high life expectancy and an aging population
- An expansive health and medical care system
- A rapidly growing private health market
- Health as a major theme in social and political discourse
- Health as a major personal goal in life
- Health as a right of all citizens

Health consumers often receive too much health information. Kickbusch said that a growing health market offers more choice. Health information is everywhere. It is available from:

- the news;
- health institutions, organizations, and associations;
- peer-reviewed literature;
- self-help books;
- health care providers;
- governmental health organizations;
- popular media such as television and radio;
- friends and family; and
- the Internet.

Health literacy that can help people decide what to do and what to buy.

Health literacy has a critical impact on how people use health services, health outcomes, and the cost of health care. Kickbusch noted that health literacy is a key action area in promoting health. Health literacy enables people to:

- navigate the system;
- find information;
- understand their rights;
- make choices that prevent and improve disease; and
- enhance quality of life.

Health literacy helps to empower people and communities to take control over and improve their health and well-being.

Public health providers need to use integrated approaches to address society's inequities. Because the health of all people is equally important in our society, the right to health care and treatment for all must be matched with the right to understandable information about health care.

Dr. Ilona Kickbusch spoke about changes in our society and how important health literacy has become for:

- our day-to-day tasks; and
- equitable access to health and health services (see text box).

Many presenters discussed:

- practices in health and literacy; and
- how to build on these practices to meet the changing needs of people getting or providing services.

Highlights of these presentations are below. They are grouped by topic.

Plain Language and Clear Communication

Presenters agreed that plain writing and clear verbal communication is necessary for health information. Many presentations focused on providing practical tools in oral and written communication for health care workers and others. A range of clear communication practices targeted Aboriginal, Francophones, immigrant, hearing-impaired, and low-literate groups.

Michele Gauthier presented a tool used to evaluate the reading level of information. As part of the session, he assessed a public health poster. Gauthier noted the following steps to find problem areas and to create user-friendly communication:

- identify the audience;
- choose a communication goal; and
- identify the behaviours to change and how they should change.

Gauthier suggested that all communication should follow these rules:

- Be relevant: adopt the audience's point of view. Consider their ability to understand.
- Be understood: formulate and organize the information in a clear and simple way.
- Be persuasive: direct the communication at action and at concrete results.

Leah Morris of the Ontario Literacy Coalition outlined five areas to consider for readability:

- overall appearance (layout and design)

- organization of material
- language
- sentence length and structure
- tone (how the text speaks to the reader)

Morris noted that clear writing has associated costs. These include time, money, and labour. To avoid being overwhelmed with the task, you should start by changing one topic or one resource. Make changes in teams of two or three to make sure that the intent stays the same and materials get more than one review. For take-home messages about prevention and treatment, have someone read the text out loud to see if it sounds helpful and similar to an informal conversation.

Diane Pouliot works with the Francophone literacy coalition, la Fédération Canadienne de l’alphabétisation en français. She discussed how to identify people with literacy barriers. She emphasized the need for service providers to learn skills for communicating clearly when talking with people. Dr. Joanne Schwartzberg presented a training video for health professionals with tips for improving verbal communication:

- Slow down.
- Convey the most important ideas.
- Use “living room” language.
- Involve family members.
- Use visual aids.
- Use a teach-back method: ask patients how they would explain the material to friends.

Overall, presenters agreed that combining easy-to-read materials for teaching patients with oral instructions in simple language enhances patient understanding. However, participants agreed that strategies beyond plain language are needed. Readability tests on their own have some limitations in evaluating whether health information can be understood and used.

For a summary of each presentation or workshop, visit <http://www.cpha.ca/literacyandhealth/BestPractices.htm#PlainLanguage> on the Internet.

| Plain Language and Clear Communication | |
|--|-----------------------------|
| Atelier pour les personnes apprenantes : Comment mieux communiquer avec les personnes qui ont des difficultés à lire et à écrire | Margo Fauchon |
| Using Plain Language: the Importance of Easy Communication in Aboriginal Communities | Melanie Ferris |
| How to Communicate with Less Literate Canadians | Michel Gauthier |
| The ABCs of Clear Writing | Leah Morris |
| Comment mieux communiquer avec les personnes qui ont des difficultés à lire et à écrire | Diane Pouliot |
| One Day Wonders | Marg Rose and Charles Moody |

Building Capacity for Health Professionals

These presentations targeted health professionals. They looked at potential changes in training through curriculum and train-the-trainer programs. Presenters emphasized the importance of the two-way human interaction between health care providers and users. A common theme in presentations and discussions was that health providers and the health system must take responsibility for improving communication and ensuring equitable access and quality care.

Joanne Schwartzberg of the American Medical Association presented the Association's efforts to improve training for health professionals through the program Health Literacy: Help Your Patients Understand. This program provides tools for providers to do their work more effectively while working with all patients, including people with low levels of literacy. She emphasized the importance of creating a shame-free environment and providing easy-to-understand information.

Judy King discussed the results of a research project that involved interviewing people in literacy programs who had health problems such as diabetes, arthritis, or asthma. She found that when people improve their literacy skills they:

- feel more confident and comfortable in health care encounters;
- learn that it is okay to ask questions;
- are able to read about their illness; and
- are able to fill out forms on their own.

In Canada, programs to build the knowledge and skills of health care providers are underway in both the health and literacy sectors. Jane Dyson talked about the British Columbia Health Literacy Network. This is a new, online network where service providers, academics, librarians, and others can share information, advice, and practices to build capacity. Lindsay Wizowski and Tracy Hutchings talked about their role as patient education specialists at Hamilton Health Science Centre. They noted that there have been positive evaluations of their participatory training workshop for health care professionals and students about plain language, clear verbal communication, and health literacy issues.

Within the literacy sector, Audrey Gardner talked about an awareness program at Bow Valley College. This program builds capacity through activities including workshops, literacy audits, and partnerships. The goals of the program are to:

- reduce literacy barriers to services, programs, and community projects; and
- increase awareness about adult literacy among community service providers and volunteer groups.

Gardner noted that the adult education sector can play a role in raising awareness. She said that there is still limited awareness among service providers about the impact of low literacy and how to improve the way services are delivered.

For a summary of each presentation or workshop, visit <http://www.cpha.ca/literacyandhealth/BestPractices.htm#Building> on the Internet.

| Building Capacity for Health Professionals | |
|--|--------------------------------------|
| Health Literacy Network Community of Practice | Jane Dyson |
| Patient Education: the Literacy Connection | Judy King |
| Effective Communication for Health Care Providers and Program Administrators | Penny Lane and Holly Smith Miranda |
| Techniques used by clinicians to improve communication with patients with limited literacy | Joanne Schwartzberg |
| Health Literacy – Help Your Patients Understand | Joanne Schwartzberg |
| Health Literacy Workshops for Professionals and Students: Building on 10 Years of Experience | Lindsay Wizowski and Tracy Hutchings |

Working with Specific Populations

Presentations in this area focused on techniques for working with families, immigrants/new Canadians, and people with disabilities.

Working with Families

Common themes among presentations on working with families included:

- ensuring active participation of community members in designing, managing, and putting programs in place;
- increasing parental awareness of their child’s development;
- providing practical support to parents with limited income; and
- working with children from a young age so they are ready to learn in school.

Pat Chisholm discussed the Young Parents Education Program. It grew out of a Prenatal Nutrition Program from Health Canada. This family-centered program helps parents understand their child’s development. It provides structured time together for parents and children to learn and play. She explained that in-depth community partnerships are very important to the success of the program. Partners include the:

- Better Babies Program;
- Columbia Basin Alliance for Literacy;
- Cranbrook Boys and Girls Club; and
- College of the Rockies.

Wazi Dlamini Kapenda presented the Home Instruction for Parents of Pre-School Youngsters Project. The project is based at the Britannia Community Services Centre in Vancouver. She gave testimonials from parents about the value of the program. She also emphasized the role of parents as the most important educator of their child and supports for bonding between parents and children.

Danielle Galipeau gave a presentation about the Projet d’harmonisation à la petite enfance. She emphasized the need to address the impact of poverty on parents and young children.

She talked about a program that includes a school breakfast program and practical resources for parents.

Working with People with Disabilities

Presentations were made about the specialized resources that are needed for adults with developmental and other types of disabilities. Common themes included:

- the value of involving peers in sharing health information and skills; and
- using alternatives to written materials such as pictures, activities, and audio-visuals.

A group of presenters from the Vocational Rehabilitation and Research Institute (VRRRI) and the Grace Women's Health Outreach Program in Calgary talked about their partnership. They provide clear health information to people with developmental disabilities.

Leah Jones explained that the VRRRI recognized the need for a clear way to tell clients about health and medical procedures. This would reduce clients' fears and enable them to talk with medical professionals about what was happening to them. Jeannette Coombe and Joseph Hnatuk spoke about "Smoke Talk – Tobacco Awareness Course in Plain Language for Adults with Developmental Disabilities." They noted the importance of peer education in helping people quit smoking along with plain language information and learning activities.

James MacDougall of the Canadian Deafness Research and Training Institute said that there are many obstacles for deaf people. For many health professionals, understanding the realities of deafness is a challenge. Access to health care for deaf people is very reliant on the use of sign language interpreters. As well, many deaf people have severe reading and writing difficulties in English and French. One solution being considered to help deaf people in health care settings is Remote Video Interpretation (RVI). It allows a deaf person to interact with a sign language interpreter at a remote location, through video conferencing.

Working with Immigrants/New Canadians

These presentations focused mainly on promoting health to immigrants/new Canadians or students of English as a Second Language.

Marcia Drew Hohn, Vanda Ivanenko, and Saiyi Diaz spoke about Operation Bootstrap. The program trains student leaders to identify health topics and provide health information to other students at a learning centre for immigrants. Hohn explained that promoting health is a new idea for many of the foreign-born students. Many have not experienced health promotion in their country of origin. Students provide health information to other students in workshops using role play, stories, and other methods. Hohn criticized an over-reliance on plain language. She emphasized the importance of group participation and student empowerment in programs for promoting health.

Elsie Petch, Norma Levitt, and Al Levitt talked about a project at the South Riverdale Community Health Centre. Seniors from different language and cultural backgrounds and with a range of literacy skills were involved in reviewing and rating health information materials. Petch explained that to actually use printed information, a reader must be able to "get beyond the text." Sometimes cultural misunderstanding can be a barrier to understanding text. The Levitts noted the value of involving community members in

developing materials and health messages. They recommended encouraging participation and peer learning to ensure that health information is communicated clearly.

For a summary of each presentation or workshop, visit the following Internet addresses:

<http://www.cpha.ca/literacyandhealth/BestPractices.htm#Families>

<http://www.cpha.ca/literacyandhealth/BestPractices.htm#Communities>

<http://www.cpha.ca/literacyandhealth/BestPractices.htm#Disabilities>

| Working with Families and Communities | |
|--|--|
| You are Your Child's Best Toy | Claudine Bennett |
| We All Benefit: Using Partners and Participatory Approach to Family Literacy | Pat Chisholm |
| Learning About Health, Student-to-Student | Marcia Drew Hohn, Saiyi Diaz, and Vanda Ivanenko |
| Project d'harmonisation à la petite enfance | Danielle Galipeau |
| Building Community Capacity: Focus on Literacy | Audrey Gardener |
| HIPPY Project/More is More | Wazi Dlamini Kapenda and Debbie Bell |
| People Who Rate: Community Involvement in the Development of Health Education Materials and Messages | Elsie Petch, Norma Levitt, and Al Levitt |

| Working with People with Disabilities | |
|---|---|
| Simply Health | Sharon Christie and Grace Carson |
| Smoke Talk- Tobacco Awareness Course in Plain Language for Adults with Developmental Disabilities | Jeannette Coombe and Joseph Hnatuk |
| Menopause- What is it? | Leah Jones |
| Literacy Barriers for Deaf People Using Health Services | Salma Kanji |
| Health Information for Deaf Canadians | James MacDougall |
| Alphabétisation et surdit  : un service populaire bilingue au centre des besoins sociaux | Anne-Marie Parisot et Rachel Berthiaume |

Sharing Health Information for Prevention and Treatment

Presentations in this area focused on different approaches to sharing health information and resources, through the Internet, interactive sessions with target audiences, and clear communication tools.

Trudy Lothian talked about working with learners in the Adult Literacy and Basic Skills Program at the Ottawa Carleton Catholic School Board. Personal stories from adult learners

provide interesting insights into what matters to them about their health. Adult learners worked with teachers in the classroom to:

- organize a health forum; and
- publish a collection of their stories and ideas about health in the *9th Adult New Readers Publication*.

This information is useful to health practitioners who work with people with literacy challenges. Lothian emphasized the need for a richer understanding of who becomes an adult literacy student and why. She acknowledged the efforts of the students in putting together this publication. It offers learners' perspectives on health and gives advice on the many things that we can do to improve our health.

Christine Villeneuve, Jocelyn Chaperon Beck, and Philippe Laurancelle presented the results of an interactive session with adult learners about using the Canadian Health Network website. Users gave suggestions to make the site more accessible to everyone. See the text box for more information.

Laureen Mackenzie and Elsie Paul led an interactive workshop about how to improve understanding of medication instructions. Paul started the workshop with a lengthy introduction in Cree. She explained that this was an example of how it felt to listen to someone speaking another language and to not understand important instructions. Some participants reacted to this introduction by saying that they felt alienated and confused. Several themes were highlighted including:

- feelings of isolation, anger, and frustration; and
- the lack of time medical professionals spend with patients.

Mackenzie ended the workshop with the following ideas of what can be done to help learners:

- Think globally, act locally.
- Count on the affected community to be part of the solution.
- Lead and delegate. Don't do.
- Partner with community literacy programs.
- Focus on educating both providers **and** patients.

Lori Kloda and Beth Wood talked about separate, hospital-based programs designed to help patients and their families cope with illness and better understand treatment. Deborah Begoray and Elizabeth Banister talked about ways of teaching teenagers about sexual health. They emphasized the importance of understanding the developmental stage and learning levels of youth. This ensures that programs are interactive and include practical ways to apply the learning.

For a summary of each presentation or workshop, visit <http://www.cpha.ca/literacyandhealth/BestPractices.htm#Sharing> on the Internet.

Sharing Health Information for Prevention and Treatment

| | |
|--|---|
| Reaching Teenagers Where They Are: Best Practices for Sexual Health Education Professionals | Deborah Begoray and Elizabeth Banister |
| Lessons Learned from Community Health Nursing in the ESL Classroom | Elizabeth Diem |
| Alphabet Soup | Candyce Jones |
| Librarians Partnering with Volunteers to Provide Health Information to Cancer Patients | Lorie Kloda |
| Health Matters | Trudy Lothian |
| How to improve understanding of medical instructions | Laureen Mackenzie |
| What would make it easier for you when you visit the doctor, a clinic or the hospital? | Fiona Murray |
| Responding to Learners' Demands for Consumer Health Information: How to Assess and Address Families' Changing Needs Online | Beth Wood |
| Learning to Use the Canadian Health Network (CHN) and What We Learned | Christine Villeneuve and Philippe Laurancelle |

Tips from Learners to the Canadian Health Network (CHN): Making Health Information Websites Easier to Use

The CHN is a web-based health information service. It helps Canadians make informed choices about their health. The Network aims to provide reliable and practical e-health information to help Canadians stay healthy and prevent disease.

The Network held a workshop to teach learners the skills they need to find information on their website. Adult learners and educators made suggestions to the Network about how to make the website easier to use:

- Know your target audience.
- Get feedback from them.
- Make your writing:
 - Clear – plain language – common words
 - Logical
 - Consistent
- Use short sentences, paragraphs, and headings.
- Avoid wordiness.
- Make key points early.
- Take out surplus information.
- Make it an invitation to read and keep reading.
- Use a friendly tone.
- Use graphics but not “bells and whistles.”
- Provide a symbol next to articles that are easy to read.
- Explain medical terms and difficult words.
- Have messages that “pop” up.
- Ensure that navigation is crystal clear.

Partner with adult literacy programs and community agencies to provide training on using the website.



Literacy and Health Resources

Some presentations gave information about literacy and health resources for practitioners. Participants noted that while there are very useful resources for literacy and health practitioners, there is still limited awareness of what exists. There is also a lack of coordination.

Lorette Chiasson made a presentation about the National Adult Literacy Database (NALD)/ la base de données en alphabétisation des adultes (BDAA). This is a database of adult literacy programs, resources, services, and activities across Canada. The database includes reports and resources about literacy and health. It also links with other services and databases in North America and overseas.

Nancy Friday and Mike Kelly gave a demonstration of Alphanoute Canada's on-line literacy learning environment. It includes over 300 health resources as part of a special library collection of adult literacy resources serving literacy practitioners, researchers, and learners in Ontario.

Sabrina Kurtz Rossi presented LINCS, the website of the Literacy Information and Communication System. This is part of a US effort to provide web-based access to information for adult literacy practitioners, students, health educators, and anyone interested in teaching health to adults who have limited literacy skills. Kurtz Rossi discussed how the site is structured to meet the different needs of learners, health professionals, and educators.

For a summary of each presentation or workshop, visit <http://www.cpha.ca/literacyandhealth/BestPractices.htm#Resources> on the Internet.

| Literacy and Health Resources | |
|---|-----------------------------|
| La base de données en alphabétisation des adultes et les ressources | Lorette Chiasson |
| Health Literacy Network Community of Practice | Jane Dyson |
| Healthy Interactions On-Line with Alphanoute | Nancy Friday and Mike Kelly |
| Helping Learners Use the Workplace Hazardous Materials Information System (WHMIS) | Monika Jankowska |
| Exploring the LINCS Health and Literacy Special Collection | Sabrina Kurtz Rossi |

How to Build Best Practices

A number of common themes and ideas came out of a discussion to build best practices. Presenters noted the importance of moving beyond a focus on plain language and testing the reading level of written materials. There are gaps in knowledge about the:

- links between low literacy and oral understanding; and
- the impact of verbal and non-written practice interventions.

There is a need for:

- ways to more formally document, promote, and share available resources;
- training opportunities and new resources for literacy practitioners and health professionals;
- strategies to link health professional and literacy networks to raise awareness and identify areas for collaboration; and
- building capacity for practitioners in program evaluation to build on evidence for developing policy.

Recommendations for Theme 1: Building Best Practices in Literacy and Health

- 1.1 Champion an inter-disciplinary approach to health and literacy programs that integrates parenting, nutrition, literacy, and developing community (example: the Healthy Living Manitoba model).

Who: The Council of Ministers of Education and the Deputy Ministers of Health Joint Committee on Education and Health

- 1.2 Link the literacy coalitions in every province and territory with the health literacy programs that are now underway.

Who: Our Association and the 27 partners of the National Literacy and Health Program and provincial and territorial agents

- 1.3 Develop and carry out a strategy to increase awareness and strengthen the capacity of health professionals to serve people with low literacy, and develop and carry out a strategy that supports collaborative approaches to providing service.

Who: Our Association in collaboration with the partners of the National Literacy and Health Program

- 1.4 Build on strategies that encourage using plain language in health settings. Focus on health environments such as hospitals, clinics, and public health and community-based health programs to improve access, help consumers to navigate the health system, and to understand and act on health information.

Who: Our Association in collaboration with the partners in the National Literacy and Health Program (engaging health professional regulatory bodies and training institutions)

- 1.5 Help programs share knowledge and resources with literacy and health workers (for example, the lessons learned and bibliographies from the Centre for Literacy in Québec's Phase 2 Program).

Who: The National Literacy Secretariat and Health Canada

- 1.6 Seek funding to safeguard/host the National Institute for Literacy LINCS health special collection and share and promote these materials to literacy and health workers in Canada.

Who: The National Adult Literacy Database

Appendix B is a list of literacy and health resources for practitioners. Many of these resources were mentioned in conference presentations. Other useful resources on this list were identified by Doris Gillis from St. Francis Xavier University.

3.3 Focusing on Language and Culture

Language and culture affect health, learning, and how people access health services. Conference participants shared knowledge. They learned from the successful programs in Canada and elsewhere that are sensitive to culture and language. Participants explored:

- Understanding why some population groups in Canada have better health than other groups
- Understanding the literacy and health issues of Aboriginal, Francophone, and ethnocultural communities
- Learning from communities to build practice, policy, and research that is sensitive to language and culture
- Improving the cultural competence of health professionals to work with diverse groups with literacy barriers
- Understanding the literacy and language of seniors from different ethnocultural groups
- Reaching out to communities whose language is neither English or French
- Learning from the Aboriginal approach to literacy and health

Dr. Janet Smylie, Director of the Indigenous Peoples Centre for Health Research, chaired a morning session. Three speakers talked about different aspects of language and culture. Each speaker stressed how important it is to consider language and culture when we work to improve people's health.

Presentations and discussions focused on the perspectives of Aboriginal, Francophone, and other ethnocultural groups.

The Cultural Context of Health Literacy



Dyanne Affonso is Dean of Nursing at the University of Toronto. She is a leading researcher in women's health care. She did one of the first major studies on the causes of postpartum depression. Her research looked at ways to improve the access of minority women to health care during pregnancy. It led to a reform of community-based health care in the United States in the 1990s. She was also a member of the committee that produced the recent report, "Health Literacy: A Prescription to End Confusion," published by the

National Academies Press in 2004.

Health literacy is more than reading and writing. Cultural and conceptual knowledge also need attention. Affonso focused on cultural context. One part of cultural knowledge is preferences and perspectives. Understanding a person's perspective and free choice are vital to grasping the significance of health, science, and technology to various people.

Language is important. We need to pay more attention to vocabulary and to the meaning of words and nouns within various cultures. For example, Aboriginal nations prefer using verbs rather than nouns because, in the dominant culture, nouns indicate finality. Verbs indicate action, a shift and flow of the Spirit in things, as compared with the permanence implied by using nouns. Nonverbal gestures, such as posture, attitude, and other aspects of cultural language, provide meaning and context.

Stories are also vital within the context of culture and language. Chanting, visual imagery, sounds, music, and touch are all ways in which people cope and heal. Rituals and traditions are important parts of literacy. Cultural healing systems and practices are an essential part of life. They need to be considered in the equation of quality health care services.

Including more values and cultural scripts and metaphors in the health care system is also important. Cultural metaphors are frameworks for thinking and doing. For example, the expression of giving thanks is a powerful metaphor in some cultures. Spanish culture is an example of a cultural script in which family is all-important.

Health literacy is a human rights issue related to quality care, patient safety, and quality of life. Affonso spoke about the need to advocate for the diversity of cultural language, equity, and cultural frameworks within the context of health literacy. The task is not simply translating language.

3.3.1 Aboriginal Focus

There were seven invited speakers who presented Aboriginal perspectives on the theme of language and culture. Overall, these speakers emphasized the need for culture-based approaches to Aboriginal literacy.

Highlights of Key Note Speech *Jan ?Kehehti:io: Longboat*

First Nations Health Symbology and Language

Jan _Kehehti:io: Longboat spoke at the first morning session about the health symbology and language for First Nations people. She is a member of the Mohawk Nation, Turtle Clan, Six Nations of the Grand River. She has a program to help Aboriginal women heal from residential school abuse. She also offers Aboriginal healing and well-being practices to communities and institutions.

_Kehehti:io: Longboat began by offering great peace from the Iroquois people. For the Iroquois people, literacy comprises all their cultural stories and symbols. In Iroquois culture, women are the keepers of culture. They are the keepers of the longhouse, the home, and everything that happens there. They are also the keepers of leadership: women pick the chiefs. Iroquois women must be very knowledgeable about economics and the entire Nation.

She explained that many Nations have used the same symbolic foundations in their language and culture. The power of language and literacy is that it teaches an entire worldview, whether the tradition is oral or symbolic. All teach the interrelatedness of life and the importance of honouring all the medicines that give life—mental, physical, emotional, and spiritual.

_Kehehti:io: Longboat said that, during her growing up on the Six Nations reserve, the word “health” was never used. Instead, elders talked about the symbology of well-being as being what language was all about. _Kehehti:io: Longboat said that symbolism is the way in which people gain balance and harmony in their lives, and it is how individuals are sustained on their life path.

Melanie Ferris discussed the links between literacy, education, socio-economic challenges facing Aboriginal communities, and the holistic definition of health. Key points were that:

- literacy includes fully understanding what one is reading and writing, not just “the ability to read and write”
- plain language is an important tool for personal and community self-determination
- lower rates of education for Aboriginal people are linked to socio-economic challenges facing Aboriginal communities

- literacy and socio-economic conditions are intertwined with a holistic definition of health that includes the physical, mental, spiritual, and social
- First Nations control of education is necessary to improve literacy

Elaine Endawas talked about the important role of spirituality in health as it is defined from an Aboriginal perspective. She explained the four directions and the animal helpers that are found in each direction. She also described Aboriginal medicines and ceremonial tools and how they can be used in healing work with clients. Key points were that:

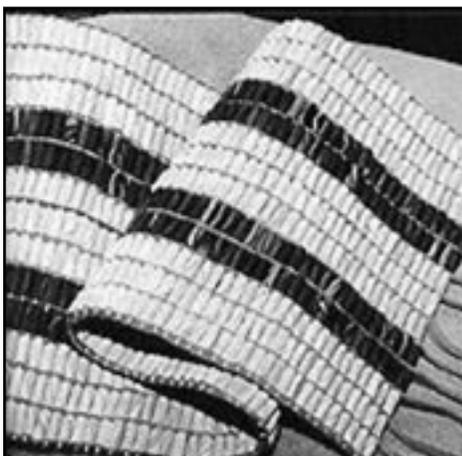
- literacy is a process of recovering a sense of positive Indigenous identity
- literacy is linked to the process of healing from colonial trauma
- the sacred is intertwined with all aspects of life, according to the Aboriginal worldview

Carole Blouin identified herself as a former learner who is now a literacy advocate. In the 1990s, she had a hysterectomy. She believes it was unnecessary because she did not understand what the hospital staff were telling her. She also suffered from illness and depression. At the recommendation of a friend, she signed up as a learner volunteer at a literacy centre. She has since received her high school diploma and enrolled in college. Her health improved during her studies, and she is now on the Boards of the College du Savoir and the Federation Canadienne pour l'alphabétisation en français.

Dr. Eileen Antone talked about language carrying culture, values, and beliefs. She believes that:

- racist and oppressive government policies, including residential schools, have contributed to a loss of language for many First Nations people
- Aboriginal literacy programs can encourage self-knowledge, self-expression, self-affirmation, and self-determination in a positive way
- Aboriginal literacy programs can also support participation in local self-governance and community development

Antone presented a picture of the Two Row Wampum. It promotes equity, peace, mutual respect, and friendship between Europeans and Aboriginal peoples.



The Two Row Wampum promotes equity, peace, mutual respect and friendship between Europeans and Aboriginal peoples, each with their own essence of life, traveling down the river alongside each other.

Maria Morrison talked about the Ningwakwe Learning Press. It publishes materials designed specifically for learners who have low levels of literacy. The “Healthy Lifestyle Series” blends evidence-based Western medicine with traditional Aboriginal practices. Through stories and pictures, the reader is able to process, understand, and apply health information more effectively than with a list of facts. Morrison pointed out that it is challenging to reflect the diversity of Aboriginal peoples and their languages in the publications.

For a summary of each presentation or workshop, visit <http://www.cpha.ca/literacyandhealth/LanguageandCulture.htm#Aboriginal> on the Internet.

| Language and Culture – Aboriginal Focus | |
|---|---------------------------|
| Aboriginal Perspectives on Health and Literacy | Eileen Antone |
| A Literacy and Health Success Story | Carole Blouin |
| Role of Aboriginal Spiritual Traditions in Healing and Wellness | Elaine Endanawas |
| Creating Aboriginal Literacy and Health Publications | Maria Morrison |
| First Nations Health Symbology and Language | Jan _Kehehti:io: Longboat |

3.3.2 Francophone Focus

A number of sessions focused on the important link between language and cultural identity for Canadians who speak French as their first language. Language and cultural identity are linked to the health of people and communities. Literacy and learning in French, both inside and outside of Quebec, are important. Research, practice, and policy need to consider the links between language, identity, health, and learning.

This section highlights a panel discussion and roundtable about literacy and health in Francophone communities. It is followed by a summary of other sessions presented in French.

Community Vitality, Language, and the Health of French-Speaking Canadians

Dr. Rodrigue Landry is the Director of the Canadian Institute of Minority Language Research. In a panel discussion, he talked about the vitality of language and how it affects the health of Francophone communities. He explained that if a community is not healthy, the health of its members is at risk. If the health of French-speaking Canadians depends on the health of the French language in Canada, then literacy and health are linked to linguistic vitality.

One test of group vitality is the ability to pass the mother tongue from one generation to the next over time. Several factors affect the strength and vitality of a language:

- Demographics (the number of language speakers)
- Institutional support (the amount of power or influence the group can wield)
- Status (the social recognition or prestige attached to the language)

Vitality in the Francophone community can affect the health of its members through participation in managing health care services, requests for services in French, and creating more literacy services and programs.

According to Landry, the vitality of the French-speaking minority in Canada is increasingly threatened because speakers of Canada's official language (English and French) live in focused geographic areas across the country. Other factors include a low rate of growth of the French-speaking population and the social attraction to use of English as the first language.

A global strategy is needed to reverse this language shift. This shift requires policies that create a healthy environment for Francophones to learn and to socialize in French.

Linking Research and Practice to Improve the Literacy and Health of Francophones

Pierre Joubert of the Public Health Institute of Quebec opened a roundtable discussion by noting that issues of literacy and health are linked to social vulnerability. Typical issues include:

- problems of access; and
- the capacity for effective interaction on the part of health care providers.

One goal of the roundtable was to find ways to address those issues in the Francophone context. Participants spoke about the challenge of transferring research knowledge to practice from the perspectives of the literacy, public health, and research communities:

- Luce Lapierre is the director of the Francophone literacy coalition, la Fédération canadienne de l'alphabétisation en français. She suggested that a direction for research and action can be determined by taking the perspective of adult learners when they access our complex health care system. Literacy programs can work toward improving the reading level of the people they serve. But, the health community must also increase its efforts to make accessing service less complex. Governments also must do a better job of offering services in French on demand. When communicating with adults who have low literacy, health care providers need to be more aware of the barriers that exist.
- Lucie Lemieux is the director of public health and social services in the Outaouais region. She spoke about the alarming rise in high school dropout rates. This problem that has been identified as a public health risk in the region. Efforts are under way to reverse the trend. Researchers are trying to understand the dropout's path and to identify the points at which youth consider leaving school, actually leave school, and consider returning to school to complete their education. Early childhood programs are in place for young children from low-income and disadvantaged families. They help prepare these children for success in school in the future.

- Rodrigue Landry said that, although research on linguistic minorities can be complicated for political and practical reasons, Francophone Canadians are fortunate that French is an official language. The potential of that status should be explored. Federal and provincial responsibilities should be defined so that Francophone Canadians can exercise their rights and express their language preferences. Canada is still far from creating the jurisdictional and sectoral synergy needed to strengthen its French language and culture.

Participants were reminded that Francophone Canadians have problems accessing health services because of low literacy and because of geography and language. The federal government's focus on evaluation may provide opportunities to do research that produces concrete results in the field. Good results will show the benefit to society of strong Francophone communities, institutions, and services.

Research shows that a strong and positive Francophone identity contributes to the development of a vital Francophone community. Participants felt that those results could provide some practical direction for developing strategies that deal with the self-esteem issues that affect the dropout rates of high school students.

Joubert closed the session by saying that research results and recommendations must be combined so that policy makers can read, understand, and apply them quickly and easily.

Other Sessions in French

A number of other sessions were presented in French about best practices and research in literacy and health. Some of these programs are designed for specific age or target groups within Francophone communities:

- early childhood and family literacy;
- seniors
- youth; and
- the hearing impaired.

Highlights of Key Note Speech *Johanne Laverdure*

Integrating Services for At-Risk Children in Quebec



Johanne Laverdure is the Scientific Coordinator of the Individual Development and Adjustment Unit at l'Institut national de santé publique du Québec (INSPQ). She spoke about how the Government of Quebec aims to ensure greater success for children by intervening at an early stage. This program helps at-risk families during perinatal care and early childhood education periods. It offers them integrated services from birth to the point of school entry. Clients include young parents and families dealing with extreme poverty. Two types of

services are offered:

- services to the family; and
- services aimed at the larger community.

The goal of the family-focused service is to promote parent–child bonding, good life habits, and maturity at school. These factors make it more likely that a young child will be ready to learn at school. The family-focused service involves at-home visits by an intervener (one per family) every second week. Interveners may also help families to find and use community services. The challenge of the family-focused service is to have a global approach to health, while offering support in specific areas, such as diet, tobacco use, and bonding.

An interdisciplinary team works with the intervener. This team includes a doctor, a social worker, a nutritionist, and a psychotherapist. The intervener creates a link between the family and the team, and between the family and the community. Two guides support the program. One guide explains how to promote bonding in families. The other guide describes healthy life habits in the context of parenting children who are between two and five years old.

The goal of the community-based service is to meet the needs of communities so that they can create better living conditions for families. The services aimed at the larger community work to ensure the community is welcoming to children and families and promote early childhood intervention to ensure that every child is ready for school.

For a summary of each presentation and workshop, visit <http://www.cpha.ca/literacyandhealth/LanguageandCulture.htm#Francophones> on the Internet.

| Language and Culture: Francophone Focus | |
|---|------------------------------------|
| Les déterminants sociaux de la santé et minorités Francophoness | Louise Bouchard |
| La base de données en alphabétisation des adultes et les ressources | Lorette Chiasson |
| Alphabétisation et santé chez les Francophoness en situation minoritaire | Sylvain Deslisle |
| Identité ethnolinguistique et autodetermination: des facteurs de la santé | Kenneth Deveau and Rodrigue Landry |
| Les aînés: Leurs santé et l’alphabétisation | Roger Doiron |
| Atelier pour les personnes apprenantes: Comment mieux communiquer avec les personnes qui ont des difficultés à lire et à écrire | Margo Fauchon |
| Projet d’harmonisation à la petite enfance | Danielle Galipeau |
| Rendre lisible l’invisible : pratiques de lecture des faibles lecteurs et représentations des organismes | Roch Hurtubise |
| Implications pour la recherche et le transfert des connaissances en alphabétisation et santé en français | Pierre Joubert |
| Recherche d’information médicale : une approche multi-factorielle | Stefan Kabene |
| La santé et la francophonie | Rodrigue Landry |

3.3.3 Ethnocultural Focus

There were five presenters who talked about the impact of language and culture on health literacy and the health of ethnocultural groups, particularly immigrants/new Canadians. Immigrants and new Canadians are more likely to face barriers to finding, understanding, and using health information and health services. As with health literacy in general, there is a two-way interaction between:

- (1) the people and organizations providing information and services; and
- (2) the people seeking them.

Speakers focused on ways that people providing service and doing research can be sensitive to language and culture to address literacy barriers and improve health outcomes.

At a lunch session, Dr. Miriam Rossi talked about a culturally sensitive approach to promoting community health and programs for preventing disease. She used the diabetes prevention program of the Toronto Health Department as an example. Working with members of the black community, a volunteer program was set up to share information and teach skills about healthy eating, healthy lifestyle, and managing stress. See the text box for more information about how this public health project builds on the strengths of community members and approaches language, culture, and health literacy.

Other presentations explained the complexity of health literacy issues when working with members of ethnocultural groups. These issues need to be addressed to improve health and access to health services.

Elizabeth Diem of the University of Ottawa made a presentation about a program that helps undergraduate nursing students work with students learning English as a Second Language (ESL). Over a term of study, nursing students spend one to two hours per week interacting with multicultural learners in classrooms or during breaks. The nursing students are trained in participatory methods to gather information about health issues that are important to the ESL learners in the classroom. Students gain valuable skills, knowledge, and experience that can be applied in health care settings working with community members with different language and cultural backgrounds. The ESL learners and teachers benefited from the presence of nurses in the classroom who provided access to health information.

Birgitte Robertson talked about the Momiji Health Care Society. It serves Japanese Canadians in the province of Ontario. Programs and services for seniors promote healthy aging, in their own language and within their own cultural context.

Other presentations explored how to do effective research that considers language and cultural barriers for immigrants/new Canadians. Presenters suggested that better research methods will lead to more effective programs and a wider base of knowledge for practitioners and policy makers.

Lisa Merry of McGill University presented the results of her own research. She examined the effectiveness of using translated questionnaires to collect data on health. Merry used interpreters to get feedback about the readability and cultural appropriateness of a variety

of self-administered questionnaires that had been translated into a range of languages. She found problems with design, translation, word choice, and cultural bias. It was recommended to adapt questionnaires to reduce problems in communication.

Jodi Tuck spoke about her work exploring issues of cultural sensitivity by examining research tools about women's reproductive health. She worked with a small group of women from different cultural backgrounds to explore their attitudes towards standard research tools, such as surveys and consent forms.

In other sessions, there were discussions about the need for new policies to reduce health disparities experienced by immigrants/new Canadians. Changes in health policy are needed at the federal and provincial levels. To inform policy development, more research is needed to understand the factors that affect the health literacy of immigrants/new Canadians and their impact on health and access to health services.

Suggested directions for future research and policy development include:

- supporting and encouraging medical and health institutions to develop cultural competency materials and curricula to be used for training health providers to improve cultural sensitivity (for example, about multiculturalism, equity, and clear communication skills)
- doing research on immigrant communities, their health, and the barriers they face to accessing health information
- developing culturally sensitive ways of promoting health literacy and service use among these communities
- increasing work between the health care system and agencies that serve immigrants
- identifying funding to bring together leaders in multicultural health and literacy networks to define issues and solutions

Highlights of Key Note Speech *Dr. Miriam Rossi*

Preventing Diabetes in Toronto

Dr. Miriam Rossi is a Professor of Pediatrics in the Faculty of Medicine at the University of Toronto. She discussed her work in setting up a program for preventing diabetes in four black communities in Toronto. She explained that while diabetes is a major killer in the black community, the condition is not discussed openly.

Health is a state of complete physical, mental, and social well-being. It is not merely the absence of disease and infirmity. Other factors also contribute to what we mean by health. One factor is the meaning of an illness to a person. If a person finds that he or she has an illness and is willing to seek help, part of the battle has already been won. Another factor is the way in which a person defines himself or herself. People will not get help if they lack feelings of worth.

Many factors influence health and health care. These include:

- biology;
- sociology;
- psychology;
- values and beliefs;
- structures; and
- symbols.

Symbols are often overlooked and are very important. For example, a doctor can be a daunting symbol. People will often fail to tell the truth to a doctor or nurse. Instead, a person tells those professionals what he or she thinks they want to hear.

The program for preventing diabetes involves community members as volunteers on a community advisory committee. The program addresses healthy eating, healthy lifestyle, and managing stress. The healthy eating part of the program requires some very involved training. It is not just a lecture on nutrition. A four-level “train the trainer” process involves coordinators and volunteers. People learn how to prepare healthy foods that are culturally appealing. Those people then train others, and those other people move into the community to demonstrate preparing food.

The healthy lifestyle part of the program recognizes that many people will not do the physical activities that are often recommended. Other activities are suggested such as “on the spot” movement and reggae or calypso aerobics. The program partners with churches, because, at every level of the black community, people (whether religious or not) are often more trusting of programs delivered through a religious institution.

Alternative, culturally appropriate options are promoted for managing stress. A yoga teacher in Toronto designed a program particularly for the black community. A number of people are now being trained to teach the classes. Other activities include spiritual drumming and prayer.

A culturally sensitive approach to transferring knowledge and skills is important for successful community health promotion and programs for preventing disease. Key factors include:

- appropriate interpretation (including cultural nuances);
- easy-to-read information and other resources in multiple languages; and
- verbal information that uses a culturally sensitive approach.

For a summary of each presentation or workshop, visit <http://www.cpha.ca/literacyandhealth/LanguageandCulture.htm#Diem> on the Internet.

| Language and Culture: Ethnocultural Focus | |
|--|--------------------|
| Lesson learned from Community Health Nursing in the ESL Classroom | Elizabeth Diem |
| Getting the data right when working with refugee and asylum-seeking groups | Lisa Merry |
| Momiji Health Care Society: a culturally sensitive program for Japanese-Canadian seniors | Birgitte Robertson |
| Unveiling sexuality: culture and gender disparities in South Asian populations | Julia Thomas |
| Using multi-ethnic, multilingual focus groups to enhance research with refugees | Jodi Tuck |

Recommendations for Theme 2: Focus on Language and Culture

- 2.1 Address health literacy among Aboriginal peoples in Canada by identifying key people and ways to build on cultural practices, traditions, and strengths.
Who: The National Indigenous Literacy Association approach the First Nations and Inuit Health Branch of Health Canada, the National Aboriginal Health Organization, and the Indigenous People’s Health Research Centre
- 2.2 Continue to build partnerships with leaders and institutions working in the areas of public health, social services, and promotion of French language and culture to develop collaborative research and practice models for Francophones in Quebec and other parts of Canada.
Who: Fédération Canadienne de l’alphabétisation en français
- 2.3 Identify funding support for outreach programs that engage ethnocultural partners working in literacy and health, and to identify opportunities for partnership.
Who: Our Association, partners of the National Health and Literacy Program, and the Canadian Ethnocultural Council

3.4 Building Knowledge in Literacy and Health

Research can provide important information for policy makers, practitioners, and health consumers. At the conference, participants shared what is being done in literacy and health research in Canada and other countries, and identified new areas for research. Participants focused on:

- Understanding the links between literacy and health
- Learning from learners, health consumers, and communities through participatory, community-based research methods
- Building knowledge on how to evaluate literacy and health programs
- Building knowledge on how to measure literacy in health and social services
- Understanding the link between literacy and mental, spiritual, physical, and emotional health
- Understanding the link between literacy and patient safety in the health system

Highlights of Key Note Speech *Dr. Rima Rudd*

Literacy and Health in America: Implications for Canada



Dr. Rima Rudd is a public health educator. Her work centers on health communication in the design and evaluation of community-based public health programs. Rudd teaches health literacy, innovative strategies in health education, and program planning at Harvard University. Rudd took part in a panel discussion about what the Institute of Medicine report on health literacy mean for Canada.

In April 2004, the topic of literacy and health moved onto the US agenda in a big way. Rudd explained that this shift of attention to the study of health and literacy took place because of three key US reports:

- “Literacy and Health Outcomes;”
- “Health Literacy: A Prescription to End Confusion;” and
- “Literacy and Health in America.”

“Literacy and Health Outcomes” found that low literacy is associated with poorer health. The report is based on a survey of nearly 700 articles evaluating the quality of intervention outcomes. It found that low literacy, as measured by poor reading skills, is associated with poorer health, for outcomes such as:

- use of services;
- health knowledge;
- screening; and
- prevention.

The survey also pointed out that interventions to address low literacy were typically limited to revision of print materials. However, as Rudd emphasized, improved materials alone do not equal a program.

“Literacy and Health in America” reinforced the limitations of an exclusive focus on the structure and complexity of written or printed texts. Using data from the National Adult Literacy Survey and the International Adult Literacy Survey, the report characterized the health-related literacy skills of American adults for the first time. It also created a task-based Health Activities Literacy Scale that more accurately captures the complexity of the tasks that people are expected to perform with health-related information.

“Health Literacy: A Prescription to End Confusion” expanded the definition of literacy. The definition acknowledges that literacy is always part of an interaction. It addresses the trend over recent decades of increased reliance on the written word in all forms of health information. Limited literacy skills may have permitted adequate functioning in health 50 years ago, but that is not the case today. Rudd praised the report for effectively expanding the scope of health literacy work, by moving it out of the context of medical institutions and into the home, the workplace, and the community.

The responsibility for effectively communicating information is a shared one. Rudd noted that the reports recognize that literacy always takes place in a context mediated by education, culture, language, and the communication skills of both the “lay” person and the health practitioner.

Rudd noted that it was important to draw from the knowledge of the health and adult education sectors to build strong evidence and to bring a focus to the issue of health literacy in the US.

Many presenters shared the results of research. Participants discussed what needs to be done to build knowledge in the field of literacy and health. Highlights of these presentations are below. They are grouped by topic.

Future Directions in Literacy and Health Research

Dr. Irving Rootman discussed an environmental scan and needs assessment of Canadian research and practice in literacy and health. This work was done through the Canadian Literacy and Health Research Program. The project is funded by the Social Sciences and Humanities Research Council of Canada. It involved developing a national program of research on literacy and health. Although there are a large number of literacy and health projects, there was a need for focused research in this area.

Rootman presented a framework that shows the complex links between:

- the determinants of health;
- actions to promote health;
- literacy; and
- the effects of literacy on health.

The way these factors interact impacts on a person's health.

- The determinants of health in the framework include education, early child development, aging, personal capacity, living/working conditions, gender, and culture.
- Actions to promote health include communication and developing personal capacity, community, organizations, and public policy.
- Basic reading skills (general literacy) impact on health as well as health literacy and other types of literacy, such as computer literacy.

The framework and a new instrument for measuring health literacy in Canada will provide more information for future directions. It may be used with various populations to build knowledge around health literacy in many contexts unique to Canada. Jim Frankish and Brenda Kwan from the University of British Columbia led a discussion about measuring health literacy. To measure health literacy, it will be important to:

- Clarify the definitions of literacy and health within both the health and education sectors
- Better understand the link between literacy and holistic health (mental, spiritual, physical, and emotional health)
- Identify what factors need to be measured to assess health literacy, such as language, culture, age, gender, geographic location, disability, etc.
- Develop tools and methods to assess access to health information
- Better understand the two-way interaction between people who provide health services and patients (rather than one-way from provider to patient)

Rick Wilson presented the results of an evaluation of our National Literacy and Health Program. He found three key areas for more study:

- The level of awareness of health care providers in different settings about low literacy and how to work effectively with people with low literacy skills
- The impact of using plain language and readability formulas in health settings
- The effectiveness of different approaches to teaching literacy that include health content and health literacy goals.

Cultural Sensitivity

Presenters discussed the importance of cultural sensitivity in gaining knowledge about the health and literacy of diverse populations. These sessions are noted in **Section 3.3 Language and Culture**. Key points relate to the importance of cultural bias, text layout, and word choice in research design and materials. Recommendations include:

- using participatory methods to involve community members;
- developing trust;
- using interpretation; and
- being aware of different cultural understandings of health and experiences of discrimination.

Access to Health Information and Services

Presenters discussed research about how people find, understand, and use health information and where it is found and how it is communicated. More research is needed in this area to build knowledge about health literacy.

Linda Shohet works with the Centre for Literacy of Québec. She shared the results of an action research project at the Montreal General Hospital. The project aimed to improve health education materials and health communication with hard-to-reach patients. The researcher who interviewed patients often had long interviews with clients who felt that this person was the first one to actually listen to their health concerns. Earlier work found that health professionals often think that a resource is fine, when testing with clients shows otherwise. This research also found that the term “literacy” carries baggage and preconceived ideas that confuse health professionals. A four-year plan has been developed to publish and share materials and to create a common form for all print materials.

Pamela Nuttall Nason and Pamela Whitty from the University of New Brunswick studied literacy activities linked with health information. Their study focused on two programs for parents and children:

- the Canada Pre-Natal Nutrition Program; and
- the Community Action Program for Children.

The study report looks like a magazine with easy-to-read text and photos to show resources produced by the programs across the country. Nason and Whitty’s study found that literacy practice in the studied programs was high, but that the program training did not reflect that fact.

Health Information on the Internet

Because of the Internet, more health information is available to people than in the past. Heather Hemming of Acadia University emphasized the need to examine the electronic communication of health information. It is important for researchers from health, education, and other areas to work together to gain understanding about health and literacy.

Ellen Balka from Simon Fraser University presented information about Internet use as a tool for health literacy. She also presented preliminary data on public access to health information through the Vancouver Public Library and the website for the BC HealthGuide OnLine. Those two projects form part of the ACTION for Health project. She explained that many factors influence whether people can access health information on the Internet, such as:

- government policies;
- governance;
- literacy skills;
- literacy and social facilitation;
- service providers;
- software tools;
- computers;
- modems;

- telephone lines; and
- facilities that carry and store information.

Balka ended by saying that a lot of money is being spent on using technology to improve health literacy, but no one yet knows if it works. The social nature of technology needs to be recognized. Steps need to be taken to create social mechanisms.

Other presenters discussed the use of the Internet by specific populations. Cameron Norman from the University of Toronto developed a tool to assess the ability of youth to find, evaluate, and use electronic health information. He said that youth are expected to be familiar with the use of computers, but they may not have the literacy skills to find and use electronic health information. Roma Harris found that rural women sought help from a hospital or doctor in urgent situations, but used the Internet for less threatening concerns. Lyn Simpson said that social inclusion and community mobilization are important factors within health literacy programs.

Empowerment and Developing Capacity

A person is empowered when they are able to find, understand, and use information to improve their well-being. Literacy and health are interconnected. They impact on opportunities for empowerment.

Leslie Bella, Rick Bishop, and Renée Walsh presented about the experience of building capacity at the MacMorran Community Centre in Newfoundland and Labrador. Community residents reported that their meaning for “capacity” was both “building on” and “building up” capacity. “Building on capacity” is understood to be building on the strengths and skills of community members. “Building up capacity” means bringing in more resources from outside.

Rick Bishop explained that a major task in developing capacity is helping people to believe in their own skills. Willingness to help is a special characteristic of the MacMorran community. People are willing to let others know they can help, and they do so freely without being asked. This giving occurs across generations and without age distinctions. Building capacity in the community involves people of all ages. There is particular emphasis on supporting young people in school.

Tiffany Veinot identified the central idea of empowerment as the control people gain over their health. Based on her experience working with people with HIV/AIDS, she reported that in rural communities, people often take more responsibility for their health because of lack of funding and access to doctors.

Other presenters talked about empowerment of families and adult learners. Trudy Lothian from the Literacy and Basic Skills Program at the Ottawa-Carleton Catholic School Board spoke about:

- empowering learners to take control of their health; and
- the importance of embracing each learner’s experience, age, and cultural background.

Terri Moar and Candyce Jones from the Bookmates Family Resource Literacy Centre in Winnipeg presented an approach to family literacy that addressed health-related information as part of literacy activities. They highlighted the importance of community connections and involvement.

Collaboration Between Health, Education, and Other Sectors

Based on discussions about building knowledge in literacy and health, a number of ideas were put forward to improve collaboration between health, education, and other sectors:

- Building new and strengthening existing multi-sector partnerships within and between communities is a key factor in building knowledge in health and literacy.
- A joint strategic program on literacy and health research between organizations and funding sources would support projects and developing capacity and infrastructure.
- An easily accessible database will help with sharing information and making connections between researchers and practitioners.
- Partnerships in the community between researchers and practitioners will help develop capacity to evaluate what works in programs for literacy and literacy and health.

For a summary of each presentation or workshop, visit

<http://www.cpha.ca/literacyandhealth/LanguageandCulture.htm#Diem> on the Internet.

| Setting Direction for Literacy and Health Research in Canada | |
|--|--|
| Alphabétisation et santé chez les Francophones en situation minoritaire | Sylvain Deslisle |
| Implications pour la recherche et le transfert des connaissances en alphabétisation et santé en français | Pierre Joubert |
| La santé et la francophonie | Rodrigue Landry |
| Implications for Canada of the Institute of Medicine Report Health Literacy: A Prescription to End Confusion | Rima Rudd, T. Scott Murray, and Irving Rootman |
| Canadian Literacy and Health Research Program: What should its future be? | Irving Rootman |
| Retrospective Evaluation of the National Literacy and Health Program | Rick Wilson |

| Methods for Research and Evaluation | |
|---|---|
| Measuring Health Literacy | Jim Frankish, Irving Rootman, and Brenda Kwan |
| Health Literacy Education Nutrition: Instrument Design | Annrose Guarino |
| Getting the data right when working with refugee and asylum-seeking groups | Lisa Merry |
| Unveiling sexuality: culture and gender disparities in South Asian populations | Julia Thomas |
| Using multi-ethnic, multilingual focus groups to enhance research with refugees | Jodi Tuck |

| Empowerment and Capacity Development | |
|--|--|
| Empowerment and Capacity Development: A Strengths-Based Approach to Literacy and Health | Leslie Bella and Rick Bishop |
| Capacity Development and the Urban CAP Program at MacMorran Community Center | Leslie Bella, Rick Bishop, and Renee Walsh |
| Challenging the Concept of Health Literacy: Action Research at the McGill University Health Centre | Linda Shoheit |
| Making Connections: A Capacity-Building Approach to Building Health Literacy | Lyn Simpson |

| How to Reach Different Groups with Health Information and Resources | |
|--|-------------------|
| Opportunities and Challenges: Using the Internet as a Tool | Ellen Balka |
| A Report on Rural Ontario Women Seeking Health Information | Roma Harris |
| The Empowerment Model on Using e-health to Distribute Information | Tiffany Veinot |
| Recherche d'information médicale : une approche multi-factorielle | Stefane Kabene |
| Promoting e-health Among Teenagers: Tools and Outcomes | Cameron D. Norman |
| A Whole Greater than its Parts: HIV/AIDS Treatment Information | Tiffany Veinot |

| Exploring Links Between Literacy and Health | |
|--|--------------------------------|
| Development of Literacy Skills in Normal and Far-sighted Children | William Bobier |
| Rendre lisible l'invisible. Pratiques de lecture des faibles lecteurs et représentation des organismes | Roch Hurtubise |
| Laying the Foundation for Life-Long Learning: Literacy Development Through Inquiry | Anne McKeough and Marya Jarvey |
| L'alphabétisation et la motivation chez des adolescents en difficulté d'apprentissage et de comportement | Ginette Plessis-Belair |

Recommendations for Theme 3: Building Knowledge in Literacy and Health

- 3.1 Seek funding from government and other sources to commission the Royal Society of Canada to study literacy and health research in Canada. This study should follow the model of the Institute of Medicine's reports on health literacy. They included a testimony from community groups and key informants in the field.

Who: Our Association and our National Literacy and Health Program

- 3.2 Adopt a funding model that builds capacity for evaluation so that evidence derived from practice can be developed and used as a driver for developing policy. This could be designed like Health Canada's fund for Population Health. It includes building capacity in evaluation (for example, two-day training sessions on using logic models in evaluation, mentorships with trained evaluators and time to do evaluation).

Who: National Literacy Secretariat

- 3.4 Undertake a joint strategic project on literacy and health research. This project would include funding for projects and developing capacity and infrastructure with the following priorities: culture, literacy and health; evaluation; cost benefits of literacy and health efforts; and the role of technology in literacy and health.

Who: Our Association, the National Literacy and Health Program, Canadian Institutes of Health Research, and the Social Sciences and Humanities Research Council

3.5 Building Healthy Public Policy

In Canada, there are many policies that affect the literacy and health of Canadians. These policies guide decision-making about programs and services in many areas, such as:

- health;
- education;
- social services;
- jobs; and
- citizenship.

At the conference, participants focused on:

- Identifying policies in Canada and other countries that affect literacy and health
- Sharing stories and experiences about how policies affect the health of people with low literacy skills
- Identifying how policies can help improve the health of Canadians with low literacy skills and what next steps are needed in developing policy
- Understanding the link between policies in education and health
- Building new partnerships across health, education, and other sectors to shape literacy and health policy
- Identifying how to raise awareness about literacy and health issues with decision makers and the public
- Identifying ways the public and private sector can promote the use of plain language

Speakers talked about the policy context for literacy and health in Canada.

- Ellen Szita, a literacy advocate, talked about the high social and economic costs of low literacy. She suggested that the adult learning system is in great need of repair.
- Senator Joyce Fairbairn noted that about eight million Canadians with low literacy skills are at risk for lower incomes, greater stress, more illness, more accidents on the job, and an earlier death. The government is addressing the problem through early child development, developing workplace skills, and creating learning bonds for children of low income families.
- Peter Calamai talked about building partnerships to make a difference in the literacy outcomes and the health of Canadians. He stressed the importance of evaluation to build evidence about what works. He challenged participants to work at the local level to generate meaningful action on literacy and health.
- Dr. Carolyn Bennett, Minister of State (Public Health), talked about the broad determinants of health. The National Forum on Health recognized literacy as a determinant of health. The Public Health Agency of Canada will be addressing the issue of literacy and health to improve the health of Canadians.

Presenters and participants discussed what needs to be done to develop policies to improve literacy, health literacy, and the health of people with low literacy skills. There were 11 sessions about literacy and health policy. This topic was also discussed within other theme areas. Based on presentations and discussions, policies in literacy and health need to address two perspectives:

- how basic literacy skills influence people's health; and
- health literacy—the degree to which a person is able to get, process, and understand basic health information and services needed to make appropriate health decisions.

How Public Policy is Made

Havi Echenberg led a two-part workshop about literacy and health in Canada. In the first part, she presented information about how issues are identified and how issues get put on the public agenda. To get on the agenda requires:

- recognition of the problem by policy makers;
- broad support and a feasible policy solution; and
- political will.

The most important step is to design policy solutions for government decision makers. The government has limited capacity to develop policy solutions and look to “policy entrepreneurs” to recommend policy solutions.

Education and health are two areas responsible for literacy and health policy. There is also an overlap of responsibility between the provinces and territories who delivers programs and the federal government who contributes funds to health and education. Health literacy has not been talked about by policy makers, but health care is a top issue. Literacy is a cross-cutting issue that can be tied to many government areas. It is important to keep working in both the literacy and the health sectors to see new policies put in place.

In the second part of Echenberg's workshop, participants discussed what needs to be done to move forward. Key points were the need to:

- further define the concept of “literacy and health” and “health literacy”
- research where literacy and health fits within government priorities for program spending
- find a “home” for the issue of health literacy (for example, within access to health services, patient safety and/or reducing health disparities).

Rima Rudd, T. Scott Murray, and Irving Rootman discussed the results of a major study of the Institute of Medicine in the US called, “Health Literacy: A Prescription to End Confusion.” The report found that limited health literacy might be a major factor in quality of care and costs to the health care system. There is a higher rate of hospitalization and use of emergency services among patients with limited health literacy. A similar study in Canada would help to inform policy makers, practitioners, and researchers in literacy and health.

Positive Programs and Policy Strategies to Address Health Literacy

Examples were presented of positive programs that address health literacy. These involve three key strategies:

- partnerships between the health and adult education sectors;
- community-based, participatory approaches to developing policy; and
- collaborative training and education practices that bring literacy and health together.

Partnerships Between Health and Adult Education Sectors

Public policy makers at the regional, provincial, and national level can build on partnership efforts between the health and adult education sectors.

- Literacy Manitoba brought together health and literacy workers in regional workshops called “One Day Wonders.” This project recognized the overlap in client groups seen by health service providers and adult educators. It aimed to help health educators break down the barriers preventing them from reaching hard-to-reach clients, to encourage literacy practitioners to include health topics in their literacy curriculum, and to encourage partnerships and working relationships between literacy and health workers.
- At the national level, our National Literacy and Health Program has brought together 27 national health associations to raise awareness about the links between literacy and health.

Community-Based, Participatory Approaches

Community-based, participatory approaches can inform policy development in both community and hospital-based settings.

- Doris Gillis talked about the “Taking Off the Blindfold” project in rural Nova Scotia. A community health board organized workshops with learners, coordinators of literacy programs, health practitioners, and other key informants. Through this process, practitioners are now looking at their own practices and making change.
- Linda Shohet talked about an action research project at the Montreal General Hospital. This project laid the groundwork for a proposed new patient education policy and a new program for professional development. This policy direction was set following a series of focus groups with patients, professionals, family members, and support staff.
- Marcia Drew Hohn presented the program “Operation Bootstrap” to show that the adult literacy system can play an important role in improving health literacy. Operation Bootstrap was developed through participatory research with adult learners. Saiyi Diaz and Vanda Ivanenko talked about their role on the student health team for this project. The team identifies health issues for immigrant women and provides peer education that is connected to everyday life.

Collaborative Training and Education Practices

Policies that support collaborative training and education practices in literacy and health can lead to improved health literacy. College and university programs that prepare doctors, nurses, and other health professionals for the field are important targets for policy development.

Elizabeth Diem outlined how the University of Ottawa placed nursing students into language instruction classrooms for new Canadians. Nursing students met weekly with the students to identify health issues. They then shared information and held discussions about topics such as nutrition, accessing health services, mental health, and exercise.

The first evaluation found that the nursing students learned to understand the socio-environmental determinants of health, to apply the standards of nursing practice in a community setting, to deal, in real time, with real people who want to learn about health, to build solid relationships with community members, and to better understand cultural perspectives.

Other health disciplines could look to this and other training models to better prepare professionals to work with our growing multicultural population.

Putting Plain Language into Public Policy

A number of presenters said that to improve health literacy, all public policies must include communication that uses plain language. This applies to print material and to media messages and e-learning, a medium that is not reaching people and groups with literacy barriers who may benefit the most. Complicated language that is hard to understand is particularly problematic in health protection, patient safety, and patient education.

- The Thought for Food project of Human Resources and Skills Development Canada found that people and groups who most needed information about food and nutrition had limited access to this health information. New policies are required to improve knowledge about food safety and food label literacy.
- Results of a Health Canada study showed that communicating health risks to low literacy adults through traditional messaging is not effective. As a result, the department is looking at adapting tobacco messages on cigarette packages into plain language. The study suggests that other factors are important to creating effective health messages, such as the relevance of the message to the audience and the capacity to put the message into practice.
- A panel discussed how plain language is critical to the marketing and packaging of medication. Information in plain language will benefit those with low literacy, and every Canadian, including doctors. Policies are needed to address industry standards for labeling and packaging, access to medication information for consumers, and standards in the health system to support the correct, safe use of medication.

Thinking Beyond Plain Language

Presenters and conference participants also discussed the importance of:

- policies that encourage plain language in *all* communications for promoting health, prevention, and treatment, not just in print materials. Best practice guidelines that include standards for plain language instruction, clear verbal communication techniques, and teach-back methods are needed to address consumer health and patient safety. Adult learners and providers noted that limited time was a key factor in understanding instructions.
- policies that consider the influence of cultural context and gender on the effectiveness of health information, and access to that information.

In summary, public policies are needed to:

- improve literacy outcomes, for example, support for a pan-Canadian literacy strategy, early childhood education and family literacy programs, and efforts to reduce high school drop out rates
- improve health literacy, for example, support integrated policy and programs across sectors, integrated research and knowledge translation programs, and efforts to build links between literacy and health networks
- reduce disparities by strengthening literacy and health literacy levels among vulnerable groups

For a summary of each presentation or workshop, visit

<http://www.cpha.ca/literacyandhealth/BuildingHealthyPublicPolicy.htm> on the Internet.

| Building Health Public Policy | |
|--|--|
| Medication Information for Consumers: A Plain Language Prescription | Andrew Aitkens, Millicent Toombs, Gerry Harrington, and Laureen MacKenzie |
| Opportunities and Challenges: Using the Internet as a Tool | Ellen Balka |
| Literacy and Health Policy 101 | Havi Echenberg |
| Read to Me! Best Practice Models for a Provincial Literacy Strategy | Richard Goldbloom, Carol McDougall, and Janice Fraser |
| Learning with Communities: Creating Public Policy Together | Marcia Drew Hohn, Doris Gillis, and Linda Shohet |
| Adapting Health Canada's Tobacco Package Warnings for Less Literate Canadians | Nancy E. Hughes |
| Implications pour la recherche et le transfert des connaissances en alphabétisation et santé en français | Pierre Joubert |
| Language, Literacy and Healthy Development: The Work of CPNP and CAPC Projects | Pamela Nuttall Nason and Pamela Whitty |

| | |
|--|--|
| Direct-to-Consumer Advertising: Challenging Health Protection in Canada | Martha Jane Paynter |
| Implications for Canada of the Institute of Medicine Report Health Literacy: A Prescription to End Confusion | Rima Rudd, T. Scott Murray, and Irving Rootman |
| Challenging the Concept of Health Literacy: Action Research at the McGill University Health Centre | Linda Shohet |

Highlights of Key Note Speech *Peter Calamai*

Making a Difference / Building Partnerships



Peter Calamai is a Member of the Board of ABC Canada. He is the former Chairperson of the Ottawa Citizen Literacy Foundation. He began his speech by saying that he has gained insights as a reporter working on issues of public policy and partnerships.

The most recent literacy survey found that one in five young Canadians who had completed high school fell below literacy level 3.

Level 3 literacy reflects the ability of an adult to attend a diabetes clinic and to read and understand about the effect of diet on glucose levels. Those young Canadians are not ready for the workforce. The 1994 survey of literacy in Canada indicated that 48 percent of adult Canadians achieved a level 1 or level 2 literacy score with about 4 million Canadians at the lowest level of literacy. Calamai noted that literacy efforts over the past 17 years have little to show in terms of improving Canada's literacy rates.

There is a need for realistic evaluation of literacy programs and tracking of the results. Calamai noted that, for 1988–1998, evaluations have not been completed on dozens of programs funded by the National Literacy Secretariat. No one, before or after that time, can show outcomes such as the number of attendance hours or grade-equivalent gains that participation in those programs produced. He questioned how it is possible to have any realistic accounting of processes without systematic evaluation.

Changing the national culture of literacy in Canada has been difficult. Calamai emphasized the failure of the literacy strategy, suggesting that most Canadians are not convinced about the personal relevance of the issue. Public awareness campaigns are likely to be aimed at children, if anyone. Calamai recommended creating and building more meaningful relationships with clients and partners.

The literacy movement must identify partners that can help it become more accountable. Partnerships with organizations such as banks or accounting firms could provide opportunities for enhancing knowledge and expertise through performance management and improvement systems. Businesses such as forest industries or optometrists could also be natural partners.

The public health and literacy sectors should both shift their efforts from the national stage to local arenas. Members of Parliament (MPs) pay more attention to local partnerships connected to their communities. The strength of community partnerships can get issues on the agenda. Calamai cited the example of how the CanWest Foundation and the Fraser Institute succeeded in firmly securing the deficit reduction issue on the national agenda by forging partnerships in communities. Inventive entrepreneurship and community ties are the most promising ways to improve literacy in Canada.

Recommendations for Theme 4: Building Healthy Public Policy

- 4.1 Initiate a meeting to discuss creating an interdepartmental program to support literacy and health practice.

Who: Minister State of Public Health, Health Canada, and Human Resources and Skills Development Canada

- 4.2 Review these and other recommendations put forward at the conference, develop a strategy for putting them in place, and monitor the outcomes.

Who: Our National Literacy and Health Program and the Program Committee for the Second Canadian conference on Literacy and Health

- 4.3 Seek funds from the National Literacy Secretariat and other partners to monitor, assist, and put these recommendations in place. Report by November 2005 with a “Literacy and Health Report Card.”

Who: Our National Literacy and Health Program

Adult learners who actively took part in the conference² also presented recommendations in the closing session of the conference. They were:

- Speakers should use more plain language when speaking, and should speak more slowly.
- Learners should be more involved. They could help simplify the program guide.
- Adult learners need to be part of the solution. Perhaps they could speak to graduating classes of health care workers.
- Adult learners could be part of the public awareness campaign needed to connect literacy and health.
- The issue needs more media attention—for example, a panel discussion on television.
- Investment in literacy will reduce health care costs. Literacy is not getting enough funding. Successful programs are too often being cut.
- Health care professionals should use plain language, review brochures, and check that patients understand information. They should not assume that everyone can read.

- It is important to continue raising awareness, including talking to governments about the links between health and literacy.
- People who have a hard time reading and writing should receive help when they need it.
- Women's health was heavily discussed at this conference; the next conference should have more information on the situation among men.

²Represented by Ellen Szita and Raymond Roy

Appendix A

General Literacy and Health Resources

The following is a general list of resources that may be of special interest to researchers and policy makers. It was adapted from a list prepared by Dr. Irving Rootman, Director of the Canadian Literacy and Health Research Program. It was prepared as background to the pre-conference research workshop for graduate students.

Organizations

1. Agency for Health Care Quality

The Agency for Health Care Policy and Research supports, does, and shares research that improves access to care and improves the outcomes, quality, cost, and use of health care services. It published a report on literacy and health outcomes. You can get more information about the organization from its web site at <http://www.ahrq.gov/>.

2. Canadian Language and Literacy Research Network

This is a national network of researchers, practitioners, and policy makers in early childhood language and literacy in Canada. www.cllrnet.ca

3. Institute of Medicine

The Institute of Medicine was created by the National Academy of Sciences in 1970. It examines policy matters for the health of the public. It has done studies which have implications for health promotion, including studies on school health, health communication, tobacco, nutrition, and health literacy. You can get more information from its web site at www.iom.edu.

4. Literacy and Health Research Unit, Centre for Community Health Promotion Research, University of Victoria

This research unit does and shares research on literacy and health. <http://web.uvic.ca/~chpc/centres.htm>

5. National Literacy and Health Program

The National Literacy and Health Program was created in 1994. It has 27 partner organizations. The Program promotes awareness among health professionals of the links between literacy and health and provides resources to help health professionals serve clients with low literacy skills more effectively. You can get more information from its website at <http://www.National Literacy and Health Program .cpha.ca/>.

6. Pfizer

Pfizer created a health literacy program about 10 years ago. It provides and helps others provide quality health information to patients that they can understand and act on. Among other things, it has supported a grants program, partnership program, and six conferences on health literacy. For more information, see their website at www.pfizerhealthliteracy.com.

7. The National Institute for Literacy

The Health and Literacy Discussion Group is one of several online discussion lists set up by the National Institute for Literacy in the United States. It has targeted discussions and information exchange about literacy issues in health education and in health care, and how the health and literacy systems can work together to address these issues.

The NIFL-Health List is for literacy practitioners, health care providers, health educators, researchers, policy makers, and others interested in exploring the links between health and literacy. http://www.nifl.gov/lincs/discussions/nifl-health/about_nifl-health.html

Internet Resources

1. Canadian Literacy and Health Research Program

This website is part of a research project done with funding from the Social Sciences and Humanities Research Council to develop a national program of research on literacy and health. It has several resources developed by the project, including an environmental scan and needs assessment, workshop report, and electronic newsletter. All are available in English and French. http://www.National Literacy and Health Program .cpha.ca/clhrp/index_e.htm

2. Health Literacy in Rural Nova Scotia Research Project

This is the website for a research project that looks at the experiences of a rural Nova Scotia population to better understand the links between literacy and health. Among other things, it has reports on the project and links to other relevant resources. http://www.National Literacy and Health Program .cpha.ca/clhrp/index_e.htm

3. Reducing Health Disparities and Promoting Equity for Vulnerable Populations: Synthesis Papers

This website has background papers prepared for an International Think Tank on Reducing Health Disparities in September 2003. It includes a paper on literacy and health. <http://www.igh.ualberta.ca/RHD/synthesis.htm>

4. ACTION for Health

Project ACTION for Health is an innovative, four-year project based at Simon Fraser University. It examines the role of technology in the health sector. www.sfu.ca/act4hlth/

Print Resources

1. Health Literacy: A Prescription to End Confusion

Nielsen-Bohlman, L., Panzer, A., Kindig, D.A. (eds.)

Available from the Institute of Medicine (<http://www.iom.edu/project.asp?id=3827>)

Report of the Institute of Medicine Committee on Health Literacy. The book can either be downloaded in whole or part from the website or ordered.

Also see: "Health Literacy and Health Promotion: Implications of an Institute of Medicine Report". Ontario Health Promotion E-Bulletin #376.1, August 27, 2004.

Rootman, I.

Available at: <http://www.ohpe.ca/ebulletin/>

2. Literacy and Health Outcomes

RTI International-University of North Carolina Evidence-Based Practice Center

Available at <http://www.ahrq.gov/clinic/evrptfiles.htm#literacy>

This study is based on an examination of the literature on literacy and health to address two questions:

- 1) Are literacy skills related to use of health care services, health outcomes, costs of health care and disparities in health outcomes?; and
- 2) For people with low literacy skills, what are effective interventions?

It found strong evidence that low reading skills and poor health are related, but less evidence on the effectiveness of interventions.

3. Literacy and Health in America

Rudd, R., Kirsch, I. Yamamoto, K.

Available from Educational Testing Service (pic@ets.org)

This report is based on an analysis of data from the US National Adult Literacy Survey (NALS) and the International Adult Literacy Survey. In contrast to earlier reports based on these data sets, this one focuses on the analysis of "health-related" tasks on the surveys and puts forward a new Health Activities Literacy Scale linked to the NALS database.

4. Literacy in Primary Care Populations: Is it a Problem?

Smith, J.L. and Haggerty, J.

Available from (2003). *Canadian Journal of Public Health*, 94, 408-416

This paper presents the findings of the health literacy of patients in a primary health care clinic in Montreal using the Rapid Estimate of Adult Literacy in Medicine test. It found that the rate of low literacy was nine percent, which was not as high as expected by the authors.

5. Literacy and Health in Canada: Is it really a problem?

Rootman, I.

Available from the *Canadian Journal of Public Health*, (2003) pp. 94 and 405-406

This is an editorial reacting to the paper by Smith and Haggerty. It concludes that we don't really know the answer to the question, based on this one study. There is a need for more research on this topic in Canada.

6. Literacy and Health Research in Canada: Where have we been and where should we go?

Rootman, I. and Ronson, B

Available at <http://www.igh.ualberta.ca/RHD/Synthesis/Literacy.htm>

This is a review of the development of the literacy and health field in Canada, of the research in this area, and suggestions for more research that needs to be done. A clear language edition is also available. It was prepared with the help of Elsie Petch and Barbara Ronson. It is available at http://www.cpha.ca/literacyandhealth/Literacy_e.pdf.

Other

1. Health Literacy: A Prescription to End Confusion CD

This is a CD related to the Institute of Medicine's (IOM) health literacy report produced by the Academy for Educational Development in collaboration with the IOM. It has four video clips related to the report, the executive summary of the report, and several other related IOM reports as well as links to more information on health literacy.

2. Health Literacy Studies, Department of Health and Social Behavior, Harvard School of Public Health

This is a website geared towards health and adult education practitioners. It has a detailed introduction to health literacy in a Powerpoint presentation and a video, a literature review, research reports, curricula for adult education and for graduate courses, and a large list of annotated links. <http://www.hsph.harvard.edu/healthliteracy>

Appendix B

Literacy and Health Practice Resources

This list includes resources for practitioners that were mentioned in conference presentations. Other useful resources on this list were identified by Doris Gillis from St. Francis Xavier University.

1. Alpharoute

Centre AlphaPlus Centre is Canada's largest provider of information and resources for adult literacy. The Centre provides information, resources, and support services to practitioners working in the deaf, native, Francophone, and Anglophone adult literacy streams. The online literacy learning environment has a special library collection of adult literacy resources. It serves literacy practitioners, researchers, and learners in Ontario. The library has over 300 health resources. Information about library services, online learning, and various literacy projects are available at <http://alphaplus.ca>. The latest research report, "What Difference Does it Make?" (2003) is available at <http://alphaplus.ca/images/pdf/whatdifferencedoesitmake.pdf>.

2. American Medical Association: Health Literacy Introductory Kit

This kit includes the video, "Low Health Literacy: You Can't Tell By Looking" and the article, "Health Literacy: Report of the Council on Scientific Affairs" (1999) by the Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs. Available online at <http://www.ama-assn.org/ama/pub/category/8115.html>.

The "Health Literacy: Help Your Patients Understand" kit is also available through the American Medical Association. You can order this kit by calling 1-800-621-8335 or visiting www.amafoundation.org on the Internet.

3. Canadian Public Health Association, National Literacy and Health Program

Plain language resources for health professionals are available at www.nlhp.cpha.ca. Information about "Staying the Course: Literacy and Health in the First Decade," the Second Canadian Conference on Literacy and Health is available at www.cpha.ca/literacyandhealth.

4. Centre for Health Literacy of Quebec

Link to the Health Literacy Project at <http://www.nald.ca/litcent.htm>. Refer to the health issue of *Literacy Across the Curriculum* Focus, Volume 17, Number 2, 2004.

5. Harvard School of Public Health, Health Literacy Studies

This site has reference resources, including the video “In Plain Language.”
<http://www.hsph.harvard.edu/healthliteracy/video.html>

6. Health Canada, Population Health

The report, “How Does Literacy Affect the Health of Canadians: A Profile Paper” (1998) positions literacy as a population health issue. <http://www.hc-sc.gc.ca/hppb/phdd/literacy/literacy.html>

7. Health Literacy Consulting

Look for resources, tips, and books by Helen Osbourne at <http://www.healthliteracy.com/>. The website includes *Health Literacy From A to Z: Practical Ways to Communicate your Health Message*, Sudbury: Jones and Bartlett Publishers, 2005.

8. Health Literacy in a Rural Nova Scotia Research Project

Go to “Reports and Resources” for links to “Taking Off the Blindfold: Seeing How Literacy Affects Health” and the Canadian Health Network article “Beyond Words: The Health Literacy Connection” at www.nald.ca/healthliteracystfx.

9. Health Literacy Network, BC

This online discussion forum links disability, health, literacy, and other community groups, people, and health care professionals, sharing resources and insight at <http://www.communityzero.com/hln>.

10. Health and Literacy Discussion Group - US National Institute for Literacy

This online discussion list has discussions and information about literacy issues in health education and in health care, and how the health and literacy systems can work together to address these issues. It is for literacy practitioners, health care providers, health educators, researchers, policy makers, and others interested in exploring the links between health and literacy. http://www.nifl.gov/lincs/discussions/nifl-health/about_nifl-health.html

11. Health Literacy: A Review

This review by M. Andrus and M. Roth has information on ordering literacy and health literacy tests, creating low-literacy education materials, sources of low-literacy education materials, and health literacy web sites. In *Pharmacotherapy*, Volume 22, No. 3, 2002, pp.282-302.

12. Institute of Medicine Report

The major US study “Health Literacy: A Prescription to End Confusion” reviews evidence about the impact of literacy on access to and use of health services. It is edited by L. Nielsen-Bohlman, A. Panzer, and D. Kindig. It is online at <http://www.iom.edu/project.asp?id=3827>.

13. LINCS Health and Literacy Special Collection

This health and literacy site is for teachers, students, health educators, or anyone interested in teaching health to people with limited literacy skills. <http://www.worlded.org/us/health/lincs/learner.htm>

14. Literacies Journal

The journal issue, “Focus on Health and Wellness,” is available at http://www.literacyjournal.ca/literacies/4-2004/readers_f04.htm.

15. National Centre for the Study of Adult Learning and Literacy

See *Focus on Basics*, Vol 5, Issue C: Literacy and Health at http://gseweb.harvard.edu/~ncsall/fob/2002/fob_5ic.pdf.

16. Ontario Health Promotion E-Bulletin,

See “Clear Language” in Bulletin #43 (February 23, 1998) and Health Literacy and Health Promotion” in Bulletin #376.1 (August 27, 2004) <http://www.ohpe.ca/ebulletin/>

17. Pfizer: Clear Health Communication Initiative

See the *Patient Education Handbook* at <http://www.clearhealthcommunication.org>.

The *Pfizer Health Literacy Manual* is available at www.pfizer.com/download/public_disparities.pdf.
www.pfizerhealthliteracy.com

18. Revue À lire

Quand alphabétisation se conjugue avec santé, Issue #11, 2004. This is a special publication of la Fédération canadienne sur l’alphabétisation en français exploring the links between literacy and health. <http://www.fcaf.net>

19. Teaching Patients with Low Literacy Skills

The second edition came out in 1996. It is written by by C. Doak, G. Doak, and J Rootm and is often called the “bible” for health literacy and patient education professionals for addressing the diverse needs of patients. Published in Philadelphia by JB Lippincott.

National Literacy Coalitions

1. La Fédération Canadienne de l'alphabétisation en français

The Federation is a countrywide organization representing Francophones groups and associations dedicated to French literacy in Canada. Over the years, the Federation has tried to interest as many groups as possible on the topic of literacy and the importance of reading and writing in French. <http://www.fcaf.net>

2. Movement for Canadian Literacy

The Movement for Canadian Literacy provides a national voice for literacy for every Canadian through networking, research, government liaison, developing learners, communication, collaboration, and building the capacity to support the people and organizations involved with adult literacy education. <http://www.literacy.ca>

3. National Indigenous Literacy Association

This national Aboriginal literacy organization was created to be the eyes, ears, and voice of Aboriginal literacy in Canada and to reflect the Spirit and values of Aboriginal peoples and nations in all its work. A holistic approach to learning is promoted to contribute to balanced physical, mental, emotional, and spiritual development of Aboriginal Peoples. Email priscilla.george@sympatico.ca.

Appendix C

Plain Language and Clear Communication Resources

Publications

1. Communication Canada. *Successful Communication: Literacy and You*. (May 2003)
Download a copy at http://www.communication.gc.ca/services/alpha_lit/2003/scr2003_toc.html
2. Fédération canadienne de l'alphabétisation en français. *J'écris simplement : Guide d'application des techniques d'écriture simple*. (1993) Visit www.fcaf.net for information about this and other publications.
3. Frontier College. *Clear Lines: How to Compose and Design Clear Language Documents for the Workplace*. (1991) For information about this and other publications, visit <http://www.frontiercollege.ca/english/public/press/clearlms.htm>.
4. National Literacy and Health Program, Canadian Public Health Association. *Easy Does It! Plain Language and Clear Verbal Communication Training Manual for Health Care Professionals*. (1998) Visit www.nlhp.cpha.ca for information. Other publications are available at this site, including:
 - *Working with Low-literacy Seniors: Practical Strategies for Health Care Providers*
 - *Good Medicine for Seniors: Guidelines for Plain Language and Design in Prescription Medication*
 - *Creating Plain Language Forms for Seniors: A Guide for the Public, Private and Not-for-Profit Sectors*
 - *Directory of Plain Language Health Information*
5. Ontario Literacy Coalition. *Clear Writing and Literacy: How to recognize, use and convince others to use clear writing*. (1990) Visit www.on.literacy.ca/research/pubform.htm for more information about this and other publications.
6. The Ontario Ministry of Agriculture and Food Fact Sheet. "Clear Writing: What is it? How do you do it?" Available at www.gov.on.ca/OMAFRA/english/rural/facts/69-021.htm

7. Wizowski, L., Harper, T., and Hutchings, T. *Writing Health Information for Patients and Families*. (2002) Hamilton: Hamilton Health Sciences. The second edition should be available in December 2005.

Internet Resources/Plain Language Services

1. ABC Canada

This site has a list of clear language service providers in Canada, by province.

http://www.abc-canada.org/workplace_education/clear_language.asp

2. Clear Language and Design.

This site has three tools: a reading effectiveness tool, an online thesaurus, and an option to email questions to an expert. <http://www.eastendliteracy.on.ca/ClearLanguageAndDesign/start.htm>

3. Fédération canadienne de l'alphabétisation en français, Communicateurs efficaces.

This is a plain language editing service available to private and public sector organizations. For more information, visit

http://fcf.net/cote_soyezclair/cote_communicateurs_efficaces.htm

4. National Literacy and Health Program, Canadian Public Health Association's Plain Language Service

This service will provide a free estimate of the literacy level of your text. For more information, visit <http://www.pls.cpha.ca/english/start.htm>