The Captain's Log

First Canadian Conference on Literacy and Health

Charting the Course for Literacy and Health in the New Millennium

May 28 - 30, 2000
Ottawa, Ontario

Canadian Public Health Association

National Literacy and Health Program

Funded by the National Literacy Secretariat

Final Report
January 2001

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- The adult learners from Canada and the United States for their participation at the conference as delegates and presenters and for their contributions to the Learners' Wall.

- The conference delegates who came from Canada, the United States and overseas to participate in this first Canadian conference on literacy and health.

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Introduction

In partnership with 26 national health associations, the Canadian Public Health Association raises awareness about the links between literacy and health among health professionals. Specifically, over the past nine years, CPHA's National Literacy and Health Program (NLHP) has promoted plain language health information and clear verbal communication in the health profession throughout Canada. The NLHP has undertaken numerous projects in the following areas:

- seniors' prescription medication use
- access to health services and health information
- poor health communication and its impact on patients' informed consent and health professional liability
- hard-to-use forms that undermine the independence and well-being of low-literacy health consumers
- health among low-literacy youth

Over the past nine years, the field of literacy and health has grown tremendously. Numerous provincial and local health and literacy organizations have joined forces with the NLHP and its partners. As a result, health professionals and administrators are becoming more aware of the need for clear communication. For instance, health professionals are using the NLHP resources to help them improve health communications in their practices. They are also exploring ways to make their facilities more friendly to people with low literacy.

At the same time, more and more academics in both the health and literacy fields are approaching the NLHP for support. They want to do research in a variety of areas related to literacy and health. These areas include the impact of low literacy on health and other factors such as income and gender.

Finally, the NLHP continues to work with national literacy organizations to expand its relationships with learners. Over the years, adult learners have helped the NLHP to "translate" health material into plain language. They have also taken part in "focus tests" to ensure the material is appropriate for low-literacy health consumers.

Quote

"I cannot and will not turn away from an issue which finds more than 40 percent of Canada's adult citizens in varying degrees of difficulty every day of their lives because of inadequate reading, writing and numeracy skills, which we take for granted."

Senator Joyce Fairbairn, P.C.

Learners and literacy providers have encouraged CPHA to continue its work with health providers. In fact, many have told us that it is just as important to teach communication skills to health professionals as it is to teach literacy skills to learners.

In 1997, through its many partnerships and networks, the NLHP learned about a strong desire among diverse sectors to boost the profile of literacy as a health issue. These sectors ranged from health professionals and administrators, to researchers and academics, to adult learners and literacy providers. In addition, these literacy and health advocates wanted to build and strengthen partnerships that would support their field work, now and in the future.

In response to this sweeping call for action, the NLHP proposed a national conference to address the connections between literacy and health. The focus of this conference would be to provide participants with practical skills and hands-on learning opportunities that could be useful in their work. In January 1999, with funding from the National Literacy Secretariat and several generous sponsors (see page ii), the NLHP and CPHA's Conference Department began planning the first Canadian conference on literacy and health. The conference, *Charting the Course for Literacy and Health in the New Millennium,* took place on May 28-30, 2000 at the Crowne Plaza Hotel in Ottawa, Ontario.

How the Conference was Organized

Early in the planning stages, the NLHP set up a committee to lay the scientific groundwork for the conference. The Scientific Program Committee was composed of two NLHP partners, a pharmacist and two consultants. One of the consultants had extensive experience in health promotion, including work with the NLHP. The other consultant had expertise in literacy and working with adult learners.

The Committee agreed that literacy and health was a new field, and that a broad-based conference could attract a wide range of stakeholders. Therefore, the committee organized the conference program around five broad themes revolving around literacy and health issues.

Five Themes

1. Making health services and health information easy to use for all Canadians
2. Looking for ways to improve the training of health professionals
3. Learning more through research
4. Learning from learners
5. Building literacy and health partnerships

Plenaries

The conference offered three plenaries, each of which had a specific purpose. The Opening Plenary, held the first evening of the conference, welcomed participants and set the tone by featuring three inspiring speeches:

- Dr. John Hastings, CPHA's Past President, eloquently situated literacy and health in a public health context.

- Senator Joyce Fairbairn, P.C., Special Advisor for Literacy to the Minister of Human Resources Development Canada, and a dedicated literacy advocate, urged participants to pursue their work in the field.

- Mrs. Dorothy Silver, an adult learner who is a spokesperson on the Board of Directors for the Movement for Canadian Literacy (MCL), gave a moving address. She talked about being an adult without literacy skills and how she struggled to navigate the health system throughout most of her life.

At the Working Plenary, held the first morning of the conference, three Theme Chairs gave an overview of each theme:

- Dr. Owen Hughes, a family physician with an active practice in Ottawa, discussed Themes 1 and 2.

- Dr. Rima E. Rudd, Director of Educational Programs at the Department of Health and Social Behavior, School of Public Health, Harvard University, presented Theme 3.

- Finally, Mr. John Daniel O'Leary, President of Frontier College, discussed Themes 4 and 5.

At the Closing Plenary, held on the last day, the three Theme Chairs summarized what we had learned at the conference on each of the five themes.

Mr. George Maher, from the Plain English Campaign in England, moderated the Working and Closing Plenaries.

*Sub-plenaries and Workshops**

Two sub-plenaries were organized, based on the conference themes, to showcase important milestones and accomplishments in the field of literacy and health. These milestones included the Ontario Public Health Association's groundbreaking *Literacy and Health Project-Phase One - Making the World a Safer Place for People who Can't Read.* They also included Health Canada's Second Report on the Health of Canadians, *Toward a Healthy Future,* which was the first federal report that identified literacy as a factor affecting health.

The conference offered 37 workshops and 2 sub-plenaries based on the five themes. Some workshops were offered in French. All workshops were participatory and designed in one of four ways:

- Case studies
- Panel discussions
- Skills and training
- Dialogue sessions

The workshops covered a variety of topics, including the following:

- informed consent and health professional liability
- literacy testing
- pictograph health instructions
- organizational change for plain language
- Internet solutions for health consumers with low literacy

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* *All workshops offered at the conference are described on the NLHP web site at www.nlhp.cpha.ca.*

- medication matters for seniors
- health communications for low-literacy deaf, hard-of-hearing and developmentally disabled people

Participants

Conference participants included the following:

- Health professionals
- Government representatives
- Researchers and academics
- Literacy providers
- Health administrators
- Policy makers
- Adult learners from both Canada and the United States
- Representatives of pharmaceutical companies

Exhibit Hall

Throughout the conference, participants had a chance to visit the Exhibit Hall. The Hall featured many colourful displays and offered important information on a variety of literacy and health-related topics and issues.

Learners' Wall

The conference was proud to display the Learners' Wall: a 10-foot high wall of learners' health stories from across the country. Mme. Luce Lapierre, Director of the Fédération canadienne pour l'alphabétisation en français, presided over the unveiling of the wall. Learners contributed their stories both before and during the conference. These stories provided conference participants with moving accounts of the struggles many adult learners face as they attempt to access vital health information and services.

Weiler Award

On the first day, the conference presented the Weiler Award. The fundamental theme of the Award is furthering social development and social justice through partnerships among individuals and organizations. The 2000 Award honoured an individual or organization who or which has made a substantial contribution to the literacy and health field in Canada, and who or which has furthered the use of plain language and clear verbal communication in Canadian health practice.

In 2000, there were two recipients.

The first Weiler Award was presented to Dr. William Hettenhausen, a dentist from Thunder Bay, Ontario. Dr. Hettenhausen has dedicated himself to developing and using plain language dental information in his practice.

The second Weiler Award was presented to The Centre for Literacy of Quebec. The Centre, located in Montreal, is committed to supporting and improving literacy practices in schools, community and workplace.

Sponsors

The National Literacy Secretariat provided major funding for the conference. The following sponsors also made generous contributions:

- Health Canada
- Pfizer Canada Inc.
- Pfizer Inc
- Canada's Research-Based Pharmaceutical Companies
- Hoffmann-La Roche Ltd.
- Canadian Medical Association
- Glaxo Wellcome Inc.
- AutoSkill International Inc.

How the Captain's Log is Organized

It was not possible to summarize each of the 37 workshops in the conference. Therefore, like the conference itself, the Captain's Log is organized around each of the five themes.

Each theme begins with an overview followed by various sections that look at specific issues. Wherever possible, we have provided sources for the information. This is usually a workshop or plenary from the conference itself. However, in some cases, we have provided additional information from published documents.

Each theme ends with recommendations presented at the Closing Plenary. (The three Theme Chairs reviewed all recommendations from the conference. At the Closing Plenary, they presented the main recommendations from each of the five themes.) Quotes from learners, case studies and success stories are scattered throughout the entire document.

The Captain's Log has been written using the principles of plain language and clear design. Please note that we have tried to respect the different terms used by each presenter. This may sometimes lead to inconsistencies. For instance, some use the term "learners" while others prefer "adult learners". Sometimes learners are referred to as low-literacy health consumers. Also, the terms "clients" and "patients" are used interchangeably.

We hope that you find the Captain's Log useful to your work.

Theme 1: *Making health services and health information easy to use for all Canadians*

Overview

Research is showing that people with low literacy skills face more barriers in the health system than other people. These barriers can be both visible and invisible. They mean that people with low literacy skills are more likely to have poor health than other Canadians. Seniors, people who live in the North, people who are poor, and people who are physically or mentally handicapped are especially vulnerable.

Health care providers need to help people with literacy problems to "navigate" the health system more easily. At the conference, health providers and learners came up with different ways to improve access.

The strategies, outlined in the pages that follow, include:

- **Build self-esteem from an early age**

  Strong parenting skills can help children build the self-esteem they need to learn. It is also true that parents with low literacy may lack the skills to help their children read. Moreover, parents may go to great lengths to hide their literacy problem. The Literacy and Parenting Skills program in Calgary, Alberta has developed a program to address this challenge.

- **Use pictographs**

  A pictograph is a drawing that represents an idea or an action. Pictographs can be very effective. However, for obvious reasons, they do not work well for people who are visually impaired. Pictographs must also reflect the cultural context in which they are used. An image that works in southern Ontario may not work in the North.

- **Make health environments more friendly and caring**

  Medical institutions must change on several levels. Health professionals must become more sensitive to the needs of low-literacy patients. At the same time, the institutions themselves can adopt simple strategies such as "footsteps" that direct patients to the reception area.

- **Provide accurate and clear health information on the Internet**

  The Internet presents both opportunities and challenges with respect to accessing information. On the one hand, it provides easy access to a wealth of material related to health. On the other hand, this information is not always reliable.

Build self-esteem

A child's path to literacy begins at home. Strong parenting skills can help children build the self-esteem that contributes to literacy. Parents – and all adults – can build their children's self-esteem in several ways: by showing interest in what children do, by encouraging them, and by listening to them.

Parents who lack literacy skills themselves face a greater challenge. Moreover, it can be difficult to attract adults to a "literacy" program since this draws attention to their problem. The Literacy and Parenting Skills (LAPS) program in Calgary, Alberta tries to attract low-literacy adults by talking to them about their children's literacy. This increases the comfort level and creates a non-threatening environment.

Quote

"As a physician, when a child comes to your office for a visit, try to remember to take five seconds to give that child a boost, not a booster, but a boost by saying something positive. It might be the only positive thing that child has heard that day."

Dorothy Silver,
Adult Learner

Use pictographs

Pictures are easier to remember than words. That is one reason why many people use pictures to tell stories. For example, some native cultures carve images on totem poles, and many religious groups paint pictures on the windows of their churches to tell a story. Bearskin Airlines uses pictographs to show people what to do in case of a problem with the airplane. The airline also includes written instructions in Aboriginal languages.

Tips for making pictographs[1]

- Keep the drawings simple, both in terms of language and the ideas you are presenting.
- Avoid warm, fuzzy pictures to create atmosphere.
- Use drawings that show actions.
- Use photos if you need them (for example, to show a product).
- Use several pictures to create a story for complex content.

- Use simple, non-ethnic drawings.

- Use artists only after you know what you want to show.

Make health environments more friendly and caring

For many people – especially seniors – a visit to the hospital or the doctor's office can be a nightmare. People with low literacy skills often have trouble filling out complex forms. They have difficulty expressing themselves to impatient or insensitive nurses and doctors. As a result, they often do not understand the verbal or print health instructions they are given.

The conference looked at ways for doctors and nurses to make medical institutions more friendly and caring places. One way is to use plain language with all patients, both when speaking and writing. Another way is to identify patients with low literacy skills, and to provide information specially adapted to meet their needs.

It is not easy to identify someone with a literacy problem. Many adults are embarrassed by their lack of literacy skills. They will go to great lengths to hide the problem.

Two solutions were offered at the conference:

- find out the reading levels of patients

- create an environment in the hospital that is friendly to people with low literacy skills

Find out reading levels of patients[2]

It can be a challenge to find out a patient's reading level. Here is a list of things you should and should not do.

Do

- Ask general questions. For example: "Tell me how you will explain what you've learned to your family."

- Ask them to think about a time when they learned something new. Did they watch someone else do it? Did they read how to

Quote

"I went to the clinic for a medical test, and I was put in a small room to watch a video which explained what was going to happen. I thought that was a very good idea."

The Learners' Wall

do it? Did they watch it on a video? Ask them how they would like to learn today.

- Develop two versions of the printed material. One can be a basic version written at a Grade 4 to Grade 6 level. The other version can have more information. Offer both versions to the patient.

Do not

- Do not ask, "Do you understand?"
- Do not give patients something to read and then ask questions to see if they understand it.
- Do not hand patients something upside down and watch to see if they turn it right side up.

Create an environment that is friendly to people with low literacy skills

There is no one single way to make hospitals and clinics friendly for patients with low literacy skills. Here are a few tips:[3]

1. Make your service easy to find

- Provide landmarks and bus stop numbers when you give directions to your office.
- Create a sign or logo that shows what you do: i.e., a dentist could use a tooth or toothbrush as a symbol.
- Help clients find your office inside the building by placing symbols, i.e., footsteps or arrows from the entrance of the building to your door.

2. Reorganize your reception area

- Create a private place in the office where clients can fill out forms themselves or where someone can sit with them and help them fill out the forms.

Quote

"Once, before an operation, I was asked to fill out forms. One question asked about allergies. Well, I'm allergic to Demerol, but I didn't know how to write it, so I left it blank. After surgery they gave me Demerol and I threw up."

The Learners' Wall

Success story

The Hamilton Health Sciences Corporation is the largest provider of comprehensive health services in Ontario. For more than 10 years, the hospital's Patient Education Services has worked with medical staff to prepare education materials for patients. It believes that "providing" information is **not** the same thing as "making sure that people understand the information."

Patient Education Services uses a consultation model that encourages teamwork among patients and families, patient care experts and patient education specialists. It challenges assumptions and thinks about change in a comprehensive way. At the same time, it does not stick to rigid rules. By taking a flexible approach, Patient Education Services juggles the needs of all the people involved and their changing priorities.

3. Change your reception routine

- Use plain language forms.
- Offer to help clients fill out the necessary forms.

4. Help prepare clients for their treatment

- Provide easy-to-read or audio-visual materials that relate to your clients' treatment while they sit in the waiting room.

5. Talk with your clients and make sure they understand

- Avoid rushing through visits with your clients.
- To reinforce your message, give them easy-to-read health information and treatment plans at the end of their visit.

Get institutions to change[4]

Change is a process, not a one-time event. Research has identified six steps that people go through to make a change. It involves pre-contemplation, preparation, contemplation, action, maintenance and termination.

Change does not move from "A" to "B". It is normal for people to "backslide" to old behaviour. In fact, it can take six months to a year before change is solid.

One study of an American farming community illustrates the process of change. The study found that 10% were "innovators," 10% were "early adapters," and 50 to 70% fell into a group that takes more time to adapt. Another 10 to 14% will simply not change.

In an organization, change creates many fears. These include fear of job loss, failure or loss of status. As a result, change takes a great deal of energy. It "shakes up the place."

Here are five steps to help promote change in a health institution:

Step 1 Determine the benefits

Use the economic benefits of plain language to get doctors on side.

Step 2 Get key players on board

Key players include deans of medicine, site committees, multidisciplinary committees and communications committees. You will need to sell the idea of a caring hospital setting to these players. For your sales pitch to work, these players must be "early adapters."

Step 3 Create a vision and a plan

Conference participants identified several ways that a vision and plan might help their organizations to change. First, it would create a space where patients could ask more questions. Doctors would have to adjust their ways of working. There would be a power shift. Second, it would create more choice for health care consumers by leading to a wider range of resource materials.

The plan would also recognize that plain language writing takes a lot of time and training. Humour can go a long way toward showing the needless complexity of government writing. For example, you could "translate" a three-minute speech full of jargon into a three-word statement.

Step 4 Communicate everything often

Communicate your message in creative ways – use everything from newsletters to bathroom signs.

Identify the communication challenges in your organization. Talk to opinion leaders. It is difficult to bring about change from the "bottom-up." Without support from senior management, real change is impossible. Timing is everything: know your limits and the economic context (if the economy is on a downslide, this may not be the time to push for plain language).

Step 5 Create success, advertise, adjust

Build on your successes. Tell people about them. Adjust your approach based on what you have learned.

Success story

The Montreal General Hospital believes in "patient education." Together with The Centre for Literacy, also located in Montreal, it is creating a Health Literacy Centre to provide culturally appropriate support for patients with low literacy, as well as for their families and caregivers. The Centre will also help health professionals develop the skills and tools to communicate with patients who have low literacy skills.

Provide accurate and clear health information on the Internet

The growth of the Internet has allowed people from all walks of life to access information from their homes and offices, as well as other sites such as public libraries.

By the end of 2000, 60% of Canadians used the Internet to find information on health. The quality of that information, however, did not always meet people's needs.[5]

People with low literacy tend to prefer the telephone over the Internet. Why? First, they may not have enough money to buy a computer and pay for a service provider. Second, they may not have the necessary literacy skills to find or understand information on the Internet.

The Information Highway holds great promise for providing information on health. However, it can also spread misinformation. The "language" of the Internet also creates a new level of literacy that people need to have.

Organizations have a responsibility to create web sites that are easy to use. They need to provide information in clear language and also use clear design principles. To that end, participants at the conference heard about two success stories:

The National Adult Literacy Database (NALD) (www.nald.ca), based in Fredericton, New Brunswick, provides the opportunity to literacy organizations in Canada to place on-line information about their projects and services. It also designs and mounts web sites for literacy organizations on its own site and registers them with search engines to ensure greater visibility of their message. In fact NALD worked closely with CPHA's NLHP to design and mount its web site, introducing the literacy and health issue to a much broader audience.

The Canadian Health Network (CHN) (www.canadian-health-network.ca) gathers Canadian resources on health issues. In its early stages, it chose organizations and individuals with expertise. This enabled CHN to build credibility right from the beginning. As one of its most innovative features, it has revised "Frequently Asked Questions" (FAQs) on a variety of health-related topics into plain language. More than 500 organizations have posted information on the site.

Recommendations from Theme 1

- Promote early learning, especially for children at risk.
- Provide better access to health services and plain language health materials.
- Restore program funding. We also have good experience with program models that work, and work well. Many jurisdictions in Canada have been cutting back on the funding that makes these services possible. Governments need to restore funding for the services that have been lost – both because the services themselves are a fundamental right, and because the economic cost of failing to provide them is staggering.
- Recognize that health literacy is a human right. In our policy work, we must also take health literacy one step beyond its recent recognition as a determinant of health, to frame it as a basic human right.

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Theme 2: *Looking for ways to improve the training of health professionals*

Overview

When people talk about the need for literacy training, they often think first about what learners need to do for themselves. However, there is also a pressing need to teach doctors, nurses and medical students about how to communicate more effectively with low-literacy health consumers.

There are two main ways to help low-literacy patients.

The first is to try to identify these patients and provide them with information that is specially adapted to their needs. Literacy tests have been developed to help the health provider find out if a patient will need special care. However, many critics claim these tests are, at best, impractical. At their worst, the tests can shame patients, and make them feel even more uncomfortable.

The second way to help low-literacy patients is to use simple and clear language, both verbal and written, with all patients. Plain language is crucial, especially with respect to consent forms. At the conference, participants explored several issues related to the plain language training of health providers, including the following:

- Clear verbal communication
- Shame-free communication
- Writing in plain language (especially consent forms)
- Understanding barriers caused by cultural differences and disabilities
- Assessing written materials
- Multi-media communication
- Introducing medical students to the needs of low-literacy patients

Clear Verbal Communication

Verbal communication includes facts, advice and "small talk." It also includes nonverbal cues and expressions such as nodding the head.

Clear verbal communication is a way of speaking that is easy to understand. For doctors, it means organizing what they say so that it is easy to remember, checking with clients to make sure they have understood and suggesting treatment plans that clients can actually follow. It also includes listening to patients and giving them the chance to express their feelings.[1]

Some doctors are concerned about the extra time it takes to use clear verbal communication. However, in simulations, it only takes about 30 seconds longer to give extra explanations. That is a small investment considering it can save countless hours in repeat visits and telephone calls.

Tips for clear verbal communication

1. Organize your information.
2. Use common words, not technical jargon.
3. Give your clients a chance to express how they feel and to tell the story of their illness.
4. Make direct eye contact.
5. Use written information as a back-up.
6. Plan with your clients what they can do.
7. Let your client know what you are thinking.
8. Explain procedures and ask permission during examinations.
9. Focus on your client, not on notes, X-rays or the computer screen.
10. Check that your clients have understood what you have said.

Shame-Free Communication

Quote

"Think about your spoken language. If someone does not read well, they likely also have difficulty with medical terms. Talk to your patients using clear language. Ask your patients to repeat directions. Make sure they understand before they leave the office or emergency room visit. It may take one or two more minutes but it will save you time and expense later."

Dorothy Silver,
Adult Learner

People with low literacy often feel shame about their inability to read and write well. For instance, it is often difficult for learners to even admit they have a problem. Any action, even well-intentioned, that draws attention to their literacy problem can make them feel more shame. It may well push them further away from getting the help they need.

A shame-free communication approach means finding ways to interact with learners that treats them with respect and that encourages them to improve their skills.

The American Medical Association has produced a video called "Low Health Literacy: You Can't Tell by Looking." It shows people with low literacy skills talking about their negative experiences with doctors and hospitals. It also shows positive interactions between patients and health professionals: a nurse educator, for example, helps a learner understand a doctor's diagnosis.

The Bayer Institute for Health Care Communication is dedicated to enhancing health outcomes through improved clinician-patient communication. The Institute has developed a training program for doctors and faculty in medical schools. The program focuses on four "E" words:

- **Engagement** – this involves making person-to-person contact, asking about family or hobbies and taking the time to treat the patient like a person.
- **Empathy** – the patient must feel that he/she has been seen, heard and accepted.
- **Education** – this means providing information (verbal or written) in a way that the patient will understand.
- **Enlistment** – this may involve the doctor saying to the patient at the end of the visit: "Do we have a deal that (you will take your medication, etc.)?" The doctor shakes hands before the visit ends.

Writing in Plain Language

Plain language is a way to organize and present information so that it is easy to read for the intended audience. When trying to reach a general audience, for example, you should write materials at a Grade 4-6 level so that the greatest number of people will get the message. See page 42 for tips on creating plain language texts.

Professional Liability and Patient Consent: Treatments and Operations

Health professionals have to inform their clients of the benefits, risks and alternatives of a medical treatment or procedure. If doctors fail to provide this information, the patient has the right to sue for negligence if something goes wrong with the operation or treatment. The breakdown in communication between patients and doctors is one of the main reasons for malpractice suits.

Before a treatment begins, a doctor should obtain "valid consent" from the patient. Canadian courts have identified several criteria[2] for valid consent:

1. The consent must be genuine and voluntary.

2. The procedure must not be illegal.

3. The consent must authorize the particular treatment or care, as well as the particular caregiver.

4. The client must have the legal capacity to consent.

5. The client must have the necessary mental competency to consent.

6. The client must be informed.

The last point is perhaps the most important. It is not enough for a patient to sign a "consent form". Several Canadian court decisions have suggested that informed consent is a process through which people receive information they can understand. They then use this information to help decide on a recommended treatment.

Professional Liability and Patient Consent: Clinical Trials

The issue of informed consent is even more crucial for people who volunteer to take part in clinical trials for new drugs or treatments. Since these participants are volunteers, they must be informed of the risks. However, a consent "form" for a clinical trial can often be up to 30 pages long. Even a person with a high level of literacy would find it difficult to understand such a lengthy form.

Here are several other considerations for consent forms that go beyond the issue of literacy:

- Cultural differences and disabilities may affect a person's ability to provide informed consent.
- Any patient can be anxious or frightened which can affect their ability to understand a consent form.
- Consent forms can be out-of-date and should be reviewed and updated every six months during ongoing trials.
- There are two types of risks, both of which should be explained clearly in the consent form or verbally to the patient: physical (harm to the body) and social (being labelled as someone with a problem if you take part in a study).

Components of informed consent[3]

- Purpose of the study
- Procedures and treatments
- Responsibilities
- Risks and benefits
- Confidentiality
- Voluntariness
- Time involvement
- Withdrawal consequences

Tips for designing consent forms

- Know the content, audience and goal of the study.
- Use clear design features like headers, 12- to 14-point type, 16- to 18-point bold type for headings, and split the page 50-50 between text and white space.
- Use clear, consistent language.
- Test for readability (remember that formulas do not address issues like format, layout, patient interest and motivation).
- Revise if necessary.
- Define technical words (for example, "nausea" = "sick to the stomach").

Understanding barriers caused by cultural differences and disabilities

Aboriginal cultures

First Nations have the lowest health status in Canada. A variety of social/economic factors such as rampant unemployment, over-crowding, lack of educational opportunities, poor community infrastructure, environmental degradation and dietary changes contribute to a poor overall health picture regardless of where the First Nations citizen resides.

Traditionally, Aboriginal people lived by hunting and fishing in a highly sophisticated oral culture – a culture in which reading and writing were not necessary. The Cree and the Inuit, for example, did not have a written form of their languages until the mid-19th century. Today's Aboriginal people walk in two worlds: the traditional and the technological.

Parkland Regional College in Saskatchewan developed an approach to bridge these two worlds called "Reaching the Rainbow."[4] In this approach, a colour code identifies the seven types of literacies needed by Aboriginal people (see next page). Whether the subject is technology literacy or spiritual literacy, the teaching must be culturally relevant to be successful.

Reaching the Rainbow:

- Red: Mother Tongue Literacy
- Orange: Oral Literacy
- Yellow: Literacy of Symbolism
- Green: English and/or French Literacy
- Blue: Literacy Using Technology
- Indigo: Spiritual Literacy
- Violet: Holistic Literacy

Ethnic and cultural groups

Ethnic and cultural groups face many barriers, including language and communication problems, beliefs and attitudes about health care and a lack of trust in the mainstream health care system.

Language

When a Chinese senior nods, it may mean that he or she understands you, agrees with you and will follow your advice. However, it may also mean that he or she thinks you are making a valid point, but does not agree with you.

Beliefs and attitudes

Many Chinese avoid hospitals because they are seen as places of bad luck.

Lack of trust

Certain elderly minorities (including those of African, Asian and Aboriginal descent) distrust the health care system because of past racism or society's mistreatment of their cultural group.

Unfortunately, many health care professionals and systems in Canada are ill-equipped and unprepared to break down these barriers.

Hearing impaired

Medical professionals often look at the deaf as people who cannot hear. Instead, they should realize that the deaf are people who simply understand the world in a visual way. At the same time, deaf people do not "see" the world in the same way as people who can hear. Deafness, therefore, should be considered as a "culture." Conference participants provided the following suggestions on how to improve communications between deaf patients and medical professionals.

Tips for better communication with the hearing impaired

Deaf patients

- Bring along a sign language interpreter.
- Bring a list of questions for the doctor.

Medical professionals

- Remember deaf patients cannot hear their name over the PA system.
- Type out everything discussed with the patient in plain language.
- Take a basic signing course to establish some rapport.

Note: for tips on working with people who have developmental disabilities, see page 41.

Assessing written materials

SMOG Readability Formula

CPHA's Plain Language Service uses the SMOG Readability Formula to assess the grade level of its written materials. SMOG involves taking groups of words from a text and then calculating the number of syllables using a simple formula.

Flesch-Kincaid Grade Level Index

The Flesch-Kincaid Grade Level Index is similar to SMOG except that your computer does all the work. Using Microsoft Word, you can automatically calculate grade levels on your documents. Under "Tools,"choose "Spelling and Grammar." After Microsoft Word checks spelling and grammar, it will display "Readability Statistics," including the Flesch-Kincaid Grade Level Index.

SAM

The Suitable Assessment of Materials (SAM) is a system that rates the suitability of written materials. It looks at 22 factors that are broken down into six larger categories:

1. Content (amount of information)

2. Literacy Demand (readability)

3. Graphics (relevance of pictures)

4. Layout and Typography (clear design)

5. Learning Stimulation, Motivation (does the reader need to act?)

6. Cultural Appropriateness (age, race, gender)

The SAM system takes about 30 minutes to help you decide if your material is suitable for your target audience.

Learner Verification and Revision[5]

Another way to assess material is to invite learners to talk about their reactions.

The Process

1. Identify the key points in the material to be tested. The two or three most important points become the focus of your questions.

2. Write the questions to ask (no more than 10 questions). These questions focus on five specific elements:

Attraction	Is the instruction appealing to read or listen to? Is this something you would like to read?
Comprehension	Will the audience understand? Tell me in your own words what this is all about.
Self-efficacy	Will it stand alone? Do you feel you have enough information to carry out the instruction? If you do not, what are you missing?
Acceptability	Will the audience accept the information given in the pamphlet?
Persuasion	Will the pamphlet persuade the audience to change their behaviour?

3. Select a sample of patients to be tested.
   You do not need a large sample of patients. Any major problem will appear in the first 10 responses.

4. Interview the patients.
   Interview patients one-on-one for a few minutes (10 minutes maximum). Be sure to record everything that is said in the patient's own words. Do not paraphrase because you may lose important information.

5. Evaluate the patients' responses and revise material accordingly. Watch for misunderstandings about behaviour and actions (such as following instructions about medication).

Multi-media communication

The success of communicating any message is knowing your audience, and developing materials that address and respect its needs. Multi-media messages can be very effective.
People remember:

- 10% of what they read
- 20% of what they hear
- 30% of what they see
- 70% of what they see AND hear

Steps to develop your message[6]

Get to know your audience:

If you know your audience, you will be better able to decide what to include in the program. You can also make materials more culturally appropriate. And you can develop the best strategies to get the message across. You can learn more about your audience from the following:

- Community observation
- Meeting community leaders
- Informal conversations
- Surveys and in-depth interviews
- Focus groups
- Testing in the field

Look at these areas when designing your materials:

- Cultural health beliefs
- Treatments and remedies
- Potential gaps
- Preferred learning style of your audience
- Previous programs and approaches

Explore different types of visual materials:

- Posters and pop-ups
- Flip charts
- Table tents
- Talk boards

- Real objects and models
- Display boards
- Fotonovelas and brochures
- Audio-visual materials (audiotapes, videotapes, slide shows, CDROM)
- Multi-media (a combination of audio, video, graphics and text)

Introducing medical students to the needs of low-literacy patients

Research shows that effective health communication is not just a matter of personality. Rather, it is a learned skill. Educators have observed that providers who receive communication skills training enjoy more effective consultations with their patients. It leads to greater patient satisfaction and less misunderstanding. Effective communication is a basic clinical skill that demands as much attention as technical skills.

Problem-Based Learning (PBL)

Problem-Based Learning (PBL) helps medical students develop practical problem-solving skills. For instance, over two weeks, students might meet with a "standardized patient" – an actor who has been trained to play the role of a patient with a particular kind of illness. Students must diagnose the patient, provide rationale for their diagnosis and recommend treatment.

As part of the AMC Cancer Research Centre's PBL program, actor-patients provide cues that they have a literacy problem. These cues include the following:

- The health history form is filled out incompletely and inaccurately.
- The patient uses words inaccurately.
- The patient is confused by complex words.
- The patient tells related stories as part of answering medical questions.

- The patient folds up written information and puts it away.
- The patient asks for instructions to be repeated.

Recommendations from Theme 2

- Train every student and every health professional in plain language and clear verbal communication.
- Provide lower liability insurance rates to professionals with plain language training.
- Adapt and broaden the scope of plain language communications to include the needs of those with cultural differences and disabilities.

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Theme 3: *Learning more through research*

Overview

In recent years, studies in both Canada and the United States have confirmed that low literacy is widespread. Research also shows that low literacy has both direct and indirect impacts on health. People with higher literacy skills can stay in better health because they can understand and interpret health information. They may also be better able to prevent health problems and to detect problems earlier.[1]

The reverse is also true. People with low literacy skills often feel alienated and have difficulty finding and accessing health information and services. As a result, they suffer poor health and die earlier than those who have higher literacy skills.

Research has also identified various kinds of "literacies." In fact, the definition of "functional literacy" is always changing. As society changes, people need to learn a new set of "literacies" that range from how to use debit cards at a banking machine to how to access information on the Internet.

While research has shown the direct and indirect impacts of literacy on health, income and other areas, there are still many issues to be explored. These issues include access to information, comprehension, learning styles and disabilities.[2]

Research and policy trends in Canada

Since the mid 1980s, many Canadian policy makers have recognized literacy as a serious issue. Below, we have highlighted important research and policy trends in Canada related to literacy.

In 1987, the Southam Survey revealed two important facts.

First, the survey showed that "functional literacy" was not about grade level. Rather it was about reading, writing and using numbers to meet the literacy demands of everyday society.

Second, it gave some indication of the problem. Partly because the survey left out northern communities and people in institutions and prisons, the results were very conservative. The survey found that 22-24% of adult Canadians needed help to meet their literacy needs (compared to 47% identified in today's research).[3]

In 1989, the Ontario Public Health Association and Frontier College identified major impacts of low literacy on health:

Direct impacts of low literacy

- older adults may not be able to use medication properly because they cannot read the label
- more visits to hospitals
- longer nursing home stays

Indirect impacts of low literacy

- poverty
- unhealthy lifestyle practices
- stress and low self-esteem
- dangerous work environments
- lack of or inappropriate use of health services

In 1990, Statistics Canada's National Literacy Survey showed that people with low literacy skills have more health problems. The survey results meant that health providers had an obligation to deal with the issue. It also meant that society could no longer blame people with low literacy skills for the problem.

In 1995, the International Adult Literacy Survey (IALS) explored three aspects of literacy: prose, document and numeracy. The survey concluded that 47% of adults have problems using the written word – these results were similar to the National Adult Literacy Survey carried out in the United States in 1992.

In 1999, the federal, provincial and territorial Ministers of Health released the public policy report *Toward a Healthy Future: Second Report on the Health of Canadians*. The report reflects a growing awareness that many factors affect "health," including genes, personal health practices, available health services, early child development, and social, economic and physical environments.[4]

The report identified the following literacy trends:

- Literacy levels are higher in the west and lower in the east.
- More males leave school early.
- Those aged 64 and over have lower literacy levels.
- The unemployed are three times more likely to have low literacy levels.
- People with low literacy levels feel alienated and have less access to health information and services and have poorer health.

The report recommended the following actions:

- Invest in the health of children, youth and Aboriginal people.
- Renew and reorient health services.
- Reduce the differences in income distribution, education and literacy across the country through these key strategies:

    1. increase employment opportunities and earning capacities for disadvantaged Canadians
    2. continue to use tax transfer and social policies to reduce inequities
    3. review the effectiveness of current programs that provide a safety net for Canadians
    4. support recreational and social services
    5. ensure that the essential needs of Canadians for food, shelter, privacy and security are met.

The economic impact of low literacy

Statistics Canada's surveys on literacy have focused on the economic impact of low literacy. The final report from the International Adult Literacy Survey (IALS), released in June 2000, examined the relationship of literacy and income in 20 countries.

Quote

"People are unemployed, are poor, are addicted, are ripped off and are discriminated against because they can't read. People get in trouble with Revenue Canada, employment insurance and have a hard time filling out their health information forms or insurance forms because they can't read. People are in jail because they can't read. I know that people die because they can't read."

Dorothy Silver,
Adult Learner

The report measured three types of literacy of adults aged 16 to 65:

- **Prose literacy** – understanding texts such as poems, news stories and fiction.
  Canada ranked 5th out of 20 nations.

- **Document literacy** – using information in formats such as maps, payroll forms and bus schedules.
  Canada ranked 8th out of 20 nations.

- **Quantitative literacy** – applying math skills such as balancing a cheque book.
  Canada ranked 9th out of 20 nations.

Other highlights:

- Literacy has a major impact on earnings, especially when education and experience are also considered.

- 40% of Canadian adults were at the lowest two levels of literacy on all three literacy scales.

- 23% of Canadian adults were at the highest two levels on the "prose scale." Only Sweden had a higher rating at this level (32%).

Literacy, seniors and cardiovascular illness

Conference participants heard about a research project[5] that is looking at the literacy needs of low-literacy seniors who are suffering from cardiovascular illness. The project is a partnership between the faculties of education and nursing at McGill University in Montreal and the University of Quebec in Quebec City.

The project has three phases:

Phase 1: Exploratory study

Phase 2: Development of education tools

Phase 3: Validation of tools and strategies

Researchers presented results of the project's first phase, which included the following:

Problem

Low-literate seniors with cardiovascular illness do not follow diets recommended by health professionals. They also do not take their medication as prescribed. Generally, seniors, especially low-literate seniors, are reluctant to change their habits.

Solution

Health care information must be adapted so that low-literate seniors understand their illness and take the necessary steps to recovery.

Focus groups with seniors revealed the following facts:

- Seniors looked positively on health care professionals who used plain language to help explain an illness.
- Seniors understood explanations when the words had meaning to them (e.g., when talking about diets, use "cups" and "tablespoons" rather than "portions").
- Seniors need time to think about how to phrase their questions. This is not due to poor memories. Rather, they need time to reconstruct and recollect information.

Research and policy trends in the United States[6]

Research into health and literacy in the United States has provided data about:

- the limited literacy skills of many American adults
- the high reading demands of most health information
- the poor health outcomes and system costs associated with limited literacy skills

The 1992 National Adult Literacy Survey (NALS) proved that almost half of American adults (90 million people) had only basic reading and math skills. It identified four groups with particularly limited skills:

- seniors
- recipients of public assistance

Case Study

A 1995 study of 3,000 emergency room and chronic care patients in Atlanta and Los Angeles revealed a clear link between literacy and health. Patients had trouble with verbal as well as written communications. Fewer than 40% with low literacy knew the name or purpose of their medications compared to more than 60% with higher rates of literacy.[1]

- people of colour/ethnic minorities
- people with disabilities

Research has also identified several types of literacy. "Documentation literacy," for example, is the ability to understand and fill out information on forms. "Quantitative literacy" is the ability to do simple math such as calculating a tip for a waiter at a restaurant. Since "functional literacy" relates to the society in which we live, it changes with the times. In earlier generations, a person could "get by" with a lower degree of literacy than today.

Collaborative research has brought greater attention to health literacy from the federal government and the medical profession. In 1998, the Clinton Administration mandated federal agencies to use plain language in their dealings with the public. And in 1999, the *Journal of the American Medical Association* recognized that health literacy is critically important to health care delivery.

Although policy makers are more aware of the literacy problem, there is no national health and literacy program in the United States. Health professionals concerned about literacy are scattered throughout the country and lack a "single voice" to push the agenda forward. Finally, few people recognize the social and economic impact of "limited health literacy."

Advocates have identified the need for the following:

- National-level public leadership (an American version of NLHP) that will "own" the issue and move the agenda forward.
- A national program that links major health, medical and literacy organizations.
- More policy development.
- More action-oriented research.
- More training for health, medical and literacy professionals.
- Funding to support these efforts.

A framework for understanding literacy

At the conference, a framework on health literacy[7] was presented that pointed out that health literacy is distinct but that it relates to general literacy (see below). Other literacies such as politics and economics are also important.

General literacy

- reading ability
- numeracy
- judgement
- critical thinking
- interpretation of evidence
- communication and negotiation skills

Health literacy

- knowledge about health
- ability to find health information
- ability to interpret health information
- knowledge and ability to seek appropriate health care
- ability to understand and give consent
- ability to understand "risk"

The Big Picture

More work is needed to understand health literacy in the areas of policy, training, community development and communications. How much of the issue or solution is literacy? Where is literacy in the context of homelessness and unsafe housing?

Quote

"It sounds as though there is a lot of money spent on literacy. Really there isn't when you compare it to the size of the issue. If you think literacy is expensive, try ignorance."

Dorothy Silver,
Adult Learner

More research is needed on the impact of other aspects of society on health, including the following:

- Welfare policies
- Age
- Neighbourhood
- Income distribution
- Work situation
- Gender
- Race/Ethnic discrimination
- Literacy

Literacy, health and seniors[8]

Seniors are one of society's most vulnerable groups, especially when it comes to health literacy:

- 40% of seniors did not complete primary school and about 80% have some degree of low literacy.
- Many seniors have spent years developing skills that help them cope with low literacy. As a result, they often overestimate their literacy skills. At the same time, seniors with low literacy are very interested in their health; they want to be well enough informed to make their own decisions.
- Few seniors take part in literacy programs compared to the number who could benefit. The International Adult Literacy Survey (IALS) estimated that 8% of seniors were involved in literacy training. A literacy project in Regina found that only 10% of participants were well over 55.
- Seniors prefer to have someone their own age teach them literacy skills. With one-on-one tutoring, explanations can be personalized; one presenter described the best atmosphere as "intimate." In small groups, tutors have to allow enough time for discussion and group bonding.

Recommendations from Theme 3

- Define the various "literacies" more clearly.
- Establish pathways between literacy and health.
- Expand studies beyond medical encounter.
- Conduct more research on awareness, access to information, vocabulary, knowledge base, comprehension, description, learning styles, disabilities and cognitive impairments, partnerships with other communities, personal action, collective advocacy, barriers, pathways, etc.
- Change policies: existing research justifies greater investment.

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Quote:

"I can't pronounce the names of my pills. I ask for them by their shape, size and colour."

The Learners' Wall

Theme 4: *Learning from learners*

Overview

Learners have expertise that needs to be used and shared. They need to be systemically involved at all stages in program and policy development – from basic concept through to delivery and evaluation. Literacy and health professionals owe it to learners to ensure they feel respected, involved and treated as people who do bring practical experience to the table.

At the conference, participants – many of whom were learners themselves – heard from learners who ranged from seniors and people from the North to people with developmental disabilities. Through the conference, learners shared their stories and offered insights into their experiences with the medical system. Many also wrote their stories on the "Learners' Wall," which served as a testament to their courage and determination.

Below, we have listed a variety of suggestions from learners related to health and literacy.

Drug labels and health forms

Packaging on no-name drugs can be a nightmare for people with low literacy skills. Learners often buy brand name drugs because they can recognize the colours and labels, even though they cost more. Generic and brand name drug companies should keep their products the same shape, colour and dosage.

Volunteers or staff can help learners in different ways. Volunteers can read questions on health forms to the learner. (Patients should carry their own case histories with them to make it easier to complete the forms.) Volunteers or nurse educators could also answer questions after patients have received instructions or other information.

The special needs of seniors

Seniors may not be able to follow their regimes because they cannot read the medication label, open the vials or keep track of dosing intervals. This results in more visits to the doctor, more lab tests, more medication and more stays in hospital or nursing homes.

Points to consider

As they package and market their products, pharmaceutical companies overlook the needs of people with low literacy skills. Different products are often packaged in similar ways, creating a lot of confusion. It also creates confusion when different pills come in the same sizes and shapes, or when manufacturers change the look of a familiar medication.

Problem
People count on finding a product in the same place every time they visit the store. They can get confused and frustrated if it is not there.

Solution
Keep products in the same place.

Problem
People with poor eyesight, especially seniors, have trouble reading medicine labels and expiry dates.

Solution
Medicine labels should be free of clutter. They should feature larger print and be stuck onto the bottle lengthwise so they are easier to read.

Problem
Written instructions can be confusing.

Solution
Pictographs could be used to show how to use a medication. Eyedrops, for example, could show a picture of an eye in the background.

Drugstores could play videos to show how to use medication.

Packaging and labelling checklist[1]

- Does your company have a clear policy on the design of packaging that respects the needs of older consumers?

- Does the product clearly explain how to use it (including large print and illustrations)?

- Do the instructions include safety and hazard warnings?
- Are labels, instructions and warnings written in plain language?
- Have you focus-tested the labelling and instructions with senior consumers?
- Is the packaging easy to open?

Lessons from the North[2]

Conference participants learned about the need for clear verbal communication in Northern settings. Using the traditional native "talking stick," participants sat in a circle and shared their fears about being misunderstood. (Only the person holding the stick has the right to talk.) The exercise reminded people of how it feels to be misunderstood, and the importance of listening.

Through a skit that was based on a true story, participants witnessed an example of "miscommunication." In the skit, a native woman goes to a health clinic to get help for an earache. The nurse quickly "processes" the patient and prescribes some pills. A few days later, the patient returns with even greater pain in her ear. The nurse is even more rude until she learns the patient had put the pill in her ear.

In the discussion that followed, participants identified some issues raised by the skit:

- The nurse did not spend enough time with the patient. She did not explain the medical information, and treated the patient like a nuisance. She did not ask about any other health concerns.
- Any strategies to improve packaging and instructions must consider the context of the North. For instance, it may not be useful to say "take medication with meals." In the North, people may have only one or two meals a day, and they will not be evenly spaced. Pictographs of "sunrise" and "sunset" on a bottle may not be useful either since daylight hours vary a great deal throughout the year.

Participants suggested ways to improve packaging of medications for people in the North:

- Explain verbally that "take this pill before bedtime" refers to "big sleeps" and not "naps."
- Use uppercase and lowercase letters rather than all uppercase.
- Write the label sideways (vertically) so the person does not have to roll the pill bottle to read the words.
- Avoid writing "Take as directed" since the person may not remember the verbal instructions.
- Use coated paper for labels so the words do not rub off if the label gets wet.

Lessons from the developmentally handicapped

Developing plain language texts[3]

The Vocational Rehabilitation and Research Institute (VRRI) of Calgary, Alberta creates plain language documents for people with developmental disabilities. At the conference, VRRI gave some ideas about how to produce these documents. The key is to involve the clients in the process right from the start to "translate" the documents – adapting them from complex prose into plain language.

Step 1 Find people with developmental disabilities to participate

Talk to social service agencies about getting clients involved as "translators." Use "word of mouth" since people with developmental disabilities do not usually look at notice boards.

Step 2 Interview potential participants to become "translators"

During the interviews, look for people who can respect each other's abilities and be able to work on words together. Two to three people in a group are ideal. You will likely choose more women because men have more trouble admitting that they have low literacy skills.

Step 3 Create a plain language text

Tips for working with your group of "translators"

- Highlight difficult words in bold and then define them.
- Work in the morning because minds are fresher.
- Since the work is tiring, only work for 1½ hours at a time.
- Do not ask translators if they "understand" the text. They may say "yes" to please you. It is always better to ask what a specific sentence or word means.
- Be prepared to listen to long stories. This is often how translators will explain the meaning of words or phrases to you.
- Be aware that some people in the group may understand a word or phrase and can explain it to others.
- If materials cannot be understood, remember that it is the fault of the materials, not the reader.
- Material relating to sexual abuse, discrimination and health problems can trigger an emotional response from your translators. For that reason, it is best to have separate translating groups for women and men. If women are triggered by the material, take a break and talk about it.

Tips for creating plain language texts

- Avoid "ING" endings.
- Do not hyphenate words over a line.
- Finish a sentence at the end of a line, if possible.
- Avoid contractions (like "don't").
- Use "someone" rather than "somebody."
- Take care with words such as "rights" since they can be confused with "right and left" or "right and wrong." Use the full term: "human rights."

- Strike a balance between being too general and too specific.
- Use a large, sans serif font such as Times Roman 13 or 14.
- Break down long sentences that include several ideas.
- Cut some words out.
- Add sub-heads and bullets.

What plain language is not

In the workshop, "Plain Language as a Social Justice Issue – England's Plain English Campaign", offered by our international guests, Mr. George Maher and Mr. John Wild, we learned what plain language is not.

Plain language is not about:

- "dumbing down" the language – proper, well-crafted plain language will not be condescending or "simple" sounding.
- speech or accents – plain language is concerned with the written word – people will not ask writers for explanations, as they might ask speakers – you only have one chance to get your message across.
- abolishing jargon – jargon is a form of professional short-hand: it can be useful, in the correct context. It is good for communication between professionals, but not for communication between professionals and laypersons.
- abolishing new words – languages evolve, and that is fine, so long as the people reading will understand the meaning of what you write.
- ruining literature, or curbing writers – people read literature by choice, but if they are reading the directions on a bottle of medicine, plain language could be a matter of life or death.

Overcoming fears about writing

At a hands-on writing workshop called "Fearless Writing," conference participants had a chance to express their fears about writing and to learn ways to overcome those fears.

Common fears about writing

- My handwriting is messy.
- People will judge what I write.

- I may not use punctuation the right way.
- Teachers can be critical.
- Teachers working with deaf people have low expectations of their students.
- I'm afraid my writing won't be good enough.
- I may lose my train of thought.
- I skirt around big words.
- I speak in $100 words and write in $10 words.

Writing Exercises

Free Writing

Participants are invited to write whatever they want for five minutes. They can ignore questions of spelling, grammar, etc. The idea is to free the writer inside to "create" without worrying about criticism.

What I really want to say to my doctor

Each participant is given a sheet with the heading: "What I really want to say to my doctor is...". For 15 minutes, each person "finished the sentence" with their own thoughts. Some examples appear below.

What I really want to say to my doctor...

"...that deaf people who sign are as intelligent as those who hear and speak."

"...that I am more than my illness. Yes, I have multiple sclerosis, but I am also a single mom with two teenage kids. You tell me to go home and rest and keep the stress in my life to a minimum. So how many kids do you have? Do you wake up and wonder if your legs will work well enough to get up and get breakfast ready?"

"I want to say thank you for understanding me and my problem."

Cloth Bag

Participants each reach into a cloth bag and pull out an object (a roll of surgical tape, a sucker, etc.). Each person then writes a few sentences to describe the item.

Recommendations from Theme 4

- Mine the expertise that learners bring.
- Respect, involve and appreciate learners.
- Recognize that learners can teach health professionals.
- Support organized learners' groups and activities.

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Theme 5: *Building literacy and health partnerships*

Overview

Just as communication requires at least two active participants, literacy programs also thrive on different kinds of partnerships.

On an organizational level, partnerships within the community allow literacy and health professionals to share ideas and resources, leverage funds and expand networks. Conference participants heard about the experiences of Action ABC, a non-profit group that provides bilingual literacy education to people recovering from substance abuse. It has established partnerships with several hospitals in Montreal and Toronto that offer treatment for substance abuse. Other examples of community-based partnerships include the Saskatchewan Literacy Network and Frontier College.

On a program level, partnerships between organizations and people with low literacy skills ensure that the expertise and experience of learners is heard and respected. Below, the *Captain's Log* features highlights of partnerships with youth such as TeenNet and What the HEALTH!, as well as partnerships with seniors.

Finally, the conference noted the importance of establishing partnerships across national borders. American participants, for example, held up CPHA's National Health and Literacy Program as a model for partnership among different sectors. A U.S. - Canadian literacy and health partnership would help both countries boost the profile of literacy and health.

Partnerships with Youth

TeenNet

TeenNet, set up in 1995, is a Web site that promotes health among at-risk youth. It has four goals:

- to produce practical tools
- to help youth identify and express their health needs
- to enhance control over personal health and support
- to generate new knowledge

There is no shortage of information on the Internet. The challenge for teens is to find what they want, and to make sense of it. To address this problem, TeenNet has a component called "Teen Clinic Online." It provides links to information on the Internet and shows teens how to evaluate the information.

TeenNet's partners include community-based organizations that deal with adolescents and/or health issues, and Frontier College (see page 48).

Quote

"We are all just one bad choice from being at risk."

Promoting Health Among Youth At-risk workshop

How to consult with youth partners

* Leave your assumptions behind.

* Be ready to listen.

* If you are telling people that they are the experts, you have to keep the promise. Do not go into a situation with expectations of what you will find.

* Pay fair value for your partners' time. If you tell people their opinions are valuable, you should pay them for their time.

* Follow through and report back. Some youth have been "focus grouped to death." It is important to follow through on your promises and be sure to get back to them with the results of your research.

What the HEALTH!

In May 2000, as part of its "Developing a Health-Literacy Curriculum for At-risk Youth" project, CPHA produced a resource kit called "What the HEALTH!" The kit was produced with the active participation of youth currently enrolled in literacy programs offered by Frontier College, street youth, youth in school, health professionals and literacy practitioners. CPHA spent six hours with groups of youth in five Canadian cities. After discussing issues related to health and literacy (housing, unemployment, etc.), the youth wrote "news stories" about what they considered to be the Top 10 issues. Each "story" is designed to stimulate more discussion.

What the HEALTH! is one example of CPHA's National Literacy and Health Program in action. The program began in 1992. By 1994 it

had 10 national partners. Today, it has working relationships with 26 national health associations. It also works closely with numerous federal government departments.

Partnerships with Seniors

The Seniors Education Centre

The Seniors Education Centre is a partnership between the Seniors' University Group Inc. and University Extension, University of Regina. The Centre, founded in 1977, provides more than 100 education programs for older adults every year. The Centre also conducts applied research and community development work in areas affecting older adults:

- literacy
- abuse prevention
- health promotion
- caregiving
- cross-cultural/intergenerational communities
- learning technology
- distance education issues

Community-Based Partnerships

Frontier College

Since 1899, Frontier College has been teaching Canadians to read and write. The College reaches out to people wherever they are and responds to their individual needs. Using an approach called Student Centred Individualized Learning (SCIL), the College creates individual programs based on students' strengths and experience. The College has specific programs targeted at inmates, street youth, teens, adults and other groups.

In 1988-89, Frontier College began working with the Ontario Public Health Association to get literacy and health on the agenda. This

partnership enabled the two organizations to access two levels of federal funding and one source at the provincial level. The partnership extended to all levels of government, literacy students, literacy staff, public health nurses, doctors and pharmacists. The high level of collaboration allowed them to field test materials with intended recipients, create opportunities for health care workers to learn about literacy in all its dimensions, and enable literacy workers to learn about health care.

The landmark study, "Literacy and Health Project: Making the World Healthier and Safer for People Who Can't Read," produced by OPHA/Frontier College paved the way for the creation of CPHA's National Literacy and Health Program.

Action ABC

Action ABC is a non-profit charity with a national mandate to provide bilingual literacy education to people recovering from substance abuse. The organization provides literacy education at several hospitals and shelters in Montreal and Toronto which offer treatment for substance abuse:

- The Jewish General Hospital's Methadone Program
- The Montreal General Hospital's Addiction Unit
- "Crossroads" at the Douglas Hospital
- Centre de Recherche et d'aide pour Narcomanes
- The Centre for Addiction and Mental Health (Toronto)

The program tracked 120 students to see if they improved their level of literacy. It also looked at other key indicators such as employment status, marital status, form of substance abuse and gender. Here are some of the conclusions:

- People who had jobs progressed in higher numbers than those without jobs.
- Married students and single women who have boyfriends progress to higher literacy levels.

- Almost twice as many females progressed two literacy levels than males.

- A criminal record hinders progress.

Action ABC is speaking with substance abuse rehabilitation centres across Canada to make front-line literacy service more available. It is also conducting clinical research to see if literacy training helps individuals who are recovering from substance abuse to re-integrate into society.

Saskatchewan Literacy Network

The Saskatchewan Literacy Network promotes literacy and health in several ways. For instance, the Network has published a study showing the links between health system use and low education levels. It has also produced a kit that shows how low literacy skills affect health. Finally, it offers plain language workshops for healthcare workers. Participants at these workshops have offered comments such as these:

"It increased my awareness of the literacy issues facing people and how that related to my communication with them."

"It gave useful tips on clear writing, focusing on information and design."

"All staff should take this workshop."

Canada-U.S. Partnerships

At the sub-plenary, "Literacy and Health into the Future – the Canada and U.S. Experience," participants identified the need to develop Canadian and American partnerships. American participants made it clear that they hold up CPHA's National Literacy and Health Program as a model to raise awareness and to explore issues related to health and literacy and build partnerships. In addition to funding available from the National Literacy Secretariat, literacy partnerships in Canada provide an infrastructure for literacy and health programs and services both provincially and nationally.

The private sector in the United States does provide money for research into literacy and health. However, American participants noted they still face the challenge of finding stable resources to support a national initiative on literacy and health. Forging a U.S. - Canadian literacy and health partnership would provide both parties with information, potential in-kind resources and contacts to boost the profile of literacy and health in both countries.

Recommendations from Theme 5

- Build on existing models.
- Meet people on their own ground.*
- Encourage consumers and adult learners to play a central role in every partnership, at both the local and national levels.
- Invest in long-term partnerships by finding a common purpose and giving each partner enough space to pursue their own path.

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* *This approach is consistent with an adult basic education model which focuses on learning materials relevant to a learner's own life and experience. This model can also be adapted into other programs, e.g., life skills, vocational training.*

Conclusion

The First Canadian Conference on Literacy and Health, *Charting the Course for Literacy and Health in the New Millennium,* brought together individuals from a vast array of health disciplines and other sectors in an effort to build and strengthen literacy and health partnerships as well as position literacy as a critical health issue.

For many participants, the conference introduced them to new ideas and broadened their understanding of the health impacts of low literacy. For others, who have worked in the literacy and health field, the conference provided them with new ways of looking at old challenges. Either way, the conference reinforced their commitment to working on an issue that affects all Canadians.

People with low literacy skills may not understand health information a health professional gives them to read. They may not understand what a health professional tells them. Barriers to the health services they require to be healthy are numerous and overwhelming. Often, people with low literacy skills may not use health services, except in emergency situations.

The conference addressed the very immediate problem of access to the health information and services that low-literacy health consumers require to be healthy. But it went further than that.

It also explored the specific challenges that people who have low literacy skills and disabilities and/or cultural differences face in accessing the health services they need.

New techniques in plain language and clear verbal communication skills training along with literacy testing tools were introduced and discussed in numerous workshops. Health professionals were introduced to ways in which plain language and clear verbal communication could form the basis of a prevention strategy for their professional liability. Current case law as it pertains to informed consent and plain language was presented and discussed at length during the proceedings.

Literacy and health research in both the United States and Canada was presented, gaps were identified, and the seeds for new research projects were planted throughout the conference.

One of the greatest strengths of the conference – which many participants made a point of sharing with us – was the involvement of adult learners from both Canada and the United States in a meaningful way throughout the event. In addition to sharing their stories on the Learners' Wall, adult learners took part in the conference as presenters and speakers. Many learners told us that the conference respected and valued their expertise.

Also, the Weiler Award made a significant contribution to the proceedings. Formally recognizing individuals and organizations who/that have made substantial contributions to the literacy and health field provided support and encouragement not only to the award recipients, but also to all those who attended the conference and whose efforts in the literacy and health field are often not recognized.

This first conference is no doubt a stone laid on the path forged by the Canadian Public Health Association's National Literacy and Health Program over nine years ago. It has allowed us to reflect upon our accomplishments, but also to identify the work we have yet to do in this field. And there is much. Ultimately, it has helped the National Literacy and Health Program to map out its role in the years ahead. For this, CPHA is grateful to all those who participated in the conference.

Quote

"More than ever, our voices must be persistent and compelling in order to keep literacy high up on the crowded agenda that faces our nation and the world as we set our course in this century."

Senator Joyce Fairbairn, P.C.

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APPENDIX 2
Resources on Literacy and Health

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Appendix 2 - Resources on Literacy and Health

Web sites:

http://www.alphaplus.ca
Centre AlphaPlus Center

http://www.bccpd.bc.ca/wdi
The Wellness and Disability Initiative (WDI) Resource Centre

http://www.canadian-health-network.ca
Canadian Health Network (CHN)

http://www.consumer.ca
Consumers' Association of Canada

http://www.literacynet.org/value
Voice for Adult Literacy United for Education (VALUE)

http://www.nald.ca
National Adult Literacy Database Inc. (NALD)

http://www.nifl.gov/lincs
Literacy Information and Communications System (LINCS)
National Institute for Literacy

http://www.nlhp.cpha.ca
National Literacy and Health Program (NLHP)
Canadian Public Health Association

http://www.plainenglish.co.uk
Plain English Campaign

http://www.pls.cpha.ca
Plain Language Service (PLS), Canadian Public Health Association

http://www.prenataled.com/healthlit/default.asp
Health Literacy Toolbox

http://www.sabes.org/health/index.htm
System for Adult Basic Education Support (SABES)

http://www.teennetproject.org
TeenNet: Engaging Teens in Health Promotion Using Information Technology

http://www.une.edu/com/othrdept/hlit/index.htm
Maine AHEC Health Literacy Center

http://www.worlded.org/us/health/lincs/
National Institute for Literacy, Health and Literacy Special Collection

Canadian Public Health Association

The Canadian Public Health Association (CPHA) is a national, independent, not-for-profit voluntary association representing public health in Canada with links to the international public health community. CPHA's mission is to constitute a special national resource in Canada that advocates for the improvement and maintenance of personal and community health according to the public health principles of disease prevention, health promotion and protection, and healthy public policy.

National Literacy and Health Program

The National Literacy and Health Program (NLHP) is a partnership of 27 national health associations working to raise awareness among Canadian health professionals about the links between literacy and health. The NLHP provides health professionals with resources designed to help them serve people with low literacy skills more effectively. The NLHP's Plain Language Service supports improved health communication by offering plain language revisions, assessments and workshops to health organizations in the public, not-for-profit and private sectors.

National Literacy and Health Program Partners

Canada's Research-Based Pharmaceutical Companies, Canadian Association for Community Care, Canadian Association of Occupational Therapists, Canadian Association of Optometrists, Canadian Association of Social Workers, Canadian Centre on Substance Abuse, Canadian College of Health Service Executives, Canadian Dental Assistants Association, Canadian Dental Association, Canadian Dental Hygienists Association, Canadian Healthcare Association, Canadian Institute of Child Health, Canadian Medical Association, Canadian Nurses Association, Canadian Paediatric Society, Canadian Palliative Care Association, Canadian Pharmacists Association, Canadian Physiotherapy Association, Canadian Psychiatric Association, Canadian Public Health Association, Catholic Health Association of Canada, College of Family Physicians of Canada, Dietitians of Canada, Institute of Palliative Care, Nonprescription Drug Manufacturers Association of Canada, Society of Obstetricians and Gynaecologists of Canada, Victorian Order of Nurses.