



# **Second Canadian Conference on Literacy and Health**

**Final Report**

**Ottawa, Ontario  
October 17–19, 2004**



**Canadian Public Health Association**

**OTTAWA, ONTARIO ..... 1**

**I. PLENARY SPEECHES..... 6**

Welcome- Christina Mills, President CPHA .....6  
Opening Remarks from the Chair of the Conference- Deborah Gordon El-Bihbety.....6  
WHAT CAN WE DO TO IMPROVE THE HEALTH OF CANADIANS WITH LOW LITERACY SKILLS? ..... 7  
Senator Joyce Fairbairn.....7  
A Story of Determination- Ellen Szita .....7  
Health Conscious Societies in the 21<sup>st</sup> Century- Implications for Health Literacy and Canada- Dr. Ilona Kickbusch .....8  
FOCUSING ON LANGUAGE AND CULTURE: PERSPECTIVES..... 9  
The Cultural Context of Health Literacy- Dr. Dyanne Affonso .....9  
First Nations Health Symbology and Language- Janice Longboat.....10  
A Literacy and Health Success Story- Carole Blouin .....11  
Integrating Services for At-Risk Children in Québec- Johanne Laverdure.....12  
Diabetes prevention in Toronto- Miriam Rossi .....13  
REPORT FROM LEARNERS’ WORKSHOP ..... 15  
What would make it easier for you when you go to the doctor, clinic or hospital?- Raymond Roy.....15  
MAKING A DIFFERENCE/PARTNERSHIPS..... 16  
A wake up call for Canadian Literacy- Peter Calamai .....16  
CLOSING PLENARY ..... 18  
Closing Remarks- The Honourable Carolyn Bennett.....18  
Learners’ Recommendations to Delegates- Raymond Roy and Ellen Szita.....19  
Recommendations- Deborah Gordon El-Bihbety.....20  
Closing Remarks- Donna Kirby and Elinor Wilson.....23

**II. PRESENTATIONS AND WORKSHOPS..... 24**

A. BUILDING BEST PRACTICES IN LITERACY AND HEALTH ..... 24  
1. Plain Language and Clear Communication..... 24  
Atelier pour les personnes apprenantes: Comment mieux communiquer avec les personnes qui ont des difficultés à lire et à écrire- Margo Fauchon.....24  
Using Plain Language: the Importance of Easy Communication in Aboriginal Communities- Melanie Ferris .....26  
How to Communicate with Less Literate Canadians- Michel Gauthier .....28  
The ABCs of Clear Writing- Leah Morris .....30  
Comment mieux communiquer avec les personnes qui ont des difficultés à lire et à écrire- Diane Pouliot .....32  
One Day Wonders- Marg Rose & Charles Moody.....34  
2. Building Capacity for Health Professionals..... 36  
Health Literacy Network Community of Practice- Jane Dyson.....36  
Patient Education: the Literacy Connection- Judy King .....37  
Effective Communication for Health Care Providers and Program Administrators- Penny Lane & Holly Smith Miranda.....38  
Techniques used by clinicians to improve communication with patients with limited literacy- Joanne Schwartzberg .....39  
Health Literacy – Help Your Patients Understand- Joanne Schwartzberg.....40  
Health Literacy Workshops for Professionals and Students: Building on 10 Years of Experience- Lindsay Wizowski & Tracy Hutchings .....43  
3. Working with Families..... 43  
You are Your Child’s Best Toy- Claudine Bennett.....43  
We All Benefit: Using Partners and Participatory Approach to Family Literacy- Pat Chisholm .....44  
Project d’harmonization à la petite enfance- Danielle Galipeau.....44  
HIPPY Project/More is More- Dlamini Kapenda & Debbie Bell.....45  
4. Working with Communities..... 45  
Learning About Health, Student-to-Student- Marcia Drew Hohn, Saiyi Diaz & Vanda Ivanenko .....45  
Building Community Capacity: Focus on Literacy- Audrey Gardener.....47  
Health Matters- Trudy Lothian.....48  
People Who Rate: Community Involvement in the Developemnt of Health Education Materials and Messages- Elsie Petch, Norma Levitt & Al Levitt .....49  
5. Working with People with Disabilities..... 50

Simply Health- Sharon Christie & Grace Carson.....	50
Smoke Talk- Tobacco Awareness Course in Plain Language for Adults with Developmental Disabilities- Jeannette Coombe & Joseph Hnatuk.....	50
Menopause- What is it?- Lean Jones.....	50
Literacy Barriers for Deaf People Using Health Services- Salma Kanji.....	52
Health Information for Deaf Canadians- James MacDougall.....	52
Alphabétisation et surdit� : un service populaire bilingue au centre des besoins sociaux – Anne-Marie Parisot et Rachel Berthiaume.....	53
6. <u>Sharing Health Information for Prevention and Treatment</u> .....	54
Learning to Use the Canadian Health Network (CHN) and What We Learned.....	54
Reaching Teenagers Where They Are: Best Practices for Sexual Health Education Professionals- Deborah Begoray & Elizabeth Banister.....	56
Lessons Learned from Community Health Nursing in the ESL Classroom- Elizabeth Diem.....	58
Alphabet Soup- Candyce Jones.....	60
Librarians Partnering with Volunteers to Provide Health Information to Cancer Patients- Lorie Kloda.....	61
How to improve understanding of medical instructions- Lauren Mackenzie.....	62
What would make it easier for you when you visit the doctor, a clinic or the hospital?- Fiona Murray.....	64
Responding to Learners’ Demands for Consumer Health Information: How to Assess and Address Families’ Changing Needs Online- Beth Wood.....	66
7. <u>Literacy and Health Resources</u> .....	67
La base de donn�es en alphab�tisation des adultes et les ressources- Lorette Chiasson.....	67
Healthy Interactions On-Line with Alpharoute- Nancy Friday & Mike Kelly.....	67
Helping Learners Use the Workplace Hazardous Materials Information System (WHMIS)- Monika Jankowska.....	68
Exploring the LINC’S Health and Literacy Special Collection- Sabrina Kurtz Rossi.....	69
B. FOCUSING ON LANGUAGE AND CULTURE.....	70
1. <u>Aboriginal Perspectives</u> .....	70
Aboriginal Perspectives on Health and Literacy- Eileen Antone.....	70
Role of Aboriginal Spiritual Traditions in Healing and Wellness- Elaine Endanawas.....	71
Creating Aboriginal Literacy and Health Publications- Maria Morrison.....	73
2. <u>Francophone Perspectives</u> .....	75
Les d�terminants sociaux de la sant� et minorit�s francophones- Louise Bouchard.....	75
La base de donn�es en alphab�tisation des adultes et les ressources- Lorette Chiasson.....	76
Alphab�tisation et sant� chez les francophones en situation minoritaire- Sylvain Deslisle.....	77
Identit� ethnolinguistique et autod�termination: des facteurs de la sant�- Kenneth Deveau & Rodrigue Landry .....	78
Les �n�s: Leurs sant� et l’alphab�tisation- Roger Doiron.....	79
Atelier pour les personnes apprenantes: Comment mieux communiquer avec les personnes qui ont des difficult�s � lire et � �crire- Margo Fauchon.....	80
Projet d’harmonization � la petite enfance- Danielle Galipeau.....	83
Rendre lisible l’invisible : pratiques de lecture des faibles lecteurs et repr�sentations des organismes – Roch Hurtubise.....	83
Implications pour la recherche et le transfert des connaissances en alphab�tisation et sant� en fran�ais- Pierre Joubert.....	84
Recherche d’information m�dicale : une approche multi-factorielle – Stefan Kabene.....	86
La sant� et la francophonie- Rodrigue Landry.....	87
Repr�sentations sociales de la sant�, du m�dicament et de l’alimentation chez des personnes analphab�tes en contexte monr�alais – Chantal Oulette et Catherine Garnier Geirson.....	89
Alphab�tisation et surdit� : un service populaire bilingue au centre des besoins sociaux – Anne-Marie Parisot et Rachel Berthiaume.....	90
L’alphab�tisation et la motivation chez des adolescents en difficult� d’apprentissage et de comportement- Ginette Plessis-Belair.....	90
Comment mieux communiquer avec les personnes qui ont des difficult�s � lire et � �crire- Diane Pouliot.....	91
Les difficult�s d’apprentissage et leurs impacts chez des familles vivant en milieu minoritaire : l’exemple de la Colombie-Britannique – Sylvie Stonehouse.....	93
3. <u>Ethnocultural Perspectives</u> .....	94
Lesson learned from Community Health Nursing in the ESL Classroom- Elizabeth Diem.....	94
Getting the data right when working with refugee and asylum-seeking groups- Lisa Merry.....	97
Momiji Health Care Society: a culturally sensitive program for Japanese-Canadian seniors- Brigitte Robertson.....	97
Unveiling sexuality: culture and gender disparities in South Asian populations- Julia Thomas.....	98

	Using multi-ethnic, multilingual focus groups to enhance research with refugees- Jodi Tuck.....	99
C.	<b>BUILDING KNOWLEDGE IN LITERACY AND HEALTH</b> .....	99
1.	<u><i>Setting Direction for Literacy and Health Research in Canada</i></u> .....	99
	Alphabétisation et santé chez les francophones en situation minoritaire- Sylvain Deslisle.....	99
	Implications pour la recherche et le transfert des connaissances en alphabétisation et santé en français- Pierre Joubert .....	101
	La santé et la francophonie- Rodrigue Landry .....	102
	Implications for Canada of the Institute of Medicine Report <i>Health Literacy: A Prescription to End Confusion</i> .....	104
	<b>1. Literacy and Health in the US and the results of the IOM report- Rima Rudd</b> .....	104
	<b>2. Literacy and Health in Canada- T. Scott Murray</b> .....	105
	<b>3. Implications for Canada- Irving Rootman</b> .....	105
	Canadian Literacy and Health Research Program: What should its future be?- Irving Rootman.....	106
	Retrospective Evaluation of the National Literacy and Health Program- Rick Wilson.....	108
2.	<u><i>Methods for Research and Evaluation</i></u> .....	109
	Measuring Health Literacy- Jim Frankish, Irving Rootman & Brenda Kwan .....	109
	Health Literacy Education Nutrition: Instrument Design- Annrose Guarino.....	112
	Getting the data right when working with refugee and asylum-seeking groups- Lisa Merry .....	113
	Unveiling sexuality: culture and gender disparities in South Asian populations- Julia Thomas .....	113
	Using multi-ethnic, multilingual focus groups to enhance research with refugees- Jodi Tuck.....	114
3.	<u><i>Empowerment and Capacity Development</i></u> .....	115
	Empowerment and Capacity Development: A Strengths-Based Approach to Literacy and Health- Leslie Bella & Rick Bishop.....	115
	Capacity Development and the Urban CAP Program at MacMorran Community Center- Leslie Bella, Rick Bishop & Renee Walsh.....	117
	Challenging the Concept of Health Literacy: Action Research at the McGill University Health Centre- Linda Shohet .....	118
	Making Connections: A Capacity-Building Approach to Building Health Literacy- Lyn Simpson.....	119
4.	<u><i>How to Reach Different Groups with Health Information and Resources</i></u> .....	120
	Opportunities and Challenges: Using the Internet as a Tool- Ellen Balka .....	120
	A Report on Rural Ontario Women Seeking Health Information- Roma Harris .....	122
	The Empowerment Model on Using e-health to Distribute Information- Tiffany Veinot.....	123
	Recherche d'information médicale: une approche multi-factorielle- Stefane Kabene .....	124
	Promoting e-health Among Teenagers: Tools and Outcomes- Cameron D. Norman .....	125
	A Whole Greater than its Parts: HIV/AIDS Treatment Information- Tiffany Veinot .....	126
5.	<u><i>Exploring Links Between Literacy and Health</i></u> .....	128
	Development of Literacy Skills in Normal and Far-sighted Children- William Bobier.....	128
	Rendre lisible l'invisible. Pratiques de lecture des faibles lecteurs et représentation des organismes- Roch Hurtubise .....	130
	Laying the Foundation for Life-Long Learning: Literacy Development through Inquiry- Anne McKeough & Marya Jarvey .....	131
	L'alphabétisation et la motivation chez des adolescents en difficulté d'apprentissage et de comportement- Ginette Plessis-Belair.....	132
D.	<b>BUILDING HEALTHY PUBLIC POLICY</b> .....	133
	Medication Information for Consumers: A Plain Language Prescription- Andrew Aitkens, Millicent Toombs, Gerry Harrington & Laureen MacKenzie .....	133
	Opportunities and Challenges: Using the Internet as a Tool- Ellen Balka .....	136
	Literacy and Health Policy 101- Part 1- Havi Echenberg .....	138
	Literacy and Health Policy 101- Part 2- Havi Echenberg .....	140
	Read to Me! Best Practice Models for a Provincial Literacy Strategy- Richard Goldbloom, Carol McDougall & Janice Fraser.....	143
	Literacy and Health in the Food Sector: A report on Essential Skills in Both Market and Community- Carol J. Henry .....	145
	Learning with Communities: Creating Public Policy Together- Marcia Drew Hohn, Doris Gillis & Linda Shohet .....	146
	Adapting Health Canada's Tobacco Package Warnings for Less Literate Canadians- Nancy E. Hughes .....	148
	Implications pour la recherche et le transfert des connaissances en alphabétisation et santé en français – Pierre Joubert .....	149
	Language, Literacy and Healthy Development: The Work of CPNP and CAPC Projects- Pamela Nuttall Nason & Pamela Whitty .....	151
	Direct-to-Consumer Advertising: Challenging Health Protection in Canada- Martha Jane Paynter.....	151

People Who Rate: Community Involvement in the Development of Health Education Materials and Messages- Elsie Petch, Norma Levitt & Al Levitt .....	152
Implications for Canada of the Institute of Medicine Report <i>Health Literacy: A Prescription to End Confusion</i> .....	154
<b>1. Literacy and Health in the US and the results of the IOM report- Rima Rudd</b> .....	154
<b>2. Literacy and Health in Canada- T. Scott Murray</b> .....	155
<b>3. Implications for Canada- Irving Rootman</b> .....	155
Challenging the Concept of Health Literacy: Action Research at the McGill University Health Centre- Linda Shohet .....	156
<b>RECOMMENDATIONS AND ACTIONS STEPS .....</b>	<b>158</b>

## **I. Plenary Speeches**

### **Welcome- Christina Mills, President CPHA**

The opening plenary session began with words of welcome from Christina Mills. Mills reminded the gathering that the Canadian Public Health Association (CPHA) is a leader in the effort to make health services and health information easier for people with low literacy skills to use and understand. The Association's National Literacy and Health Program (NLHP) has worked with 26 national partners over the past 10 years to raise awareness among Canadian health professionals about the links between literacy and health. Its important contributions include helpful resources, practical tools, and a plain-language service that offers plain-language revisions, assessments, and workshops to health organizations in the public, not-for-profit, and private sectors.

Following the welcome by Mills, Elaine Endanawas opened the conference with a traditional First Nations prayer.

### **Opening Remarks from the Chair of the Conference- Deborah Gordon El-Bihbety**

Deborah Gordon El-Bihbety welcomed delegates on behalf of the conference organizing committee. She reminded the audience that 10 years ago, a national study confirmed that nearly one half of adult Canadians had difficulty with daily activities that require basic reading and writing skills. In 2000, the First Canadian Conference on Literacy and Health met to chart a course for literacy and health in the new millennium. That gathering set a solid foundation for future research investments in literacy and health, raising the profile of many health literacy initiatives across the country.

Gordon El-Bihbety noted that the multi-sectoral conference committee put together an ambitious program with the aim of satisfying diverse interests in the literacy and health field. The goals of the conference include providing delegates with the opportunity to share experiences, to discover practical tools, and to build partnerships. The committee will use workshop reports and questionnaires to capture delegate perspectives and recommendations relating to the four conference themes:

- Building Best Practices in Literacy and Health
- Focusing on Language and Culture
- Building Knowledge in Literacy and Health
- Building Healthy Public Policy

The perspectives and recommendations will be summarized and reported back to the group to set a direction for future actions in practice, policy, and research.

## *What can we do to improve the health of Canadians with low literacy skills?*

### **Senator Joyce Fairbairn**

Joyce Fairbairn is a long-time champion of literacy. In her speech, Fairbairn expressed her gratitude to the CPHA for taking bold action on a stubborn problem. Literacy levels affect not only the well-being of people, but also the welfare of the entire country, she said.

Advocating for literacy became the cause of Fairbairn's life when she came to realize that in a prosperous country like Canada, 40% of the adult population have difficulty with routine communication tasks and cannot fully participate in life. It is important, she said, to remember that literacy statistics represent people; children and families who are at greater risk for illness, disability, and accidents because of low literacy. Studies confirm that low literacy skills result in lower incomes, greater stress, more illness, more accidents, and earlier death. Canada cannot afford to have 8 million of its citizens threatened with limited access to the health care system and health care providers.

In tackling the links between literacy and health, advocates of health literacy have increased government awareness and sharpened policy focus. As a result, strategies such as those relating to early childhood development, workplace skills development, and the creation of learning bonds for children of low-income families have been developed. These strategies are addressing the need to raise the literacy levels of Canadians. However, much more work needs to be done. Working together, all levels of government must develop a public policy framework since literacy cuts across all jurisdictions, ages, and races, and both sexes.

The Prime Minister is committed to paving the path to universal literacy and lifelong learning. Conference delegates need to continue participating in a volunteer army that fights for the right of each individual to learn to read, so that all people can have a strong and healthy life for themselves and their families.

Fairbairn concluded with a passionate promise that "we will succeed, and I will march with you every step of the way."

### **A Story of Determination- Ellen Szita**

Ellen Szita is an adult learner and member of the conference's Learners' Advisory Committee of the Movement for Canadian Literacy. She narrated her moving life story in her opening address. Mocked and shunned as a dunce, Szita grew up in England without friends. Undiagnosed learning disabilities made school a nightmare. Introverted and feeling unworthy, Szita dropped out of

school and began working in a factory at the age of 14. An unsuccessful suicide attempt followed at age 16.

At age 18, hoping to leave her pain and humiliation behind, Szita immigrated to Canada. It didn't work. Her inability to read signs made her feel lost. Her inability to read menus made her feel embarrassed. Her inability to pay bills made her feel ashamed, and her inability to complete job application forms or prepare a curriculum vitae made her feel angry. Szita, now a wife and mother of four children, grew ever more fearful of being discovered, which led to depression. Later, a divorce left her a single mother, and Szita blamed the teachers when three of her four children dropped out of school.

Szita decided to be a positive example to her children, and enrolled in a literacy program. Her success is told in the documentary film *Ellen's Story*. Today, she sits on the boards of various literacy organizations, participates on panels, addresses conferences, visits prisons and schools. Ellen gives interviews to raise awareness that education is a birthright and that the long-term costs of low literacy are enormous.

Three years ago, Szita received her diploma as a professional grief and loss counselor. Following her lead, her three children who dropped out of school have returned to finish. Two of her five grandchildren are honour students.

The adult learning system is in great need of repair so that it can successfully help people like Szita to look forward to the future without fear and to leave to their children the legacy of freedom that education can bring.

"Children love as we have loved them, learn what we have taught them, and give back to society that which was given to them," concluded Szita.

### **Health Conscious Societies in the 21<sup>st</sup> Century- Implications for Health Literacy and Canada- Dr. Ilona Kickbusch**

The aim of Ilona Kickbusch's address was to highlight some of the health issues that arise for society overall and to explain why literacy is so important in the type of society in which we live. She told delegates that health has become the signature theme and driving force of modern society. It is a social, political, and economic driving force. Political platforms are built and elections are won and lost based on people's health care expectations.

Health-conscious societies have six dimensions:

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

Increased knowledge and the omnipresence of health consciousness result in greater risk. For example, a growing health market offers more choice. The consumer is often the victim of information overload. Health information is everywhere. It is available from the news media, health institutions and organizations, peer-reviewed literature, self-help books, health associations, health care providers, governmental health organizations, popular media such as television and radio, friends and family, and the Internet. Health literacy is potentially a filter that can help consumers decide what to do and what to buy.

The development of the health-conscious society is a turning point for public health. Political debate confirms that modern society cannot survive without health literacy because the cost is too high. A golden opportunity for health promotion is thus presented. Health literacy is a key action area in health promotion and a way of empowering people to navigate the health system, to research the health market, and to understand their rights. Health is indeed about rights.

Public health providers need to pursue integrated approaches in addressing society's inequities. Because the health of all citizens is equally important in socially cohesive societies, the right to health care access and treatment for all must be matched with the right to understandable health care information.

### *Focusing on Language and Culture: Perspectives*

#### **The Cultural Context of Health Literacy- Dr. Dyanne Affonso**

Dyanne Affonso, a leading researcher in women's health care, conducted one of the first major studies on the causes of postpartum depression. Her research, examining ways to improve access to health care by minority women during pregnancy, led to a reform of community-based health care in the United States during the 1990s. She was a member of the committee that recently produced *Health Literacy: A Prescription to End Confusion*, a report published by National Academies Press in 2004.

Affonso stated that health literacy has three aspects:

- The conceptual aspect (capacity to obtain, process, and understand information)
- The health policy aspect (information services, decisions)
- The public policy aspect (helping people to become knowledgeable)

Quality information spans two domains:

- The domain of information process (comprehension and understanding)
- The domain of context (meaning and coherence)

Affonso focused her presentation on the cultural context of health literacy. Health literacy is more than reading and writing. Cultural and conceptual knowledge also need attention. One component of cultural knowledge is preferences and perspectives. An understanding of individual perspective and the presence of free choice are vital to comprehending the significance of health, science, and technology to various people.

Language is an important component in the cultural context of Health Literacy. Attention should be paid to vocabulary and to the meaning of words and nouns within various cultures. For example, Aboriginal nations show a preference for 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. Nonverbal gestures (posture, attitude, and other aspects of cultural language) also provide meaning and context.

Stories are another important element in the context of culture and language. Chanting, visual imagery, sounds, music, and touch are all ways in which individuals cope and heal. Rituals and traditions are important aspects of literacy. For some, cultural healing systems and practices are an essential part of life. These parts of the cultural context of literacy need to be considered in the equation of quality health care services.

Affonso said that including more values and cultural scripts and metaphors in the dominant health care system is also important. Cultural metaphors are frameworks for thinking and doing. For example, the expression of gratitude—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. Cultural scripts signify the value concept to a particular cultural group. Cultural stories introduce new vocabularies, and cultural rituals enhance capacity building.

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. Health literacy is a human rights issue related to quality care, patient safety, and quality of life.

### **First Nations Health Symbology and Language- Janice Longboat**

Jan\_Kehehti:io: Longboat is a member of the Mohawk Nation, Turtle Clan, Six Nations of the Grand River. Longboat focuses on the “power of the Good Mind” to bring about well-being. She currently conducts a program to help Aboriginal women heal from residential school abuse. She also offers indigenous healing and well-being practices to communities and institutions.

Longboat began by offering great peace from the Iroquois people. She recalled a saying that memory is the whole of man, and the whole of man is memory. Iroquois teachings talk of the “Good Mind” and the power of the “Good Mind.” For the Iroquois people, literacy comprises all their cultural stories and symbols. In Iroquois culture, women are the keepers of culture - 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.

Longboat said that throughout her years, she has listened to the grandmothers of many Nations, including the Hopi, Navaho, Cree, and Ojibwa. 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.

Longboat said that growing up on the Six Nations reserve, the word “health” was never used. Instead, elders talked about the symbology of well-being. She gave the example of a word in her language whose main root is the concept “everything that keeps us alive.” She said that the word means “love.” It is the “love medicine.” When a person talks about befriending all of life, all of the senses that correspond with emotional and mental health are magnified and stimulated. Two other words with the same root are “intuition” and “telepathy.” Those words teach about the reciprocity of all Nations and the connection to everything that sustains life. They are symbolic.

In Longboat’s language, no word exists for ‘why’, and three words convey the meaning of ‘now’. When she was growing up, the ‘old people’ told her that their world had no words for past, present, or future. There was instead the word ‘now’. In the ‘now’, a person has a responsibility to learn from yesterday, so that the teachings can be understood and brought into the ‘now’. If learning does not occur ‘now’, then the person cannot teach for the next seven generations to come.

Longboat suggested it is time to step further into understanding all of life, including people, rocks, songs, dances, dreams, and medicines. The Earth guides people through life. Elders have earned the right to teach the symbolism of language, because they have had the experience of the “now, now, now.”

Longboat closed by saying that she felt honoured to carry the eagle feather that was given to her by one of the late chiefs who was a great speaker and oracle for their people. She said that the feather tells her how to behave, when to do things, when to speak up, and when not to speak. The feather had just told her that her time was up. She 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.

### **A Literacy and Health Success Story- Carole Blouin**

Dr. Janet Smylie, the moderator for this plenary introduced Carole Blouin. Smylie stated that literacy leads to health, and that Blouin’s life path has been an example of that truth. Smylie described some of the hardships that Blouin experienced with illness, a dysfunctional family, medication, learning disabilities, and alcohol abuse.

Carole Blouin is a literacy advocate. She left school at the age of sixteen because of difficulties in her personal life. Later in life, she completed literacy courses at Collège du Savoir in Brampton, Ontario. In early 2003, she received her secondary school diploma, and in the fall of the same year, she was accepted into a teacher's aid program at Collège Boréal.

Blouin is vice-president of the board of directors of Collège du Savoir. She has been a member of the board of directors of La Fédération canadienne pour l'alphabétisation en français (FCAF) since June 2002.

In 1995, not speaking a word of English, Blouin moved to Toronto. She encountered significant literacy challenges. One tragic result of poor health literacy for Blouin was a hysterectomy that she believes was unnecessary. She said that the situation came about because she did not understand what the hospital staff were telling her. For several years, she suffered from illness and depression. Eventually, a friend who was a volunteer in a French literacy centre recommended the centre to her. As a result of the assessment she received there, she signed up as a learner and a volunteer.

Blouin received her secondary school diploma in 2003. Her growing network of contacts led her to enroll at Collège Boréal, where she continues to study to become a teacher's aide. Blouin's health has improved significantly since she became involved with her studies. She really enjoys being able to teach others what she has learned.

Blouin thanked the CPHA committee for giving her the opportunity to participate in the conference and to share her experience. Conference participants gave Blouin a standing ovation.

### **Integrating Services for At-Risk Children in Québec- Johanne Laverdure**

Johanne Laverdure, Scientific Coordinator, Individual Development and Adjustment Unit, l'Institut national de santé publique du Québec (INSPQ), spoke about how the government of Québec aims to ensure greater success for children by intervening at an early stage. A program by INSPQ helps at-risk families during perinatal care and early childhood education periods, by offering integrated services from birth to the point of school entry. Some clients include young parents and families dealing with extreme poverty. Two types of services are offered: services to the family itself and services aimed at the larger community.

The family-focused service involves at-home visits by an intervener (one per family) every second week. The goal is to promote parent-child bonding, good life habits, and maturity at school. Interveners may also help families to locate and obtain community services. The challenge of the family-focused service is to have a global (standard) approach to health, while offering support in specific areas - for example, diet, tobacco use, bonding.

Although the assigned intervener is the main contact with the family, he or she works as part of an interdisciplinary team. The team includes a physician, a social worker, a nutritionist, and a psychotherapist. The intervener establishes a link between the family and the interdisciplinary team, and between the family and the community.

Two guides support the program. One guide explains how to promote bonding in families; the other describes healthy life habits in the context of parenting children who are between two and five years old.

The guide focused on bonding in families consults about the quality of at-home care, discussing factors such as proximity, commitment, sensibility, and reciprocity. Awareness of a child's signals on the part of a parent is important - such awareness can help to build a secure bond between parent and child.

To promote secure bonding, the intervener visits the family for 60–90 minutes every second week. Interveners help parents to solve problems, often using role-play to help the parents develop new attitudes that will lead to new behaviour toward a child. Maintaining a relationship of trust between the intervener and the parents is important.

The intervener tries to increase the parents' skill in developing an appropriate response to signs of distrust from the child. For example, using role-play, the intervener will assess the parent's response to a child who is crying. Feedback and suggestions are offered. It is important that the tone of the discussion is never negative.

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 community service operates at the local, regional, and national levels.

Laverdure summarized the goals and challenges of this work:

- Maintaining a trusting relationship with the family
- Dealing with funding challenges
- Promoting early childhood intervention
- Offering ongoing training, guidance, and critical support for staff
- Taking action in the community to ensure that it is welcoming to children and families
- Evaluating and assessing the impact of integrated services
- Intervening as early as possible to ensure that every child is ready for school

### **Diabetes prevention in Toronto- Miriam Rossi**

Dr. Miriam Rossi, Professor of Paediatrics in the Faculty of Medicine, University of Toronto, discussed her work in setting up a diabetes prevention program in four black communities in Toronto. She explained that while diabetes is a major

killer in the black community, it is a quiet killer because the condition is not discussed openly.

The World Health Organization defines health as “a state of complete physical, mental, and social well-being, and not merely the absence of disease and infirmity.” That was a landmark statement when the definition was first created, because it went beyond the medical model of health. Other factors also contribute to the conceptualization of health. One is the personal concept of illness—the meaning of an illness to an individual. If a person identifies 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. If people lack feelings of worth, then they will not get help.

Many factors influence health and care: biology, sociology, psychology, values and beliefs, structures, and symbols. Symbols—often overlooked—are very important. For example, a physician can be a daunting symbol. People will often fail to tell the truth to a doctor or nurse; instead, the person tells those professionals what he or she thinks they want to hear.

The Toronto program involves visiting a community and asking people to volunteer for a community advisory committee. The program addresses healthy eating, healthy lifestyle, and stress management.

The healthy eating component of the program requires some very involved training, not just a lecture on nutrition. A four-level “train the trainer” process involves coordinators and volunteers. People are instructed how to prepare healthy foods that are culturally appealing. Those people then train others, and those other people move out into the community to demonstrate food preparation.

The healthy lifestyle component encourages physical activity. Rossi explained that many people will simply not engage in the activities that they are normally advised to engage in—walking or swimming, for example. The program suggests a wider variety of activities, including “on the spot” movement and reggae or calypso aerobics, among others. The program partners with churches, because, at every level of the black community, people (whether religious or not) are more trusting of programs delivered through a religious institution.

The stress management component of the program initially focused on yoga. A yoga teacher in Toronto designed a program particularly for the black community, and a number of people are now being trained to teach the classes. Yoga works in some parts of the black community, but not in others. Yoga involves chants, and some people believe that, if they chant in a foreign language, spirits from that language could take over their ancestors. Hidden issues of this sort may not be evident at the planning stage. Alternative, culturally appropriate options for stress management include spiritual drumming and prayer.

The described approaches to community health promotion and disease prevention are not usual, said Rossi, but they seem to be working because of the many dedicated volunteers. A key factor in that success is the knowledge and skills transfer process, which includes communication, delivery language, literacy issues, and a culturally sensitive approach. Providing universal health services to clients of all backgrounds requires the provision of appropriate interpretation (including cultural nuances), easy-to-read literature and other resources in multiple languages, and verbal information.

Sensitivity to the fact that some people cannot read or write well is important, as is an awareness that these individuals will not necessarily announce themselves.

### *Report from Learners' Workshop*

#### **What would make it easier for you when you go to the doctor, clinic or hospital?- Raymond Roy**

A report from the morning learners' workshop on using health services was presented. This included recommendations for health professionals, the health care system, and people who have literacy challenges.

The francophone learners group had these messages for health care professionals:

- Give the main information only.
- Talk more slowly.
- Use simple words.
- Ask which language the person would prefer.
- Ask if the person wants to answer in writing or verbally.
- Use images and videos.
- Make sure that the person understands everything before leaving the office.

The group made these suggestions to people who have a hard time reading and writing:

- Ask a trusted friend to come along to appointments.
- Be patient with people who do not know about your difficulty with reading and writing.
- Ask for help from the start.
- Ask to bring forms home, and ask for help in completing them.

The English-speaking learners group had the following messages for health care professionals:

- Invite learners to speak to groups of medical students before those students graduate from training.
- Use visual props and pictures to explain things.

- Use tools such as the literacy audit from Literacy Alberta to educate service providers.
- Present information on video screens in waiting rooms. (This strategy is especially useful in explaining procedures and answering routine questions.)
- This group also had a message for adult learners: Ask for help!

The group discussing the health care system made the following recommendations:

- Slow things down so that patients and medical staff have time to build trust and to exchange information.
- Include literacy information on a patient's record so that service providers know about the patient's literacy level and the patient does not have to explain the situation every time.
- Hire staff to follow up with people after appointments.
- Develop questions that are universal—don't single people out. For example, tell patients, "We have people who can help you."

## *Making a Difference/Partnerships*

### **A wake up call for Canadian Literacy- Peter Calamai**

Peter Calamai began his speech by saying that he is not very active in the delivery of services. However, the insights that he gleaned as a reporter working on issues of public policy qualify him to talk about partnerships.

Calamai expressed disheartenment with educational performance in Canada. An October 7, 2004 report in Montreal's *The Gazette*, quoted that fewer than two out of three eligible high school students are actually graduating. In Ontario, the dropout rate is also rising, reversing a decade-long trend. Calamai questioned the reasons for this situation.

Some blame the dropout rate on the Ministry of Education, who set the literacy standard at level 3. At a level 3 literacy standard, an adult would be able to attend a diabetes clinic and to read and understand about the effect of diet on glucose levels. The most recent literacy survey found that one in five young Canadians who had completed secondary school fell below literacy level 3. Calamai stated that those young Canadians are not ready for the workforce.

In 1987, similar statistics indicated that one in seven young Canadians was functionally illiterate. At the time, ministers of education called the reports "journalistic sensationalism," claiming that nothing was wrong with the literacy level of Canadians. Ontario took more than 10 years to introduce standard literacy tests, and today, people are complaining that those tests are so demanding that more and more students are dropping out of high school. If school board trustees, middle-class parents, and politicians are saying that level 3

literacy tests are too tough, Calamai asked, what chance is there for a wider literacy culture in the country?

Calamai suggested that literacy efforts over the past 17 years have little to show in terms of moving the needle on Canada's literacy gauge. No national figures provide a rigorous tallying of the state of literacy in Canada.

Calamai noted that for the 1988–1998 period, evaluations were not completed on dozens of programs funded by the National Literacy Secretariat (NLS). 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 realistic evaluation and tracking of results.

One reason for the failure in obtaining evaluation results is that grant allocations did not include funding for the associated costs. The federal government under then-Finance Minister Paul Martin took \$1 million back from the NLS.

In the five years that have passed since the last literacy assessment, no detectable improvement in literacy scores has been achieved. In 1988, fewer than 2% of people were actually getting any help. The best estimate now is 5%. The literacy needle has barely moved. No data exist on how the 5% are actually faring. Even if 5% or 2% were improving their literacy skills, one in five young Canadians is still graduating with a literacy level of 3 or less. If tougher standards are producing an increase in high school dropout rates, then the needle that gauges the literacy of the Canadian population is not moving.

Calamai referred participants to the ABC Canada Literacy Foundation website ([www.abc-ca.org](http://www.abc-ca.org)) for information on patterns of participation in Canadian literacy programs. Half of those who make a telephone call to a literacy program do not enrol. The primary reason they give for not enrolling was that no one called them back.

The 1996 survey of literacy in Canada indicated that 48% of adult Canadians achieved a level 1 or level 2 literacy score. That translates to approximately 4 million Canadians functioning at literacy level 1. Calamai remarked that the literacy needle is not only failing to move forward, it is beginning to spin in reverse!

Calamai emphasized the failure of the current 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. Changing the national culture of literacy in Canada has proven difficult. Calamai recommended establishing 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 financial institutions 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 the literacy situation in Canada.

Calamai then invited questions from conference participants.

A participant commented that the curriculum in high schools is getting larger and larger, that many more children are being assessed with learning disabilities (LDs), and that 50% of teenagers who commit suicide have been diagnosed with an LD.

Another participant suggested that statistics were giving the wrong picture. She spoke of persistent and significant efforts being made to return calls from learners, many of whom are living in crisis mode or dysfunctional situations. She also mentioned a problem with the pressures that were applied to learners by welfare workers who wanted proof that the learners were obtaining literacy help.

## *Closing Plenary*

### **Closing Remarks- The Honourable Carolyn Bennett**

Carolyn Bennett noted that as the first Minister of State for Public Health, she had told the Prime Minister that the job should focus not just on infectious disease, but that it must also reflect the broader picture of health determinants and must address the goal of keeping all Canadians as healthy as possible.

Commenting on the importance of literacy as a requirement for full citizenship and participation in society, Bennett noted that the National Forum on Health had recognized literacy as a health determinant. She said that she was proud of the federal government for its investments in this area. But she added, "We have a lot more work to do."

Government can do a better job in "making the links," so that Canadians can understand the importance of literacy in relation to health. Bennett promised to do a better job ensuring that the government addresses literacy issues related to health. "Your work here is a huge reminder to all of us that we need to work much harder in not taking things for granted," she told participants.

Bennett then presented a diagram of a tree, an image she used to map the determinants of health. She explained that the image frames the work on public health in Canada. In the diagram, the root system represents the social determinants of health. The roots symbolize that the goals for public health should not focus just on disease but should also include determinants, common risks, and outcomes. The goals also need to be understood in terms of various populations (rural, urban, women, men, and so on). "We all have a hugely collaborative job to do in keeping Canadians well," said Bennett.

Bennett invited participants to provide feedback on the diagram, and offered to change the tree if necessary. She added that the tree diagram can help create coherent public policy in which all departments and jurisdictions have a role to play in public health.

Asked where literacy fits in the new structure, Bennett said that everything formerly handled by the Population and Public Health Branch of Health Canada has been moved to the Public Health Agency of Canada. That is where the issue of literacy and health will be addressed.

A participant suggested that the term "Aboriginals" used in the tree diagram be changed to "Aboriginal peoples." Another participant suggested using the term "First Nations."

Participants also suggested adding several other groups to the list of "populations" in the tree diagram: people with disabilities, new Canadians, federal and provincial inmates, children in care, and gay/lesbian/transgendered people.

### **Learners' Recommendations to Delegates- Raymond Roy and Ellen Szita**

Ellen Szita and Raymond Roy presented some impressions from the adult learner perspective:

- Everyone was very welcoming.
- "Thank you for recognizing us and inviting us. We were pleased to meet so many educated people who recognize us. This has been a very uplifting experience and we feel validated."
- The workshops were good and informative, but the choice was overwhelming.
- "We learned that we are experts on some things: we have our degree in literacy. We believe you have learned some things from us, and we want to have adult learners continue to educate you. We still have a lot to learn together. Let's continue."
- Learners will leave with new tools and information and will share these with others at home to promote the cause of literacy.
- It is interesting to realize that some people have other difficulties in addition to problems reading and writing (for example, people with deafness or an inability to speak).

Szita and Roy also presented some recommendations:

- Speakers should use more plain language when speaking, and should speak more slowly.
- Learners should be more involved. They could help in simplifying 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 receiving 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.
- The organizing committee should forward these suggestions to all participants.

### **Recommendations- Deborah Gordon El-Bihbety**

Deborah Gordon El-Bihbety outlined the recommendations and actions arising from the conference.

#### ■ *Theme 1: Building Best Practices in Literacy and Health*

- Literacy and health working together
  - The Council of Ministers of Education and the Deputy Ministers of Health Committee should champion approaches that integrate parenting, nutrition, literacy, and community development.
  - CPHA and National Literacy and Health Program (NLHP) partners should direct provincial agents to link with existing literacy coalitions, and literacy and health programs. (Provincial agents might include organizations such as the Ontario Public Health Association and the Ontario Nurses’ Association. Linking means sharing information and looking for opportunities for collaboration.)
- Building capacity of health professionals

- CPHA, in collaboration with National Literacy and Health Program partners, should deliver a strategy to improve health professionals' awareness and competency in health literacy. The strategy should also support collaborative service approaches—for example, bringing in advocates).
  - Work should build on plain language strategies. The work should focus on healthy environments, improved access, system navigation, and ability to take action on health information.
- Sharing literacy and health resources
    - The National Literacy Secretariat and Health Canada should help programs to disseminate knowledge and resources to literacy and health workers—for example, The Centre for Literacy of Québec.
    - The National Adult Literacy Database should seek funding to safeguard, host, and disseminate the Literacy Information and Communication System (LINCS) health special collection.
- *Theme 2: Focusing on Language and Culture*
    - The National Indigenous Literacy Association should approach the First Nations and Inuit Health Branch, the National Aboriginal Health Organization, and the Indigenous Peoples Health Research Centre to identify people and methods that build on Aboriginal cultural practices and strengths.
    - The Fédération canadienne de l'alphabétisation en français should continue building partnerships with public health, social services, and programs that promote French language and culture.
    - CPHA, in collaboration with NLHP partners, should work with the Canadian Ethnocultural Council to identify support for outreach to ethnocultural partners.
- *Theme 3: Building Knowledge in Literacy and Health*
    - Reviewing what we know
      - CPHA and NLHP should seek funding to commission a Royal Society of Canada study on literacy and health research. Modelled on the Institute of Medicine Report on health literacy, the study should include testimony from community groups and key informants.
    - Evaluating what we do
      - The National Literacy Secretariat should adopt a project funding model that builds capacity for evaluation and evidence-gathering. The approach could be based on Health Canada's Population Health Fund model, which includes an evaluation component.

- Funding new research
  - CPHA and NLHP should approach the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council of Canada to undertake a joint strategic initiative on literacy and health research.
  - Funding should cover projects, capacity development, and infrastructure. Priorities would include culture, literacy and health, evaluation, the cost benefits of literacy and health efforts, and the role of technology in literacy and health.

■ *Theme 4: Building Healthy Public Policy*

CPHA should invite the Minister of State for Public Health to convene a meeting to discuss the establishment of an interdepartmental program to support literacy and health programs and practice.

Participants should include the Canadian Public Health Agency, Health Canada, and Human Resources and Skills Development Canada.

■ *Following Up on Recommendations*

CPHA and the Conference Program Committee should review all recommendations and develop an implementation and monitoring plan. CPHA should seek funding from the National Literacy Secretariat to monitor, assist, and implement conference recommendations and to issue a Literacy and Health Report Card in November 2005.

■ *Action Steps*

Encourage all conference participants to take local action. Focus on strengthening literacy and health efforts and developing innovative partnerships. Seek opportunities for health educators to collaborate with literacy leaders. Use literacy and health programs as a base to build capacity among learners, advocates, local citizens, and professionals.

■ *Discussion*

When it was brought to her attention that the territories had been excluded from the recommendations, Gordon El Bihbety agreed to include them.

A participant commented on the situation faced by seniors, who have “slipped off the agenda.” That group is growing, and not enough services are available.

Another participant stressed the need for research and evaluation, and recommended that CPHA and NLHP develop a strategy to entice researchers and to recruit graduate students. The additional recruitment would create greater capacity for research and help community groups build capacity for

evaluation. The effort should go beyond evaluation and include academic research as well.

The group noted that many research recommendations had been made, but few concrete recommendations were forthcoming for learners and literacy practitioners.

Finally, a participant commented on the problems with current evaluation practices for literacy programs. Literacy programs are devalued when attendance drops. Although this is categorized as a motivational issue, the major factors affecting attendance are socioeconomic. Funding programs are not recognizing the complex issues surrounding the determinants of health. Literacy programs are not opposed to assessment and evaluation, but the criteria are not working. Evaluations should support the complexities of the work and the partnerships.

### **Closing Remarks- Donna Kirby and Elinor Wilson**

The National Literacy Secretariat and CPHA have worked together on various projects over the last year, Donna Kirby said. Those projects confirm the interconnectedness of health and literacy.

The present conference has reviewed current work on health and literacy. Participants have looked at research, explored the needs of linguistic and ethnic communities, and discussed the experiences of health professionals, communicators, learners, educators, and researchers.

Kirby pointed to a paradox: Canada has an international reputation as having the highest levels of educational attainment in the world, and yet a large segment of the country's population has weak literacy levels. She noted that from a federal perspective, outcomes have become increasingly important. Equally important is the ability to identify and share best practices. Kirby agreed, however, that evaluation should support partnerships and reflect the complexity of the work.

In closing, Kirby thanked the delegates for their enthusiasm and insight.

Elinor Wilson closed the conference by thanking participants for their input: "The recommendations you put forward will challenge us; but, most importantly, they will help us grow together so that in Canada [literacy and health] is no longer an issue."

## II. Presentations and Workshops

### A. *Building Best Practices in Literacy and Health*

#### 1. 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**

Le but de l'atelier, a expliqué Madame Fauchon, est d'arriver à des suggestions pour rendre les services de la santé plus accessibles aux personnes avec des difficultés en ce qui concerne l'alphabétisme. Elle a expliqué que l'atelier prendrait la forme d'une table ronde et que les participants feraient un remue-méninges à ce sujet. Elle a posé deux questions au groupe, pour mieux cerner la question □ Comme personne qui a de la difficulté, qu'est-ce que je peux faire pour faciliter mon accès aux services de la santé? Qu'est-ce que le professionnel de la santé peut faire pour rendre les services offert plus accessibles?

Les participants, eux-mêmes des personnes ayant des difficultés à lire et écrire et ayant rencontré des problèmes dans leurs contacts avec les services de santé, ont attribué ces problèmes à un faible niveau d'alphabétisme et au peu d'efforts des fournisseurs de services pour s'adapter en fonction des difficultés de leurs patients. On aussi parlé de la difficulté de recevoir des services en français, surtout dans un français accessible.

Mme Fauchon a posé quatre questions précises pour orienter la discussion.

##### **Est-ce qu'il y a eu des fois où vous n'avez pas compris le médecin?**

Il y avait consensus chez les participants – cela leur est arrivé à toutes et à tous. Les participants ont cité les raisons suivantes □

- les «grands» mots
- des formulaires compliqués à remplir
- pas d'aide pour remplir les formulaires
- des «grands» mots en anglais et en français – «Ça ne fait pas de différence dans quelle langue, si on ne comprend pas, on ne comprend pas»
- une taille de police trop petite
- des styles de police difficiles
- des fournisseurs de services de santé qui ne vérifient pas si les directives ont été comprises
- la tentation de prétendre que l'on a compris plutôt que d'admettre qu'on n'a pas compris
- des médecins qui utilisent un niveau de langue trop élevé

- des médecins et des garde-malades qui ne prennent pas le temps suffisant pour discuter du problème et pour s'assurer que leur interlocuteur a compris et des rapports de supériorité entre le patient et le médecin
- donnant le sentiment au patient qu'il n'est pas respecté

Il est très important d'être compris, ont conclu les participants. Ils se sont entendus pour dire que les fournisseurs de services de santé doivent passer plus du temps et s'y prendre différemment avec les personnes qui ont de la difficulté à lire et à écrire afin de les comprendre et de comprendre leur problème.

### **Quelle est la relation entre l'alphabétisation et la santé?**

De l'avis d'une participante, il s'agit d'un problème de mobilité, les personnes avec des problèmes de lecture restant à la maison et en marge de la société. Elle a ajouté que cet isolement conduit souvent à la dépression.

Un autre participant a expliqué que, pour lui, il s'agit aussi d'un problème de sécurité au travail. Il a donné l'exemple des contacts avec les produits toxiques et ajouté qu'il ne s'agit pas uniquement d'un risque pour la personne en question, mais aussi pour ses collègues.

Les gens qui ont de la difficulté à lire, a souligné une autre participante, ne peuvent pas facilement comprendre les directives sur les boîtes de médicaments et risquent donc de prendre les mauvais médicaments ou de mal les prendre. À l'inverse, certaines personnes ne prennent aucun médicament par peur de commettre une erreur fatale.

On ajoute que les nouvelles technologies de l'information et de la communication ont multiplié les difficultés pour les personnes avec des problèmes de lecture et d'écriture.

Le rapport est simple, résume-t-on il faut comprendre pour rester en bonne santé. Il ne faut pas non plus oublier la relation entre l'alphabétisme et l'estime de soi.

### **Quelles sont les responsabilités des professionnels de la santé vis-à-vis des personnes qui ont des difficultés de lecture et d'écriture?**

On cite à nouveau les «grands» mots. Un participant a expliqué que, à son avis, il est important que les fournisseurs des services de santé se servent de ces termes pour qu'on puisse les apprendre, mais qu'ils doivent prendre le temps de les expliquer.

Une participante a souligné combien il est important pour le corps médical de vérifier si le patient a effectivement bien compris, ce qui soulève la question des services en français pour les francophones.

On a ensuite parlé des formulaires. Le groupe convient que l'on doit donner l'occasion aux personnes qui éprouvent des difficultés de lecture et d'écriture de répondre oralement aux questions.

Pour des communications écrites, on a souligné l'importance de limiter le texte à l'essentiel dans un langage simple, clair et précis. Une participante a proposé qu'on fournisse, en plus des brochures et des dépliants, des informations sous forme d'enregistrements audio et vidéo.

### **Qu'est-ce que je peux faire comme personne avec des difficultés pour faciliter mon accès aux services de la santé?**

Une participante a souligné l'importance de dire d'entrée que l'on a des difficultés de lecture et d'écriture. Elle a suggéré qu'une petite carte identifiant ce problème pourrait aider à la situation car on n'aurait pas à dire à haute voix qu'on a un problème et on éviterait ainsi des situations embarrassantes. Poussant plus loin cette idée, une autre participante a dit que cette information pourrait être inscrite dans le dossier médical pour ne pas que la personne ait besoin de répéter la même chose à chaque visite.

En conclusion, ont décidé les participants, il faut que l'on fasse preuve d'empathie et de patience des deux côtés. La personne avec des difficultés de lecture doit se rappeler que les fournisseurs de services de santé travaillent dans des conditions très difficiles, compte tenu de tous les problèmes que connaît actuellement le système de soins de santé. Elle peut aussi ne pas savoir que la personne en face d'elle éprouve des difficultés. Les fournisseurs de services de santé, pour leur part, doivent être sensibilisés aux problèmes qu'éprouvent les personnes avec des difficultés de lecture et d'écriture pour accéder aux services.

### **Using Plain Language: the Importance of Easy Communication in Aboriginal Communities- Melanie Ferris**

Melanie Ferris introduced her session about Plain Language and Easy Communication in Aboriginal Communities by first giving some background about herself as a young Aboriginal woman. She grew up in a single family home, headed by her mother. Her mother, an Ojibwa, was raised by white foster families. As a result, she and her mother both experienced loss of traditional language, culture and community support. This in turn affected Melanie's self-esteem.

Literacy is an important and holistic issue for Aboriginal peoples. To provide context, she talked about the history of the residential school system, education on reserves and their impact on current conditions that impact Aboriginal literacy.

The residential school system has a direct impact on the literacy of Aboriginal people. In the 1800s, government policy required that all Aboriginal children

attend residential schools. The goal of this system was to raise Aboriginal children with European language, culture and values. They were taught Christian values and English. They were not permitted to wear their traditional clothing, or speak in their own language. The loss of culture experienced through attendance at residential schools still impacts the educational situation of Aboriginal people. This in turn impacts literacy, and therefore, historical treatment of Aboriginal people in residential schools is one of the reasons why the literacy rate is so low among Aboriginal people.

The history of the reserve system and land treaties is also important. Based on land treaties, First Nations people received reserve lands separated from Canadian society, often with limited access to basic services. Today about half of all Aboriginal peoples live on reserve in Canada.

In the past, aboriginal language skills in English and French were basic or nonexistent. These are the languages treaties were written in. Furthermore, some English and French words have no comparable meaning in Aboriginal languages. Had the treaties been fully understood, it is possible that Aboriginal people would not have some of the land claim issues, and economic challenges that they are facing today.

Melanie spoke about the importance of using plain language for Aboriginal communities, so that informed decisions can be made. She emphasized the necessity of making documentation accessible for everyone. The Canadian government needs to make this a priority, by ensuring that there is awareness on the part of policy makers that people with lower literacy levels need to be considered when creating policy documents.

When defining literacy, Melanie made the distinction between simply the ability to read and write, and the ability to understand what one is reading and writing. Melanie made special note of how Aboriginal cultures define health, and how this impacts an Aboriginal definition of literacy and health. For Aboriginal culture, a definition of health is holistic. It is based on the sacred medicine wheel which considers four aspects of a person: Spiritual, Mental, Physical and Social. Each of these aspects plays a part in literacy and health.

She also commented on the need for adequate language skills to participate actively in the job market. These skills are also important to participate in government programs. For Aboriginal people to reach the same standard of living as other Canadians, it is important that they are able to take advantage of various programs such as health benefits and the post-secondary education assistance program. Having easy access to government information will enable increased self-sufficiency and economic development, which will have a positive effect on Aboriginal communities. Furthermore, fostering self-sufficiency of Aboriginal communities will provide better access to education for all members of the community and will increase literacy levels.

Melanie made some of the following recommendations to ensure that documentation is accessible to Aboriginal people:

- Putting complex information into map format which is simpler to understand
- Language training in official languages, as well as information provided in Aboriginal languages
- Sensitivity training for government employees to ensure that documentation intended for the public is accessible to people of all literacy levels
- Reforming the communications policies of the Government of Canada to reflect the needs of all people
- “Watchdogs” to assess external government communications and ensure that plain language is being used
- More emphasis on the importance of education funding for Aboriginal people

### **How to Communicate with Less Literate Canadians- Michel Gauthier**

Maude Downey, a nurse and writer/editor, introduced the session and provided her perspective on the tool developed by Michel Gauthier. Downey has experience working with less-literate patient groups. She asked patients many times to tell, in their own words, the information they’d been given. Responses consistently reflected a lack of understanding of information. This experience emphasizes the value of effectively and appropriately communicating health information to less literate Canadians. From a health provider’s viewpoint, there are three comments on Gauthier’s tool:

- It offers a way of understanding and objectively measuring how a document delivers its message.
- It provides a relationship with data from the International Adult Literacy Survey (IALS), which provides target groups by literacy levels.
- It covers many things previously not considered because of its systematic approach.

#### **Introduction**

The session itself provided an opportunity to talk about the theory behind Gauthier’s assessment tool, to view some practical examples, and to attempt to apply, in a short activity, the knowledge gained.

Gauthier introduced the topic by discussing five easy steps to effective communication:

- Learning to “read” the target audience
- Knowing how that audience processes information
- Finding and removing communication barriers
- Working with the audience
- Adding the human touch

Clear communication is a process that uses speech or the written word to transmit information that can be easily understood and acted on by the intended audience.

Gauthier reminded participants to note the difference between literacy and health literacy: health literacy can be viewed as a domain to which literacy skills are applied.

### Literacy in Canada

Gauthier provided an overview of the literacy functioning of Canadians. Unfortunately, many Canadians with low literacy levels use strategies to help them function, rather than address the problem. Some of the strategies are:

- Adapting their life to hide the problem
- Discarding government information
- Overestimating their skills and not admitting it
- Fearing any new or different situation
- Preferring contact with people and avoiding information technology
- Often using trusted intermediaries

### Assessing Communication

Why do communications break down? Language can be a hiccup - an information frame mismatch - when information based on complex words tries to communicate with individuals who have a different information frame. Literacy complexity assessments attempt to match complexity to reader abilities. In assessing documents, identifying the information that will work well with the user is important. For example, lists, charts, or tables may not be appropriate for people who are not used to seeing information presented in that format.

### Applying What Was Learned: Document Assessment Activity

The session concluded with an opportunity to assess the complexity of a public health poster. Gauthier noted the key steps in this process of identifying problem areas and trying to create a more user-friendly communication:

- Identify the audience.
- Choose a communication objective.
- Identify the behaviours to be changed and how they should change.

In concluding the exercise, Gauthier reminded the participants that all communication should follow these rules:

- Be relevant: Adopt the audience point of view and take into account their ability to understand
- Be understood: Formulate and organize the information in a clear and simple manner
- Be persuasive: Direct the communication at action and at concrete results

## **The ABCs of Clear Writing- Leah Morris**

Leah Morris conducted this practice-based workshop, condensing a half-day presentation into a 90-minute session. She discussed these topics:

- What makes material hard to read and understand?
- The benefits of clear writing
- Clear writing principles, with a checklist
- Evaluating written materials
- Additional formatting tips

Throughout the presentation, Morris provided examples of written materials for group evaluation against clear writing principles. She then handed out improved versions for the group's feedback. Exercises for writing clear sentences and vocabulary choice in clear writing were also covered.

Morris opened the workshop with definitions of literacy (according to the International Adult Literacy Survey, 1995) and an explanation of the five literacy levels. She noted that 22% of the general population functions at literacy level 1; 28% are at level 2. About 50% of the general population do not function at a literacy level that prepares them to work productively in society.

Morris contrasted health literacy issues and overall literacy according to the Pfizer Health Literacy Manual. She noted that this excellent resource with clear language guidelines is available at the Pfizer website. Most health education materials exceed the abilities of average readers; people with lower literacy skills therefore experience compromised health and health outcomes - for example, increased hospitalizations, more medication side effects, more illnesses, more anxiety and fear, and so on.

Morris noted that the definition of literacy changes with time and context. To be literate is to have the skills required to function in the current environment. To be illiterate is to lack a skill - for example, computer skills. Literacy is therefore a broad and complex issue that reaches beyond written information or the English language.

Moreover, the English language changes through time. That constant change means that literacy skills must also keep up. For example, "bite" now has a sound-alike in "byte." It is important to revisit written materials every three to five years to ensure that they are relevant to their time and context. Morris also suggested that readability scales that evaluated materials for the public at a Grade 6-8 level would now likely rate the same materials at a Grade 4-6 level, given the current standards within the Canadian education system.

Health literacy and clear writing requires the delivery of information to the target audience so that they understand what you want them to know (the "why"). The goal of written materials is to impart information, not to impress the audience. Getting to the point as directly as possible, and never using a big word if a little one will do are important principles to observe.

Practitioners need to ask themselves three questions before they begin to write:

- Who is my audience?
- What are the needs and abilities of my audience?
- What do I want them to know?

Morris reviewed a number of resources and references that can guide the development and evaluation of written materials. Included was *Clear Writing and Literacy* (revised second edition) by the Ontario Literacy Coalition ([www.on.literacy.ca](http://www.on.literacy.ca)). This resource summarized the five areas to consider when analyzing the readability of any material:

- Overall appearance (layout and design)
- Organization of material
- Language
- Sentence length and structure
- Tone (how the text speaks to the reader)

Morris also gave some practical tips:

- Don't use all capital letters, and use a font appropriate for the target audience. Generally, a 12-point serif face with line-and-a-half spacing between the sentences is good.
- Aim for no more than 20–30 words in a sentence.
- Leave enough white space. Don't use unnecessary graphics to fill space, and make sure that the graphics are appropriate for the context. Margins need to be a minimum of one inch on all sides of the document.
- Put the organization's name at the top of the handout so that it is visible.
- Resources in more than one language should be presented in two different documents or in "tumble" format (one language starts from each cover of the document).
- Use dark ink and light backgrounds. Never use blue ink and a blue background. Avoid red and orange ink, and don't use high gloss or fluorescent paper. Ensure that watermarks do not interfere with the text.
- Information on websites and in PowerPoint presentations should be based on clear writing principles, not marketing principles. Avoid flashiness.

More guidelines and tips are available in the Ontario Ministry of Agriculture and Food fact sheet titled *Clear Writing: What is it? How do you do it?*

Morris used materials from Frontier College ([www.frontiercollege.ca](http://www.frontiercollege.ca)) to review the benefits of clear writing. She noted that clear writing has associated costs, including time, money, and labour. To avoid being overwhelmed with the task, practitioners should start by revising one topic or one resource. Revisions should be undertaken in teams of two or three to make sure that the intent remains unchanged and that the materials receive more than one review. When a resource is complete, use a checklist to assess it as it relates to the intended reader, purpose, organization, tone, style, and design. For take-home messages have someone read the text out loud to determine if it sounds helpful and similar to an informal conversation.

Use readability tests to evaluate written material. Some examples are Fry, computer word and syllable counts, the Gobbledegook Detector, and the Gunning Fog Index. Obtaining feedback from the public - using focus groups, one-on-one discussions, and surveys, is another possibility. Practitioners could also consider asking a class of adult learners to evaluate the resource. This last possibility requires the development of relationships with organizations such as adult literacy networks (16 exist in Ontario) and school boards.

### **Comment mieux communiquer avec les personnes qui ont des difficultés à lire et à écrire- Diane Pouliot**

Madame Pouliot oeuvre au sein de la Fédération canadienne pour l'alphabétisation en français ([www.fcaf.net](http://www.fcaf.net)). Créée en 1991 et regroupant 300 groupes d'alphabétisation en français au Canada, la Fédération a pour mission de promouvoir l'alphabétisation en français et d'assurer une concertation entre les intervenants en alphabétisation en français au Canada. Le présent atelier avait pour but d'aider les participants à mieux comprendre comment les personnes qui ont de la difficulté à lire et à écrire abordent, lisent et utilisent l'information écrite qui leur est présentée.

L'atelier a commencé par un exposé sur la situation actuelle de l'alphabétisme – au Canada en général et chez les francophones en particulier. Une étude réalisée par Statistique Canada en 1994 classe les Canadiens et les Canadiennes d'âge adulte selon cinq niveaux de lecture. Les résultats pour le Canada sont les suivants:

- Niveau 1: 22%
- Niveau 2: 26%
- Niveau 3: 33%
- Niveau 4 et 5: 20% (ces pourcentages sont approximatifs).

Chez les francophones les résultats sont légèrement plus faibles:

- Niveau 1: 25%
- Niveau 2: 27%
- Niveau 3: 39%
- Niveau 4 et 5: 9% (pourcentages approximatifs).

Sont dans les niveaux 1 et 2 des gens ayant des difficultés majeures à lire et à écrire et, comme le souligne Pouliot, c'était le cas de 52% des francophones d'âge adulte au Canada en 1994. Les personnes de niveau 1 éprouvent des difficultés très importantes en lecture. Elles ne réussissent même pas à interpréter les consignes qui se trouvent sur une boîte d'aspirine. Les personnes du niveau 2 sont en mesure de lire et d'écrire, mais de façon très limitée. Par exemple, elles ont de la difficulté à faire des comparaisons entre les informations écrites. On note que les personnes avec ce niveau de lecture ne sont pas toujours conscientes de leurs difficultés de lecture et ont tendance à éviter les situations où il faut lire ou écrire. Elles sont souvent moins optimistes, elles ont tendance à résister aux changements, elles sont moins confiantes et elles ont tendance à avoir moins d'estime de soi.

L'animatrice présente ensuite certaines caractéristiques du comportement des personnes avec des difficultés de lecture et d'écriture. Elle souligne d'abord qu'elles ont les mêmes priorités que les autres canadiens, soit la santé, l'éducation et le chômage. Elles se distinguent toutefois sur certains points:

- Elles préfèrent généralement des informations anecdotiques portant sur le vécu de tous les jours présentées sous forme de témoignages personnels
- Elles évitent toutes les formes de technologies de l'information et de la communication, les guichets automatiques par exemple
- Elles ne font presque jamais référence à l'information écrite
- Elles ne prennent pas en note les renseignements importants
- Elles se font souvent accompagner pour aller à leurs rendez-vous et hésitent à lire ou trouvent des excuses pour ne pas avoir à le faire – «J'ai oublié mes lunettes», par exemple

Après avoir dressé ce portrait des personnes avec des difficultés de lecture et d'écriture, l'animatrice a énuméré cinq responsabilités pour les fournisseurs de services:

- Être à l'affût des attitudes et des comportements qui indiquent que la personne n'a pas compris.
- Veiller à ce que suffisamment d'information soit fournie pour lui permettre de comprendre.
- Reconnaître que la personne en question peut éprouver des difficultés à s'expliquer.
- Parler lentement.
- Parler et écrire simplement et clairement.

Divers éléments peuvent nuire à la communication orale. Une information qui ne répond pas aux besoins, un objectif mal défini, un débit trop rapide, un excédent d'information et l'emploi de jargon, par exemple. Pour pouvoir communiquer plus clairement, il est important de comprendre d'abord ce que la personne avec qui l'on parle sait déjà, de faire attention à ce qui est dit et de faire attention au ton utilisé. Pour ce faire, il faut écouter attentivement, encourager le dialogue, faire attention à la simplicité de son langage, employer des phrases courtes et vérifier régulièrement la compréhension.

Les personnes avec des difficultés de lecture et d'écriture expliquent souvent que le problème se résume à l'emploi de mots trop «grands», comme en témoigne un vidéo présentant les témoignages de gens ayant ce type de difficultés.

Pouliot a expliqué toutefois que les mots utilisés ne sont qu'un aspect du problème. Elle a cité à l'appui les résultats d'une étude portant sur la compréhension d'un message au téléphone et en personne. Dans une communication en personne, l'étude attribue seulement 7% des problèmes de communication à la compréhension des mots, alors qu'elle en attribue 38% à la voix et 55% à la gestuelle. Pour ce qui est de la communication au téléphone, 16% des problèmes tiennent aux mots et 84% à la voix.

Abordant ensuite la question de la communication écrite, l'animatrice a énuméré certaines caractéristiques des communications écrites efficaces. La personne qui

écrit doit tenir compte du lecteur éventuel. Dans le cas des directives, il est préférable de présenter l'information par ordre chronologique. En d'autres mots, le rédacteur doit se demander «Qu'est-ce que le lecteur a besoin de savoir en premier pour agir?». Les textes qui guident le lecteur étape par étape sont plus faciles à comprendre. L'utilisation de sous-titres peut également aider et il est préférable d'écrire en phrases courtes et claires, avec des mots simples et concrets.

En guise de conclusion, Pouliot a présenté une série de recommandations pour faciliter la communication avec une personne qui a des difficultés de lecture et d'écriture:

- Il faut apprendre à connaître ses besoins, ses intérêts et sa disponibilité.
- Il faut comprendre ses difficultés à lire, à écrire et à communiquer.
- Il faut tenir compte de ses problèmes de compréhension.
- Il faut adapter les messages à ses besoins.

### **One Day Wonders- Marg Rose & Charles Moody**

Marg Rose and Charles Moody shared the results of 16 one-day workshops given in Manitoba's urban and rural communities last year. More than 300 health and literacy workers attended these "One-Day Wonders."

The community workshops had four objectives:

- To demonstrate the link between low literacy and poor health;
- To help health educators break down the barriers preventing them from reaching hard-to-reach clients;
- To encourage literacy practitioners to incorporate health topics in their literacy curriculum;
- To encourage partnerships and working relationships between literacy and health workers.

At each workshop, the agenda alternated between theory and practice.

In the first part of each workshop, the definition of literacy is addressed; an adult learner tells his or her life story; information about the International Adult Literacy Survey (IALS) is presented and discussed; the links between literacy and health are reviewed; and literacy statistics for local communities are presented and discussed.

Discussions on how to overcome literacy barriers include a focus on oral and written communications and on effective teaching principles in oral communications. Effective principles include knowledge of the audience, interaction, context, active testing, organization, repetition, and reinforcement. The idea that "less is more" was addressed in terms of the importance of limiting materials.

Next, Moody handed out a checklist called *ClearDoc Index* and explained how the checklist identified the essential elements of effective written communications. For example, key features that contribute to the creation of clear and understandable written communications are simple words, short sentences, and short paragraphs. Participants were given several documents to compare against the required elements in the *ClearDoc Index*. The participants discussed the documents, assessed their clarity and readability, and made recommendations for changes as needed.

The second part of the “One-Day Wonders” workshop is focused on the fundamentals of plain language. The PASS principle- keep documents personal (P), active (A), short (S), and simple (S), is a helpful test of the use of plain language.

To illustrate his point about the importance of clear language, Moody drew on the examples of Shakespeare and George Orwell. He asked participants to think back to their school days and recall a favorite Shakespearean quotation. George Orwell said: “Never use a long word when a short one will do” and “If it is possible to cut a word out, cut it out.” Moody reminded participants that plain language is not “dumbing down”; it is good writing.

Participants were given the chance to work on their own documents from their workplaces, using the skills learned in the morning sessions. Documents such as an authorization for surgeons to operate were examined and revised with the goal of ensuring the use of plain language.

In conclusion, literacy and health practitioners identified ways and means of working together to improve health literacy.

Rose then presented information about research that evaluated the effectiveness of the one-day workshops in achieving their goals. She explained that Health Canada had provided a two-day workshop on project evaluation to assist contractors. In addition, a graduate student had been assigned to develop survey designs, forms, and check boxes. A pre-workshop survey was also completed to ensure that comparative qualitative and quantitative measurements could be taken.

Six months after the workshops, another survey was conducted with workshop participants. That survey looked at whether the participants were working together or making mutual referrals to increase health literacy. Focus groups were conducted with workers who had not attended the workshops, and interviews were held with learners and key policy informants. The survey results showed that the workshops were very positively rated- 91% of participants “loved” attending them and 90% of health worker respondents were committed to improving their ability to use plain language. Seventy per cent indicated that low literacy affected their daily work.

Workers in each field (literacy and health) advised those in the other field to take more responsibility for improving health literacy. Some health care workers who

had previously been unaware of their clients' low literacy skills realized that adjusting print materials was not the only answer. The opportunity to participate in the workshop with adult learners changed the attitude of some health care workers toward people with low literacy skills.

Of all workshop participants, 68% wanted more health materials written in plain language; 64% requested a plain language audit of their facility; and 64% wanted the presenters to provide information to more people in their respective health districts.

Encouraging signs have emerged that new relationships between literacy programs and health facilities are developing. For example, shared focus group testing of health documents has been organized. Among literacy participants, 60% had shared workshop information with their colleagues and had checked over their own documents for plain language, and 42% had added health topics to their lessons and materials. One-third had contacted a health facility or educational organization to bring in guest speakers, to arrange tours, or to gather materials.

For next steps, literacy workers advised health workers to improve plain-language skills; to refer clients with low literacy to programs; to visit literacy programs to deliver clinics on health topics such as breast cancer screening, dental care, and prenatal care; and to provide health materials to programs.

Health workers advised the literacy workers to review the health workers' documents; to give advice on how to reach clients with low literacy; to teach healthy living topics; and to refer learners to health-promotion events.

In closing, Rose asked participants in the current session to consider some questions:

- If literacy practitioners are reluctant to take responsibility for teaching health literacy, then how will an integrated approach be built?
- How can a more direct causal relationship between better literacy skills and better health be shown?

## 2. Building Capacity for Health Professionals

### **Health Literacy Network Community of Practice- Jane Dyson**

The British Columbia Coalition of People with Disabilities initiated the Wellness Disability Initiative in recognition of the unique health information needs of people with disabilities. Issues are more complex than the format of materials; they include the role of caregivers in providing education on sensitive topics such as sexuality. The Coalition became aware of health literacy issues in the 1980s, and it recognized the need for HIV prevention in an accessible format, for instance, plain language and Braille.

In 1999, the Wellness and Disability Initiative was initiated to provide a safe and non-threatening way to engage people with disabilities. For example, a newsletter includes reader-friendly stories, tips on how to live a healthy lifestyle with a disability and “people” articles.

In 2000, the Health Literacy Network was launched. Its members are primarily service providers, academics, and librarians, but anyone with an interest in accessible health services is invited to join. The need to reach a broader population in the province led to the idea of an online network. For those who lack Internet access, periodic updates are provided by fax or mail. Members share information and advice, and discuss situations and needs.

In 2004, the Health Literacy Community of Practice was created. This online community seeks to engage and share health literacy information and practices. To meet the challenges of this virtual format, participation has been encouraged from the full range of individual members. Identified issues include comfort level in sharing information, learning styles, time constraints, and feeling overwhelmed and not knowing where to start. Upcoming discussions and topics in the community are health literacy, HIV prevention, and sexual and reproductive health. Visit the site at [www.communityzero.com](http://www.communityzero.com).

### **Patient Education: the Literacy Connection- Judy King**

Judy has worked as a physiotherapist for over 18 years with a variety of patients in hospitals and rehabilitation centres. She is currently finishing her PhD in the area of patient education and literacy and health.

She began the presentation with some background information on the indirect and direct impacts and effects of low literacy on health. The indirect impacts of low literacy on health are deeply rooted in the economic and social conditions of people’s lives. They include: poverty; barriers to healthy lifestyle practices; low self-esteem; and, dangerous work.

Some of the direct effects of living with low literacy skills include increased hospitalizations (Baker et al. 2002); misinterpreted medication instructions (Williams et al. 1995); reduced use of preventive health services (Scott et al. 2002); and not seeking medical attention (Baker et al. 1993). Other direct impacts are problems with navigating the health system, finding departments in the hospital, completing forms, and communication with health care professionals.

Judy’s research for her thesis involved talking to people in literacy programs who had health problems such as diabetes, arthritis, or asthma, and asking them about the educational information they received. Past research has shown significant gaps between the readability of patient education material and the literacy levels of patients (Merriam et al. 2002). People with low literacy skills also tend to have problems with verbal explanations. Often, they will not ask

questions to hide their lack of understanding. (Parikh,1996). Judy 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.

Some tips for better patient communication:

- use common words not medical jargon
- take your time and give enough details in patient education so that the information can be integrated into daily living
- use diverse tools for patient education, not just pamphlets

### **Effective Communication for Health Care Providers and Program Administrators- Penny Lane & Holly Smith Miranda**

Penny Lane and Holly Smith Miranda provided practical suggestions for developing easy-to-read program materials. The presentation began with an overview of some of the challenges that readers face in reading documents and educational materials. Many real-world examples were shown of challenging resources currently in use.

Following that introduction, Lane and Miranda presented a number of strategies for making program materials more readable. They encouraged participants to consider the audience and to keep in mind that reading skills may be lower than verbal skills. They also presented the drawbacks of strict reliance on reading level scores. Scores of readability such as the Fog or Flesch tests are purely mathematical calculations; they do not take into consideration whether the reader has the appropriate motivation or experience for the materials.

The presenters suggested that all readers, regardless of their reading level, want written materials to have the following qualities:

- They are inviting to read.
- They are well-organized, with streamlined content.
- They are written in plain language.
- The design is appealing and easy to follow.
- There are short sentences and the material is not too long.

Common design problems were then reviewed. Lane and Miranda encouraged the use of a clear and consistent design that is organized and not overwhelming. They named these design problems as the most common:

- Insufficient white space
- Too-small print
- An 11-point font is the minimum recommended; for older adults, a 12-point font should be used
- Poor font choice. A maximum of two fonts is suggested, because additional fonts can be hard to follow. For headlines, Helvetica, Futura, and Arial are recommended. For paragraph information, Garamond, Goudy, and Times New Roman are good choices

- Use of confusing text effects , for example, shadows can be distracting, as can text over graphics
- Use of long blocks of text. Each line should include no more than 7 to 10 words
- Overuse of colour- colour is useful in headings and to identify help information, but should be used sparingly
- Use of cross-referencing. Persons with lower literacy find such references difficult to follow
- Poor navigability, sections and pages should be numbered for clarity

The presenters then reviewed common writing problems:

- Inappropriate tone. This aspect of writing is very important. Avoid using an intimidating, unwelcoming, or unfriendly tone
- Poorly organized content. Organize the content the way the reader needs to see it
- Too many messages
- Difficult numbers and vocabulary. If statistics and legal documentation are required, footnoting such information is often useful
- Complicated sentences
- Use of passive voice

Field testing documents with the intended population is important. A question-and-answer format can help clarify complex information.

Designing web-based information requires additional thought, because users have the ability to “click away” in an instant. In general, “less is more” on a website. The Verdana font is the most readable onscreen. Guidelines for setting up a readable website are available by performing a Google search. In general, information should be brief and should include in-place instructions with a clear message for “next steps.”

In summary, keep in mind that presenting information in a simpler format may not always be shorter. Considering the cost of printing, longer documents may present barriers to organizations.

### **Techniques used by clinicians to improve communication with patients with limited literacy- Joanne Schwartzberg**

An education curriculum on health literacy was developed based on a baseline study and assessment of clinicians awareness, current practices and beliefs about techniques to improve communication with low literacy patients. Ninety-nine physicians, 87 nurses and 121 pharmacists were surveyed about their own techniques to improve communication with low literate patients. Schwartzberg commented that no study has documented the range of strategies employed by health care providers to communicate with low literate patients. A greater understanding of the patient perspective is also important to improve communications overall.

The self-reported techniques used by these health care professionals included:

- using simple language
- handing out printed materials
- speaking more slowly
- reading aloud instructions
- writing out instructions
- presenting 2 or 3 concepts at a time and checking for understanding
- asking patients how they will follow instructions at home
- asking the patient if they would like a family member to be in the discussion
- asking a patient to repeat information (“Teach Back”)
- underlining key points in patient information handout
- follow-up with office staff to review instructions
- drawing pictures
- follow-up with telephone call to check understanding / compliance
- using models to explain

As part of the survey, nine patients were interviewed. These interviews identified barriers to accessing health information and care, and barriers to understanding health information. When asked to compile forms requiring reading and writing skills, people with literacy barriers felt shame and humiliation, sometimes resorting to evasive behaviour to avoid exposure.

Barriers to understanding health information were:

- medical vocabulary
- complexity of content
- time constraints and inadequate confirmation of their understanding (either through not being asked, or being ashamed to admit)

The research study yielded the following recommendations:

- further research about clinician and patient communication
- development of an educational program based on the research
- development of a curriculum and train-the-trainer program
- an evaluation of clinical behaviour change.

•  
The results of the two studies were incorporated into the educational program ‘Health Literacy: Help Your Patients Understand’.

### **Health Literacy – Help Your Patients Understand- Joanne Schwartzberg**

Health literacy is defined as the ability to read, understand, and act on health care information. Because of low literacy, up to half of the U.S. population may be at risk for medical misunderstandings, mistakes, excess hospitalizations, and poor health outcomes. The same is true for other populations as well, for example, Canada. Why? Because today, greater reliance is placed on the written word for patient instruction, and the health care system is increasingly complex.

Schwartzberg discussed some of the changes in the health care system, commenting that being a patient is much harder now than it used to be. Thirty years ago, treatment of acute myocardial infarction involved six weeks' bed rest in hospital; today, it involves two to four days in hospital and subsequent use of many more drugs with a variety of instructions. Thirty years ago, about 650 prescription drugs were available; today, more than 10,000 are in use. Thirty years ago, treatment of new-onset diabetes involved three weeks in hospital, with 30 hours of diabetes education classes; today, outpatient treatment is the norm. Patients rely on written materials, information obtained over the Internet, and telemedicine, and they receive between zero and three hours of diabetes education classes.

Everyone feels "health illiterate" on first hearing a new diagnosis, said Schwartzberg. However, only half the population can read the instructions and brochures, ask questions, and connect to the Internet to learn more. The other half cannot, because they lack the skills.

The 1993 the National Adult Literacy Survey showed that 21% of people had inadequate literacy (level 1) and that 27% had marginal literacy (level 2). People at level 1 have problems with tasks such as reading and finding street intersections on maps. They will have considerable difficulty with the health care system. People at level 2 can read, but they still have problems with literacy and numeracy. They would have trouble with the instruction "Take one teaspoon four times a day." The words are simple, but not everyone understands the context.

Schwartzberg showed a text in which the words were written backwards. That text demonstrates what the experience of reading can be like for people with literacy problems.

When the participants were asked how they felt when reading the text, they said that they felt terrible. They became tired, and they had trouble focusing on the meaning. Schwartzberg noted that, technically, all participants were able to read the text. They would therefore be able to say "yes, I can read," and yet they still had literacy problems. Low health literacy affects a person's ability to read pill bottles, appointment slips, discharge information, and many other important pieces of health information.

Schwartzberg showed a 2003 video created by the American Medical Association to train medical professionals. It provides two key tips for working with people with lower literacy: create a shame-free environment and improve communication.

The video made these suggestions for creating a shame-free environment:

- Create an attitude of helpfulness
- Convey a safe, non-judgmental environment
- Be alert to clues (for example, social and educational history)
- Engage the entire staff
- Review medications with the patient

The video made these suggestions for improving communication:

- Slow down
- Convey the most important concepts
- Use “living room” language
- Involve family members
- Use visual aids
- Employ a teach-back method: Ask the patient how he or she would explain the material to friends

Patients with lower literacy skills encounter barriers to access, diagnosis, and treatment, said Schwartzberg. She discussed the shame of low literacy, commenting that in a doctor’s office, patients may feel fearful, anxious, angry, stupid, embarrassed, ashamed, and suspicious. That emotional burden affects the whole relationship. Patients may try to protect themselves by seeking help only when illness is advanced, by walking out of the waiting room, by making excuses, by pretending they can read, by becoming angry, by using humour, by being quiet and passive, or by making evasive conversation.

Health care workers should be alert for “red flags.” Common red-flag statements include “I forgot my glasses,” “I will read it at home,” “Can you read it to me?” and “I will discuss it with my children.”

Shame-free communication involves

- being curious
- asking before you advise
- giving the patient time to respond
- taking the patient’s concerns seriously
- discussing how you can best help the patient to care for himself or herself
- asking patients how they want information communicated to them
- using plain, non-medical language
- being positive, hopeful, and empowering

Practitioners are advised to review medications with patients, watching for signs of low literacy. A medication review involves asking the patient to bring in all current medications and to explain the purpose of each one and how it is taken. People who can read will explain how to take their medications by reading the labels; those with low literacy will open the bottles and look at the appearance of the pills.

Interpreters for patients who speak a language other than the one common to the current setting must be articulate not only in medical language, but also in “living room” language, Schwartzberg said. A participant suggested that all audiovisual tools should use captioning—not just for people who are deaf, but for others as well.

In conclusion, Schwartzberg presented two guiding principles:

- Provide easy-to-understand information for *all* patients.

- Ensure that the environment is patient-friendly and shame-free for *all* patients.

For more information on health literacy, Schwartzberg invited participants to visit the American Medical Association Foundation website: [www.amafoundation.org](http://www.amafoundation.org). Health care providers can order the *Health Literacy: Help Your Patients Understand* kit using the toll-free number 1-800-621-8335.

### **Health Literacy Workshops for Professionals and Students: Building on 10 Years of Experience- Lindsay Wizowski & Tracy Hutchings**

Lindsay Wizowski and Tracy Hutchings are Patient Education Specialists at the Hamilton Health Sciences Centre. They explained that as Patient Education Specialists, part of their role is to help health care providers develop plain language patient education materials, and to train health care professionals and students in the health care field about plain language, clear verbal communication and health literacy issues.

Training workshops employ a variety of participatory methods to ensure that students have a clear understanding of health literacy and can identify the challenges of the health system to the low literate. Examples of clear language versus complex language are presented so students can get a sense of the differences between the two, and where some potential caveats may be in working with low literacy patients. Students leave the workshops with a new sensitivity for health literacy and an understanding of how to use the skills they have learned in their future careers in the field of health care.

Evaluations of the workshops have been very positive. Students say that the workshops are well organized and easy to follow, the teaching methods are effective and that they would recommend the workshop to other colleagues. Those who had taken the workshop also stated what they had learned was applicable to their work and that they had changed some of their practices because of it.

Wizowski and Hutchings have also created a resource book for health care providers entitled “Writing Health Information for Patients and Families”.

### 3. Working with Families

#### **You are Your Child’s Best Toy- Claudine Bennett**

This presentation was the second in a series of three, whose focus was working with families. It was facilitated by Claudine Bennett and June LeDrew, and discussed a program offered from the region of Peel, ON. The project is called ‘You Are Your Child’s Best Toy’. The project’s goals were to increase parents’

awareness of interactive play and to provide parents with tips of how to play with children interactively.

This project arose from the realization that some parents are overburdened with being a parent and need simple, good information that is easy to understand. This information pertains to interaction with their child and the need for the child to play. The underlying message of the program is that parents and children do not always communicate easily, and that play activities can be done together, increasing the bond between parent(s) and child.

### **We All Benefit: Using Partners and Participatory Approach to Family Literacy- Pat Chisholm**

This presentation described the Young Parents Education Program (YPEP). It is a participant-designed literacy program in Cranbrook, B.C, which grew out of a Health Canada Prenatal Nutrition program- Better Babies. This program is for young parents and their children, who have barriers to a healthy life.

The YPEP consists of four components:

- Children's development program
- Parent and child together time
- Parental education for high school completion
- Comprehensive parental support

These four components provide a unique opportunity to keep parent and child together in a nurturing, learning environment. The health connection maintained between mother and child in a supportive environment leads to parental success, enhanced early childhood development and socio-economic benefits for participants and the community.

The in-depth community partnerships with the Columbia Basin Alliance for Literacy, the Cranbrook Boys and Girls club, the College of the Rockies and Better Babies, are very important to the success of the program. Also very important to the success of the program is the opportunity for participants to provide input on all aspects of program design, implementation and management.

### **Project d'harmonization à la petite enfance- Danielle Galipeau**

Ayant vu le jour en septembre 2000, le but du Projet d'harmonisation à la petite enfance est de faciliter l'intégration des jeunes enfants au système d'éducation et de mieux les préparer à affronter l'école à six ans. Le programme a trois composantes principales☐

- **Programme éducatif** pour la maternelle en partenariat avec le Centre parascolaire Quatre-Saisons.

- **Services périphériques** pour assurer le bien-être des élèves (petit déjeuner, service d'orthophonie, etc.).
- **Programme d'appui aux parents** (ateliers, ressources, références, etc.).

Le profil sociodémographique de l'école a aussi incité le CECLFCE à développer des initiatives pour contrer les effets de la pauvreté. Les objectifs du programme sont:

- Le développement et un apprentissage optimaux chez les enfants dès la petite enfance
- La préparation des enfants à la réussite, à l'école et tout au long de la vie.
- Entretenir un rôle parental positif, un milieu stimulant et une alimentation saine pour les enfants.
- Répondre aux besoins de la collectivité
- Orienter les familles qui ont besoin de services variés vers d'autres programmes publics destinés aux enfants.
- Faciliter l'épanouissement et le développement des parents.
- Offrir la formation nécessaire à tous les intervenants en éducation.

En plus de présenter les composantes et les buts du programme, Mme Galipeau a aussi présenté son rôle de coordonnatrice et les liens qui existent avec le centre des services communautaires Vanier.

### **HIPPY Project/More is More- Dlamini Kapenda & Debbie Bell**

The HIPPY Project: The Home Instruction For Parents Of Pre-school Youngsters Project. This project is a skills based program that works with low income and low literacy families. HIPPY is a program that supports parents with low literacy skills, in their roles as the primary and most important educator of their child. The program strengthens the bond between parent and child which is essential to healthy development.

The project is a three-year program that deals with parents and their children from ages 3, 4, and 5. The program provides parents with tools, materials and instruction about how to teach their child and prepare them for school. The program includes home visits, group visits, curriculum, and parents as teachers. The *PIE* Project focuses on parents whose children are in the 5-6 year category and involves direct child, direct parent and child and direct parent time. There is also a parent education and support group. The presentation included testimonials from parents noting the benefits of the program.

#### 4. Working with Communities

**Learning About Health, Student-to-Student- Marcia Drew Hohn, Saiyi Diaz & Vanda Ivanenko**

Operation Bootstrap is a literacy and adult basic education program that accommodates 260 students who attend both day and evening classes. The Student Action Health Team was established in 1994. It was originally funded by tobacco tax dollars and is now funded by the Massachusetts Department of Education.

Marcia Drew Hohn has been team leader since 1996. She conducted a two-year action research project that examined how adults learn in literacy classes about health issues. Much of the work now carried out by the health team is based on the results of that research. Saiyi Diaz, originally from Cuba, was a student with Operation Bootstrap. Now in college, Diaz works with Operation Bootstrap and at a community health centre. At the health centre, she helps with Spanish–English translations. Vanda Ivanenko is originally from Ukraine. This grandmother speaks Russian, Ukrainian, German, and English, and helps immigrants adjust to their new home.

To demonstrate what the health team does, the panelists took the session participants through a typical program. Health team workshops address many topics, but stress and depression are the two most popular. The presenters emphasized that allowing Operation Bootstrap students to choose the health topic to study is important. Students vote for the topic to be covered. Student leaders first have to learn about the health topic before they teach it to the other students. The process can take three to four months.

The workshops use information from the Internet, pamphlets, and life experience. For example, the workshop on depression invited a person with depression to come and speak to the class. Sometimes a health educator speaks at a workshop, but students mostly teach students. Health educators used to give the workshops regularly, however, they spoke too quickly, and students did not feel comfortable asking questions.

Health care providers will also sometimes present, but usually only to speak about health prevention topics such as blood pressure or flu shots. Health promotion is a very new idea for many of the foreign-born students. Many have not experienced health promotion in their country of origin. For example, mammogram advertisements will be meaningless: either they have never heard of the test, or they have heard bad stories.

Class size for each workshop is about 25 students. A schedule is established, and the student presenters travel from one class to another, repeating the workshop. They emphasize the importance of all students having about the same level of knowledge. For example, English as a second language (ESL) and adult basic education students are never both in the same workshop. Before the workshop, the teacher receives a list of all the big words that will be used in the health workshops. No assumptions are made about what people might know.

As an example of a typical workshop, presenters demonstrated what a workshop on stress would include. Various techniques are used, such as:

- Actions and Drama: the presenters might explain the physical nature of stress by pointing to the head to indicate headaches, or rubbing the stomach to indicate stomach aches. A drama called “Busy Mother and Crying Baby,” which deals with a single mother, a ringing telephone, and a crying baby at dinnertime, demonstrates the sort of situation that causes stress. Another drama shows the stress of a new immigrant dealing with an irritable bank teller.
- Small Group Discussion: the class is divided into small groups for a discussion. They discuss the situations that produce stress for them, and what they do to deal with that stress. The individual groups then report back to the whole class. The workshop presenters try to show how attempting to live up to the expectations of society can cause additional stress. Word webs from the workshop are left with the regular teachers, who might then help students to search for information and/or write stories.
- Videos: the video *Letting Go of Stress: A Guide to Achieving Deep Relaxation* might be shown to the class. A demonstration and some practice of the stretching and massage techniques shown in the video follows.

The presenters then handed out a stress kit to all the participants. It held

- an eraser, to make mistakes disappear
- a string, to tie things together when everything else falls apart
- a rubber band, for stretching beyond personal limits
- a hug and a kiss, as a reminder that someone, somewhere cares.

(The Operation Bootstrap Student Action Health Team acknowledged the Student Empowerment Team at Lutheran Community Services for the kit idea.)

### **Building Community Capacity: Focus on Literacy- Audrey Gardener**

Audrey Gardener introduced the purposes of the Bow Valley College project:

- To increase awareness about adult literacy among community service providers and volunteer groups
- To reduce literacy barriers to services, programs, and community initiatives

One of the main literacy barriers is the ongoing public perception that the issue is an individual one, rather than a broader one of social justice. Unfortunately, many individuals who experience systemic discrimination rely on health services and community programs.

The Bow Valley College program seeks to build capacity in literacy through numerous activities including workshops, literacy audits, and partnerships. The capacity-building outcomes achieved are:

- Increased sense of responsibility by service providers for literacy
- Increased accessibility to services and programs
- Reduced literacy barriers

- Initiation of literacy projects
- Incorporation of literacy activities

Through project activities, organizations have learned to think about literacy barriers in their day-to-day communications. The project targets community agencies and organizations, health services, volunteer groups, local businesses, and government services.

### **Health Matters- Trudy Lothian**

Adult learners' personal stories provide interesting insights into what matter to them about their health. Adult learners worked with teachers in the classroom to organize a health forum and to publish a collection of their stories and ideas about health in the 9<sup>th</sup> Adult New Readers Publication. This project was organized through the Literacy and Basic Skills (LBS) Program of the Ottawa-Carleton Catholic School Board, Continuing and Community Education. Trudy Lothian, coordinator of the LBS program, shared some learners' stories and highlighted key themes that emerge from the learners' thoughts, ideas and experiences. This information is useful to health practitioners who work with people with literacy challenges.

The stories, poems, facts, book reviews and quotes in the publication show a deep understanding that good health means physical health, and it also means much more than that. The writings show that to be really, wholly healthy, the mind, body and spirit need to be working well together. Having friendships and support is also very important. Lothian noted that the themes and ideas behind their stories are similar to the themes and ideas Susan Lefebvre identified in her article "Learners at literacy for East Toronto Talk about Wellness" published in *Literacies*, Fall 2004.

The collection also offered advice on keeping healthy and made it clear that, as individuals there are many things that we can do to improve our health. As one student said, when you put good things into your body, then your body thanks you. When you go to the doctor, he or she would say, "Oh my, you are looking fine".

Topics in the publication, called *Health Matters*, included:

- Health and happiness
- Stress
- Depression
- Dieting and healthy eating
- Positive attitude and activities (eg doing crafts, music, exercise, art is good for your health)
- Allergies
- Pollution
- Quitting smoking
- Health care and funding

- Spiritual health

In her talk, Trudy emphasized a richer understanding of who becomes an adult literacy student and why. She acknowledged the efforts of the students in putting together this fine publication.

### **People Who Rate: Community Involvement in the Development of Health Education Materials and Messages- Elsie Petch, Norma Levitt & Al Levitt**

In this interactive workshop, Elsie Petch and Norma and Al Levitt described how they work with health information to create accessible text. They advocate for clear language and design in health policy.

Their literacy work began in 1989, after they learned that 50% of Canadians were not able to read or had difficulty reading. In South Riverdale, 20% of residents had not completed Grade 9. In comparison, the average in the city of Toronto was 10%. South Riverdale is also home to many immigrants whose first language is not English.

In 1988, the South Riverdale Community Centre developed a coordinated approach and services plan for English and Chinese seniors in the community. They started to use a new storefront location where health information could be distributed. Feedback from readers indicated that some pamphlets were understandable, but that many others were difficult to read. Pictures were confusing or unattractive.

Project funding from Health Canada enabled the Centre to work with 30 seniors to review and rate health information materials. The seniors had a range of literacy skills. They reviewed 300 pamphlets and videos. The conclusion was that many of the materials did not meet the group's health information needs. As others heard about the project, the group was invited to review more materials intended for seniors. Some of the first clients were the Ontario Ministry of Agriculture and Food, a chiropodist, and the Ontario Ministry of Health. Mary Breen, a well known writer of accessible health information, acted as a consultant to the group. Over time, the seniors became very adept at the work. To maintain a critical stance, they also involved new people with no previous experience.

The Centre found that seniors were not the only people who needed clear health information. Other audiences included people who do not read, people with English as a second language, people who hear or see poorly or have memory problems, and people of all literacy levels. To actually use printed information, a reader must be able to "get beyond the text." Sometimes cultural misunderstanding can be a barrier to comprehending a text resource.

Most health information pamphlets are prepared by professionals. They are not tested with the target population. This can be because of a lack of time, money, or both. Petch and the Levitts suggested that partnerships with the target

populations are useful. Through these partnerships, writers can learn about the target population's culture. Then, clear language materials can be shared and programming developed. Additional community members can be involved as projects progress. Reaching beyond the health community can be worthwhile.

Respect is important for all members of a group, because ownership results from full participation. To work with a community, use these guiding principles:

- Start with a simple plan
- Be flexible and pursue opportunities that arise
- Build in rewards for everyone
- Respect everyone's contribution
- Incorporate agreed-upon suggestions

Petch and the Levitts spoke about the many benefits of groups, and the range of activities they can undertake.

- Groups can write articles for community newspapers.
- They can organize education sessions that encourage participation and peer learning. Clear language encourages participation.
- Groups can choose and distribute materials that are deemed to be "clear," and they can develop others with community members.
- The South Riverdale group has even held clear language workshops for health providers.

Petch and the Levitts have contributed to the development of clear messages about health and related topics, while changing the "gloom and doom" view of aging to one of productivity and participation. The story is one of true empowerment. Norma Levitt explained that when the seniors are approached by an outsider who wants to make a presentation at the Centre, that person is asked to formally commit to a clear language format and an evaluation by the participants. Recently, a physician who presented at the Centre said that although he was responsible for the information, Norma had told him how to present it to the group!

During this workshop, participants were able to critique some written health-related materials and to discuss them with the presenters. Copies of the *Safe Medication Card* developed by the South Riverdale seniors were distributed to all participants.

## 5. Working with People with Disabilities

**Simply Health- Sharon Christie & Grace Carson**

**Smoke Talk- Tobacco Awareness Course in Plain Language for Adults with Developmental Disabilities- Jeannette Coombe & Joseph Hnatuk**

**Menopause- What is it?- Lean Jones**

The five presenters in this workshop work closely with one another, so the presentation became one large workshop instead of three topic seminars.

The presenters come from the Vocational Rehabilitation and Research Institute (VRRI) and the Grace Women's Health Outreach. VRRI works with people who have developmental disabilities. Grace Women's Health Outreach Program delivers health education and information to people in the Calgary region who experience barriers in accessing health services and resources.

VRRI recognized their need to tell clients about health and medical procedures, to reduce clients' fears and enable them to talk with medical professionals about what was happening to them. Leah Jones showed one booklet on menopause that VRRI had developed. The booklet was developed as part of a group of booklets that could be reviewed together or used separately. Examples of titles include *What Is Menopause?* and *What the Hard Words Mean*.

Grace Women's Health Outreach Program worked with VRRI, and also realized that clear messages about health were appropriate for other people who have difficulties accessing health literature. For example, those for whom English is a second language, and people who have difficulty with reading and writing. The two organizations then developed the "Simply Health" series of workshops, booklets, and videos on health topics including dental health, eye health, foot health, ear health, breast health, and prostate health.

The importance of those topics was emphasized with examples of client situations. Imagine a client's fear and surprise seeing a chiropractor pull out a dremel, a tool that the client had seen being used for woodworking in television commercials. Or imagine undergoing a prostate exam after years of being taught about appropriate and inappropriate touch. Or imagine having your first Pap smear when you come from a country in which routine preventive medical testing is not the norm.

The Simply Health workshops, booklets, and videos all reinforce one another. They are about building community capacity and helping people to understand the importance of taking care of their bodies. The different formats recognize the value of different health promotion techniques. For example, workshops may normalize a health problem. It has been proven that people are more likely to make changes when they attend a group program at which other people say that they will make changes, too.

There is also power in community. The presenters gave the example of a group of women who came to a workshop on cervical health and committed to having Pap smears. For one woman, the test resulted in the early detection of cervical cancer. Had she not come to the workshop, she would not have had the Pap test.

The tools developed from the Simply Health series can be used in a variety of settings. Health professionals and client support workers can use videos and booklets to help in their teaching. A client support worker might review the menopause booklet series with a client going through menopause. An office

manager at an optician's office may show a client the video on eye health and then answer questions before the eye examination takes place.

"Smoke Talk" takes the format of Simply Health a step further: educational materials are available, but a peer educator component is introduced to help people quit smoking. Funded by the Alberta Alcohol and Drug Abuse Commission, Smoke Talk focuses on using plain language, pictures, and activities to increase learning. Smoke Talk teaches how

- people breathe
- what tobacco is
- what the chemicals in cigarettes are
- what tobacco does to your health
- how sick smoking can make you, what passive smoking is
- what addiction is

Like Simply Health, Smoke Talk has kits available for loan to groups wanting to implement a program. The kit contains workbooks for participants, props, and games that can be played with groups or individuals.

### **Literacy Barriers for Deaf People Using Health Services- Salma Kanji**

This presentation focused on explaining why some Deaf people have poor literacy and health. Deaf culture, language and tips for communication were also covered. Kanji discussed the importance of awareness raising when it comes to interactions with Deaf people. Knowing how to deal with these interactions, and how these interactions could be improved is valuable.

Kanji gave the example of a Deaf person going to see a doctor. In order to communicate, the doctor and the Deaf patient were writing notes back and forth. The Deaf person requested an interpreter, and the doctor did not understand why this was necessary. The patient felt that he was not communicating effectively through notes, and that the doctor was not understanding his health concerns. The doctor felt that these concerns were being met, and that he was understanding the interaction and what the patient required.

Kanji emphasized the importance for all health care providers to learn to understand how to assist Deaf people in the most effective way. She believes that health care providers need to understand deaf language and culture, so that they can be fluent in deaf communication.

### **Health Information for Deaf Canadians- James MacDougall**

This presentation by James MacDougall, of the Canadian Deafness Research and Training Institute, focused on literacy and health access for Deaf Canadians. As background information, MacDougall shared that approximately 1 in every 1000 Canadians are Deaf, this amounts to 30 000 Canadians. The majority of Deaf

people use sign language to communicate, either American Sign Language (ASL) or Langue des Signes Québécoise (LSQ).

In terms of access to health care, there are many obstacles for Deaf people. Communication with health professionals is an issue. Access to health care for Deaf people is very reliant on use of sign language interpreters. Additionally, for many health professionals, understanding the realities of Deafness is a challenge. Furthermore, while basic communication between Deaf people and non-Deaf people is in itself a challenge, there is sometimes the added difficulty of many Deaf people having severe reading and writing difficulties in English and French. Surprisingly, the average grade equivalent reading level for Deaf high school graduates is 3-5 years. Of course, there are exceptions to this and many Deaf people have high literacy levels.

MacDougall emphasized that literacy is a major issues for access to health care. Communication is of utmost importance in health care. Reading and writing cannot be used as a means of communication in the health setting and lip reading is not a reliable method of communication in a hospital. Since reading is an issue for many Deaf people, sign language interpretation is essential. In 1997 the Supreme Court of Canada mandated sign language interpretation as a free service for Deaf Canadians under the Canada Health Act. An important part of this decision was the acceptance of the reality that written English or French were not viable means of communication for Deaf people.

One solution being considered to aid Deaf people in healthcare settings is Remote Video Interpretation (RVI). This systems allows the Deaf client live interaction with a sign language interpreter at a remote location, through video conferencing. This would provide a unique form of visual literacy to all Deaf people who require it in order to gain access to health services.

### **Alphabétisation et surdit   un service populaire bilingue au centre des besoins sociaux – Anne-Marie Parisot et Rachel Berthiaume**

Anne-Marie Parisot et Rachel Berthiaume ont parl   de la pr  valence des faibles capacit  s de lecture et d'  criture chez les Canadiennes et les Canadiens sourds (65%, contre 30% dans le reste de la population canadienne). Ce chiffre est inqui  tant, car la connaissance du fran  ais demeure essentielle pour participer    la soci  t   qu  b  coise. Lorsqu'on veut accro  tre les niveaux d'alphab  tisation en fran  ais chez les adultes sourds au Qu  bec, les principales difficult  s sont les   checs pass  s, le manque de motivation et l'insuffisance des ressources.

Vue comme un handicap, la surdit   est d  finie comme   tant l'absence d'acuit   auditive et une d  ficiance biologique n  cessitant une r  adaptation. Cet   tat de sant   complique beaucoup l'acc  s au fran  ais   crit. Vue dans une perspective culturelle, la surdit   est d  finie comme une acuit   visuelle accrue et comme une fa  on particuli  re d'agir, de penser et d'  tre. Le langage gestuel est consid  r   comme la «langue maternelle» de la culture sourde.

Adoptant une perspective culturelle de la surdité, les présentatrices ont expliqué que pour être bilingues, les personnes sourdes doivent faire de la langue des signes québécoise (LSQ) leur langue maternelle, et du français écrit leur langue seconde. La recherche tend à montrer que les Canadiennes et les Canadiens sourds nés dans une famille francophone apprennent beaucoup plus facilement à maîtriser le français écrit s'ils ont acquis au préalable une bonne connaissance de la LSQ.

Un logiciel d'alphabétisation très polyvalent, appelé *Le français au bout des doigts*, favorise l'apprentissage de l'orthographe, du vocabulaire et de la reconnaissance des mots dans leur contexte et s'est avéré efficace pour améliorer les niveaux de littératie des francophones du Canada atteints de surdité.

Pour améliorer l'accès de cette population mal desservie à l'information sanitaire, deux étapes sont importantes ☐

- Élaborer des vidéos d'information sanitaire en LSQ,
- Adapter les règles du style clair et simple pour qu'elles respectent la structure de la LSQ dans les documents écrits à l'intention des personnes sourdes.

## 6. Sharing Health Information for Prevention and Treatment

### **Learning to Use the Canadian Health Network (CHN) and What We Learned**

This workshop was developed and presented in English and in French. Each workshop was done in two parts.

Part I: Skills Training and Participant Feedback (Learning to Use the Canadian Health Network)

This was a hands-on session intended to:

- (1) provide learners with training on how to use a health information website, using the Canadian Health Network (CHN) site as a model, and
- (2) to provide first-hand feedback to CHN about their website, and the changes they might make to increase accessibility for people with literacy challenges.

Part II: Panel Session (What We Learned)

The second part of this workshop was a panel session where reporters presented took place in Part I. Part II included feedback from learners on what was good and bad about the website. Based on the recommendations, CHN will make changes to the site to increase accessibility. Recommendations from the English and French workshops were reported separately, but have been consolidated in this report. The results below reflect what was reported in the panel session, which explained the workshop.

In the Part I, small groups of learners worked with a facilitator and a reporter. Each learner had a computer, and the facilitator had a data projector. Learners navigated the site without guidance to see what it was like, and then took part in guided activities. The reporters supported the participants and took notes of their comments concerning the site.

One of the first activities that was done was to show the participants the home page and ask them to locate information of interest. The purpose of this exercise was to see first impressions, how they used CHN, where they went, what problems they had and what they found easy.

Although there were only a small number of learners in attendance, they were very articulate in expressing their views about the website. Generally, participants liked the CHN website.

- They preferred to click on links to find information, rather than type in terms for a search.
- They found the Quick Search option on the site worth trying, but frustrating if information was not there.
- They also assumed that if they did not find information on the first try, that it was not available on the site.
- Nobody found the FAQs while navigating without guidance.
- Overall the vocabulary on the site was too difficult.

CHN learned that the following changes could improve the site overall:

- Introductory paragraphs must be very clear, should include definitions and examples of hard words
- Include important information in the top part of the webpage so users do not need to scroll down to complete reading about an idea. Avoid surplus information and wordiness
- Use pictures and headings that are relevant to attract attention
- Be consistent in use of terms and icons. For example, do not switch between 'adolescent' and 'teenager'
- Pictures can also be links to more information
- Include pop-up definitions that appear when the cursor hovers over important words
- Increase to font size would help readability
- Locate FAQs more obviously
- Make sure the "Home" button is easily found
- Different search methods are easily identifiable, navigation and search methods need to be very clear
- Place an 'easy to read' icon beside these articles

Another activity was the Frequently Asked Questions (FAQs) challenge. This activity was aimed at showing participants how to use the FAQs. Participants were given a choice of scenarios and were asked to find information on that scenario in the FAQs.

In the French workshop, an example of a scenario was about a friend learning that they have Lou Gehrig's disease. The friend is slowly losing control of

their legs. He wants to know how it can get financial aid and social services support. Here the FAQ search should be around the topic of assistance with everyday living. Findings from the FAQ challenge showed that:

- Participants who are not confident readers do not skim and scan, they read sequentially the whole FAQ list from top to bottom.
- Some FAQs were not categorized by headings.
- Sentences that are underlined, such as the titles of FAQs, are difficult to read.

With regards to the FAQs section, some recommendations from learners were:

- Make key points early in the text as some readers may only read the first part of a paragraph before giving up
- Put all the headings at the top and make them links to the lists of FAQs
- Avoid underlining of FAQ titles

Learners also participated in an A-Z Index Finding activity. The feedback was that the A-Z index was useful and effective, however not all important information is in the index. A recommendation that came from the activity was to use more common vocabulary.

A keyword search was also performed. This activity was challenging for people who have trouble spelling. One participant recommended a 'Google' type feature which would suggest spelling corrections when words are not entered properly. Words that are hard to spell should be accessible in the A-Z index.

The outcomes of the hands-on session and panel discussion were that learners learned how to navigate the site, how information on the site is organized and where to look for useful information. These are skills that could be applied when navigating the web for health information. CHN learned what is difficult or confusing about the site and how improvements can be made. They also learned what participants liked about the site, and therefore what to keep and continue doing on the site in the future.

### **Reaching Teenagers Where They Are: Best Practices for Sexual Health Education Professionals- Deborah Begoray & Elizabeth Banister**

This presentation was examining best practices for Sexual Health Education Professionals. The presenters, Deborah Begoray and Elizabeth Banister, were interested in developing methods to best reach teenagers, and use these methods when implementing sex education programming.

Begoray and Banister began the session by giving some background about adolescent sexual health. They stated that over 50 % of teens have had sexual intercourse by the time they are 18 years of age. Additionally, over half of sexually active adolescents are not using condoms.

They also presented background of Banister's research study of 15-16 year old girls and their dating habits. This study was being used in conjunction with

Begoray's study of how teenagers learn. It was hoped that from an understanding of teenage girls' dating health, and an understanding of practices in teenage learning, a set of best practices could be developed for presenting sexual health education materials

Begoray presented various stages of adolescent development, learning readiness and developmentally appropriate teaching strategies. According to the study, cognitive processes, ie. 'how teens learn', change significantly over the period of adolescence. Knowing the stage of cognitive development plays a big part in determining how sex education should be presented.

Teens in their early adolescence (12-14 years) may see themselves as invulnerable, and are interested in same sex friendships. At this stage, teens are also starting to examine their own sexual feelings. Teenagers in this phase will need concrete approaches to teaching, such as help with basic problem solving, clarification of terms and help with identifying risks. Since they feel invulnerable, asking 'what if?' questions will not be the most effective technique in presenting sex education materials. Keeping the session interactive, by avoiding yes/no questions, keeping speech short and focused, and using methods like role plays, hands on activities and physical props are effective.

Middle adolescents (ages 15-17) have the capacity for increased abstract reasoning, and can appreciate the consequences of some of their actions. Studies have shown that they may revert to concrete thinking when faced with confusing or stressful situations. Additionally, teens in this age group are likely to be involved in risk-taking and influenced by their peers. Role playing, and rehearsing specific situations are effective teaching techniques. Rehearsal is important because of a lack of ability to work through situations themselves. Also important is to help teens build communication skills. They should rehearse saying 'yes' and 'no' to having sex and other situations where they might feel pressure.

Teens in late-stage adolescence (18-21 years) have likely established abstract reasoning, and developed moral, religious and sexual values. They can also appreciate the link between actions and consequences, but might still need health information, advice and guidance. Teens in this age bracket will also find it easier to discuss healthy living.

Knowledge of teens' level of learning led to some of the following adolescent teaching principals. Teaching activities should be:

- Learner Centered
- Developmentally Appropriate
- Involve Concrete Activities
- Attempt to build meaningful relationships between teachers and learners
- Take a genuine interest in the person
- Show compassion, respect and friendliness
- Bring personhood into the interaction
- Use humour

Some focused strategies for developing effective teaching activities are:

- Efficiency in planning
- To have an instructional framework like the following;
- Opening - motivating learners, getting learner's background- find out current understanding of topic, introduce the topic, provide definitions and examples
- Body - connecting learners with new content and strategies through techniques such as role playing, brainstorming
- Closing - reviewing, questioning, individual written response to activities- what they learned, important issues, how to apply the learning, suggesting practice

### **Lessons Learned from Community Health Nursing in the ESL Classroom- Elizabeth Diem**

This workshop described a program that helps undergraduate nursing students work with learners for whom English is a second language (ESL). The program was necessitated by a drastic change in the way the community clinical placement of nursing students was organized. Formerly, students spent two days with a public health nurse each week for six weeks. In 1998, that schedule was changed to one day each week for eight months, giving the students an opportunity to work at sites and on projects for an extended period of time.

In 2001, clinical placements in ESL or language instruction for new Canadians (LINC) classes were organized with a school board and in community homes associated with a community health centre. Since then, 28 projects have been undertaken with multicultural adult learners. The nursing students worked in teams of two to six members.

The presenters explained the processes and events that constituted their involvement with the adult learners. Clinical placements consisted of an assessment phase and an action phase, both of which lasted between 6 and 12 weeks. Once weekly during the assessment phase, the nursing students spent one to two hours interacting with multicultural learners in classrooms or during breaks. Once every second or third week during the action phase, they spent time in the classroom on specified activities. They found that between two and four weeks were required to establish relationships, between two and six weeks to assess secondary data, between two and six weeks to initiate a community assessment, four weeks to conduct a specific assessment, and two weeks to determine a direction for future action.

The students used a process called "progressive inquiry" to gather information. This process is a non-threatening approach to gathering qualitative data, because it avoids written questionnaires or surveys. The process was used to engage community members in identifying issues that they would like to change. These activities were found to be relationship-building.

In preparation for engaging in the process, the nursing students were asked to use this three-step procedure:

- Decide on one of three questions.
- Determine how and when to approach people.
- Allow learners to tell their stories first, and then move into other areas such as barriers to health and health goals.

Emphasis was placed on asking questions gently. The students were also encouraged to approach people where they gathered, to record responses in field notes after the encounter, and to record other issues of interest.

In the analysis phase, students reviewed findings with a professor, determined a second cycle of questions, and repeated the process until all pertinent questions had been asked and most of the community members had been reached or people in a variety of settings were responding in the same way.

In the action phase (once weekly for 12 weeks), students planned what would be done, how it would be done, and how it would be evaluated.

Through their 28 projects, the students determined that the two chief areas of interest were nutrition and accessibility of health services. The next two topics of concern were mental health (for example, stress and relaxation) and exercise. With respect to exercise, one concern of adult learners from warm countries was their difficulty exercising during the cold Canadian winter. The students were able to address that concern with indoor activities. One such project was titled "Walking! It Feels Great." Another reflected the concern of some learners that tap water should always be boiled before consumption. That project was titled "Turning on to Tap Water: Assisting Healthy Adaptation to Canada."

The ESL teachers felt that having nursing students in the classroom produced benefits. One was quoted as saying "[They are] a great resource for [learners] and teachers on health-related topics. [Learners] seem to feel comfortable asking questions about their concerns. Interacting with the nurses gives them a chance to feel connected to their new community."

All participants experienced some challenges:

- The adult learners often saw the nursing students as a source of information for their individual treatment needs.
- Teachers had limited time to understand the terms and activities used by the nursing students. They also needed to help the students adjust the amount and delivery of health information.
- Initial challenges for the nursing students included handling this first-time exposure to professional practice outside the acute and chronic care settings, shifting from individual to population-based care
- Challenges for the nursing instructors included understanding what the students would be able to accomplish and conveying that understanding to students and advisors alike. They also needed to support the nursing students and the teacher advisors in finding common ground, so that learners and student nurses would both benefit.

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
- that building relationships takes time and is as important as providing a service such as health information delivery
- health care, and being healthy
- to develop clinical judgment in a community setting
- to feel that they had made a difference

The ESL and LINC organizations learned:

- that they can contribute to the preparation of health care professionals with a cultural perspective,
- that simple projects work best
- that small amounts of money can go a long way
- that small projects build community and capacity one project at a time

Proposed future directions for the program include:

- making changes in community nursing education to include multicultural clinical experience with the same population over several weeks
- organizing partnerships between the school of nursing and organizations that serve multicultural communities, and organizing similar partnerships with Public Health
- Suggested changes included assessing the needs of groups while encouraging partnerships and funding small local initiatives that directly address needs

One suggestion from the participants at the workshop was to involve an adult learner in introducing the student nurses to the issue of health literacy.

### **Alphabet Soup- Candyce Jones**

Alphabet Soup is a 6-week family learning program based on family literacy and healthy eating. It emphasizes literacy, healthy lifestyle habits, such as eating and exercise, and socialization through a play-based approach to learning. The program was developed by Bookmates in partnership with the Winnipeg Regional Health Authority, and is supported by the Winnipeg Foundation and Healthy Child Manitoba. Parents and children are engaged in a weekly two hour session, each session having a different weekly theme.

During this presentation, those in attendance were shown a condensed version of a two-hour alphabet soup class and asked to participate. Each session has a parents and children literacy component, where food-related songs, rhymes and books are used. Different reading styles and techniques are presented during each session for parents to learn and practice at home with their children. Snack time is also a scheduled part of each session. This part of the program is

important as it teaches social skills, routines like washing hands, and other lessons.

The session also has a children's and parents' program. The children's program consists of crafts, story-time, free play and physical activities. It is during some of these activities that parents have their own 50 minute program. During this time, parents receive instructions and handouts on topics such as making a game to take home, literacy, and nutritional information.

### **Librarians Partnering with Volunteers to Provide Health Information to Cancer Patients- Lorie Kloda**

Lorie Kloda spoke about her current study within a larger Canadian Institutes of Health Research (CIHR) project called Interactive Health Communication (IHC) - Health and Wellbeing of Oncology Patients. The purpose of the overall project is to assess the impact of IHC on adjustment by patients to their medical condition (measuring for example, quality of life and cancer experience).

Kloda's study involves hospital volunteers, cancer patients, and patients' families at six Montreal hospitals. This controlled study plans to enroll 300 patients (150 on treatment, 150 controls) and 20 hospital volunteers. The study participants are recruited through a printed advertisement. The study has these inclusion criteria:

- Only patients with breast, colon, and prostate cancer are eligible
- Only patients with anticipated good clinical outcomes are eligible so that participation can continue for the length of the study
- Patients must have no diseases other than the cancer
- Patients must be computer literate or have support for computer use (This criterion was added as a consequence of time constraints and delays in implementing the study.)

Hospital volunteers were recruited by staff social workers and were trained to use an existing bilingual CD-ROM in the Oncology Interactive Education series. Some facilities were already using the CD-ROM, but now all cancer patients in the study will be consistently using it. The treatment group receives the CD-ROM and a list of selected websites presenting current and credible information. The control group receives traditional print materials.

To date, between 50 and 60 patients have been enrolled in the study. The feedback and lessons so far are:

- Use hands-on practice and plain language; relate concepts to real-life situations
- Volunteers were enthusiastic with the training and feel more reassured in their roles and actions
- Patient feedback has been positive

## How to improve understanding of medical instructions- Lauren Mackenzie

This workshop was opened by Elsie Paul. 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. Others expressed feelings of confusion.

Lauren Mackenzie explained how these situations can create discomfort and misunderstanding. Mackenzie went on to describe LAPS (Literacy and Parenting Skills). Research was conducted prior to the design of the program, so that the program would be as useful as possible to the parents that attend. In this way, LAPS was designed as a program based on the communities it served.

The participants were then divided into groups of three. Each group was given a scenario and a set of questions to answer. The questions included:

- What is the main problem / issue?
- How does the patient feel?
- What are some strategies to deal with this? With limited dollars? With unlimited dollars?

The groups worked for 15 minutes on their scenarios and then reported back to all the workshop participants.

The first scenario that the groups discussed was the following:

I went to the hospital, thinking I was having an appendicitis attack. I was told I had PFD, Pelvic [In]Flamatory Disease. I didn't know what that was, and I was scared. I asked many times what it was and what I meant. Finally someone wrote it down for me. I left the hospital not knowing what was really wrong with me.

Group 1:

With regards to the first question, some of the main problems / issues identified were:

- doctors not taking enough time to explain directions properly to the patient
- the patient feeling fear
- being intimidated
- not being listened to

Using the limited dollars scenario, some of the solutions that were developed were:

- That the patient and his community could make a complaint to the government, the doctor and contact the media.
- That the doctor could get education on how to communicate with patients more clearly
- The patient could complain to the medical association.

Using the unlimited dollars scenario, the group thought that more staff could be trained in order to share information properly.

Group 2:

The main problems identified were:

- doctor / patient communication
- drug labeling
- over reliance on print communication
- patient not feeling encouraged to participate
- issues of time
- parents not knowing basic rules about medication such as not to use expired medications

Participants thought that the patient in this scenario might feel frustrated, angry, exhausted, and that the patient might not see the barriers to access that they are facing.

Using the limited dollar scenario, the solution developed by group 2 was labeling and instructions should be in clear language.

If unlimited funds were at their disposal, more doctors would be hired and would be looking at prevention work. Staff would have special roles in the doctor's office.

Some of the other scenarios that were discussed were:

Sally\*, a 53-year-old woman with diabetes, was back in the emergency department again and in shock from blood sugar levels that were dangerously high. Her doctor was puzzled: If Sally was taking her insulin every day, as she'd claimed, what was the problem?

After Sally was treated and had recovered, a nurse asked her to demonstrate how she took her medicine. She drew up her insulin in a syringe, injected the drug into an orange – and then ate the fruit. In an earlier hospital visit, nurses had taught Sally how to take insulin by having her practice injections on an orange. Then, they gave her a booklet on diabetes and sent her home. She never read the booklet. Reading stop signs and writing her own name were the extent of Sally's literacy skills.

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 if blank. After surgery they gave me Demerol and I threw up.

The large group continued to problem solve various scenarios involving learners interacting with medical professionals. Several universal themes were

highlighted including feelings of isolation, anger, 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 programs (literacy).
- Focus on education providers and patients.

### **What would make it easier for you when you visit the doctor, a clinic or the hospital?- Fiona Murray**

The workshop was divided into the following parts:

- Ice breaker
- Workshop overview
  - Your experiences dealing with health literacy
  - What is health literacy?
  - Discussion
- Key messages and recommendations

The workshop began with a role-play, which was a dramatic presentation of what might be a typical experience for a low literate person in a health care environment. Wanda, a Russian immigrant, was seeking assistance in a medical clinic from Cylie, a Spanish nurse living in the United States. With English as her second language, Wanda was having difficulty understanding the information on an application. The nurse was unaccommodating and unsympathetic to Wanda's situation. In essence, Cylie was sarcastic, abrupt, and rude. Wanda became so frustrated that she decided to leave the clinic without being seen by a physician.

After the role-play had finished, Murray generated discussion among the participants about how to minimize occurrences like the one just presented. The discussion focused on tips for professionals from people with literacy barriers. Also discussed were actions that people with low literacy skills could take to avoid such situations and take charge of their healthcare experiences.

The group discussed the difference between 'Literacy and Health' and 'Health Literacy'. Literacy and Health refers to how literacy (which was defined as the ability to use written information in society to achieve goals and develop knowledge and potential) can affect a person's health or access to health care. Reading, writing, and numeracy skills will all have a direct impact on reading prescriptions, health brochures, understanding nutrition labels, preparing food for babies and children or understanding safety instructions.

Health Literacy is a specific kind of literacy. It is the ability to read, understand and act upon health information. Health literacy is about the skills to manage health care information and interact successfully with the health care system. Health literacy therefore includes skills such as seeking information, understand that information and asking appropriate questions.

It is possible for a person to have poor general literacy (reading and writing skills), but good health literacy, if for example, a low literate person always brought a literate intermediary with them to their medical appointments. The reverse is also possible- someone with high literacy, but low health literacy. For instance, someone with good literacy skills who is overwhelmed by health information and does not know what type of questions to ask.

During the discussion, several common themes became apparent:

- Embarrassment
- Frustration
- Lack of self-esteem
- Shamefulness

Based on the discussions, participants developed key messages:

1. Messages to health care professionals:
  - Seek sensitivity training to: (1) understand how literacy affects health and access to health services and (2) how to identify people with literacy challenges
  - Use universal screening so no person feels singled out or observe patients filling out forms
  - Encourage patients to bring an intermediary
  - Take time to listen- patience and empathy are as important to health as knowledge and skills.
  - Frame questions in a positive way. For example, instead of “Do you need help?” say “ We have people to help if you need it
  - Follow-up appointment to ensure that health information is understood and followed
  - Health information presented in creative ways:
    - Videos running in waiting rooms to explain routine procedures, such as the registration process, other questions and potentially confusing issues
    - Use visual props, models, diagrams, symbols and pictures
    - Visual aids and translators for deaf patients
  - Provide brochures on literacy programs in clinic waiting rooms
  - Use tools like the “Literacy Audit” toolkit from Literacy Alberta to evaluate services, offices and waiting rooms
2. Messages for government policy and the healthcare system:
  - The system needs to be slowed down so patients and medical staff have time to build trust and exchange information
  - Give health care professionals the skills, resources and support to determine where low literacy barriers exist and strategies to deal with

- these barriers appropriately. For example, access to translators, hiring staff to help patients who require extra assistance and for follow-up, and more time to observe and allow for discussion
- Health care professionals should work together to develop positive questions that will be asked to everyone so that no patient feels singled out
  - Involve adult learners in any work that needs to be done to make improvements. They can educate about the realities for less literate patients
  - Audit information and services to determine accessibility
  - Simplify written health information with pictures, symbols and diagrams
  - Improve sensitivity to those with special needs and accommodate these needs
  - Consider a phone service to deal with questions about the clinic experience, prescriptions and follow-up issues
3. Messages for people with low literacy skills:
- 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
  - Make a follow-up appointment if you realize you have new questions once you have left the clinic
4. Messages for Literacy Workers:
- Work with health workers to help them figure out ways to provide services to people with literacy challenges, especially appropriate screening questions
  - Encourage literacy learners to bring a support person to medical appointments
  - Create awareness about learning difficulties

### **Responding to Learners' Demands for Consumer Health Information: How to Assess and Address Families' Changing Needs Online- Beth Wood**

Beth Wood, Coordinator, Family Resource Centre, Children's Hospital of Eastern Ontario (CHEO), introduced a project designed to develop a resource that listed reliable cancer websites. This resource is aimed at families, hospital staff, schools, and related organizations and agencies who work with families. Cancer was chosen as the topic because of an increase in cancer diagnoses at the CHEO in recent years. That increase has created a need for more information and improved quality of service, including information access 24 hours per day, seven days per week, across the Internet from any location.

The resource is meant to provide current and reliable health information; to assist families in becoming active and informed partners in the health care process; and to reduce patient and family anxiety by helping them find answers to their health questions.

Input from families and hospital staff was obtained during the development of the resource, and updates are added as needed. Revisions use the input from a multidisciplinary committee of staff, volunteer, and family representatives who meet monthly.

The benefits of this project have been numerous. Some examples include:

- increased reach and dissemination of health information
- “hands on” workshops for staff and partner agencies on how to find and evaluate online health information

Wood provided the group with tips on how to find reliable health information on the Internet, including Canadian, American, and international websites. She also provided the project’s most recent website list. Additional dissemination of the resource takes place through Interlink Nurses (a networking group of pediatric oncology nurses) and other opportunities for sharing, such as conferences.

## 7. Literacy and Health Resources

### **La base de données en alphabétisation des adultes et les ressources- Lorette Chiasson**

L’objectif de cette présentation était de partager l’information sur des ressources dans le domaine de l’alphabétisation et de la santé. Un des buts de la base de données en alphabétisation des adultes (BDAA) est de tisser de nouveaux partenariats dans le domaine de l’alphabétisation et de la santé. Les discussions qui ont eu lieu lors de cette présentation se sont révélées le commencement de ce réseautage.

La base de données en alphabétisation des adultes veut jouer un rôle de chef de file pour former une infrastructure en alphabétisation. Le site Web de la BDAA fournit des renseignements complets sur les événements et les activités, les ressources disponibles, les prix d’excellence, et les nouveautés dans le domaine de l’alphabétisation ou de l’éducation des adultes.

A chaque semaine, l’organisation publie le témoignage d’une personne apprenante qui est inscrite à un programme d’alphabétisation. La BDAA a aussi des liens sur son site, avec plusieurs organismes qui oeuvrent en alphabétisation, telles que la Fédération canadienne pour l’alphabétisation en français (FCAF) et l’Association canadienne d’éducation de langue française (ACELF). Des liens se trouvent également sur la page de chaque province ou territoire, par exemple, au Nouveau-Brunswick, un lien avec la Fédération d’alphabétisation du N.-B.

### **Healthy Interactions On-Line with Alpharoute- Nancy Friday & Mike Kelly**

Nancy Friday and Mike Kelly provided an overview of AlphaRoute and its intended audience. Friday also spoke about Centre AlphaPlus Centre, a provincial literacy resource centre located in Toronto.

For 8 years, AlphaRoute has provided an online management system for onsite and distance literacy delivery across Canada. The latest research report is: "What Difference Does it Make?" (2003) is available online at <http://alphaplus.ca/images/pdf/whatdifferencedoesitmake.pdf>. Alpharoute is meant to be used as a supplementary resource, not as a stand alone product/curriculum. It is also not designed for ESL learners.

Kelly showed the group the Learning Edge, a learners' online newspaper that is part of the Alpharoute site. On the French AlphaRoute site there is a newspaper called Le Scribouillard.

There is a three day trial period for those wishing to try out AlphaRoute. Log onto <http://alphaplus.ca> and follow the links to AlphaRoute.

The group was shown an article from the online newspaper called "Men Don't Eat Enough Vegetables". Three small discussion groups were formed to discuss the following questions:

1. What makes this article a good health promotion activity?
2. How would you make this a literacy learning activity?
3. What makes it a good online learning activity?

Friday and Kelly took the group through other tools on the site including the dictionaries, the word list, and the note pad. The Café on the English site was also visited with the cybersearch tool highlighted. Every three weeks a new cybersearch activity is posted for learners to try out. Learners do the activity and then go to the discussion to chat about the activity with other learners. Friday demonstrated the discussion by posting a message.

### **Helping Learners Use the Workplace Hazardous Materials Information System (WHMIS)- Monika Jankowska**

Monika Jankowska-Pacyna, AlphaPlus Centre, explained that the Workplace Hazardous Materials Information System (WHMIS) is a nationwide system that provides workers with knowledge and tools to enable them to work safely in the workplace. The standardized WHMIS classifications describe the control, safe handling, storage, and disposal procedures for hazardous materials in the workplace. Employers are required by law to ensure that employees exposed to hazardous materials are properly trained in using WHMIS.

Hazardous materials in the workplace include cleaning products, paints, toners, gasoline, explosives, chemicals, and fumes. If handled improperly, hazardous materials can cause skin irritation, burns, sensitization, heart problems, kidney or lung failure, and cancer.

Many individuals working in the literacy field are experiencing difficulty obtaining WHMIS information. Monika Jankowska–Pacyna presented an option called “Practical WHMIS,” an introductory online course on the concepts and language of WHMIS that can be taken at home, in the classroom, or at work. The course is easy to access, navigate, and complete. It is user-friendly, makes use of plain language, and provides a WHMIS certificate. It is designed to teach about hazardous materials, safety symbols, protective equipment, documentation, and regulations. After taking the course, job seekers have a better chance of gaining employment in facilities where WHMIS training is required.

The course includes an introductory section on how to use a computer, keyboard, and mouse. The subsequent two sections provide a WHMIS overview, with follow-up questions and answers. Jankowska–Pacyna said that individuals with level 3 literacy can complete the course on their own; those with level 1 or 2 literacy need more help.

Visit [www.practicalwhmis.com](http://www.practicalwhmis.com) to see two training modules. Access can be obtained using a temporary ID and password: guest@alphaplus.ca (ID), and h6154j (password). The support contact is Frank Sroka ([support@owlware.com](mailto:support@owlware.com)).

Practical WHMIS courses can be purchased from the AlphaPlus Centre at [www.alphaplus.ca](http://www.alphaplus.ca) (Purchase section). The cost is \$39.95 per user, which covers the administrative costs of setting up an account. Full access is provided for one full year from the time of registration. Users can print a WHMIS certificate upon completion of the course.

### **Exploring the LINCS Health and Literacy Special Collection- Sabrina Kurtz Rossi**

The Literacy Information and Communication System (LINCS) website is part of a U.S. 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. World Education supports this site with help from the U.S. National Institute for Literacy (NIFL).

The Health and Literacy Collection is one of several collections of resources available. It provides information about health curricula and resources of basic health information in plain language. The site also offers regional resources and provides culturally appropriate health information, including an index of materials written in languages other than English.

The site provides easy-to-read and easy-to-understand material, including interactive audio and video materials. It values input from practitioners in the field aimed at developing and expanding the site to meet ongoing needs.

To see the site, visit [www.worlded.org/us/health/lincs](http://www.worlded.org/us/health/lincs).

## ***B. Focusing on Language and Culture***

### **1. Aboriginal Perspectives**

#### **Aboriginal Perspectives on Health and Literacy- Eileen Antone**

Janice Longboat introduced the session and Dr. Eileen Antone. Longboat expressed the need to understand health and literacy from an Aboriginal perspective using the medicine wheel.

Dr. Antone began the presentation by speaking in her Native tongue, which was followed with an English introduction. She said: "Today when we focus on language and culture, it is important that I begin in my language." She greeted everyone in the room and said she is from Turtle Island, Ontario.

In the longhouse, when Antone was doing her research on Aboriginal education, an elder gave Antone the Native name "Gulliweechatch" – she who gathers information. This elder had been taken to a residential school in Brandon, Ontario. She managed to keep her language by hiding with fellow students and speaking in secret.

Growing up, Antone never learned to speak in her Native tongue because her parents refused to speak their own language as a result of their own experiences. They wanted to protect Antone from the consequences they had suffered when they spoke their Native language instead of English. Now, Antone is in the process of learning her language.

Antone feels that because of racist government policies and oppression she did not learn her language. Language is very important because it carries culture, values, and beliefs. By not learning her language, Antone couldn't learn these as well.

"The elders tell us we give thanks every time we gather together. Thanks to you for gathering." Antone went to thank Mother Earth, for the water that flows, for the animals, for the plants, the medicines, and the four directions. She gave thanks for the birds, thunders that bring warm winds and rains, the sun which gives warmth, grandmother moon which regulates the Earth, the stars and their part in ceremonies of harvesting, and the Creator.

Antone told about herself, her work, and what she went through to reclaim her voice. She received her Masters degree at the end of her journey through the EuroWestern education system. However, Antone recognized that her journey was in fact incomplete.

Antone discussed a poem by Arthur Solomon about Western education versus the traditional way. Antone said the circle of life and the continuity had been broken. Now, the continuity has to be taken up again. It is a life long process.

Education, through residential and other forms of formal Euro-Western schooling, had become mandatory miseducation.

This poem challenged and empowered Antone to search, to create awareness, and to promote holistic education.

Antone stressed the importance of Literacy and Health based on a holistic world view. Being literate is the beginning of being. Reflective and reflexive critical thinking hold the key.

- Aboriginal literacy programs enhance literacy skills in a positive, self-fulfilling way.
- Self-knowledge reflects Aboriginal literacy in a cultural context.
- “Literacy culture” serves to motivate the learner to self-expression, self-affirmation, self-determination, and participation in local self-governance and community development through self-improvement.

In closing, Antone asked participants to consider the four aspects of development:

- mental
- emotional
- spiritual
- physical

She also showed a picture of the Two Row Wampum. This promotes equality that Canadian society was built on. It shows the Europeans were able to come to live alongside the Native peoples. Of the two rows of purple beads, one stands for the European vessel and one stands for the Aboriginal vessel, each with their own essence of life. If the two vessels travel down the river alongside each other, there will be peace, respect, and friendship.

### **Role of Aboriginal Spiritual Traditions in Healing and Wellness- Elaine Endanawas**

After an opening prayer, participants introduced themselves and described their interest in the topic.

One participant discussed a research project that focuses on maintaining small communities as distinct entities in a context of assimilation. He noted that literacy is an important variable in the maintenance of a community.

A psychiatrist commented that health literacy is an important element in helping people become more aware of and engaged in the journey of wellness.

“Health promotion is about self-determination,” said a participant. She asked, “How can literacy be a gateway for self-determination?”

A representative of the Aboriginal Head Start on-reserve program discussed how the program helps children with school and with studying English in addition to their own culture, language, and traditions. He noted that First Nations children have a double challenge: to learn English or French and their own language.

Some participants discussed their experiences at residential school, noting that they were forbidden to speak their own language while at school. One speaker commented that having an "Indian name" kept her strong during that time.

"Literacy work is healing work," a speaker commented. She said that she has accompanied students to medical appointments as an advocate to ensure that the students are heard. She expressed interest in learning effective ways of addressing members of the medical community and of informing them about these issues.

The literacy coordinator for an Ontario Aboriginal community said that self-direction and self-management are personal skills that are an important part of literacy. The health of the whole person is therefore the focus.

Endanawas described the role of spirituality in health from an Aboriginal viewpoint. She explained that she calls herself an Indian, saying that there is nothing wrong with that word. At the time of Columbus, the country of "India" had a different name. The word "Indian" came from a European word that meant "people of God." Therefore, Endanawas said, she is comfortable with the word because "we are all people of God." On the other hand, name-calling and negative images of Aboriginal people can be very hurtful. Racism and discrimination are very hard on children's self-esteem.

In addition, when an Aboriginal child lives in a French or English home rather than an Aboriginal home, the language and way of being are different. "Part of literacy is knowing who you are," said Endanawas. Many Aboriginal people grew up without knowing who they were, and they absorbed a lot of negativity. Once a person internalizes negative ideas, no one has to say anything - that person just believes those things about himself or herself.

Endanawas commented on the stories of Aboriginal people who were removed from their homes as children, noting that any child taken out of his or her home suffers trauma. Such children have no one to turn to and must live by someone else's rules. When such children grow into adults, addiction or death in the family create more trauma - trauma that is not resolved if there is no one available to talk to.

Endanawas spoke about Aboriginal worldviews, giving some information on the four directions and the animals that stand at the doorway of each direction. She noted the many variations involving different animals.

In Endanawas's version, eagle is in the East. Eagle has keen eyesight and vision, useful qualities when envisioning the type of literacy program to create. In the South is deer, the provider of food and clothing. Deer gives love

unconditionally, showing how to share. In the West is buffalo, who was once weak but is now standing. Buffalo symbolizes the strength of the people. In the North is bear, who signifies movement and healing.

Endanawas discussed several sacred objects that come from the earth and that Aboriginal people use as tools. Sweet grass, when braided, represents the hair of mother Earth, symbolizing the people's connection to the earth. It also represents the connections between mind, body, and spirit.

Water is also very important. It is the blood of mother Earth. Like blood, water enters the Earth's system (from the sky) and travels through the earth in various forms, nourishing everything there. Every glass of water drunk is a celebration of being part of the sacredness of the whole system.

Other tools include feathers, tobacco, and sage. Endanawas explained that tobacco is offered in prayers. Aboriginal family therapists may give tobacco ties to their clients, who then hold those ties when talking. The therapists tell their clients to pray with the tobacco, and they reassure the clients that they are being heard. At the beginning of a session, clients will be asked if they want to smudge. Smudging brings a person into balance and helps that person to stay open. Smudging is also good for the therapist. It helps him or her keep an open mind and to focus on the client. Another option is to open and close sessions with a prayer.

To end the discussion, Endanawas picked up a drum, explaining that its sound is the heartbeat of mother Earth - and the heartbeat is the first sound humans hear in the womb. The drum can be a powerful way to find a voice.

Endanawas explained that the Aboriginal worldview is a way of life, not just an occasional practice. "You are sacred," she reminded everyone. "Light is within you, and you are responsible to keep it shining." Aboriginal people have many ways of connecting with their culture. For example, they can attend powwows, spiritual gatherings, and healing circles. Also, people can look for the many available opportunities to listen to elders speak.

### **Creating Aboriginal Literacy and Health Publications- Maria Morrison**

Having worked for Ningwakewe Learning Press (Owen Sound, Ontario) since its inception, nine years ago, Morrison is well-placed to discuss creating Aboriginal and Health Publications. From this experience, Morrison discussed her knowledge of print literacy.

NLP produces five to six publications a year. They are funded provincially and through the National Literacy Secretariat (NLS). NLP sells materials across North America, from northern Canada to the United States.

Examining their publications, the team at NLP realized they had not created any health materials. The decision was made to do a “Healthy Life Series”. NLP looked at contemporary issues that are affecting Aboriginals today. For example, the death rate by cancer is 25% higher for Aboriginals than non-Aboriginals. Diabetes is three times the national average. The number of AIDS cases in the Aboriginal community has steadily risen over the last ten years. Suicide rates are at least three to 5 times higher than the national average. As well, low literacy rates are more extreme among Aboriginal Canadians.

Gilles Pinette, from Manitoba, is the author of the Healthy Life books. The approach to the materials is to blend evidence-based Western medicine with traditional Aboriginal practices. NLP uses a story-telling approach to gain emotional attachment with readers. The reasoning behind this is that readers remember stories and their morals better than lists of facts. There is an attempt to touch the reader with the story and the illustrations or pictures.

An essential part of materials development is the curriculum task team. Many people, including a professor, literacy learner, literacy teacher, and others with various backgrounds, work together. Everyone gives feedback that is taken into consideration before a final draft is sent for publication.

NLP tries to reach as broad an audience as possible, but Morrison says a lesson she has learned is that you cannot please everybody all of the time. NLP does its best to reflect all Aboriginal communities but recognizes that there are limits. One participant commented that there are many distinctions between Aboriginal groups, but she feels they are lumped together. She also pointed out that the materials are being published in English and not in Aboriginal languages. Morrison responded that this is an example of what she meant about not being able to please everyone. As a result of funding, NLP has to meet specific guidelines. Cree syllabics is the Native language published by NLP.

Morrison discussed the role of the internet in health literacy. While she herself finds this a useful tool for gathering health information, it is not always a method low literacy learners can easily access and should not be relied on.

Morrison listed a number of elements NLP considers before publishing a piece. These include:

- language
- sentence length
- bullets and summaries
- use of every day words
- real life examples
- material that is engaging to reader
- questions and answers
- links to more information – this may be regional specific, placed on the back of the publication
- visual appeal and clues to reinforce learning – this can boost cost, unfortunately.

Some other clear language tips relating to layout and design from Morrison were:

- pay attention to the font. When publishing, be sure you choose a readable font, for example Arial or Times New Roman
- Do not use only capital letters or shaded letters.
- The length of lines should be no longer than five inches
- The right side should be left jagged, not justified
- Avoid hyphens
- Avoid clutter

Morrison emphasized that it is important to field test your material before distributing. She said her primary field tester is her son. He spots little things that other people might have missed.

A question and answer period concluded the session. Some of the issues discussed were creating resources in languages other than English, and some of the restraints around this.

## 2. Francophone Perspectives

### **Les déterminants sociaux de la santé et minorités francophones- Louise Bouchard**

La présentation de Louise Bouchard, intitulée «Les déterminants sociaux de la santé et les minorités francophones», portait sur

- l'approche des déterminants sociaux de la santé pour l'étude des minorités francophones, la santé et la prise en charge de la santé;
- l'utilité du concept de capital social;
- le contexte sociopolitique des minorités francophones;
- un modèle conceptuel du capital social;
- l'enquête de santé dans les collectivités canadiennes.

On en sait peu sur la santé des francophones en situation minoritaire.

Cependant, des études ont permis d'en arriver à quelques constats intéressants, à savoir que

- Les francophones de l'Ontario, comparés aux francophones d'ailleurs, sont moins nombreux à se dire en très bonne santé.
- Davantage de francophones se disent limités dans leurs activités et souffrir de problèmes de santé chroniques.
- Les francophones déclarent une consommation plus importante de médicaments.
- Un pourcentage élevé de francophones dit ne pas avoir accès aux services nécessaires.
- La consommation d'alcool et de tabac serait plus élevée et plus régulière chez les francophones.

- Les francophones de l'Ontario ont peu accès à des services de santé en français.
- Les membres des collectivités francophones en situation minoritaire ont tendance à avoir des niveaux d'instruction et d'emploi plus faibles.

La recherche montre que dans l'ensemble, il existe des inégalités régionales prononcées sur le plan de l'accès aux services en français. L'étude de M<sup>me</sup> Bouchard partait des hypothèses selon lesquelles la santé a des dimensions individuelles et sociales, et le capital social est un élément important d'une bonne santé. Le capital social peut se définir de nombreuses façons, mais la présentatrice a employé les définitions suivantes ☐

- Selon Bourdieu (1986), le capital social comprend les ressources liées à la possession d'un réseau stable de relations, autrement dit l'appartenance à un groupe.
- Le capital social défini par Coleman (1990) prend différentes formes ☐ les normes de réciprocité (confiance), les réseaux d'information, les normes et sanctions sociales, les organisations.
- Pour Putnam (1995), le capital social est composé des normes de réciprocité et des réseaux d'engagement civique qui renforcent l'efficacité de la société.

La question du capital social et des enjeux sociaux qui ont une incidence sur la santé est importante. Selon M<sup>me</sup> Bouchard, il existe une corrélation entre l'espérance de vie et les divers indicateurs de la position sociale, comme le revenu, le niveau d'instruction, la profession et le lieu de résidence. M<sup>me</sup> Bouchard croit aussi qu'il existe une corrélation directe entre l'état de santé d'une personne et son rang dans la hiérarchie sociale.

### **La base de données en alphabétisation des adultes et les ressources- Lorette Chiasson**

L'objectif de cette présentation était de partager l'information sur des ressources dans le domaine de l'alphabétisation et de la santé. Un des buts de la Base de données en alphabétisation des adultes (BDAA) est de tisser de nouveaux partenariats dans le domaine de l'alphabétisation et de la santé. Les discussions qui ont eu lieu lors de cette présentation se sont révélées le commencement de ce réseautage.

La Base de données en alphabétisation des adultes veut jouer un rôle de chef de file pour former une infrastructure en alphabétisation. Le site Web de la BDAA fournit des renseignements complets sur les événements et les activités, les ressources disponibles, les prix d'excellence, et les nouveautés dans le domaine de l'alphabétisation ou de l'éducation des adultes.

A chaque semaine, l'organisation publie le témoignage d'une personne apprenante qui est inscrite à un programme d'alphabétisation. La BDAA a aussi des liens sur son site, avec plusieurs organismes qui oeuvrent en alphabétisation,

telles que la Fédération canadienne pour l'alphabétisation en français (FCAF) et l'Association canadienne d'éducation de langue française (ACELF). Des liens se trouvent également sur la page de chaque province ou territoire, par exemple, au Nouveau-Brunswick, un lien avec la Fédération d'alphabétisation du N.-B.

### **Alphabétisation et santé chez les francophones en situation minoritaire- Sylvain Deslisle**

Sylvain Deslisle est analyste à la Division de la démographie de Statistique Canada. Il a présenté les données préliminaires du dernier recensement en ce qui concerne les niveaux de littératie des francophones du Canada hors-Québec.

Plusieurs enquêtes importantes de Statistique Canada ont touché à la santé ou à l'alphabétisation

- l'Enquête internationale sur l'alphabétisation des adultes (1994),
- l'Enquête internationale sur l'alphabétisation et les compétences des adultes (2003),
- Le Profil statistique des communautés canadiennes,
- l'Enquête nationale sur la santé de la population.

Si Statistique Canada s'intéresse aux liens entre l'alphabétisation et la santé, c'est parce que les adultes faiblement alphabétisés sont plus vulnérables aux problèmes de santé et peuvent être limités dans leurs activités quotidiennes, et que l'accès à une information sanitaire variée présente des avantages pour leur santé.

Aux États-Unis, l'organisme ETS (Educational Testing Service) définit cinq types d'activités liées à la santé

- la promotion de la santé,
- la protection de la santé,
- la prévention des maladies,
- les soins de santé,
- l'orientation dans le système de soins de santé.

ETS a mis au point un nouvel indicateur de la littératie en matière de santé qui définit et mesure 190 tâches liées aux cinq activités susmentionnées. Il devrait être possible d'appliquer cette méthode aux données du recensement canadien de 2003.

Selon les résultats d'enquêtes en cours, les personnes qui n'ont pas achevé leurs études secondaires, les membres de groupes linguistiques minoritaires et les plus de 65 ans sont parmi les segments démographiques les plus à risque d'avoir un faible niveau de littératie en matière de santé. C'est pourquoi il est important d'étudier les francophones du Canada hors-Québec, qui sont pour la plupart plus âgés que leurs compatriotes québécois. Par le passé, ils ont aussi été relativement moins nombreux à achever leurs études secondaires.

D'autres résultats de recherche indiquent que les francophones du Canada ont plus tendance à être atteints de handicaps physiques et de maladies chroniques. Enfin, ceux et celles qui n'ont pas terminé leurs études secondaires sont moins susceptibles que les anglophones dans la même situation d'évaluer leur santé comme étant «bonne» ou «excellente».

Une prochaine enquête sur la vitalité des minorités de langue officielle aura deux grands objectifs : recueillir de l'information sur les priorités communautaires comme l'éducation et la santé, et produire de l'information pour aider divers ministères à élaborer des politiques et des programmes appropriés. Cette enquête comblera aussi les lacunes dans nos informations sur l'accès aux services de santé dans les langues minoritaires.

### **Identité ethnolinguistique et autodétermination: des facteurs de la santé- Kenneth Deveau & Rodrigue Landry**

Pour commencer leur présentation, Kenneth Deveau et Rodrigue Landry ont expliqué le lien entre l'alphabétisation et la santé, d'une part, et les notions d'identité et d'autodétermination, d'autre part. Ils ont posé trois questions clés :

- Qu'entend-on par l'identité ethnolinguistique?
- Qu'entend-on par l'autodétermination?
- Quelle est la relation entre ces deux variables et l'alphabétisation et la santé?

En réponse à la première question, «qu'entend-on par l'identité ethnolinguistique?», les présentateurs ont commencé par une définition. L'identité ethnolinguistique comporterait deux grands éléments : l'autodéfinition et l'engagement identitaire.

L'autodéfinition signifie reconnaître et affirmer son appartenance ethnolinguistique à un groupe, ce qui veut dire comprendre qui l'on est à la lumière de nombreux facteurs, dont la culture, la langue, l'instruction, l'appartenance ethnique, la géographie, par rapport au passé et par rapport au futur.

L'engagement identitaire est le sentiment d'appartenir à un groupe; il émane de l'évaluation d'actions personnelles et de leur importance émotionnelle. Il se compose de trois éléments :

- L'autocatégoriesation (Je suis comme les membres du groupe X.)
- L'estime de soi collective (Je sens que l'image du groupe X est positive.)
- L'engagement émotionnel (Je suis prêt/Je suis prête à défendre le groupe X.)

La question suivante, «qu'entend-on par l'autodétermination?», a été expliquée au moyen d'une brève description de la théorie de l'autodétermination (Deci et Ryan, 1985, 2000, 2002), dont voici l'énoncé :

- Les humains ont une propension naturelle à la croissance, à l'apprentissage et à l'intériorisation et à l'intégration des valeurs et des normes sociales qui motivent le comportement.
- La motivation des personnes ne varie pas uniquement en fonction de sa quantité mais aussi en fonction de sa qualité.
- Une typologie de la motivation varie en fonction du degré d'autodétermination ou de la proximité du moi de la régulation du comportement.

La dernière question, «quelle est la relation entre ces deux variables et l'alphabétisation et la santé?», a été abordée par le biais d'une étude des avantages éducatifs de la motivation autodéterminée.

- Apprentissage conceptuel
- Résolution de problèmes
- Rendement scolaire
- Plaisir à l'école
- Créativité
- Intérêt
- Confiance

Les présentateurs ont ensuite discuté de la relation entre l'identité ethnolinguistique et l'autodétermination. Selon la recherche, le développement d'une identité ethnolinguistique forte et positive contribue à la satisfaction des besoins d'appartenance, d'autonomie et de compétence. Une identité ethnolinguistique forte et positive se développe par la socialisation et par les expériences de prise en charge de soi.

Les résultats finals de la recherche étaient les suivants

- Des contacts linguistiques fréquents, autonomisants et conscientisants dans la langue maternelle et avec des membres de l'endogroupe conduisent à une identité ethnolinguistique forte et positive.
- Le développement d'une identité ethnolinguistique forte et positive contribue à la satisfaction des besoins psychologiques.
- La satisfaction de ces besoins conduit à une motivation autodéterminée pour l'apprentissage et l'utilisation du français.

Compte tenu de ces résultats, il semble que la santé des membres d'une communauté ethnolinguistique minoritaire pourrait être reliée à la santé de la communauté elle-même. Des recherches ultérieures pourraient étudier la relation entre l'identité ethnolinguistique et des indicateurs de la santé.

### **Les aînés: Leurs santé et l'alphabétisation- Roger Doiron**

Beaucoup de Canadiennes et de Canadiens âgés n'ont jamais terminé leurs études secondaires, ce qui explique pourquoi la plupart ont de faibles capacités de lecture et d'écriture. Mais comme les différents ordres de gouvernement

appuient l'alphabétisation dans une perspective d'employabilité, les programmes d'alphabétisation des aînés sont sous-financés.

Au Nouveau-Brunswick, le Réseau-action communautaire (RAC) fait la promotion de la santé et du bien-être dans les populations acadienne et francophone, en insistant tout particulièrement sur la prestation de services de santé de qualité aux aînés, dans leur propre langue. À cette fin, le RAC met l'accent sur

- la sensibilisation communautaire à l'importance des collectivités en santé,
- la responsabilisation des particuliers, des collectivités et des populations à leur santé et à leur bien-être,
- l'intégration des besoins des populations acadienne et francophone dans la planification et la prestation des services régionaux et locaux,
- la participation accrue à la formulation des politiques.

Entre autres activités, le RAC

- organise des campagnes de sensibilisation au bien-être,
- associe à sa mission et à ses buts les organismes et associations qui représentent les intérêts des communautés francophone et acadienne du Nouveau-Brunswick,
- s'associe avec d'autres groupes à la stratégie du Nouveau-Brunswick pour favoriser le bien-être,
- fait de la sensibilisation sur l'alphabétisation en tant qu'élément du bien-être,
- souligne les pratiques exemplaires en matière de promotion du bien-être.

Le RAC concentre ses efforts sur le système de santé du Nouveau-Brunswick, qu'il veut aider à répondre aux espoirs et aux attentes de la clientèle (et même à les dépasser), à trouver des moyens d'améliorer la prestation de services en français et à former du personnel soignant francophone.

Le RAC est très préoccupé par la situation des aînés, car beaucoup ne comprennent pas le système, ont honte de demander des services dans leur langue et, même s'ils se font soigner en français, ont du mal à comprendre le jargon professionnel.

En Ontario et au Nouveau-Brunswick, le taux de mortalité des francophones âgés est supérieur à celui des anglophones âgés. Ce lien entre la langue de son choix et la qualité des soins reçus mériterait une étude approfondie.

### **Atelier pour les personnes apprenantes: Comment mieux communiquer avec les personnes qui ont des difficultés à lire et à écrire- Margo Fauchon**

Le but de l'atelier, a expliqué Madame Fauchon, est d'arriver à des suggestions pour rendre les services de la santé plus accessibles aux personnes avec des difficultés en ce qui concerne l'alphabétisme. Elle a expliqué que l'atelier prendrait la forme d'une table ronde et que les participants feraient un remue-

méninges à ce sujet. Elle a posé deux questions au groupe, pour mieux cerner la question. Comme personne qui a de la difficulté, qu'est-ce que je peux faire pour faciliter mon accès aux services de la santé? Qu'est-ce que le professionnel de la santé peut faire pour rendre les services offerts plus accessibles?

Les participants, eux-mêmes des personnes ayant des difficultés à lire et écrire et ayant rencontré des problèmes dans leurs contacts avec les services de santé, ont attribué ces problèmes à un faible niveau d'alphabétisme et au peu d'efforts des fournisseurs de services pour s'adapter en fonction des difficultés de leurs patients. On a aussi parlé de la difficulté de recevoir des services en français, surtout dans un français accessible.

Mme Fauchon a posé quatre questions précises pour orienter la discussion.

### **Est-ce qu'il y a eu des fois où vous n'avez pas compris le médecin?**

Il y avait consensus chez les participants – cela leur est arrivé à toutes et à tous. Les participants ont cité les raisons suivantes:

- les «grands» mots
- des formulaires compliqués à remplir
- pas d'aide pour remplir les formulaires
- des «grands» mots en anglais et en français – «Ça ne fait pas de différence dans quelle langue, si on ne comprend pas, on ne comprend pas»
- une taille de police trop petite
- des styles de police difficiles
- des fournisseurs de services de santé qui ne vérifient pas si les directives ont été comprises
- la tentation de prétendre que l'on a compris plutôt que d'admettre qu'on n'a pas compris
- des médecins qui utilisent un niveau de langue trop élevé
- des médecins et des garde-malades qui ne prennent pas le temps suffisant pour discuter du problème et pour s'assurer que leur interlocuteur a compris et des rapports de supériorité entre le patient et le médecin
- donnant le sentiment au patient qu'il n'est pas respecté

Il est très important d'être compris, ont conclu les participants. Ils se sont entendus pour dire que les fournisseurs de services de santé doivent passer plus du temps et s'y prendre différemment avec les personnes qui ont de la difficulté à lire et à écrire afin de les comprendre et de comprendre leur problème.

### **Quelle est la relation entre l'alphabétisation et la santé?**

De l'avis d'une participante, il s'agit d'un problème de mobilité, les personnes avec des problèmes de lecture restant à la maison et en marge de la société. Elle a ajouté que cet isolement conduit souvent à la dépression.

Un autre participant a expliqué que, pour lui, il s'agit aussi d'un problème de sécurité au travail. Il a donné l'exemple des contacts avec les produits toxiques et

ajouté qu'il ne s'agit pas uniquement d'un risque pour la personne en question, mais aussi pour ses collègues.

Les gens qui ont de la difficulté à lire, a souligné une autre participante, ne peuvent pas facilement comprendre les directives sur les boîtes de médicaments et risquent donc de prendre les mauvais médicaments ou de mal les prendre. À l'inverse, certaines personnes ne prennent aucun médicament par peur de commettre une erreur fatale.

On ajoute que les nouvelles technologies de l'information et de la communication ont multiplié les difficultés pour les personnes avec des problèmes de lecture et d'écriture.

Le rapport est simple, résume-t-on il faut comprendre pour rester en bonne santé. Il ne faut pas non plus oublier la relation entre l'alphabétisme et l'estime de soi.

### **Quelles sont les responsabilités des professionnels de la santé vis-à-vis des personnes qui ont des difficultés de lecture et d'écriture?**

On cite à nouveau les «grands» mots. Un participant a expliqué que, à son avis, il est important que les fournisseurs des services de santé se servent de ces termes pour qu'on puisse les apprendre, mais qu'ils doivent prendre le temps de les expliquer.

Une participante a souligné combien il est important pour le corps médical de vérifier si le patient a effectivement bien compris, ce qui soulève la question des services en français pour les francophones.

On a ensuite parlé des formulaires. Le groupe convient que l'on doit donner l'occasion aux personnes qui éprouvent des difficultés de lecture et d'écriture de répondre oralement aux questions.

Pour des communications écrites, on a souligné l'importance de limiter le texte à l'essentiel dans un langage simple, clair et précis. Une participante a proposé qu'on fournisse, en plus des brochures et des dépliants, des informations sous forme d'enregistrements audio et vidéo.

### **Qu'est-ce que je peux faire comme personne avec des difficultés pour faciliter mon accès aux services de la santé?**

Une participante a souligné l'importance de dire d'entrée que l'on a des difficultés de lecture et d'écriture. Elle a suggéré qu'une petite carte identifiant ce problème pourrait aider à la situation car on n'aurait pas à dire à haute voix qu'on a un problème et on éviterait ainsi des situations embarrassantes. Poussant plus loin cette idée, une autre participante a dit que cette information pourrait être inscrite dans le dossier médical pour ne pas que la personne ait besoin de répéter la même chose à chaque visite.

En conclusion, ont décidé les participants, il faut que l'on fasse preuve d'empathie et de patience des deux côtés. La personne avec des difficultés de lecture doit se rappeler que les fournisseurs de services de santé travaillent dans des conditions très difficiles, compte tenu de tous les problèmes que connaît actuellement le système de soins de santé. Elle peut aussi ne pas savoir que la personne en face d'elle éprouve des difficultés. Les fournisseurs de services de santé, pour leur part, doivent être sensibilisés aux problèmes qu'éprouvent les personnes avec des difficultés de lecture et d'écriture pour accéder aux services.

### **Projet d'harmonization à la petite enfance- Danielle Galipeau**

Ayant vu le jour en septembre 2000, le but du Projet d'harmonisation à la petite enfance est de faciliter l'intégration des jeunes enfants au système d'éducation et de mieux les préparer à affronter l'école à six ans. Le programme a trois composantes principales☐

- **Programme éducatif** pour la maternelle en partenariat avec le Centre parascolaire Quatre-Saisons.
- **Services périphériques** pour assurer le bien-être des élèves (petit déjeuner, service d'orthophonie, etc.).
- **Programme d'appui aux parents** (ateliers, ressources, références, etc.).

Le profil sociodémographique de l'école a aussi incité le CECLFCE à développer des initiatives pour contrer les effets de la pauvreté. Les objectifs du programme sont:

- Le développement et un apprentissage optimaux chez les enfants dès la petite enfance
- La préparation des enfants à la réussite, à l'école et tout au long de la vie.
- Entretenir un rôle parental positif, un milieu stimulant et une alimentation saine pour les enfants.
- Répondre aux besoins de la collectivité
- Orienter les familles qui ont besoin de services variés vers d'autres programmes publics destinés aux enfants.
- Faciliter l'épanouissement et le développement des parents.
- Offrir la formation nécessaire à tous les intervenants en éducation.

En plus de présenter les composantes et les buts du programme, Mme Galipeau a aussi présenté son rôle de coordonnatrice et les liens qui existent avec le centre des services communautaires Vanier.

### **Rendre lisible l'invisible : pratiques de lecture des faibles lecteurs et représentations des organismes – Roch Hurtubise**

Roch Hurtubise a fait le compte rendu d'une étude triennale des liens qu'entretiennent les personnes faiblement alphabétisées avec l'écrit. Il s'agit d'une étude importante, car la plupart des services sociaux dépendent beaucoup

de l'écrit dans leur travail avec leur clientèle, et que celle-ci est souvent faiblement alphabétisée.

Voici quels étaient les buts de l'étude

- Repérer les personnes faiblement alphabétisées parmi la clientèle des services sociaux.
- Analyser pourquoi ces personnes ne lisent pas et comment les encourager à lire davantage.
- Découvrir ce que signifie la lecture pour ces personnes, et le rôle qu'elle joue dans leur vie quotidienne.

Pendant la phase 1 de l'étude, l'équipe de recherche a interviewé des dispensateurs et des dispensatrices de services pour recueillir leurs impressions sur les personnes faiblement alphabétisées et sur les rôles des intervenantes et des intervenants qui les aident à accéder aux services. Ces rôles seraient les suivants

- La médiation observer et repérer les clientes et les clients faiblement alphabétisés et les aiguiller directement vers les services appropriés.
- La traduction utiliser des pictogrammes, des couleurs, des modèles et d'autres stratégies de communication non écrites.
- L'accompagnement aider la clientèle faiblement alphabétisée à maîtriser la lecture.

En général, le personnel soignant se dit préoccupé par les difficultés d'accès des personnes faiblement alphabétisées, mais reconnaît que l'on manque de soutien organisationnel pour résoudre ce problème.

Au cours de la phase 2 de l'étude, l'équipe de recherche a interviewé des personnes faiblement alphabétisées en étudiant leur rapport à la lecture et à l'écriture dans leur vie quotidienne. L'équipe a observé que pour une personne faiblement alphabétisée, les buts de l'alphabétisation sont l'humanisation, la participation et l'affirmation.

D'après ces résultats, l'équipe de recherche a conclu que le personnel soignant devrait scruter plus attentivement son propre rapport à la lecture et à l'écriture. Cette introspection devrait l'aider à établir de meilleurs rapports avec la clientèle. Par ailleurs, pour élargir l'accès aux services, les organismes qui desservent une clientèle faiblement alphabétisée devraient remettre en question leur utilisation exclusive de l'écrit et adapter les documents écrits qu'ils jugent essentiels pour la prestation de leurs services.

Pour consulter les résultats de l'étude (en français), prière de s'adresser à la coordonnatrice du projet, Lilyane Rachedi ([Lrachell01@courrier.usherb.ca](mailto:Lrachell01@courrier.usherb.ca)).

**Implications pour la recherche et le transfert des connaissances en alphabétisation et santé en français- Pierre Joubert**

Cette séance était une table ronde animée par Pierre Joubert, à laquelle ont participé Luce Lapierre, Lucie Lemieux et Rodrigue Landry.

Dans son mot d'ouverture, l'animateur Pierre Joubert a fait remarquer que les enjeux de l'alphabétisation et de la santé dépeignaient de façon particulièrement convaincante la vulnérabilité sociale. Les enjeux types étaient les problèmes d'accès et la capacité du personnel soignant d'intervenir efficacement. L'un des buts de la table ronde était de trouver des moyens de résoudre ces problèmes dans le contexte francophone.

Les panélistes ont discuté de la difficulté pour les responsables des domaines de l'alphabétisation, de la santé publique et de la recherche de transférer dans la pratique les résultats d'études. Le débat a donné lieu à d'autres idées et à des stratégies d'intervention pour l'avenir.

Luce Lapierre a proposé que l'on oriente la recherche et les interventions en analysant l'accès aux systèmes de soins de santé complexes du point de vue des apprenantes et des apprenants adultes. Les programmes d'alphabétisation peuvent viser à améliorer le niveau de lecture de leurs bénéficiaires, mais la collectivité de la santé doit aussi faire plus d'efforts pour simplifier l'accès à ses services, les gouvernements doivent améliorer les services en français, et lorsqu'il communique avec des adultes faiblement alphabétisés, le personnel soignant doit être suffisamment averti des écueils dans la communication.

Lucie Lemieux a parlé de la hausse inquiétante des taux de décrochage au secondaire, un problème que l'on considère en Outaouais comme étant un risque pour la santé publique. On fait actuellement des efforts pour contrer cette tendance. On tente de comprendre par la recherche le cheminement des décrocheurs et des décrocheuses – les points-clés où les jeunes songent à abandonner l'école, décrochent pour de bon ou envisagent un retour aux études.

Il existe déjà des programmes pour la petite enfance à l'intention des jeunes enfants de familles défavorisées ou à faible revenu. Ces programmes aident à préparer les enfants à la réussite scolaire et réduisent le nombre de jeunes qui abandonnent prématurément leurs études secondaires.

Les taux actuels de décrochage et d'échec des élèves du secondaire peuvent s'expliquer de deux façons – d'une part, les programmes scolaires favorisent les élèves qui se dirigent vers l'université, et d'autre part, ils ne reconnaissent pas la valeur de la formation professionnelle. Pour redresser cette situation il faudrait offrir davantage de cours pouvant intéresser les élèves qui n'iront pas à l'université ou mener une campagne de sensibilisation à l'utilité des métiers spécialisés.

Rodrigue Landry a affirmé que les francophones du Canada avaient de la chance que le français soit une langue officielle, car il est parfois compliqué, pour des raisons politiques et pratiques, de faire de la recherche sur les minorités linguistiques. Les possibilités de ce statut officiel devraient être explorées, et il faudrait définir les responsabilités fédérales et provinciales de manière à ce que

les francophones du Canada puissent exercer leurs droits et exprimer leurs préférences. Le Canada est encore loin d'avoir créé la synergie entre les différents secteurs et les différents ordres de gouvernement qui serait nécessaire pour renforcer la langue et la culture françaises.

Le débat qui a suivi les présentations a clairement fait ressortir que le personnel soignant ne devrait pas seulement penser au message à transmettre, mais à la capacité de la cliente ou du client de recevoir et de comprendre ce message. Il faudrait commencer à intégrer à la formation du personnel soignant l'apprentissage d'approches de communication efficaces et compréhensibles. Il devrait être pratique courante, durant les consultations, de demander aux patientes ou aux patients ce qu'ils ont compris et ce qu'ils vont faire.

Les panélistes ont rappelé à l'auditoire que les francophones du Canada ont du mal à accéder aux services de santé, non seulement en raison de leur faible niveau d'alphabétisation, mais des barrières géographiques et linguistiques. La préoccupation actuelle du gouvernement pour l'évaluation pourrait être l'occasion d'amorcer des recherches qui donneront des résultats concrets sur le terrain. De bons résultats montreront les avantages que comportent des collectivités, des institutions et des services francophones vigoureux.

La recherche a montré qu'une identité francophone forte et positive contribue au dynamisme de la communauté francophone. Selon les panélistes, ces résultats pourraient orienter concrètement l'élaboration de stratégies à l'égard des problèmes d'estime de soi qui influencent les taux de décrochage.

Pour clore la séance, Pierre Joubert a indiqué qu'il faudrait résumer les résultats et les recommandations des études sous une forme que les responsables des décisions puissent lire, comprendre et appliquer rapidement et facilement.

### **Recherche d'information médicale – une approche multi-factorielle – Stefan Kabene**

Stefan Kabene a discuté de l'accroissement de la popularité et de l'importance d'Internet comme voie d'accès à l'information sanitaire. En encadrant son propos par les cinq attributs de l'adoption d'une innovation selon la théorie de Rogers, il a expliqué les défis à surmonter pour que le public puisse profiter pleinement d'Internet.

- L'avantage relatif de la technologie – cet avantage existe lorsqu'une innovation est perçue comme étant plus avantageuse qu'une idée, un produit ou un service existant.
- Sa compatibilité – sa cohérence par rapport aux valeurs actuelles, à l'expérience du passé et aux besoins.
- Sa complexité : le niveau de difficulté associé à la compréhension et à l'utilisation d'une innovation.
- La possibilité de la tester – la capacité d'essayer l'innovation sans que cela nécessite une dépense ou un engagement majeur.

- Sa visibilité : le mesure dans laquelle une personne peut observer les effets et les avantages d'une innovation dans son milieu.

L'augmentation du nombre et de la fréquentation des sites d'information sanitaire en ligne donne à penser qu'Internet est une innovation que l'on adapte et que l'on adopte. Selon diverses études, les personnes atteintes de maladies chroniques ou de problèmes cardiaques qui consultent de l'information sanitaire en ligne font état d'un moindre niveau de stress, d'une meilleure adaptation à leur vie et d'une meilleure qualité de vie.

Le personnel soignant devrait se renseigner sur le nombre croissant de ressources en ligne pour pouvoir utiliser certaines de ces ressources par lui-même et faire des recommandations efficaces aux patientes et aux patients à ce sujet.

Qu'ils soient établis par des professionnels de la santé ou à l'aide d'une base de données, les « profils personnels de santé » adaptent une information sanitaire à une patiente ou un patient en particulier. Internet joue un rôle central dans la diffusion croissante de ces profils. Le site américain Heart Profilers offre un tel service ([www.americanheart.org/profilers](http://www.americanheart.org/profilers)).

Les internautes qui fréquentent les sites de ce genre manifestent une capacité accrue de reconnaître et de nommer leurs symptômes et d'agir en conséquence. Ces sites doivent donc fournir une information exacte et proposer des activités de soutien en ligne faciles à consulter et à comprendre.

Mais même par rapport à la popularité croissante de cette technologie, les francophones du Canada sont défavorisés. Non seulement ont-ils de trois à sept fois moins accès aux services de santé dans leur propre langue, mais ils possèdent de moindres aptitudes à comprendre et à utiliser l'information sanitaire trouvée sur Internet, car les membres des communautés francophones minoritaires sont relativement plus âgés, moins scolarisés et moins présents sur le marché du travail. Pour redresser ces inégalités, il faudrait élargir leur accès à Internet et créer de nouveaux sites d'information sanitaire de haute qualité en français.

### **La santé et la francophonie- Rodrigue Landry**

Le directeur général de l'Institut canadien de recherche sur les minorités linguistiques, Rodrigue Landry, est convaincu que si une collectivité n'est pas vigoureuse, la santé de ses membres risque de s'en ressentir. Dans une perspective générale, la santé et le bien-être ne comprennent pas seulement la santé physique, mais englobent une opinion positive de sa propre culture et de sa propre langue. Si la santé des francophones du Canada dépend de celle de la langue française au Canada, alors l'alphabétisation et la santé sont liées à la vitalité linguistique.

L'un des tests de la vitalité d'un groupe est sa capacité de transmettre sa langue maternelle d'une génération à l'autre. Plusieurs facteurs influent sur la force et la vitalité d'une langue

- les données démographiques (le nombre de locuteurs et de locutrices),
- le soutien institutionnel (le pouvoir ou l'influence que peut exercer le groupe),
- le statut de la langue (la reconnaissance sociale ou le prestige qui lui sont rattachés).

La vitalité de la communauté francophone peut influencer la santé de ses membres à plusieurs égards : par la participation à la gestion des services de santé, par la demande de services en français et par l'établissement d'autres services et programmes d'alphabétisation.

Le français est-il en bonne santé au Canada? Selon Rodrigue Landry, la vitalité de la minorité francophone est de plus en plus menacée. Les tendances démographiques sont inquiétantes

- Les langues officielles sont « territorialisées » plutôt que d'être intégrées à l'échelle du pays.
- La population anglophone a augmenté de 20%, contre 4% seulement pour la population francophone.
- La tendance sociale à adopter l'anglais comme langue maternelle dans les populations traditionnellement francophones se confirme.
- L'assimilation des locuteurs et des locutrices d'autres langues se fait en anglais plutôt qu'en français.
- De plus en plus de francophones épousent des non-francophones, ce qui a pour conséquence de réduire l'usage du français à la maison.
- L'urbanisation et l'exode rural affaiblissent les bastions francophones.

Les politiques qui ne changent rien à l'expérience des gens sont inefficaces. Il faut donc élaborer une stratégie globale pour maximiser les chances de renverser la tendance à l'anglicisation. Pour devenir francophone, une personne doit être socialisée en tant que francophone. Les gens ne naissent pas francophones, ils le deviennent.

Il ne suffit pas de résister à l'affaiblissement de la culture et de la langue françaises. Il faut redonner de la vitalité aux communautés francophones et acadiennes. Une stratégie de revitalisation globale doit miser sur la collaboration entre les communautés et les institutions francophones, établir des priorités et créer une synergie entre les gouvernements et la vie communautaire. Une telle stratégie doit comporter un marketing social efficace pour informer les francophones du Canada de leur droit à se faire servir en français et pour les encourager à exprimer leurs préférences. Le français est une langue minoritaire au Canada, mais c'est une langue officielle. Le gouvernement est donc tenu d'appuyer les efforts pour protéger et renforcer l'utilisation du français dans tous les endroits où vivent et travaillent des francophones au Canada.

## **Représentations sociales de la santé, du médicament et de l'alimentation chez des personnes analphabètes en contexte montréalais – Chantal Oulette et Catherine Garnier Geirson**

Voulant mieux comprendre l'incidence d'une faible alphabétisation sur la santé et le mode de vie des immigrantes vivant dans les quartiers économiquement faibles de Montréal, Chantal Oulette et Catherine Garnier Geirson ont interviewé 14 immigrantes (affichant une maîtrise fonctionnelle du français oral et inscrites à des programmes d'alphabétisation). Elles leur ont posé des questions sur leur santé, leur consommation de médicaments et leur nutrition, tout cela par rapport à leur utilisation de l'écrit.

Les questions liées à la santé portaient sur la santé en général et sur les relations avec les professionnels de la santé. Treize des 14 femmes ont dit jouir d'une bonne santé. Cependant, au fil des discussions, neuf d'entre elles ont admis qu'elles souffraient d'anémie, de diabète, de douleurs à l'estomac, de migraines, d'arthrite ou de problèmes liés à la ménopause. Cette contradiction apparente pourrait être liée à la croyance culturelle voulant que tant qu'une femme n'est pas clouée au lit ou hospitalisée, elle est en bonne santé. C'est une divergence qui mériterait d'être étudiée plus avant. À propos de leurs relations avec les professionnels de la santé, huit femmes ont dit comprendre l'information verbale, quatre ont dit qu'elles évitaient le système de soins de santé, et trois ont affirmé qu'elles pouvaient consulter des spécialistes parlant leur langue maternelle.

À propos de leur compréhension des consignes d'utilisation des médicaments, cinq femmes sur 14 ont dit avoir besoin de l'aide d'amis, de membres de leur famille ou d'un pharmacien ou d'une pharmacienne. Sur les cinq femmes qui prenaient régulièrement des médicaments pour soigner des maladies chroniques, quatre ont dit n'avoir aucun problème à observer les consignes des ordonnances du médecin. Ce constat ne signifie pas que ces quatre femmes avaient de meilleures capacités de lecture, mais plutôt que la consommation régulière d'un médicament porte moins à confusion qu'une consommation épisodique. Les réponses obtenues à une autre question révèlent que la plupart des femmes ne comprenaient pas en quoi le médicament qu'elles prenaient pouvait améliorer leur santé, et qu'elles ne se sentaient pas libres de poser des questions.

À propos de nutrition, seulement la moitié des femmes (7/14) avaient déjà consulté un livre de recettes, et de ce nombre, quatre seulement s'en étaient servi pour essayer de nouvelles recettes. Ces réponses donnent à penser que le fait de ne pas savoir lire pourrait nuire au régime alimentaire familial.

Les femmes interviewées se fiaient principalement à leur mémoire et à leur expérience personnelle pour résoudre les problèmes qu'elles rencontraient dans les domaines visés par l'enquête. Elles se fiaient à d'autres pour accroître leurs connaissances et prenaient peu de décisions par elles-mêmes en matière de santé, de médicaments et de nutrition.

## **Alphabétisation et surdité : un service populaire bilingue au centre des besoins sociaux – Anne-Marie Parisot et Rachel Berthiaume**

Anne-Marie Parisot et Rachel Berthiaume ont parlé de la prévalence des faibles capacités de lecture et d'écriture chez les Canadiennes et les Canadiens sourds (65%, contre 30% dans le reste de la population canadienne). Ce chiffre est inquiétant, car la connaissance du français demeure essentielle pour participer à la société québécoise. Lorsqu'on veut accroître les niveaux d'alphabétisation en français chez les adultes sourds au Québec, les principales difficultés sont les échecs passés, le manque de motivation et l'insuffisance des ressources.

Vue comme un handicap, la surdité est définie comme étant l'absence d'acuité auditive et une déficience biologique nécessitant une réadaptation. Cet état de santé complique beaucoup l'accès au français écrit. Vue dans une perspective culturelle, la surdité est définie comme une acuité visuelle accrue et comme une façon particulière d'agir, de penser et d'être. Le langage gestuel est considéré comme la « langue maternelle » de la culture sourde.

Adoptant une perspective culturelle de la surdité, les présentatrices ont expliqué que pour être bilingues, les personnes sourdes doivent faire de la langue des signes québécoise (LSQ) leur langue maternelle, et du français écrit leur langue seconde. La recherche tend à montrer que les Canadiennes et les Canadiens sourds nés dans une famille francophone apprennent beaucoup plus facilement à maîtriser le français écrit s'ils ont acquis au préalable une bonne connaissance de la LSQ.

Un logiciel d'alphabétisation très polyvalent, appelé *Le français au bout des doigts*, favorise l'apprentissage de l'orthographe, du vocabulaire et de la reconnaissance des mots dans leur contexte et s'est avéré efficace pour améliorer les niveaux de littératie des francophones du Canada atteints de surdité.

Pour améliorer l'accès de cette population mal desservie à l'information sanitaire, deux étapes sont importantes :

- Élaborer des vidéos d'information sanitaire en LSQ,

Adapter les règles du style clair et simple pour qu'elles respectent la structure de la LSQ dans les documents écrits à l'intention des personnes sourdes.

## **L'alphabétisation et la motivation chez des adolescents en difficulté d'apprentissage et de comportement- Ginette Plessis-Belair**

Dans cette présentation, Ginette Plessis-Bélaire a parlé du programme des écoles Centres de formation en entreprises et récupération (CFER). La mission du réseau des CFER est de travailler avec des adolescents qui ont des difficultés d'apprentissage et de comportement. Les CFER sont des écoles de la dernière chance qui permettent aux jeunes d'obtenir un diplôme certifié par le Ministre de

l'éducation du Québec. Sans cela, ces élèves ne pourraient obtenir un diplôme d'études secondaires essentiel dans la quête d'un bon emploi.

Mme Plessis-Bélaïr a expliqué que le travail avec des jeunes qui ont des difficultés d'apprentissage et de comportement est à la fois exigeant et stimulant. À leur arrivée dans le programme les jeunes ont déjà un lourd passé d'échecs scolaires. Leur confiance est très affectée. C'est pour cette raison que la motivation est une composante importante du programme.

Le programme offre à ces adolescents la formation requise afin d'acquérir les aptitudes leur permettant de devenir des personnes autonomes, des citoyens engagés et des travailleurs productifs. Le nécessaire développement de la littératie, dans ce contexte, est un défi. Cette présentation explique la perception des enseignants et des étudiants des CFER quant aux moyens utilisés, afin de poursuivre le développement de l'alphabétisation de ces jeunes dans ce contexte. La formule CFER préconise, entre autres choses, l'utilisation d'un journal intime comme élément déclencheur et prétexte au développement de la littératie et les élèves semblent accepter de poursuivre leurs efforts d'apprentissage.

### **Comment mieux communiquer avec les personnes qui ont des difficultés à lire et à écrire- Diane Pouliot**

Madame Pouliot oeuvre au sein de la Fédération canadienne pour l'alphabétisation en français ([www.fcac.net](http://www.fcac.net)). Créée en 1991 et regroupant 300 groupes d'alphabétisation en français au Canada, la Fédération a pour mission de promouvoir l'alphabétisation en français et d'assurer une concertation entre les intervenants en alphabétisation en français au Canada. Le présent atelier avait pour but d'aider les participants à mieux comprendre comment les personnes qui ont de la difficulté à lire et à écrire abordent, lisent et utilisent l'information écrite qui leur est présentée.

L'atelier a commencé par un exposé sur la situation actuelle de l'alphabétisme – au Canada en général et chez les francophones en particulier. Une étude réalisée par Statistique Canada en 1994 classe les Canadiens et les Canadiennes d'âge adulte selon cinq niveaux de lecture. Les résultats pour le Canada sont les suivants:

- Niveau 1: 22%
- Niveau 2: 26%
- Niveau 3: 33%
- Niveau 4 et 5: 20% (ces pourcentages sont approximatifs).

Chez les francophones les résultats sont légèrement plus faibles:

- Niveau 1: 25%
- Niveau 2: 27%
- Niveau 3: 39%
- Niveau 4 et 5: 9% (pourcentages approximatifs).

Sont dans les niveaux 1 et 2 des gens ayant des difficultés majeures à lire et à écrire et, comme le souligne Pouliot, c'était le cas de 52% des francophones d'âge adulte au Canada en 1994. Les personnes de niveau 1 éprouvent des difficultés très importantes en lecture. Elles ne réussissent même pas à interpréter les consignes qui se trouvent sur une boîte d'aspirine. Les personnes du niveau 2 sont en mesure de lire et d'écrire, mais de façon très limitée. Par exemple, elles ont de la difficulté à faire des comparaisons entre les informations écrites. On note que les personnes avec ce niveau de lecture ne sont pas toujours conscientes de leurs difficultés de lecture et ont tendance à éviter les situations où il faut lire ou écrire. Elles sont souvent moins optimistes, elles ont tendance à résister aux changements, elles sont moins confiantes et elles ont tendance à avoir moins d'estime de soi.

L'animatrice présente ensuite certaines caractéristiques du comportement des personnes avec des difficultés de lecture et d'écriture. Elle souligne d'abord qu'elles ont les mêmes priorités que les autres canadiens, soit la santé, l'éducation et le chômage. Elles se distinguent toutefois sur certains points:

- Elles préfèrent généralement des informations anecdotiques portant sur le vécu de tous les jours présentées sous forme de témoignages personnels
- Elles évitent toutes les formes de technologies de l'information et de la communication, les guichets automatiques par exemple
- Elles ne font presque jamais référence à l'information écrite
- Elles ne prennent pas en note les renseignements importants
- Elles se font souvent accompagner pour aller à leurs rendez-vous et hésitent à lire ou trouvent des excuses pour ne pas avoir à le faire – «J'ai oublié mes lunettes», par exemple

Après avoir dressé ce portrait des personnes avec des difficultés de lecture et d'écriture, l'animatrice a énuméré cinq responsabilités pour les fournisseurs de services:

- Être à l'affût des attitudes et des comportements qui indiquent que la personne n'a pas compris.
- Veiller à ce que suffisamment d'information soit fournie pour lui permettre de comprendre.
- Reconnaître que la personne en question peut éprouver des difficultés à s'expliquer.
- Parler lentement.
- Parler et écrire simplement et clairement.

Divers éléments peuvent nuire à la communication orale. Une information qui ne répond pas aux besoins, un objectif mal défini, un débit trop rapide, un excédent d'information et l'emploi de jargon, par exemple. Pour pouvoir communiquer plus clairement, il est important de comprendre d'abord ce que la personne avec qui l'on parle sait déjà, de faire attention à ce qui est dit et de faire attention au ton utilisé. Pour ce faire, il faut écouter attentivement, encourager le dialogue, faire attention à la simplicité de son langage, employer des phrases courtes et vérifier régulièrement la compréhension.

Les personnes avec des difficultés de lecture et d'écriture expliquent souvent que le problème se résume à l'emploi de mots trop «grands», comme en témoigne un vidéo présentant les témoignages de gens ayant ce type de difficultés.

Pouliot a expliqué toutefois que les mots utilisés ne sont qu'un aspect du problème. Elle a cité à l'appui les résultats d'une étude portant sur la compréhension d'un message au téléphone et en personne. Dans une communication en personne, l'étude attribue seulement 7% des problèmes de communication à la compréhension des mots, alors qu'elle en attribue 38% à la voix et 55% à la gestuelle. Pour ce qui de la communication au téléphone, 16% des problèmes tiennent aux mots et 84% à la voix.

Abordant ensuite la question de la communication écrite, l'animatrice a énuméré certaines caractéristiques des communications écrites efficaces. La personne qui écrit doit tenir compte du lecteur éventuel. Dans le cas des directives, il est préférable de présenter l'information par ordre chronologique. En d'autres mots, le rédacteur doit se demander «Qu'est-ce que le lecteur a besoin de savoir en premier pour agir?». Les textes qui guident le lecteur étape par étape sont plus faciles à comprendre. L'utilisation de sous-titres peut également aider et il est préférable d'écrire en phrases courtes et claires, avec des mots simples et concrets.

En guise de conclusion, Pouliot a présenté une série de recommandations pour faciliter la communication avec une personne qui a des difficultés de lecture et d'écriture:

- Il faut apprendre à connaître ses besoins, ses intérêts et sa disponibilité.
- Il faut comprendre ses difficultés à lire, à écrire et à communiquer.
- Il faut tenir compte de ses problèmes de compréhension.
- Il faut adapter les messages à ses besoins.

### **Les difficultés d'apprentissage et leurs impacts chez des familles vivant en milieu minoritaire: l'exemple de la Colombie-Britannique – Sylvie Stonehouse**

Sylvie Stonehouse a fait le compte rendu des résultats d'une enquête auprès des familles affiliées à Educacentre, un centre de formation de Vancouver pour les adultes francophones. Parmi ces familles, 36,6% avaient des enfants qui éprouvaient des difficultés en français oral et écrit. Ces familles, qui font partie d'une minorité linguistique, ont peu de ressources à leur disposition pour intervenir rapidement et avec succès.

L'enquête, qui a obtenu un taux de réponse de 57%, mesurait entre autres l'utilisation du français à la maison et le taux d'assimilation de la langue majoritaire.

Voici quels étaient les buts de cette enquête :

- Offrir de l'aide aux parents dont les enfants éprouvent des difficultés d'apprentissage,
- Offrir une aide particulière aux apprenantes et aux apprenants adultes qui éprouvent des difficultés d'apprentissage (ils sont de plus en plus nombreux),
- Établir des liens de collaboration avec les associations francophones et le conseil scolaire de langue française de la Colombie-Britannique,
- Sensibiliser les francophones de la Colombie-Britannique aux difficultés d'apprentissage et aux ressources qui existent.

L'enquête portait spécifiquement sur les difficultés d'apprentissage liées au manque d'aptitudes verbales et à la dyslexie. Ces difficultés ont été classées dans les catégories suivantes :

- Compréhension verbale
- Communication verbale
- Lecture
- Écriture
- Mathématiques
- Capacité de suivre des consignes

De toutes les familles ayant répondu, 39,6% ont dit éprouver des difficultés sur le plan de la langue parlée et écrite ou de l'apprentissage en général. En moyenne, 15 familles avaient reçu une aide particulière en réponse à plus de deux difficultés (motivation, hyperactivité, aptitudes verbales, écriture et mathématiques). Dans 60% des cas, au moins un des parents avait lui-même ou elle-même éprouvé des difficultés d'apprentissage.

Recommandations :

- Élaborer un plan de formation qui offre à cette communauté linguistique minoritaire des ressources humaines supplémentaires pour aider les élèves éprouvant des difficultés d'apprentissage.
- Exercer un dépistage précoce et aiguiller les familles vers des programmes de soutien.
- Fournir aux élèves en difficulté une aide en enseignement individualisée.
- Créer un réseau de collaboration pour faciliter l'accès aux ressources en français.
- Embaucher un spécialiste ou une spécialiste de la langue et des difficultés d'apprentissage.

### 3. Ethnocultural Perspectives

#### **Lesson learned from Community Health Nursing in the ESL Classroom- Elizabeth Diem**

This workshop described a program that helps undergraduate nursing students work with learners for whom English is a second language (ESL). The program was necessitated by a drastic change in the way the community clinical

placement of nursing students was organized. Formerly, students spent two days with a public health nurse each week for six weeks. In 1998, that schedule was changed to one day each week for eight months, giving the students an opportunity to work at sites and on projects for an extended period of time.

In 2001, clinical placements in ESL or language instruction for new Canadians (LINC) classes were organized with a school board and in community homes associated with a community health centre. Since then, 28 projects have been undertaken with multicultural adult learners. The nursing students worked in teams of two to six members.

The presenters explained the processes and events that constituted their involvement with the adult learners. Clinical placements consisted of an assessment phase and an action phase, both of which lasted between 6 and 12 weeks. Once weekly during the assessment phase, the nursing students spent one to two hours interacting with multicultural learners in classrooms or during breaks. Once every second or third week during the action phase, they spent time in the classroom on specified activities. They found that between two and four weeks were required to establish relationships, between two and six weeks to assess secondary data, between two and six weeks to initiate a community assessment, four weeks to conduct a specific assessment, and two weeks to determine a direction for future action.

The students used a process called “progressive inquiry” to gather information. This process is a non-threatening approach to gathering qualitative data, because it avoids written questionnaires or surveys. The process was used to engage community members in identifying issues that they would like to change. These activities were found to be relationship-building.

In preparation for engaging in the process, the nursing students were asked to use this three-step procedure:

- Decide on one of three questions.
- Determine how and when to approach people.
- Allow learners to tell their stories first, and then move into other areas such as barriers to health and health goals.

Emphasis was placed on asking questions gently. The students were also encouraged to approach people where they gathered, to record responses in field notes after the encounter, and to record other issues of interest.

In the analysis phase, students reviewed findings with a professor, determined a second cycle of questions, and repeated the process until all pertinent questions had been asked and most of the community members had been reached or people in a variety of settings were responding in the same way.

In the action phase (once weekly for 12 weeks), students planned what would be done, how it would be done, and how it would be evaluated.

Through their 28 projects, the students determined that the two chief areas of interest were nutrition and accessibility of health services. The next two topics of concern were mental health (for example, stress and relaxation) and exercise. With respect to exercise, one concern of adult learners from warm countries was their difficulty exercising during the cold Canadian winter. The students were able to address that concern with indoor activities. One such project was titled "Walking! It Feels Great." Another reflected the concern of some learners that tap water should always be boiled before consumption. That project was titled "Turning on to Tap Water: Assisting Healthy Adaptation to Canada."

The ESL teachers felt that having nursing students in the classroom produced benefits. One was quoted as saying "[They are] a great resource for [learners] and teachers on health-related topics. [Learners] seem to feel comfortable asking questions about their concerns. Interacting with the nurses gives them a chance to feel connected to their new community."

All participants experienced some challenges:

- The adult learners often saw the nursing students as a source of information for their individual treatment needs.
- Teachers had limited time to understand the terms and activities used by the nursing students. They also needed to help the students adjust the amount and delivery of health information.
- Initial challenges for the nursing students included handling this first-time exposure to professional practice outside the acute and chronic care settings, shifting from individual to population-based care
- Challenges for the nursing instructors included understanding what the students would be able to accomplish and conveying that understanding to students and advisors alike. They also needed to support the nursing students and the teacher advisors in finding common ground, so that learners and student nurses would both benefit.

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
- that building relationships takes time and is as important as providing a service such as health information delivery
- health care, and being healthy
- to develop clinical judgment in a community setting
- to feel that they had made a difference

The ESL and LINC organizations learned:

- that they can contribute to the preparation of health care professionals with a cultural perspective,
- that simple projects work best
- that small amounts of money can go a long way
- that small projects build community and capacity one project at a time

Proposed future directions for the program include:

- making changes in community nursing education to include multicultural clinical experience with the same population over several weeks
- organizing partnerships between the school of nursing and organizations that serve multicultural communities, and organizing similar partnerships with Public Health
- Suggested changes included assessing the needs of groups while encouraging partnerships and funding small local initiatives that directly address needs

One suggestion from the participants at the workshop was to involve an adult learner in introducing the student nurses to the issue of health literacy.

### **Getting the data right when working with refugee and asylum-seeking groups- Lisa Merry**

Lisa Merry outlined the results of her research project, an evaluation of the effectiveness of using translated questionnaires to collect data on health. With the help of interpreters, feedback was gathered from monolingual men and women on the readability and cultural appropriateness of a variety of self-administered questionnaires that had been translated into French, Tamil, Urdu, Spanish, and Hindi. The feedback revealed problems in design, word choice, and cultural bias.

- Participants who had never encountered a questionnaire before had difficulty completing one.
- Rating scales and skip-pattern questions (if “a,” go to “1”; if “b,” go to “2”) were difficult for many.
- Complex questions with conjunctions posed problems.
- Errors in grammar, spelling, and diction arose during the translation process.

Responses to several questions revealed areas of cultural difference that tended to skew the accuracy of the information given. The differences included

- expectations of privacy (what is and is not okay to talk about);
- notions of time;
- hypothetical or opinion-based responses;
- open-ended or context-dependent responses;
- and concept of the “self.”

Adaptation of the questionnaires to minimize the potential for ethnocultural miscommunication was recommended.

### **Momiji Health Care Society: a culturally sensitive program for Japanese-Canadian seniors- Brigitte Robertson**

Momiji Health Care Society believes that language and culture affect access to better health care. They also believe that healthy aging is linked to access to

health services and professionals. For this reason they offer programs and services to seniors, in their own language and culture in relation to healthy aging. This presentation drew on their experience with this type of programming. How literacy and language can be barriers to healthy aging for seniors was explained through examples of the centre's own work.

The presentation also emphasized how partnerships between healthcare providers and community centres can foster understanding for culturally appropriate best practices in health care and also provide better healthcare for seniors.

### **Unveiling sexuality: culture and gender disparities in South Asian populations- Julia Thomas**

Julia Thomas spoke about her research, which examined sexual power dynamics in South Asian immigrant couples. An Ethno-Cultural Liaison Group (ECLG) of newly arrived couples from Pakistan, India, Sri Lanka, and Bangladesh was recruited to provide feedback on survey and educational materials about AIDS and sexuality, and on study procedures in general. The husbands' and wives' groups held markedly different opinions in two main areas: ideas about sexuality and ideas about truthfulness.

On the subject of sexuality, the men expressed strong views that asking explicit questions about sex is always culturally inappropriate and insulting. They felt it very unlikely that their ethnocultural community would accept questions from the UNAIDS General Population Survey such as "Do you think this partner has other partners?" One husband commented, "I am angry just for reading it." The men also called the images in an HIV prevention pamphlet about proper condom use "pornographic" and "not suitable for women and children."

In contrast, the women's group felt that the materials presented could be effective tools for gathering data from individuals in their community, and for educating them, provided that the potential gains from the process (such as disease prevention and health care access) were made clear at the start.

Men and women also differed in their estimation of how truthfully members of their ethnocultural community would respond to the questionnaires being reviewed. Men expressed more fear that the information might make it back to their communities or somehow affect their application to remain in Canada. They recommended revisions to the process such as providing reassurance that all responses are kept secret and offering a verbal consent procedure in lieu of a written signature.

Ultimately, Thomas concluded, even though men and women in the South Asian community differed considerably in their viewpoints, those differences need not prohibit future investigation of taboo issues. Future research requires an awareness that the language and approach used with each partner is important and that instruction and education have to occur in a culturally appropriate way.

Because the symbolic meaning of language is perceived through a cultural lens, the oral and written communication surrounding research tools and procedures need to be tailored with ethnocultural sensitivities in mind.

### **Using multi-ethnic, multilingual focus groups to enhance research with refugees- Jodi Tuck**

Jodi Tuck spoke about her work exploring issues of cultural sensitivity triggered by research tools investigating women's reproductive health. For that study, Tuck worked with an Ethno-Cultural Liaison Group (ECLG) of 11 women from ten different countries. Each of the women spoke at least one other language in addition to English. She found that this multicultural group was able to provide rich feedback in a cost-effective manner. Speaking with them was a good way to make research more responsive to the community.

Despite the enormous diversity of the group, researchers were able to foster trust in the process and between the participants. Work with a discrimination questionnaire originally developed in Sweden, and that showed a real depth of knowledge about the experiences of refugee women helped to "break the ice" early on and established that the needs of the participants and their communities were the ultimate goal of the process. Building sessions around shared meals helped, too. One participant impressed upon Tuck the importance of female researchers making a conscious effort not to neglect simple greetings and "woman to woman" courtesies. Those simple courtesies communicate respect for refugee women as people. "You should ask a woman how her baby is before asking if she had sex last night," she suggested.

Feedback from the ECLG resulted in changes to consent forms and compensation. Many women did not want to tell their husbands about the nature of the study in which they were participating, but they felt that they could not sign the consent form for themselves, either. Some group members rejected any form of monetary compensation, finding it insulting. Others were insulted that the amount offered was so low. In the end, researchers gave a gift of a baby card and \$10 for each participant. Sensitivity to participants' opinions and concerns helped to sustain the researchers' connection with the communities.

## ***C. Building Knowledge in Literacy and Health***

### **1. Setting Direction for Literacy and Health Research in Canada**

#### **Alphabétisation et santé chez les francophones en situation minoritaire- Sylvain Deslisle**

Sylvain Deslisle est analyste à la Division de la démographie de Statistique Canada. Il a présenté les données préliminaires du dernier recensement en ce qui concerne les niveaux de littératie des francophones du Canada hors-Québec.

Plusieurs enquêtes importantes de Statistique Canada ont touché à la santé ou à l'alphabétisation

- l'Enquête internationale sur l'alphabétisation des adultes (1994),
- l'Enquête internationale sur l'alphabétisation et les compétences des adultes (2003),
- Le Profil statistique des communautés canadiennes,
- l'Enquête nationale sur la santé de la population.

Si Statistique Canada s'intéresse aux liens entre l'alphabétisation et la santé, c'est parce que les adultes faiblement alphabétisés sont plus vulnérables aux problèmes de santé et peuvent être limités dans leurs activités quotidiennes, et que l'accès à une information sanitaire variée présente des avantages pour leur santé.

Aux États-Unis, l'organisme ETS (Educational Testing Service) définit cinq types d'activités liées à la santé

- la promotion de la santé,
- la protection de la santé,
- la prévention des maladies,
- les soins de santé,
- l'orientation dans le système de soins de santé.

ETS a mis au point un nouvel indicateur de la littératie en matière de santé qui définit et mesure 190 tâches liées aux cinq activités susmentionnées. Il devrait être possible d'appliquer cette méthode aux données du recensement canadien de 2003.

Selon les résultats d'enquêtes en cours, les personnes qui n'ont pas achevé leurs études secondaires, les membres de groupes linguistiques minoritaires et les plus de 65 ans sont parmi les segments démographiques les plus à risque d'avoir un faible niveau de littératie en matière de santé. C'est pourquoi il est important d'étudier les francophones du Canada hors-Québec, qui sont pour la plupart plus âgés que leurs compatriotes québécois. Par le passé, ils ont aussi été relativement moins nombreux à achever leurs études secondaires.

D'autres résultats de recherche indiquent que les francophones du Canada ont plus tendance à être atteints de handicaps physiques et de maladies chroniques. Enfin, ceux et celles qui n'ont pas terminé leurs études secondaires sont moins susceptibles que les anglophones dans la même situation d'évaluer leur santé comme étant «bonne» ou «excellente».

Une prochaine enquête sur la vitalité des minorités de langue officielle aura deux grands objectifs : recueillir de l'information sur les priorités communautaires comme l'éducation et la santé, et produire de l'information pour aider divers ministères à élaborer des politiques et des programmes appropriés. Cette enquête comblera aussi les lacunes dans nos informations sur l'accès aux services de santé dans les langues minoritaires.

## **Implications pour la recherche et le transfert des connaissances en alphabétisation et santé en français- Pierre Joubert**

Cette séance était une table ronde animée par Pierre Joubert, à laquelle ont participé Luce Lapierre, Lucie Lemieux et Rodrigue Landry.

Dans son mot d'ouverture, l'animateur Pierre Joubert a fait remarquer que les enjeux de l'alphabétisation et de la santé dépeignaient de façon particulièrement convaincante la vulnérabilité sociale. Les enjeux types étaient les problèmes d'accès et la capacité du personnel soignant d'intervenir efficacement. L'un des buts de la table ronde était de trouver des moyens de résoudre ces problèmes dans le contexte francophone.

Les panélistes ont discuté de la difficulté pour les responsables des domaines de l'alphabétisation, de la santé publique et de la recherche de transférer dans la pratique les résultats d'études. Le débat a donné lieu à d'autres idées et à des stratégies d'intervention pour l'avenir.

Luce Lapierre a proposé que l'on oriente la recherche et les interventions en analysant l'accès aux systèmes de soins de santé complexes du point de vue des apprenantes et des apprenants adultes. Les programmes d'alphabétisation peuvent viser à améliorer le niveau de lecture de leurs bénéficiaires, mais la collectivité de la santé doit aussi faire plus d'efforts pour simplifier l'accès à ses services, les gouvernements doivent améliorer les services en français, et lorsqu'il communique avec des adultes faiblement alphabétisés, le personnel soignant doit être suffisamment averti des écueils dans la communication.

Lucie Lemieux a parlé de la hausse inquiétante des taux de décrochage au secondaire, un problème que l'on considère en Outaouais comme étant un risque pour la santé publique. On fait actuellement des efforts pour contrer cette tendance. On tente de comprendre par la recherche le cheminement des décrocheurs et des décrocheuses – les points-clés où les jeunes songent à abandonner l'école, décrochent pour de bon ou envisagent un retour aux études.

Il existe déjà des programmes pour la petite enfance à l'intention des jeunes enfants de familles défavorisées ou à faible revenu. Ces programmes aident à préparer les enfants à la réussite scolaire et réduisent le nombre de jeunes qui abandonnent prématurément leurs études secondaires.

Les taux actuels de décrochage et d'échec des élèves du secondaire peuvent s'expliquer de deux façons – d'une part, les programmes scolaires favorisent les élèves qui se dirigent vers l'université, et d'autre part, ils ne reconnaissent pas la valeur de la formation professionnelle. Pour redresser cette situation il faudrait offrir davantage de cours pouvant intéresser les élèves qui n'iront pas à l'université ou mener une campagne de sensibilisation à l'utilité des métiers spécialisés.

Rodrigue Landry a affirmé que les francophones du Canada avaient de la chance que le français soit une langue officielle, car il est parfois compliqué, pour des raisons politiques et pratiques, de faire de la recherche sur les minorités linguistiques. Les possibilités de ce statut officiel devraient être explorées, et il faudrait définir les responsabilités fédérales et provinciales de manière à ce que les francophones du Canada puissent exercer leurs droits et exprimer leurs préférences. Le Canada est encore loin d'avoir créé la synergie entre les différents secteurs et les différents ordres de gouvernement qui serait nécessaire pour renforcer la langue et la culture françaises.

Le débat qui a suivi les présentations a clairement fait ressortir que le personnel soignant ne devrait pas seulement penser au message à transmettre, mais à la capacité de la cliente ou du client de recevoir et de comprendre ce message. Il faudrait commencer à intégrer à la formation du personnel soignant l'apprentissage d'approches de communication efficaces et compréhensibles. Il devrait être pratique courante, durant les consultations, de demander aux patientes ou aux patients ce qu'ils ont compris et ce qu'ils vont faire.

Les panélistes ont rappelé à l'auditoire que les francophones du Canada ont du mal à accéder aux services de santé, non seulement en raison de leur faible niveau d'alphabétisation, mais des barrières géographiques et linguistiques. La préoccupation actuelle du gouvernement pour l'évaluation pourrait être l'occasion d'amorcer des recherches qui donneront des résultats concrets sur le terrain. De bons résultats montreront les avantages que comportent des collectivités, des institutions et des services francophones vigoureux.

La recherche a montré qu'une identité francophone forte et positive contribue au dynamisme de la communauté francophone. Selon les panélistes, ces résultats pourraient orienter concrètement l'élaboration de stratégies à l'égard des problèmes d'estime de soi qui influencent les taux de décrochage.

Pour clore la séance, Pierre Joubert a indiqué qu'il faudrait résumer les résultats et les recommandations des études sous une forme que les responsables des décisions puissent lire, comprendre et appliquer rapidement et facilement.

### **La santé et la francophonie- Rodrigue Landry**

Le directeur général de l'Institut canadien de recherche sur les minorités linguistiques, Rodrigue Landry, est convaincu que si une collectivité n'est pas vigoureuse, la santé de ses membres risque de s'en ressentir. Dans une perspective générale, la santé et le bien-être ne comprennent pas seulement la santé physique, mais englobent une opinion positive de sa propre culture et de sa propre langue. Si la santé des francophones du Canada dépend de celle de la langue française au Canada, alors l'alphabétisation et la santé sont liées à la vitalité linguistique.

L'un des tests de la vitalité d'un groupe est sa capacité de transmettre sa langue maternelle d'une génération à l'autre. Plusieurs facteurs influent sur la force et la vitalité d'une langue

- les données démographiques (le nombre de locuteurs et de locutrices),
- le soutien institutionnel (le pouvoir ou l'influence que peut exercer le groupe),
- le statut de la langue (la reconnaissance sociale ou le prestige qui lui sont rattachés).

La vitalité de la communauté francophone peut influencer la santé de ses membres à plusieurs égards : par la participation à la gestion des services de santé, par la demande de services en français et par l'établissement d'autres services et programmes d'alphabétisation.

Le français est-il en bonne santé au Canada? Selon Rodrigue Landry, la vitalité de la minorité francophone est de plus en plus menacée. Les tendances démographiques sont inquiétantes

- Les langues officielles sont «territorialisées» plutôt que d'être intégrées à l'échelle du pays.
- La population anglophone a augmenté de 20%, contre 4% seulement pour la population francophone.
- La tendance sociale à adopter l'anglais comme langue maternelle dans les populations traditionnellement francophones se confirme.
- L'assimilation des locuteurs et des locutrices d'autres langues se fait en anglais plutôt qu'en français.
- De plus en plus de francophones épousent des non-francophones, ce qui a pour conséquence de réduire l'usage du français à la maison.
- L'urbanisation et l'exode rural affaiblissent les bastions francophones.

Les politiques qui ne changent rien à l'expérience des gens sont inefficaces. Il faut donc élaborer une stratégie globale pour maximiser les chances de renverser la tendance à l'anglicisation. Pour devenir francophone, une personne doit être socialisée en tant que francophone. Les gens ne naissent pas francophones, ils le deviennent.

Il ne suffit pas de résister à l'affaiblissement de la culture et de la langue françaises. Il faut redonner de la vitalité aux communautés francophones et acadiennes. Une stratégie de revitalisation globale doit miser sur la collaboration entre les communautés et les institutions francophones, établir des priorités et créer une synergie entre les gouvernements et la vie communautaire. Une telle stratégie doit comporter un marketing social efficace pour informer les francophones du Canada de leur droit à se faire servir en français et pour les encourager à exprimer leurs préférences. Le français est une langue minoritaire au Canada, mais c'est une langue officielle. Le gouvernement est donc tenu d'appuyer les efforts pour protéger et renforcer l'utilisation du français dans tous les endroits où vivent et travaillent des francophones au Canada.

## **Implications for Canada of the Institute of Medicine Report *Health Literacy: A Prescription to End Confusion***

This panel addressed the implications for Canada of the Institute of Medicine (IOM) report on health and literacy in the United States. In her opening remarks, moderator Deborah Gordon El-Bihbety observed that *Health Literacy: A Prescription to End Confusion* represented a landmark in the study of a traditionally unappreciated area that presents hidden barriers to health. The shame and silence surrounding the issue has made the gap between knowledge and practice in health even wider for millions of individuals.

### **1. Literacy and Health in the US and the results of the IOM report- Rima Rudd**

April 2004 was a shining moment for the study of health and literacy in America, said Rima Rudd, School of Public Health, Harvard University, because of the publication of three key U.S. reports: *Literacy and Health Outcomes*, *Health Literacy: A Prescription to End Confusion*, and *Literacy and Health in America*. Those reports moved the topic of literacy and health onto the U.S. agenda in an unprecedented way.

*Literacy and Health Outcomes* is 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 (NALS) and the International Adult Literacy Survey (IALS), 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 (HALS) that more accurately captures the complexity of the tasks that individuals are expected to perform with health-related information.

Rudd described the findings in two major areas of the IOM report *Health Literacy: A Prescription to End Confusion*. First, she praised the report for expanding the definition of literacy. The expanded definition acknowledges that literacy is always part of an interaction, and 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 the health area 50 years ago, but that is certainly no longer the case in contemporary society. 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.

Second, the report recognizes that literacy always takes place in a context mediated by education, culture, language, and the communication skills of both the lay individual and the health practitioner. The burden of responsibility for effectively communicating information is a shared one. Arcane medical terms such as “nephrology” present unreasonable barriers to communication, and Rudd drew on that example to underscore the report’s finding that the U.S. health care system demands an unreasonably high level of literacy.

## **2. Literacy and Health in Canada- T. Scott Murray**

T. Scott Murray, Director General, Social and Institutional Statistics, Statistics Canada, presented a detailed analysis of Canadian literacy and health data. He noted that on average, health literacy levels in the U.S. adult population are slightly better than those in Canada. However, the Canadian level varies widely by province, with the level in Alberta being the highest and that in Québec being the lowest.

Murray pointed out that the Canadian data reveals an extraordinary correlation between levels of health literacy in the population and measures of self-perceived wellness. Past work on literacy has found that the educational level attained by an individual accounts for 60% of that person’s literacy skill level. Canadian data shows that this finding also holds true for health literacy.

Age becomes a factor in low levels of health literacy for two reasons: people tend to lose literacy skills as they age, and the senior population generally has a lower level of education. Another factor that Murray pinpointed for further discussion is the size of the area being surveyed. It affects the measurement of health literacy proficiency in the population. In urban areas, the proficiency is lower because of a high concentration of immigrants. In rural populations, the proficiency is lower because individuals are hard to reach with technologies.

These findings matter because the health literacy scores for specific populations affect where funding dollars are allocated first. A differential study of population health literacy assessment jointly administered with the United States could be very revealing, Murray suggested, if it sampled each of the domains that Rudd described in her recent research.

Murray ended his presentation by saying that he has no doubt that the conclusions and recommendations from the IOM report pertain to Canada too.

## **3. Implications for Canada- Irving Rootman**

Irving Rootman, Professor and Michael Smith Foundation Scholar for Health Research, University of Victoria, the final panellist, whole-heartedly supported Murray’s closing sentiment. Rootman asserted that the IOM’s report will very likely have a spillover value, raising the public and political profile of literacy and health in Canada as has already happened in the United States.

Rootman's presentation then focused on the report's implications for Canada in four specific areas: theory, knowledge, action, and research.

He introduced these implications for theory:

- Health literacy work will expand to include consideration of contexts outside direct health care settings.
- The onus of responsibility will shift as an individual's skill level comes to be viewed as just one element in a complex, interactive process.
- Literacy is being recognized as the necessary foundation of health literacy.
- The education system, the health care system, and media culture are being identified as key areas for intervention.

He then highlighted these implications for knowledge:

- The report brings information together in a way that Canadian researchers can use as a basis for comparisons.
- Attention is drawn to the consequences of low health literacy in the United States, suggesting that a strong relationship may exist between low health literacy and poor health outcomes.
- The importance of contextual barriers that impede the successful communication of health-related information is underscored, one such example being the mismatch between the complex level at which health materials are written and the literacy level of the users.

In terms of action, Rootman again emphasized that the list of recommendations in the report applies equally in Canada.

As for the implications for research, Rootman said that the report had already become the basis for a National Institutes of Health application for health literacy research. The findings will no doubt also influence research policies in Canada for years to come.

### **Canadian Literacy and Health Research Program: What should its future be?- Irving Rootman**

In this roundtable discussion, pressing questions about the future of the Canadian Literacy and Health Research Program (CLHRP) were addressed. Moderator Irving Rootman opened the discussion by explaining that, with project funding set to expire in March 2005, he and the fellow panelists, as well as the CLHRP team members, were seeking feedback from the delegates in two main areas:

- Program evaluation
- How to sustain the initiative if a majority of delegates agreed with this direction

Each panelist made a brief presentation followed by discussion. Comments from delegates were then shared in plenary.

Rootman presented a summary of the history and accomplishments of the CLHRP. A Social Sciences and Humanities Research Council (SSHRC) of Canada grant started the project in 2002. At that time, the team proposed to develop a national program of research on literacy and health in Canada. In just over two years, the team achieved nearly all of its initially stated goals. Rootman cited the previous day's very productive pre-conference workshop with more than 30 graduate students as just one example of CLHRP's significant and concrete success.

Research team member Heather Hemming spoke next about her current research into electronic communication of health information. She also described how this piece of research demonstrates another CLHRP objective: the stimulation of collaboration among researchers from various disciplines. Although her academic background is in literacy, Hemming has joined with members of the kinesiology department on that project, to the benefit of all.

Next, Jim Frankish shared his ideas about the directions that health and literacy research should take in the future. He emphasized the need to create a motive for future literacy and health research. Frankish suggested that the heightened awareness in the academic and health communities that has resulted from CLHRP's past efforts, must be broadened to include politicians and the public. Educating policy analysts and decision-makers about the payoffs of health and literacy research should enhance the likelihood of better funding for programs and scholarship. However, incentives for academics working in the area are very different from those delivering programming at the community level. Frankish concluded with the comment that good tools and methods for assessing the effectiveness of policies, practices, and interventions were by far the most urgent research needs.

CLHRP team member Deborah Gordon El-Bihbety prefaced her remarks by assuring delegates that her commitment to health and literacy research remains as strong as ever despite the broader scope of her new position. She praised the CLHRP for starting to address Canada's traditional status as a nation that is "program-rich but research-poor" in the health literacy area, and added that the country's unique multicultural makeup (Aboriginal, francophone, and ethnocultural) means that Canada is in an ideal position to make enormous contributions to health and literacy research.

However, under the new federal government, competition for funding dollars in health research will be even more intense than in the past. Gordon El-Bihbety called for the development of a draft policy for a strategic plan for health and literacy research. She also identified a need to frame the issue in a way that convinces policy and decision-makers to allocate scarce funding dollars for further research. Research projects with a clearly demonstrable impact on health or commercial potential are most likely to succeed in the current climate. For her, the key is to highlight the potential that such research holds to help people become more productive citizens.

The roundtable discussions fell short of thoroughly assessing the program. Most delegates in the room, although impressed by the CLHRP's accomplishments, did not feel informed enough to evaluate the program in any formal way.

During the discussion, Frankish observed that funding organizations have "pie-in-the-sky" expectations of what can be achieved by service delivery programs. He recommended that a better practice for the future would be to attempt to deliver less, but to accept accountability for reasonable and measurable outcomes. Frankish also drew delegates' attention to the fact that thousands of existing literacy-based initiatives will never bloom into full-blown research projects. This translates to a loss of aggregate information and resources that never make it onto policy-makers' radar screens.

In response, Rima Rudd, the woman Rootman identified as "the mother of literacy and health research," suggested that future research concentrate on creating a vehicle for capturing and sharing such information. Smaller groups need evaluation tools that are straightforward and easy-to-use, but uniform. A registry of feedback from such evaluations would also need to be created so that knowledge and experience can accumulate.

A participant from Ontario emphasized the need to educate university faculties about the concept of health literacy and to explore models used in other countries, such as Brazil.

Rootman commented on the need to move literacy and health onto the agenda of the next World Conference on Health Promotion and Education (to be held in Vancouver in 2007). He indicated that he may personally be well placed to accomplish that goal, because he currently sits on the conference planning committee.

A participant challenged the use of the term "literacy" as being too narrow to communicate the holistic dimensions of the research. Another suggested expanding the focus of the term to include a critical appraisal of information use. Yet another delegate recommended adopting a return-on-investment approach to policy-makers, so as to frame the benefits of research in terms that match the ways in which policy-makers really think.

### **Retrospective Evaluation of the National Literacy and Health Program- Rick Wilson**

Rick Wilson spoke about a study which reviewed the 10-year history of the National Literacy and Health Program (NLHP). The study considered impacts, outcomes, limitations, conclusions, and recommendations of the NLHP. The study aimed to raise awareness among health professionals about the links between literacy and health, to build commitment to literacy as a critical determinant of health, and to establish literacy partnerships within and outside of the health field.

Data was gathered from key documents, project reports by Human Resources Development Canada (now HRSDC), and a survey of key informants. A main finding was that, 10 years ago, professional organizations were paying more attention to literacy and health through journals and by offering educational activities such as workshops. A subsequent decline in attention to the topic could be related to a loss of capacity and resources in those professional organizations.

One of the major limitations of the study was that formal records and formal evaluations of partnerships were lacking. Much of the activity studied was funded by short-term grants and contracts, and data collection and reporting requirements in those activities varied widely. Over 10 years, partner groups have also undergone reorganization.

The study concluded that awareness was raised, that useful resources and services were developed, and a solid foundation for further work was established. More research is needed to identify best practices in health literacy and effective health literacy policies.

These topic areas were recommended for further study:

- The degree of literacy sensitivity among health care providers in diverse settings
- The impact of using plain language and readability formulas
- The effective approaches to literacy instruction and to incorporating health content and health literacy goals.

## 2. Methods for Research and Evaluation

### **Measuring Health Literacy- Jim Frankish, Irving Rootman & Brenda Kwan**

In this roundtable discussion about measuring health literacy, Jim Frankish served as moderator, while Irving Rootman and Brenda Kwan were discussion presenters.

Rootman began by saying he was looking forward to input from participants on their work into measuring health literacy, and said that the purpose of the roundtable was to stimulate discussion on these points:

- A draft conceptual framework of health literacy
- A draft instrument to measure health literacy (based on the conceptual framework)

Rootman said that he became interested in the question of health literacy after working in the field of evaluation and health promotion. During this work, he discovered some research which stated that health literacy is one of the few outcomes in health promotion intervention for which individuals can be legitimately held responsible.

Rootman outlined the objectives of his research:

- To develop a measure of health literacy appropriate to the Canadian context
- To test the application of the new measure with specific populations (the first population of interest is older adults, followed by immigrants and people living in poverty)
- To further develop a conceptual framework for a better understanding of health literacy and its role in Canadian society
- To develop a foundation for a descriptive and predictive model of the role of health literacy in relation to use of health services, determinants of health, and quality of life.

The team began its work by reviewing the existing definitions of health literacy. Those definitions were revised to develop an operational definition that would form the basis of further work. The operational definition is “the ability to access, understand, and communicate information to engage with the demands of different health contexts to promote good health across the life-course.”

Frankish mentioned that he had heard many people at the conference discussing issues related to health literacy but that are not necessarily health literacy itself. He asked participants to keep that distinction in mind during their discussions.

Frankish stressed the importance of clearly identifying what is to be measured before beginning any work of this nature. Once that clarity has been achieved, health literacy can be situated to determine its predictors and its change (or lack of change) over time. Identifying the main characteristics of health literacy and determining how to measure them are also important. Upon completion of that work, it is up to researchers to develop intervention strategies that can improve the situation. The next step is to develop criteria for health literacy - that is, standards or tests against which aspects of literacy can be assessed. Finally, one question remains: How is success defined? How much change is enough?

Frankish showed an illustration depicting three intersecting circles: the public’s perceived needs and priorities; actual needs; and resources, feasibilities, and policy. The intersection of the three circles marks the ideal situation: the coming together of what the community wants, what the data supports, and what resources and policy initiatives are available.

Kwan explained to participants the conceptual framework that the research team had developed. Highlighting some aspects of the framework, Kwan said the team views health literacy as a two-way interaction within varying contexts. For example, public health, health care, and population health. The framework also assumes that the point of health information is to help people make decisions. Those decisions in turn lead to actions and outcomes. In addition, the framework takes into account personal influencing factors (elements that are intrinsic to the individual) and external influencing factors (the determinants of health as identified by Health Canada).

Frankish asked participants to discuss the framework and to answer these questions:

- Are there elements of health literacy that are missing from the framework?
- Are there elements included in the framework that do not belong?

The group contributed these question and comments about the framework:

- Should gender be included as an external influencing factor?
- The definition of health literacy refers to the individual; however, it is not apparent where the individual fits into the framework.
- Is the model being developed to assess a client's level of health literacy, or will it be used as a tool to determine the ability of the practitioner to communicate? Problems arise when a deficit model is the starting point. In response, Frankish said that the team had contemplated the possibility of thinking about health literacy in a more interactive way—for example, communication between individuals. The difficulty is in trying to develop a means to measure those interactions. He added that health literacy is something that a person accrues by going through an exchange; however, the exchange itself does not constitute health literacy.
- A concern was raised about the focus on action in the model.
- "Skill" is sometimes seen as a problematic word. A participant suggested using "outcome" instead.
- Another participant put forward an alternate framework that begins with demand and moves into the process of response that ultimately leads to outcomes.
- "Observing" should be added to the general literacy box.

Frankish told the group that the researchers have created a semi-structured interview schedule to collect information from people in various contexts. People will be asked where they looked for health information in the last six months, and how the information they obtained was understood and communicated. The interview schedule will be used in conjunction with a larger battery of tests, including existing general and health literacy measures.

Comments on the interview schedule:

- A participant questioned whether the schedule was measuring practice and habits or skills and abilities. She added that assessing the degree of difficulty of the information accessed by the respondent would be impossible.
- Some people do not know what constitutes the broader definition of health information. Many see health information as disease-specific information rather than healthy living information.
- Problems are inherent in any self-assessment tool.
- The language used in the schedule needs to be simplified. Learners may have difficulty with phrases such as "actively looked-for information."
- The six-month time period is too long. The interview could possibly become a memory test.

Rootman thanked the participants for their comments, which he said will be very helpful as the project moves forward.

## **Health Literacy Education Nutrition: Instrument Design- Annrose Guarino**

Annrose Guarino presented a study that forms part of the evaluation work of the U.S. Food Stamp Nutrition Education Program. The program has been evaluated using written materials, but Louisiana has a very high illiteracy rate. The purpose of Guarino's study was therefore to develop an evaluation instrument for adult, limited-resource participants with diverse literacy skills and to establish the validity and reliability of the instrument.

Guarino summarized the four phases of the study.

In phase 1, the instrument design was determined. It included ten questions (three on knowledge and seven on behaviour). The instrument was a self-reporting, written questionnaire with both text and simple graphic illustrations. Food safety was the nutrition education component to be evaluated by the participants.

Readability of the instrument was aimed at the general level of the participants (Grades 3–5). The previous evaluation instrument had a Grade 8 readability score. Unfortunately, the first version of the new instrument scored at an even higher grade level.

Phase 2 of the study, to establish validity, followed these steps:

- An item rating scale was developed by an expert panel of eight professors in food safety.
- Focus groups were held with the target audience. Both semi-functional readers (10 people) and functional readers (8 people) were included.
- Modifications were made to the evaluation instrument.
- The final reading level was determined.

The key qualitative data findings from the focus groups were:

- More white space was required.
- Revisions to the text and graphic illustrations were required.
- One of the four response categories needed to be dropped.
- The drawings needed to be simplified (removing shading and details).

In phase 3 of the study, reliability was established by administering the evaluation instrument to 100 participants after a food safety lesson. Trained researchers then interviewed each participant.

In phase 4, the data analysis phase, the instrument was found to have a content validity of 4.25 (where 1 is "poor" and 5 is "excellent"), and a reliability of 87% agreement.

From a theoretical perspective, the implications of this work are that pictures and response symbols, together with orally presented text, can provide a measurable

degree of validity and reliability for group-administered evaluations among limited-resource adults with diverse literacy skills.

Numerous implications for practice and research were uncovered. The key messages were:

- Don't assume that limited-resource adults can read.
- Further evaluation research using mixed education strategies (for example, video and audio tapes) is needed.

Guarino also summarized several recommendations, including expanding the evaluation instrument to other Food Stamp education topics.

### **Getting the data right when working with refugee and asylum-seeking groups- Lisa Merry**

Lisa Merry outlined the results of her research project, an evaluation of the effectiveness of using translated questionnaires to collect data on health. With the help of interpreters, feedback was gathered from monolingual men and women on the readability and cultural appropriateness of a variety of self-administered questionnaires that had been translated into French, Tamil, Urdu, Spanish, and Hindi. The feedback revealed problems in design, word choice, and cultural bias.

- Participants who had never encountered a questionnaire before had difficulty completing one.
- Rating scales and skip-pattern questions (if "a," go to "1"; if "b," go to "2") were difficult for many.
- Complex questions with conjunctions posed problems.
- Errors in grammar, spelling, and diction arose during the translation process.

Responses to several questions revealed areas of cultural difference that tended to skew the accuracy of the information given. The differences included

- expectations of privacy (what is and is not okay to talk about);
- notions of time;
- hypothetical or opinion-based responses;
- open-ended or context-dependent responses;
- and concept of the "self."

Adaptation of the questionnaires to minimize the potential for ethnocultural miscommunication was recommended.

### **Unveiling sexuality: culture and gender disparities in South Asian populations- Julia Thomas**

Julia Thomas spoke about her research, which examined sexual power dynamics in South Asian immigrant couples. An Ethno-Cultural Liaison Group (ECLG) of

newly arrived couples from Pakistan, India, Sri Lanka, and Bangladesh was recruited to provide feedback on survey and educational materials about AIDS and sexuality, and on study procedures in general. The husbands' and wives' groups held markedly different opinions in two main areas: ideas about sexuality and ideas about truthfulness.

On the subject of sexuality, the men expressed strong views that asking explicit questions about sex is always culturally inappropriate and insulting. They felt it very unlikely that their ethnocultural community would accept questions from the UNAIDS General Population Survey such as "Do you think this partner has other partners?" One husband commented, "I am angry just for reading it." The men also called the images in an HIV prevention pamphlet about proper condom use "pornographic" and "not suitable for women and children."

In contrast, the women's group felt that the materials presented could be effective tools for gathering data from individuals in their community, and for educating them, provided that the potential gains from the process (such as disease prevention and health care access) were made clear at the start.

Men and women also differed in their estimation of how truthfully members of their ethnocultural community would respond to the questionnaires being reviewed. Men expressed more fear that the information might make it back to their communities or somehow affect their application to remain in Canada. They recommended revisions to the process such as providing reassurance that all responses are kept secret and offering a verbal consent procedure in lieu of a written signature.

Ultimately, Thomas concluded, even though men and women in the South Asian community differed considerably in their viewpoints, those differences need not prohibit future investigation of taboo issues. Future research requires an awareness that the language and approach used with each partner is important and that instruction and education have to occur in a culturally appropriate way. Because the symbolic meaning of language is perceived through a cultural lens, the oral and written communication surrounding research tools and procedures need to be tailored with ethnocultural sensitivities in mind.

### **Using multi-ethnic, multilingual focus groups to enhance research with refugees- Jodi Tuck**

Jodi Tuck spoke about her work exploring issues of cultural sensitivity triggered by research tools investigating women's reproductive health. For that study, Tuck worked with an Ethno-Cultural Liaison Group (ECLG) of 11 women from ten different countries. Each of the women spoke at least one other language in addition to English. She found that this multicultural group was able to provide rich feedback in a cost-effective manner. Speaking with them was a good way to make research more responsive to the community.

Despite the enormous diversity of the group, researchers were able to foster trust in the process and between the participants. Work with a discrimination questionnaire originally developed in Sweden, and that showed a real depth of knowledge about the experiences of refugee women helped to “break the ice” early on and established that the needs of the participants and their communities were the ultimate goal of the process. Building sessions around shared meals helped, too. One participant impressed upon Tuck the importance of female researchers making a conscious effort not to neglect simple greetings and “woman to woman” courtesies. Those simple courtesies communicate respect for refugee women as people. “You should ask a woman how her baby is before asking if she had sex last night,” she suggested.

Feedback from the ECLG resulted in changes to consent forms and compensation. Many women did not want to tell their husbands about the nature of the study in which they were participating, but they felt that they could not sign the consent form for themselves, either. Some group members rejected any form of monetary compensation, finding it insulting. Others were insulted that the amount offered was so low. In the end, researchers gave a gift of a baby card and \$10 for each participant. Sensitivity to participants’ opinions and concerns helped to sustain the researchers’ connection with the communities.

### 3. Empowerment and Capacity Development

#### **Empowerment and Capacity Development: A Strengths-Based Approach to Literacy and Health- Leslie Bella & Rick Bishop**

This presentation by Leslie Bella and Rick Bishop provided some of the theoretical context and background for their second presentation, which focused on the same themes, but illustrated them through the example of the MacMorran Community Centre.

The concepts of empowerment and capacity building were presented as background theory. These elements are very important to developing literacy and health strategies that are effective.

Bella and Bishop discussed community capacity building, and the many complementary issues and ideas that surround it. Such supporting ideas include:

- Social capital- Bella and Bishop discussed the difficulty in defining this term. A working definition which might be employed is: “the connections among individuals and social networks and the norms, interaction and trustworthiness that arise from them”, as stated by Putnam. To understand social capital, it is also important to understand community capacity. A community with capacity will have:
  - A sense of community

A sense of community is “the degree to which community members feel connected”. It is important in community capacity building because a community with these feelings will support a common good and can work for the betterment of the whole.

- Commitment

Commitment is the responsibility that persons, groups, or organizations take for what happens in their community

- Ability to solve a problem

The ability to solve a problem is important to community capacity development. This is because commitment to an issue must translate into action, in order for a community to make a difference.

- Access to resources

Community capacity and capacity development also requires access to resources. Resources include economic, human, physical and political. Resources are important for capacity development because they allow the community to link to the larger context.

- Social agency- Bella and Bishop rely on research which states that community capacity is engaged through varying combinations of three levels of social agency:
  - Individual/human capital
  - Organizational
  - Networks of association

Social agency at the individual level involves the skills, knowledge, and resources of individual residents and their participation in community-improving activities. Investment in the skills, knowledge, and resources of individual residents can improve their ability to find resources and their economic well-being. The presence of this human capital among the residents of a community can in turn strengthen community capacity through both individual and collective contributions

At the Organization level social agency operates through collective bodies including community based organizations, local branches of larger institutions, and smaller organized groups.

Within the Network level of social agency, community capacity works through relationships among individuals, informal groups, and formal organizations.

Empowerment is another term that is difficult to define. Bella and Bishop discussed it as a psychological state, a sense of competence, control and entitlement that allows one to pursue concrete activities aimed at becoming powerful. The relationship between capacity development and empowerment is mutual. As a community develops capacity, they become empowered to deal with community issues as needed.

## **Capacity Development and the Urban CAP Program at MacMorran Community Center- Leslie Bella, Rick Bishop & Renee Walsh**

Leslie Bella, Professor; Rick Bishop, Master of Social Work candidate; and Renee Walsh, recent graduate, the School of Social Work, Memorial University, combined their scheduled presentations into one, entitled "Capacity Development and the Urban CAP Program at MacMorran Community Center." The structure of the presentation was as follows:

- Bella began by presenting some context information for the combined presentation
- Bishop presented a literature review on capacity development
- Bella commented on the feedback received from community members at the MacMorran Community Center
- Walsh presented a study of the community development process in the same community
- Handouts were available

Bishop quoted Chaskin's 1996 definition of community capacity:

... the interaction of human capital, organizational resources, and social capital existing within a given community that can be leveraged to solve collective problems and improve or maintain the well being of that community. It may operate through formal social processes and/or organized efforts by individuals, organizations, and social networks that exist among them and between them and the larger systems of which the community is a part.

Bishop said that literature by Chaskin lacks important information, such as the effect of poverty and racial differences. Oppression also needed to be added to the community capacity-building framework. Bishop then defined "power" in two ways:

- as a process by which power is attained (what is done to exercise influence)
- as an outcome (the extent to which community preferences are met)

Empowerment was defined as "a sense of competence, control, and entitlement that allows one to pursue concrete activities aimed at becoming powerful."

The mission statement of the MacMorran Community Center was presented:

To provide access and equal opportunity for community members to participate in social, health, recreational, educational and cultural programs and services. As well, our mission includes provision of opportunities for individual capacity building. Opportunities will be provided for a collaborative, cooperative community development process that will help provide and sustain a healthy, supportive and safe community.

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 existing strengths and skills of community members. “Building up capacity” means bringing in additional resources from outside.

A major task in capacity development is helping people to believe in their own skills. Jim McSheffrey was a major figure in the Center’s development in its first 20 years. McSheffrey was instrumental in empowering people to recognize their own skills. His philosophy emphasized instilling pride and helping people to believe in themselves. That philosophy remains a major characteristic of the Center’s approach.

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 spontaneous giving of self occurs across generations and without age distinctions. Capacity building in the community involves people of all ages, with particular emphasis on supporting young people in school.

Walsh then presented an overview of a project that she completed with Gary MacDonald. The two researched the history of the acquisition and use of computers at the MacMorran Centre. Of particular interest was information about technology development, policy development, and individual capacity development. Issues of computer access and policies and procedures were examined. Narratives were written that showed how the community had provided opportunities for individual capacity building.

The consultation provided an opportunity to show the members of the community that they were the experts and that the membership had confidence. Community consultation is a key factor in getting people involved.

### **Challenging the Concept of Health Literacy: Action Research at the McGill University Health Centre- Linda Shohet**

The Centre for Literacy held plain language workshops for 300 health care providers at the Montreal General Hospital between 1995 and 1998. While productive, these presentations highlighted the need for more work. Organizers submitted a funding proposal for a needs assessment, focusing on three medical units in the hospital: dialysis, hematology / oncology, and pre-operation.

Phase 1 consisted of a literature review and interviews with health care providers (mainly nurses), support staff, patients, and patient families and caregivers. Staff at the hospital had designated this segment of the patient population “hard to reach”. However, the study found that this term said more about the caregivers than it did about the clients. The ethics committee at the hospital had cautioned the research team that they might have problems in getting a response, but the researchers found the opposite. The researcher who interviewed patients often had quite long interviews with clients who felt that this person was the first one to actually listen to their health concerns.

Phase 2 of the project focused on participatory health measures. Writers and graphic artists developed 24 versions of three messages, which were then tested with patients and families to determine how understandable they were.

Phase 3 involved determining a conceptual framework and undertaking another literature review. In this literature review, researchers found that little evaluation existed for interventions involving clients with a less than Grade 9 education and non-speakers of English.

Phase 4 is in the proposal stage. The four-year plan that was developed from the earlier research is waiting to be funded. In the first year of the plan, more action research is intended. Then, information will be disseminated, materials will be published, and a common form will be developed for all print materials. Woven into those activities will be constant assessment with the client population. Earlier work found that health professionals often think that a resource is fine, when testing with clients shows otherwise. Earlier work also found that the term “literacy” carries baggage and preconceived notions that confuse health professionals.

Details of the project can also be found online at The Centre for Literacy ([www.nald.ca/litcent.htm](http://www.nald.ca/litcent.htm)).

### **Making Connections: A Capacity-Building Approach to Building Health Literacy- Lyn Simpson**

Lyn Simpson, an Assistant Dean and Director at Queensland University of Technology, began her presentation by outlining a number of fundamental tenets that form the foundation for her work;

- A healthy community is a strong community.
- Strong social networks and social supports underpin a strong community.
- Health literacy includes the cognitive and social skills that determine the motivation and ability of individuals to access information.
- A healthy community is a community that is working together toward a common future.
- The set of assets and strengths that individuals bring to an issue is called an assets-based approach.

Simpson stated that policy development should extend beyond computer technology access issues. It must focus on strategies that foster social inclusion and community mobilization. She challenged the notion that the “digital divide” is about those who have access to technology and those who do not. Instead, she said that what is important is the way that technology is embedded in social systems and processes, as part of social networks involving relatives, friends, and colleagues. A socio-technical perspective is vital.

Simpson spoke about the goals of a particular project. The goals were to build skills and to facilitate skills sharing. The LIFE cycle approach was used in the program:

- Listening to the learners
- Identifying the needs
- Formulating effective programs
- Evaluating and modifying the delivery

Project delivery intentionally focused on individuals who had previously failed training or were marginalized. The marginalized participants were engaged to focus on social isolation and access to information. Individuals considered “unteachable” or too hard to deal with, were targeted.

In the LIFE cycle approach, “listening” means valuing individuals as capable equals who can help themselves and each other. The focus is on helping them to demonstrate what they know, to share their needs, and to validate their experiences. They are treated with respect, and their needs and concerns are never viewed as unacceptable. Programs are designed around individual needs and interests. Outcomes are continually evaluated. The result is movement away from marginalization and towards inclusion. Individuals develop self-confidence and experience a safe environment that values and celebrates their individual capacities and experiences.

Simpson presented case studies that demonstrated the success of the LIFE cycle approach in building health literacy capacity. She emphasized the importance of building local support and networks.

#### 4. How to Reach Different Groups with Health Information and Resources

##### **Opportunities and Challenges: Using the Internet as a Tool- Ellen Balka**

Dr. Ellen Balka, Professor of Communications at Simon Fraser University (SFU), reviewed a research paper on the technological challenges and opportunities related to health literacy. She also presented preliminary data on public access to health information through the Vancouver Public Library and the B.C. HealthGuide OnLine website. Those two projects form part of the ACTION for Health project ([www.sfu.ca/act4hlth/](http://www.sfu.ca/act4hlth/)).

ACTION for Health examines the changing role of information technology (IT) with regard to health practitioners, health care recipients, and other stakeholders. Research is conducted in settings that range from libraries to hospitals, and from rural communities to urban centres. Research questions examine how health IT is designed, implemented, used, and regulated.

The role of IT in Canada’s health sector is expanding. IT initiatives absorb millions of dollars every year in health care spending. The increased importance

of IT can be seen in everything from the prevalence of health promotion websites, through the expansion of patient-tracking databases, to the implementation of automated drug dispensing units. ACTION for Health explores whether Canada's current use of health IT is meeting the expectations that Canadians have for their health care system.

Currently, health technology in Canada is reviewed in terms of its clinical and cost-effectiveness. ACTION for Health goes beyond the limits of such traditional assessments by considering the social, ethical and legal aspects of introducing new technologies into the health sector.

Technology and health literacy focus on two areas: computer-aided health promotion, and patient navigation (helping patients find the information they need for the right constellation of services).

Given the increase in the number of Canadians using the Internet (for example, from 22% in 1998 to 40% in 2000), the assumption has always been that access is not an issue. The Internet is now the second most common source used by Canadians to obtain health information. It ranks ahead of radio, television, and newspapers, and is surpassed only by face-to-face meetings. However, Internet use declines with age and increases with income and education. Notably, there is little data regarding ethnicity and Internet usage.

A range of factors influence whether individuals or communities can access health IT. Those factors include government policies, governance, literacy skills, literacy and social facilitation, service providers, software tools, computers, modems, telephone lines, and facilities that carry and store information.

Policies encouraging access should consider factors such as geographic location, cognitive ability, language, physical disability, cultural origin, educational background, age, sex, income, social differences, technophobia, and traditional and digital literacy.

The increased accessibility of health information can improve opportunities for providing social support through on-line support groups, for example, Weight Watchers. However, challenges and problems arise with regard to the quantity of information to be navigated and the ability to obtain data on effectiveness and outcomes. Changes in patient and provider roles suggest that increased consumption of health information may be producing an increase in visits to doctors.

Balka concluded this part of the presentation by saying that the conceptualization and measurement of technologically mediated health literacy is inadequate. A lot of money is being spent on technologically mediated health literacy, but no one yet knows if it works. The social nature of technology needs to be recognized, and steps need to be taken to create social mechanisms.

Next, Balka presented information on a data collection plan. She credited the work of Anne-Marie Nicol, a postdoctoral fellow at the ACTION for Health Project, for the development of measurement tools.

The data collection plan examined issues related to the consumption of online health information, the demographics of health information seekers, the information chain, and places on the health continuum where participant seekers were located.

Various information providers were examined with the goals of learning more about the demographics of users, how those demographics vary across different means of access, and how the use of information intermediaries varies. The providers examined included the Vancouver Public Library and the B.C. HealthGuide OnLine.

Preliminary data indicates that more women than men use the B.C. HealthGuide OnLine. Users in the older age range tended to use the reference desk at the Vancouver Public Library. The level of education was high: the vast majority of users had some college or university, or had graduated from college or university. Household income was also significantly high. Of those using the B.C. HealthGuide OnLine, 32% earned \$70,000 or more annually. English was the first language of 86% of users. Most users were seeking information for themselves.

Balka concluded the second part of her presentation by saying that access should not be confused with use. Access and use reflect several forms of literacy, including general literacy, computer literacy, information literacy, health literacy, and scientific literacy.

Complex processes characterize making sense of health information. Information seekers often go to health information intermediaries after unsuccessful Internet searches. In British Columbia, those seeking Internet health information are largely well-educated, and speak English. Balka expressed concern that technologically based health information is doing little for the less educated, non-white population.

### **A Report on Rural Ontario Women Seeking Health Information- Roma Harris**

Roma Harris, University of Western Ontario, began her presentation by acknowledging and thanking the coauthor of her report on rural Ontario women seeking health information. Rural women face an increased risk of poor health, stemming from reduced access to information and lack of social conditions that foster health. Some of the barriers that prevent rural women from accessing professional health care are distance to clinics and a low number of female physicians (because women often prefer to see female physicians).

Harris added that poor health among rural women is usually determined by social factors, especially stress, and the pressure associated with their social roles. Research has found that women in rural areas shoulder most of the responsibility for the emotional and physical health of their families and communities. Poor health among men, on the other hand, is determined by behavioural factors such as smoking.

A prevalent assumption today is that people want more control over their health, and thus are becoming empowered by using resources such as the Internet. Physicians may still be the first source of information, but rural women also seek information from family, friends, pharmacists, and alternative health care providers.

Harris's study explored the places that rural women seek health information. She found that when selected participants were presented with an urgent health concern, most said that they would turn to hospital services or the doctor. When presented with a nagging health concern, most said that they would rather consult the Internet.

Rural women rely on information from various sources to make important health decisions. Because of concerns such as the lack of rural health services and the competence of health care providers, many women turn to alternative sources, such as health food stores.

Harris concluded that e-health is only a partial solution for meeting the health needs of rural women. Although many rural women actively seek health information from the Internet, they still want to discuss that information with a person they trust.

A session participant asked about antagonism toward conventional information sources. Harris responded that many doctors do not take time to explain things, or to talk with the patient. Rural women feel that their needs are not being met, and they therefore consistently rely on personal networks to discuss health information.

### **The Empowerment Model on Using e-health to Distribute Information- Tiffany Veinot**

Tiffany Veinot, a PhD student at the University of Western Ontario, studies with Roma Harris. She began her presentation by thanking Harris for assistance with her project. Veinot then talked about the growing popularity of the concept of empowerment. The concept is used in a variety of contexts, but Veinot highlighted its central idea: individuals gaining control.

In a social context, patient empowerment has led to huge growth in self-help and mutual aid groups. The increase in the use of alternative medicine has also been staggering. For Veinot, an important social issue related to empowerment is the

reduction in health care spending. As a result of doctor shortages in rural communities, and caps on the hiring of new physicians, responsibility for care has been transferred to individuals.

According to Veinot's research, the resulting effect on health outcomes has not yet been proven. Also, among health care providers, a gap exists between the ideal and the reality of support for patient empowerment. Because of the doctor shortage and physician overwork, visits are often rushed. When patients contribute outside information, some physicians feel that the visit becomes less efficient. On the other hand, some patients do not search for outside information. Some feel that it might confuse them; others lack access to the Internet. The concept of empowerment therefore has value to only some patients.

Veinot spoke briefly about HIV / AIDS in Canada. HIV / AIDS is seen as a "big city" issue. Those faced with it in rural communities feel isolated. Anonymous testing is not available, and family physicians may not be sufficiently knowledgeable. The HIV / AIDS Information Networks Study on which Veinot worked was an attempt to learn more about how information flows through and affects rural communities.

One session participant asked if empowerment is affected by age. Harris replied that, although younger people might be more comfortable using the Internet, older people go to the library.

Another participant suggested that, to help bridge the gap between patient and doctor, web pages should contain warnings to readers to consult physicians. Harris explained that such warnings already exist, but that they are ignored, because the readers think that they know best. A participant added that some people cannot access health professionals and so they become their own "expert."

Another participant asked why doctors did not welcome outside information. Veinot replied that although the patients' knowledge might be increased, physicians felt that the patients' understanding of issues was not always accurate.

### **Recherche d'information médicale: une approche multi-factorielle- Stefane Kabene**

Stefane Kabene a discuté de l'accroissement de la popularité et de l'importance d'Internet comme voie d'accès à l'information sanitaire. En encadrant son propos par les cinq attributs de l'adoption d'une innovation selon la théorie de Rogers, il a expliqué les défis à surmonter pour que le public puisse profiter pleinement d'Internet ☐

- L'avantage relatif de la technologie □ cet avantage existe lorsqu'une innovation est perçue comme étant plus avantageuse qu'une idée, un produit ou un service existant.
- Sa compatibilité □ sa cohérence par rapport aux valeurs actuelles, à l'expérience du passé et aux besoins.
- Sa complexité : le niveau de difficulté associé à la compréhension et à l'utilisation d'une innovation.
- La possibilité de la tester □ la capacité d'essayer l'innovation sans que cela nécessite une dépense ou un engagement majeur.
- Sa visibilité : le mesure dans laquelle une personne peut observer les effets et les avantages d'une innovation dans son milieu.

L'augmentation du nombre et de la fréquentation des sites d'information sanitaire en ligne donne à penser qu'Internet est une innovation que l'on adapte et que l'on adopte. Selon diverses études, les personnes atteintes de maladies chroniques ou de problèmes cardiaques qui consultent de l'information sanitaire en ligne font état d'un moindre niveau de stress, d'une meilleure adaptation à leur vie et d'une meilleure qualité de vie.

Le personnel soignant devrait se renseigner sur le nombre croissant de ressources en ligne pour pouvoir utiliser certaines de ces ressources par lui-même et faire des recommandations efficaces aux patientes et aux patients à ce sujet.

Qu'ils soient établis par des professionnels de la santé ou à l'aide d'une base de données, les « profils personnels de santé » adaptent une information sanitaire à une patiente ou un patient en particulier. Internet joue un rôle central dans la diffusion croissante de ces profils. Le site américain Heart Profilers offre un tel service ([www.americanheart.org/profilers](http://www.americanheart.org/profilers)).

Les internautes qui fréquentent les sites de ce genre manifestent une capacité accrue de reconnaître et de nommer leurs symptômes et d'agir en conséquence. Ces sites doivent donc fournir une information exacte et proposer des activités de soutien en ligne faciles à consulter et à comprendre.

Mais même par rapport à la popularité croissante de cette technologie, les francophones du Canada sont défavorisés. Non seulement ont-ils de trois à sept fois moins accès aux services de santé dans leur propre langue, mais ils possèdent de moindres aptitudes à comprendre et à utiliser l'information sanitaire trouvée sur Internet, car les membres des communautés francophones minoritaires sont relativement plus âgés, moins scolarisés et moins présents sur le marché du travail. Pour redresser ces inégalités, il faudrait élargir leur accès à Internet et créer de nouveaux sites d'information sanitaire de haute qualité en français.

**Promoting e-health Among Teenagers: Tools and Outcomes- Cameron D. Norman**

Cameron Norman, University of Toronto, thanked his colleagues, and explained that before he started his study, he assumed that youth are the most connected to the Internet and therefore know how to use it. Norman and his colleagues realized that this assumption was incorrect, and that work remained to help youth learn how to effectively use and navigate the Internet.

Norman noted that people are now both consuming and producing health information. However, no benchmark is currently available to help determine the trustworthiness of any given information. Norman developed his eHealth Literacy Scale (eHEALS) to finding out if youth knew where to find resources on the Internet and how to evaluate and apply the resources located. eHEALS is just a first attempt to measure e-health literacy, but it is a promising tool.

One participant asked if Norman had looked at ethnicity in his study. Norman replied that he had wanted to; however because of the various definitions of ethnicity in use, he could not make any claims in that area for the data from this first trial.

### **A Whole Greater than its Parts: HIV/AIDS Treatment Information- Tiffany Veinot**

Tiffany Veinot began her presentation by outlining various community needs for HIV/ AIDS treatment information:

- People living with HIV/ AIDS (PHAs) need information for decision-making, empowerment, and choice.
- AIDS service organizations need information on how to access, develop, and deliver information; on training materials for staff and volunteers; and on easy-to-read, concise, and specific information for clients.
- Health care providers require high-quality, credible, authoritative information for professional development; current awareness information on HIV/ AIDS treatments; and easy-to-read, concise materials to give to patients.

Veinot provided some background on the Canadian AIDS Treatment Information Exchange (CATIE). CATIE is a national, community-based, non-profit organization governed by an elected board of directors. It has been in operation for 10 years. Their mandate is as follows:

*CATIE serves PHAs, and the people and organizations that support them, by providing accessible, accurate, unbiased and timely treatment information. CATIE works in partnership with a network of other information providers to ensure that people have access to the information they need, in the form they desire, to make informed health care choices.*

CATIE is working in these strategic directions:

- Promoting empowerment of PHAs and their caregivers
- Enhancing access to CATIE programs and services
- Building network capacity for information exchange

- Responding to diverse and evolving needs.

CATIE's key target audiences include PHAs, community intermediaries (support workers, family, friends, caregivers), and health care intermediaries (physicians, nurses, pharmacists). CATIE's programs and services include bilingual publications (books, newsletters, magazines), a treatment inquiry service (1-800 number), workshops and training in partnership with local communities, a website ([www.catie.ca](http://www.catie.ca)) containing 10,000 pages of content and modules for various audiences, a national reference library of medical information for health care providers, and community capacity development and collaborations for delivery of services.

Recently, Veinot and Rogers conducted a thematic analysis of nine evaluations, completed between 2002 and 2004, of CATIE's programs and services. The evaluations used 106 key informant interviews to examine program outcomes and treatment information needs and issues. Evaluators also conducted 1,792 user surveys with users of the CATIE website, workshop attendees, publication recipients, and members. Evaluation data was analyzed to determine outcomes and the elements of success.

The evaluation identified several benefits for individuals and communities.

- Most interviewees felt that the information was presented in a manner that empowers individuals and organizations.
- Among member-survey respondents, 92% thought that CATIE increased their capacity to understand, manage, and exchange treatment information.
- Among workshop attendees, 91% thought that CATIE workshops empowered them to make decisions about managing their health, and 96% felt better able to assist PHAs.
- Among publication recipients, 90% felt able to make decisions about managing their health as a result of reading *The Positive Side*.
- Visitors to [www.catie.ca](http://www.catie.ca) used information from the website to manage their own health (44%), to share with friends and family members (29%), to contribute to professional development (28%), to contribute to a research project (23%), and to give to clients or patients (16%).

The first element of the organization's success was "community-based action," said Veinot. CATIE mobilizes individuals and communities to respond to HIV/AIDS treatment issues. Mobilization is accomplished through these avenues:

- Partnerships with diverse communities in all regions of Canada
- Involvement with regional partners in community capacity development, disseminating treatment information customized to regional needs and populations
- Dissemination and building awareness
- Connections with regional work
- Involvement of PHAs in CATIE's governance, publications, and workshop delivery and treatment inquiry services

The second element of success is quality information. Users see CATIE as having high-quality information that is unbiased, current, comprehensive, and based on trustworthy sources.

Accessibility is the third element of success. CATIE uses these means to ensure that the target audiences can use its products and services:

- Providing information through multiple channels (for example, print, Internet, telephone)
- Targeting diverse audiences
- Providing context through personal stories
- Being a responsive community presence.

The fourth element is the adult education approach. CATIE supports PHAs and their caregivers in developing their abilities and enriching their knowledge. CATIE provides that support by developing skills, disseminating plain language information, and respecting choice in treatment decisions.

The final element of success is the “determinants of health” approach. CATIE attempts to have an effect on social factors and individual health behaviours alike by working from broad concept of treatment, by increasing social support for PHAs, and by maintaining a quality-of-life focus.

## 5. Exploring Links Between Literacy and Health

### **Development of Literacy Skills in Normal and Far-sighted Children- William Bobier**

William Bobier began by explaining he had changed the title of his presentation to “Preschool Vision Screening and Literacy.” He provided a brief overview of the decade-old preschool vision screening program of the Oxford County Board of Health (OCBH) in Woodstock, Ontario. The program has now been expanded to include literacy.

Bobier described the OCBH as “a forward thinking organization” that holds health fairs, and screens 85% of all kindergarten registrants. Because the government does not mandate vision screening, it is carried out at the discretion of public health units. Bobier acknowledged the assistance of the Canadian Optometry Association, the Welch Allyn Company, the Canadian Language and Literacy Network (a new partner), and faculty and students involved in the project.

Bobier explained that the earlier vision problems are detected, the better. Good techniques now exist for screening young children: the Preschool Screening Standard tests letter acuity and ocular alignment.

The test for visual acuity involves letter matching: the child points to the letter from a distance of ten feet. Bobier discussed the differences in testing outcomes

for single and “crowded” letters, and explained that preschool children tend to score lower with crowded letters than with single letters. The test of depth perception is carried out with preschool children by asking them to point to the picture that stands out.

Because both tests are quick and easy to administer, delivery rates tend to be high. They are completed with 97% of children who attend the screening program. A study in which Bobier was involved found that the yield of the screening tests was 85%, the sensitivity was 64%, and the specificity was 75%.

Bobier explained that, in preschool children, hyperopia tends to be more common than myopia. Myopia is nearsightedness, occurs when light entering the eye focuses in front of the retina instead of directly on it. This is caused by a cornea that is steeper, or an eye that is longer, than a normal eye. Astigmatism means that the cornea is oval like a football instead of spherical like a basketball. Most astigmatic corneas have two curves – a steeper curve and a flatter curve. This causes light to focus on more than one point in the eye, resulting in blurred vision at distance or near. Astigmatism often occurs along with nearsightedness or farsightedness. Nearsighted people typically see well up close, but have difficulty seeing far away.

In research on visual disorders and reading, hyperopia—not myopia—has been linked with poor reading. Current research has moved away from just visual testing to include literacy tests. Literacy is tested by examining phonological awareness, letter and word reading skills, receptive vocabulary, emergent orthography, and home experience.

Bobier’s study with 27 preschool children found that high hyperopes had lower scores for visual-orthotic discrimination, lower scores for phonological awareness, and lower scores for receptive vocabulary than did children with normal vision. In the end, hyperopia in preschool children has been associated with delays in visual development (letter acuity), in higher brain function (cognitive), and in emerging literacy skills.

One audience member asked if parents could notice visual problems in the child’s daily life. Bobier replied that identifying visual difficulties is difficult within the home; to identify problems, children must undergo vision screening.

Another member of the audience asked if recent changes to the Ontario Health Insurance Plan (OHIP) would affect vision screening for children. Bobier responded that OHIP has maintained coverage for children under the age of 19.

Bobier was then asked about the recommended frequency of examinations. He replied that testing for errors of focus and alignment can be done for children as young as 6 months of age.

In response to another question about whether screening might miss far-sighted children and whether they could be the ones with literacy problems down the

road, Bobier said that those who were far-sighted did not perform as well as their peers.

Another audience member asked how the impact of developmental disabilities is incorporated into screening tests. Bobier explained that the tests can usually be successfully used with children exhibiting delays; however, in some situations, the administration of the tests can be difficult.

Asked if any specific disorders are found in children with vision problems, Bobier noted that the complicated relationship between vision and literacy requires more research.

### **Rendre lisible l'invisible. Pratiques de lecture des faibles lecteurs et représentation des organismes- Roch Hurtubise**

Roch Hurtubise a fait le compte rendu d'une étude triennale des liens qu'entretiennent les personnes faiblement alphabétisées avec l'écrit. Il s'agit d'une étude importante, car la plupart des services sociaux dépendent beaucoup de l'écrit dans leur travail avec leur clientèle, et que celle-ci est souvent faiblement alphabétisée.

Voici quels étaient les buts de l'étude☐

- Repérer les personnes faiblement alphabétisées parmi la clientèle des services sociaux.
- Analyser pourquoi ces personnes ne lisent pas et comment les encourager à lire davantage.
- Découvrir ce que signifie la lecture pour ces personnes, et le rôle qu'elle joue dans leur vie quotidienne.

Pendant la phase☐1 de l'étude, l'équipe de recherche a interviewé des dispensateurs et des dispensatrices de services pour recueillir leurs impressions sur les personnes faiblement alphabétisées et sur les rôles des intervenantes et des intervenants qui les aident à accéder aux services. Ces rôles seraient les suivants☐

- La médiation☐observer et repérer les clientes et les clients faiblement alphabétisés et les aiguiller directement vers les services appropriés.
- La traduction☐utiliser des pictogrammes, des couleurs, des modèles et d'autres stratégies de communication non écrites.
- L'accompagnement☐aider la clientèle faiblement alphabétisée à maîtriser la lecture.

En général, le personnel soignant se dit préoccupé par les difficultés d'accès des personnes faiblement alphabétisées, mais reconnaît que l'on manque de soutien organisationnel pour résoudre ce problème.

Au cours de la phase☐2 de l'étude, l'équipe de recherche a interviewé des personnes faiblement alphabétisées en étudiant leur rapport à la lecture et à

l'écriture dans leur vie quotidienne. L'équipe a observé que pour une personne faiblement alphabétisée, les buts de l'alphabétisation sont l'humanisation, la participation et l'affirmation.

D'après ces résultats, l'équipe de recherche a conclu que le personnel soignant devrait scruter plus attentivement son propre rapport à la lecture et à l'écriture. Cette introspection devrait l'aider à établir de meilleurs rapports avec la clientèle. Par ailleurs, pour élargir l'accès aux services, les organismes qui desservent une clientèle faiblement alphabétisée devraient remettre en question leur utilisation exclusive de l'écrit et adapter les documents écrits qu'ils jugent essentiels pour la prestation de leurs services.

Pour consulter les résultats de l'étude (en français), prière de s'adresser à la coordonnatrice du projet, Lilyane Rachedi ([Lrachell01@courrier.usherb.ca](mailto:Lrachell01@courrier.usherb.ca)).

### **Laying the Foundation for Life-Long Learning: Literacy Development through Inquiry- Anne McKeough & Marya Jarvey**

Anne McKeough began her presentation by acknowledging the support of the Canadian Language and Literacy Network. She encouraged the audience to ask questions throughout the presentation.

McKeough explained that her research is founded on the belief that reading should be motivated by desire. She examined the "inquiry approach," which is intended to help children become lifelong learners. The inquiry approach to learning states that learning should be motivated by the desire to know and understand. In other words, learning activities that are student driven, where the student truly desires knowledge and is highly motivated to gain it, is most effective. This motivation is expressed in the form of inquiry, learners asking their own questions, formulating answers and elaborating on their own theories. Inquiry is an approach to learning that recognizes and supports children's developmental trajectories

According to research, the inquiry process builds on children's natural process of 'theorize, test, revise' as opposed to the traditional process of 'collect, organize, present'. The inquiry approach operates on the assumption that lifelong learning can be driven by the desire to know and to understand. When children inquire, that is, ask questions, seek resources and formulate 'theories', they are developing skills and habits that are conducive to lifelong learning. Inquiry allows educators to target instruction in ways that acknowledge children's placement along knowledge building trajectories and support them in developing key knowledge building skills.

McKeough said that the aims of inquiry are

- to engage students in productive knowledge work
- to create a knowledge-building community
- to integrate language acts with knowledge work across subjects
- to monitor knowledge advances

- to communicate ideas in ways that reflect deep understanding.

Marya Jarvey gave a definition of “differentiation” as a way of “tailoring classroom instruction such that content, processes, and products are adjusted to suit individual strengths and needs.” Differentiation allows all students to participate in purposeful and valued learning activities. It can reach students with varying needs, such as diverse social and cultural experiences and different kinds of minds.

McKeough explained how inquiry is used to achieve differentiation. Inquiry is “an approach to learning that recognizes and supports children’s developmental trajectories.” Educators can then pursue children’s interests in particular topics and take their reading in various directions. Children are encouraged to theorize about their topics, to research answers, and then to revise their theories and ideas.

McKeough then explained that the inquiry approach views children as natural “knowledge builders.” In our current “knowledge age,” fostering that capacity is important. Inquiry provides another lens through which to view the learner. It may also encourage reluctant readers (those who have the ability but not the motivation) to read about a topic in which they have an interest.

Jarvey explained that inquiry differs from a theme approach in that it is a student-led learning process that the educator strongly supports and encourages. Several examples of topics used in the study classrooms included “Shadows” and “Wind” for the kindergarten classes, and “Things That Go,” “Weather,” and “Games” for the Grade 1 classes. The inquiry process was deemed successful if the children’s existing understanding increased, whether their answers were completely correct or not.

Jarvey explained how skills of inquiry assist in achieving health, and she noted that literacy extends beyond knowing how to read. Literacy also includes formulating key questions and clarifying the nature of problems; knowing how to access resources; building communication networks; designing, implementing, and revising plans of action; and monitoring progress.

An audience member asked how the researchers were able to influence teachers and school boards to implement their project during class time. McKeough replied that she had many community connections that made it possible.

### **L’alphabétisation et la motivation chez des adolescents en difficulté d’apprentissage et de comportement- Ginette Plessis-Belair**

Dans cette présentation, Ginette Plessis-Bélair a parlé du programme des écoles Centres de formation en entreprises et récupération (CFER). La mission du réseau des CFER est de travailler avec des adolescents qui ont des difficultés d’apprentissage et de comportement. Les CFER sont des écoles de la dernière

chance qui permettent aux jeunes d'obtenir un diplôme certifié par le Ministre de l'éducation du Québec. Sans cela, ces élèves ne pourraient obtenir un diplôme d'études secondaires essentiel dans la quête d'un bon emploi.

Mme Plessis-Bélaïr a expliqué que le travail avec des jeunes qui ont des difficultés d'apprentissage et de comportement est à la fois exigeant et stimulant. À leur arrivée dans le programme les jeunes ont déjà un lourd passé d'échecs scolaires. Leur confiance est très affectée. C'est pour cette raison que la motivation est une composante importante du programme.

Le programme offre à ces adolescents la formation requise afin d'acquérir les aptitudes leur permettant de devenir des personnes autonomes, des citoyens engagés et des travailleurs productifs. Le nécessaire développement de la littératie, dans ce contexte, est un défi. Cette présentation explique la perception des enseignants et des étudiants des CFER quant aux moyens utilisés, afin de poursuivre le développement de l'alphabétisation de ces jeunes dans ce contexte. La formule CFER préconise, entre autres choses, l'utilisation d'un journal intime comme élément déclencheur et prétexte au développement de la littératie et les élèves semblent accepter de poursuivre leurs efforts d'apprentissage.

#### ***D. Building Healthy Public Policy***

##### **Medication Information for Consumers: A Plain Language Prescription- Andrew Aitkens, Millicent Toombs, Gerry Harrington & Laureen MacKenzie**

This was a panel discussion about the status of plain-language medication information in Canada. Panelists offered a wide range of perspectives on the issue.

Andrew Aitkens, a former Project Coordinator for the Canadian Public Health Association, served as moderator for the discussion. He started the proceedings with a presentation on the development and content of *Good Medicine for Seniors: Guidelines for Plain Language and Design in Prescription Medication*. Seniors make up about 13% of the Canadian population, and they receive between 28% and 40% of prescription medication. Statistics Canada found that 8 of 10 seniors have reading difficulties which restrict daily activities and lead to dependence on others. The Canadian Public Health Association, with funding from the National Literacy Secretariat, undertook a two-year project with the goal of improving medication management in this vulnerable population. Broad consultations were held with stakeholder focus groups during the project, which culminated in 1998 with the publication of *Good Medicine for Seniors*.

Pharmaceutical manufacturers are the target audience of *Good Medicine for Seniors*. The document offers guidelines on how to revise patient information packages and package design of prescription medications, to make them easier for seniors with low literacy levels to use. The publication also includes:

- demographic information about Canadian seniors
- statistics on literacy rates in Canada
- research findings on sources of patient information
- a guide to the basics of plain language
- advice on clear design, layout, and graphics
- a discussion of techniques for enhancing patient compliance.

Ideally, all forms of prescription-related communication that manufacturers produce should be written and designed with the needs of the patient as the first priority, as opposed to those of the scientific community.

Aitkens described the current efforts to give force of law to the plain language guidelines contained in the document for prescription drug information. A post-publication meeting of 40 stakeholders recommended that the guidelines become the foundation for a new national standard. That idea has the backing of the National Standards System.

Aitkens also cited two additional advances for plain language communication in the pharmaceutical area:

- The Therapeutic Products Directorate of Health Canada has developed a template for product monographs that mandates the use of the plain-language guidelines in the patient information section.
- The Canadian Pharmacists Association have recently launched an initiative to make their annual comprehensive listing of prescription drug product monographs—including the plain-language sections on patient information—publicly available on the world wide web.

Millicent Toombs, a Senior Project Manager for the Canadian Medical Association, gave the viewpoint of Canadian physicians. She assured the group that the need for accurate, understandable, and easy-to-access information about prescription medications was not limited to the low-literacy population. Every Canadian, including doctors, would benefit from such a reform.

Drugs are the fastest growing sector of the health care system. More money is currently being spent on prescriptions than on physicians. The staggering rate of growth in the number of prescription medications on the market in Canada has generated an unprecedented demand for more information.

With “so much information, so little time,” Toombs said health professionals and the public are tempted to take a fast and easy “sound bite” approach to medication information. Indeed, studies have shown that the media is the number one source of health education for most Canadians. But separating marketing hype from hard facts in the information derived from media sources can be difficult.

Toombs summarized the 10 principles of the CMA policy for the provision of information about prescription drugs to consumers. She concluded her presentation with these recommendations:

- Canadians need to have unbiased sources of drug information.

- Safeguards against deceptive advertising of health claims need to be strengthened.
- The Canadian ban on brand-specific advertising of prescription drugs needs to continue.

Gerry Harrington, Non-Prescription Drug Manufacturers Association of Canada, shared research results concerning medication information and over-the-counter (OTC) drugs. Public opinion research into consumer preferences show that Canadians rank the “user-friendliness” of OTC medication information second only to reliability. At the same time, they want the information to be available from a variety of sources. More than 50% of consumers polled identified advertisements, television programs, and newspaper and magazine articles as influential sources of information for them about OTC drugs. Label information on non-prescription drugs is read in its entirety by no more than half of Canadians.

Harrington pinpointed three specific actions that the non-prescription drug industry in Canada can take in the future:

- Educate the adult population about the importance of reading labels and being fully informed consumers of OTC drugs.
- Strike a better balance between label information requirements and label comprehension and readability issues.
- Disseminate self-care information to patients in a way that respects what is known about consumer demand for information from multiple sources.

On that third point, Harrington praised the B.C. HealthGuide program, which takes a multi-access approach to communicating health information. The program, which cross-references readily available print, Web, and telephone sources, acts as an existing best practices model.

As a spokesperson for the low-literacy community, closing panelist Lauren MacKenzie, Co-Director, Further Education Society, reported that health and medical issues are a constant source of stress for the parents who participate in her family literacy groups. MacKenzie drew on examples of people with low literacy to illustrate how their frustrations and challenges are far more complex than a “plain-language prescription” alone can address.

MacKenzie encouraged government and industry alike to make every effort to draw on the rich talents and problem-solving abilities available in the low-literacy population, allowing them to participate actively in finding more effective ways to communicate medication information. “Thinking big” about health and literacy is invaluable, MacKenzie concluded, but it is also vitally important to ensure that the knowledge and tools derived through research and policy lead to flourishing partnerships and effective interventions within local communities.

## **Opportunities and Challenges: Using the Internet as a Tool- Ellen Balka**

Dr. Ellen Balka, Professor of Communications at Simon Fraser University (SFU), reviewed a research paper on the technological challenges and opportunities related to health literacy. She also presented preliminary data on public access to health information through the Vancouver Public Library and the B.C. HealthGuide OnLine website. Those two projects form part of the ACTION for Health project ([www.sfu.ca/act4hlth/](http://www.sfu.ca/act4hlth/)).

ACTION for Health examines the changing role of information technology (IT) with regard to health practitioners, health care recipients, and other stakeholders. Research is conducted in settings that range from libraries to hospitals, and from rural communities to urban centres. Research questions examine how health IT is designed, implemented, used, and regulated.

The role of IT in Canada's health sector is expanding. IT initiatives absorb millions of dollars every year in health care spending. The increased importance of IT can be seen in everything from the prevalence of health promotion websites, through the expansion of patient-tracking databases, to the implementation of automated drug dispensing units. ACTION for Health explores whether Canada's current use of health IT is meeting the expectations that Canadians have for their health care system.

Currently, health technology in Canada is reviewed in terms of its clinical and cost-effectiveness. ACTION for Health goes beyond the limits of such traditional assessments by considering the social, ethical and legal aspects of introducing new technologies into the health sector.

Technology and health literacy focus on two areas: computer-aided health promotion, and patient navigation (helping patients find the information they need for the right constellation of services).

Given the increase in the number of Canadians using the Internet (for example, from 22% in 1998 to 40% in 2000), the assumption has always been that access is not an issue. The Internet is now the second most common source used by Canadians to obtain health information. It ranks ahead of radio, television, and newspapers, and is surpassed only by face-to-face meetings. However, Internet use declines with age and increases with income and education. Notably, there is little data regarding ethnicity and Internet usage.

A range of factors influence whether individuals or communities can access health IT. Those factors include government policies, governance, literacy skills, literacy and social facilitation, service providers, software tools, computers, modems, telephone lines, and facilities that carry and store information.

Policies encouraging access should consider factors such as geographic location, cognitive ability, language, physical disability, cultural origin, educational background, age, sex, income, social differences, technophobia, and traditional and digital literacy.

The increased accessibility of health information can improve opportunities for providing social support through on-line support groups, for example, Weight Watchers. However, challenges and problems arise with regard to the quantity of information to be navigated and the ability to obtain data on effectiveness and outcomes. Changes in patient and provider roles suggest that increased consumption of health information may be producing an increase in visits to doctors.

Balka concluded this part of the presentation by saying that the conceptualization and measurement of technologically mediated health literacy is inadequate. A lot of money is being spent on technologically mediated health literacy, but no one yet knows if it works. The social nature of technology needs to be recognized, and steps need to be taken to create social mechanisms.

Next, Balka presented information on a data collection plan. She credited the work of Anne-Marie Nicol, a postdoctoral fellow at the ACTION for Health Project, for the development of measurement tools.

The data collection plan examined issues related to the consumption of online health information, the demographics of health information seekers, the information chain, and places on the health continuum where participant seekers were located.

Various information providers were examined with the goals of learning more about the demographics of users, how those demographics vary across different means of access, and how the use of information intermediaries varies. The providers examined included the Vancouver Public Library and the B.C. HealthGuide OnLine.

Preliminary data indicates that more women than men use the B.C. HealthGuide OnLine. Users in the older age range tended to use the reference desk at the Vancouver Public Library. The level of education was high: the vast majority of users had some college or university, or had graduated from college or university. Household income was also significantly high. Of those using the B.C. HealthGuide OnLine, 32% earned \$70,000 or more annually. English was the first language of 86% of users. Most users were seeking information for themselves.

Balka concluded the second part of her presentation by saying that access should not be confused with use. Access and use reflect several forms of literacy, including general literacy, computer literacy, information literacy, health literacy, and scientific literacy.

Complex processes characterize making sense of health information. Information seekers often go to health information intermediaries after unsuccessful Internet searches. In British Columbia, those seeking Internet health information are largely well-educated, and speak English. Balka

expressed concern that technologically based health information is doing little for the less educated, non-white population.

### **Literacy and Health Policy 101- Part 1- Havi Echenberg**

In this presentation, Havi Echenberg provided an overview of a process for influencing the development of public policy. Her comments focused on federal policy development, but she said that they are equally applicable to the provincial and territorial processes.

Echenberg began by showing a diagram of the policy development process. The diagram illustrated four main cells:

- Issue identification
- Agenda setting
- Policy design
- Implementation, monitoring, and impact assessment

Echenberg said that the process is always ongoing, with various issues at different stages in the process.

Issue Identification can happen in many ways:

- Data monitoring
- Media attention
- Learners' stories
- Polling
- Crisis

Data monitoring can flag significant changes as they occur. Identification of those changes can be a way to move an issue onto the public agenda.

Polling has shown that health care is a primary issue for Canadians. However, health literacy is buried within health care and is not being identified separately. Few of the many existing problems are on the public agenda. For solutions to be reached, political will is required. Echenberg said that she is not certain whether anyone in the political process is talking about literacy and health. She added that she is also not certain if the issue is currently at the stage of requiring a champion.

In some situations, programs can be more effective than policies. However, the current political reality is that programs are not being developed outside of a policy context. Nonetheless, policy solutions can come from outside of government. A "policy entrepreneur" can develop policy and then "shop around for a government priority to tie it to," she said. That approach could be particularly useful for literacy, which is a "chameleon" issue; it can be tied to many government priorities. Echenberg added that when groups start to talk about literacy and health, they are effectively "fixing the colour" of the issue.

Policy implementation can take many forms, including legislation, regulation, program development, and funding for third parties. Echenberg urged participants to collect their own data to help monitor the effects of any policy that is developed. Data can help to position organizations to effect change to policies after implementation.

As an issue, health literacy exists at the crossroads of two policy areas: education and health. Collaboration in social policy development between the federal and provincial or territorial governments is increasing in importance. Echenberg pointed to the Social Union Framework Agreement as one of the current collaborative mechanisms. She also emphasized that understanding where policy is located is important. Echenberg listed places where policy resides:

- Party policy and election platforms
- Throne speeches
- Budgets (particularly the “ways and means” motions, which actually detail what Parliament intends to do)
- Annual expenditure plans (prepared at the departmental level, these plans detail the department’s mandate, its business lines, its priorities for the coming year, and the money that is attached to each priority)
- Ministerial speeches
- Parliamentary and caucus committee reports

At the federal level, politicians, bureaucrats, and researchers create federal policy. Policy-making in a minority government is unique, because opposition members chair half of all parliamentary committees. As a result, they become more important, because they influence the committee’s agenda. Echenberg said that she had been surprised to discover that parliamentary committees have associate members - for example, the Health Standing Committee has 30 such members. Finding and contacting those members is important.

Echenberg urged non-governmental organizations to arrange annual briefings with members of parliament. To build an organization’s credibility, the first contact with the member should offer assistance rather than request it.

For the most part, bureaucrats are dedicated and smart individuals, Echenberg said. They make wonderful allies and dangerous enemies. She divided bureaucrats into two groups: “those who slam doors” and “those who help you find windows.” Echenberg believes the latter group makes up more than 90% of bureaucrats.

People often underestimate the influence of researchers on policy development. Echenberg mentioned that the Research and Information Services staff of the Library of Parliament can be valuable allies, as they respond to ministerial requests for information and often write the parliamentary committee reports. One cannot lobby these individuals, but it is important to get to know them.

Responding to a question about the Council of the Federation, Echenberg said that she views that body as a “collective bargaining unit for the provinces and

territories.” She said the Council is not particularly important in terms of policy development; their discussions tend to focus on power and money.

When asked how best to position the issue of literacy and health, Echenberg urged participants to keep the issue in both the literacy and the health realms. The approach may be more complex, but the chances of success could be greater.

A participant asked which would be better: starting with “band-aid” solutions, or moving straight to “open-heart surgery.” Echenberg said that both were important. She advised participants to continue working at all levels, from local to federal.

Another participant asked Echenberg where in the policy development process she thought the issue of literacy was positioned. Echenberg replied that the solutions are what is missing. Groups have articulated the problem and have asked for money, but they have not been able to clearly articulate what that money will be used for. “It is hard for politicians to say yes when they do not know what they are saying yes to.”

Echenberg concluded the session by telling participants that “public policy will never be perfect. What matters is how it gets translated down the line.”

### **Literacy and Health Policy 101- Part 2- Havi Echenberg**

Havi Echenberg reminded the group that program dollars are typically tied to a policy framework. Organizational decisions about how to move forward should therefore be consistent with the government’s priority list. To be effective in influencing government policy, Echenberg urged participants to prepare by reviewing existing government and government-funded research and to review policy proposals from a variety of sources (for example, the Conference Board of Canada). Direction can be found in unusual places, she said.

To date, issues associated with literacy have been identified, but the concept of literacy and health needs further definition. Echenberg emphasized the importance of viewing literacy and health simultaneously as a single issue, as well as two separate issues. She added that the concept of literacy has grown beyond simply an ability to read words, into an ability to read words relevant to the reader’s life.

Echenberg said that the issue of health literacy is unlikely to appear on government radar as a big issue; however, it can fit into many other issue areas. That being the case, working with bureaucrats rather than with politicians could prove to be the most effective course.

In the policy cycle, if the problem has been identified, the solution has been developed, and the political will exists, Echenberg said that the next step is to identify the ‘gatekeepers’. In the political realm, gatekeepers include staff in the

parliamentary and constituency offices of ministers and opposition critics, and staff supporting relevant parliamentary committees. Useful information about how to move an issue onto a committee's agenda and how to prepare briefs is available on the Web.

On the bureaucratic level, gatekeepers include policy staff in all political parties and government departments, and program and funding officers. Echenberg reminded participants that the best approach is to form relationships before approaching them with requests. She added that another good strategy is to bring a small group of representatives from like-minded organizations together for a group meeting with such officials.

When a group is ready to make a request, it is vital to ensure that the request is for something specific and doable, and that the message is framed wisely. "If you go into a meeting hostile, there is no reason to believe that you will be greeted warmly." People often have the mistaken idea that bureaucrats are hostile and are looking for ways to say no. Echenberg said that is not the case.

Before any meeting, organizations have to do their homework: find out the mandate, mission, priorities, and budget of the department being approached. Know as much as possible about the people who will be in the meeting.

Echenberg said that avoiding "drive-by lobbying" is also important. "Drive-by lobbying" is making an approach in a crisis, asking for something, and then never contacting the relevant officials again.

Follow-up is a necessity. A thank-you telephone call or e-mail message is always appropriate. But she cautioned that the line between persistence and nagging is a fine one. Walking the tightrope means being aware of how messages are being framed: "How can I help you" rather than "Why haven't you done what I asked?"

Organizations have to keep in mind that change is slow and incremental. Commitment to the issue for the long term is a must. Relationships with politicians and bureaucrats must also be sustained. That advice is also applicable at the provincial or territorial level, and with the media.

Responding to a question about whether it is possible to alienate government members of Parliament by approaching members of the opposition, Echenberg said that everyone must be aware of who is being approached and for what purpose. "Your allies have to know what you are doing," she said. She added that it is rarely wise to use a critic's question to embarrass a minister.

In terms of the media's role, Echenberg said that the media help by bringing issues to the attention of the public and people in power. "The media [are] an important tool, but [they] won't transform the world."

When asked if she had ever been involved in a successful effort to bring a variety of players together around an issue, Echenberg said the best example was the

work she did to have social housing recognized as an election issue. In that effort, she worked with government ministers, opposition critics, and party caucuses.

A session participant said that the recent formation of the new Public Health Agency of Canada might provide a good opportunity to get health and literacy on the agenda. Echenberg said that the issue might find a home under access and patient safety. She urged participants to form a loose coalition to approach government and get the message to them. "Often the echo effect is more effective than one loud voice," she added.

Echenberg then assigned each table group one of these topics for discussion:

- Existing policy framework
- Gatekeepers
- Message
- Message delivery
- Follow-up

The group assigned to the existing policy framework mentioned these sources: autumn 2004 Throne Speech, 2003 Health Accord, the *Canada Health Act*, and the *Immigration and Refugee Act*.

The group assigned to discuss gatekeepers instead spent their time discussing the need to develop a common language when talking about literacy and health. Health people tend to talk about human rights; literacy people tend to take a human capital approach.

The "message" group said that developing a message in such a short time was difficult. They felt that it was important to connect literacy to Health Canada's mandate and to ensure that Health Canada uses a literacy lens when developing policy.

The group considering message delivery felt that developing the same message in different forms to serve various audiences was important. It is important to identify a champion and determine who should deliver the message, and to a target audience.

Taking the message to the local level, the group that discussed follow-up said that collecting local stories and looking for local partnerships would be important. It would also be important to thank people, celebrate successes, and identify next steps.

Echenberg thanked the participants for their small-group work. She said that the exercise illustrated the complexity of the task. Policy development is "a balancing act between planning carefully and not letting the planning paralyze you," she said.

Echenberg concluded the session by suggesting that someone to take a lead and establish a literacy and health e-mail discussion list, a mechanism that allows for the easy sharing of information.

### **Read to Me! Best Practice Models for a Provincial Literacy Strategy- Richard Goldbloom, Carol McDougall & Janice Fraser**

Richard Goldbloom, an internationally renowned pediatrician, opened the session by introducing himself and his fellow panelists. He then reviewed the medical science behind how and when children learn to read. He emphasized that brain development is a “use it or lose it” phenomenon.

The number of brain cells that a child possesses reaches its maximum at birth and is fixed for life by age two. However, the number of synapses (connective pathways between brain cells), crucial for learning, must be stimulated if they are to fully develop. The growth in the brain’s raw capacity for learning ceases by about age three. Medical science postulates that babies’ brains are capable of learning to distinguish between closely related speech sounds in infancy and of remembering music heard in the womb. Given these findings, literacy programming targeted at newborns and their families is relevant.

A latecomer to the literacy cause, Goldbloom expressed regret that he had rarely taken the opportunity in his former pediatric practice to ask parents if they were reading to their children. An experience on a Nova Scotia task force opened his eyes. The high rate of illiteracy in the province was identified as the number one obstacle standing in the way of the province’s economic growth. He now believes that encouraging early childhood literacy could be the most potent “immunizing agent” available. Literacy confers a high degree of lifetime immunity against poverty, educational failure, low self-esteem, and poor health. He asked, “Can you think of any vaccine that offers such a high level of lasting protection against so many serious human afflictions?”

Carol McDougall presented an overview of the *Read to Me!* Nova Scotia Family Literacy Program. This hospital-based program reaches out to parents within 24 hours of a child’s birth, providing free books, literacy tools, and training. The program started in 2002 in response to the fact that 52% of the population in Atlantic Canada struggles with reading. After just three years, the *Read to Me!* program is being delivered bedside, province-wide, to more than 10,000 families annually, by more than 100 volunteers and hospital staff. Each participating family receives a kit containing:

- two high-quality infant board books.
- an invitation to join the public library.
- a resource booklet about the importance of reading to babies. Included is information on community literacy resources.
- a compact disc of lullabies and nursery rhymes.
- an award-winning video showing how to read to a child.
- discount coupons for books.

The rapid growth in the Books for Babies program in Nova Scotia's public libraries is one indication of the remarkable success of the *Read to Me!* program.

The hospital setting has proved to be an ideal location for this public health education initiative. Very few babies are delivered at home in Nova Scotia. Maternity ward visits therefore create a point of contact that captures nearly 100% of parents. Delivering the literacy message in a health care setting reinforces the idea that reading is important to the overall health of children and adults alike. The timing also works for non-readers, who are known to be more receptive to seeking help with literacy when they become parents. In addition, *Read to Me!* literacy trainers are skilled at demonstrating how every item in the kit can do double duty as part of a "parents of newborns survival skills strategy." On the whole, parent reaction to the *Read to Me!* program ranges from "positive" to "ecstatic."

After its first six months, the *Read to Me!* program expanded to include the emergency department and clinics of the IWK Health Centre in Halifax. Janice Fraser described the positive results that children, parents, and health care workers have been experiencing because of the initiative, which is the first of its kind in Canada.

More than 30 volunteers read to kids awaiting treatment at the IWK. Reading takes place one-on-one or in small groups in the waiting rooms, or in the treatment cubicles themselves. Children benefit by being entertained and comforted in stressful circumstances. They also receive exposure to the joys of literacy. The *Read to Me!* volunteers were also modeling reading behaviours for the observing parents, who pick up new techniques for making books fun for kids. Hospital staff reported fewer parent complaints about wait times.

Fraser made it clear that the *Read to Me!* program could not have happened without the creative partnerships between organizations and individuals in the health care, government, and private sectors. Funding came from government at the federal and provincial levels, from the Halifax Youth Foundation, and from a variety of corporate sponsors and private donors. The program is partnering with the Medical Society of Nova Scotia to promote a continuum of literacy support throughout the province. *Read to Me!* is also a co-investigator with Research Works!, a program funded by the Social Sciences and Humanities Research Council of Canada for the purpose of developing partnerships between universities and community programs.

Fraser referred those seeking information on how to start a similar reading program in their community to the program catalogue maintained by Research Works!. The catalogue provides consumer reports on gift book programs and information on the methods and costs of implementing such programs.

## **Literacy and Health in the Food Sector: A report on Essential Skills in Both Market and Community- Carol J. Henry**

Carol Henry spoke about *Thought for Food*, a multidisciplinary project to extend research on literacy and health in new directions, and to probe questions triggered by changes in society, new technologies, corporate food systems, and shifts in consumer values. The current focus of the project is to identify essential skills that retail employees and community food-sector actors require to reduce community food insecurity and to improve health and quality of life.

Human Resource and Skills Development Canada (HRSDC) manages the Essential Skills Research Project (ESRP). The project has identified nine essential skills that cumulatively represent the capacities an individual requires to learn all other skills and to participate fully in the workplace and in the community:

- Reading text
- Using documents
- Understanding numbers
- Writing
- Communicating orally
- Working with others
- Exhibiting thinking skills (problem-solving, decision-making, job-task planning and organizing, using memory significantly, and finding information)
- Using computers
- Learning continuously

The *Thought for Food* project examines the nine essential skills and their use by consumers and service workers alike, with a view to determining how health literacy can be improved among consumers.

The project explores specific applications of essential skills in Saskatchewan within retail food service workplaces and community settings. The research examines the essential skills that are required by employees at retail food outlets and by food preparation workers to maintain healthy and food-secure families. The project is also determining how useful the essential skills approach is for community organizations. Often the individuals and groups with the greatest need, for example those involved with food banks, school meal programs, and community kitchens, have limited access to health information. Literacy needs to be addressed if health care provision is to be improved and health disparities removed.

Changes in technology, growth of corporate food systems, and shifts in consumer values that influence food purchase and preparation practices are all part of the problem. Food-sector employees require different skills than those of previous generations. Furthermore, consumers frequently lack knowledge about food safety, such as how to read labels and store food.

Food-label literacy is a key concern. A large proportion of the population may not be able to read labels. The public needs to be shown how to use nutrition

labels. The project is interested in identifying, for example, the essential skills exhibited by knowledgeable food purchasers. Currently, consumers tend to focus on particular nutrients on labels.

As the project proceeds, it will assess the degree to which food is incorporated into family and community culture as a quality-of-life-enhancing strategy.

### **Learning with Communities: Creating Public Policy Together- Marcia Drew Hohn, Doris Gillis & Linda Shohet**

This workshop was a panel discussion about public health and literacy. Marcia Drew Hohn, Doris Gills and Linda Shohet all provided their perspectives on the topic.

Marcia Drew Hohn explained that she had conducted a two and a half year participatory research project with adult education students at Operation Bootstrap. Operation Bootstrap offers a range of literacy services and is dedicated to ensuring participation by its students.

Hohn worked with an eight-person student health team composed mainly of immigrant women. The purpose of the research project was to identify the problems that people with limited literacy had with health education and to develop solutions.

The student health team said that the written materials used in health education were too hard to understand, and that such materials are too heavily relied. They also said that health care workers did not really know them (the students) as a group. The workers tended to speak too quickly and did not create an environment for asking questions or for talking about different cultural beliefs regarding health.

The students were afraid of being discriminated against in a health care setting, and they said that that situation would prevent them from seeking care. The question in their minds was “How are people going to treat me - not in the clinical sense, but in the social sense?”

Most students did not think in terms of health prevention because they often came from cultures that lack an understanding of it. The students also said that if they are to understand health information, the information has to be connected to everyday life.

As a result of Hohn’s research, a peer education model was developed. Using the model, adult learners provided “a very different kind of health education” based on several principles:

- Start from scratch: give basic information.
- Let the students choose the health topics they want to learn about.

- Engage in hands-on activities connected with everyday life—for example, drama.

As a policy recommendation, Hohn said that research participants can be usefully involved in the dissemination of research results. Such participation builds leadership capacity, catalyzes literacy instruction, and helps literacy programs. Acknowledgement that the adult literacy system can play a role in addressing health literacy issues is also crucial.

The study report can be found at [www.nifl.gov](http://www.nifl.gov).

Doris Gillis, Associate Professor, Department of Human Nutrition, St. Francis Xavier University, explained that as part of the restructuring of the Nova Scotia health system, focus groups were held to find out what citizens in the region thought about health services.

Gillis conducted her research through the local community health board. Her findings showed that people needed to know more about where to obtain services. As a result, the community health board developed a resource directory that went out to every household. However, they realized afterwards that some people might not be able to read it.

That experience led the community health board to recognize literacy as an important issue for health planning. It then organized workshops with learners, coordinators of literacy programs, health practitioners, key informants, and others. Those groups agreed that literacy and health were linked, and they suggested that the community health board talk both to people who experienced limited literacy and to health care workers.

Partner organizations helped to conceptualize and develop a proposal and to identify people for participation in focus groups. The project acted as both a needs assessment and a capacity-building exercise. In the focus groups, participants discussed key issues and identified strategies for change.

The research provided information on the relationship between literacy and health. Literacy and health are both “resources for everyday living,” Gillis said. Researchers identified a need to increase awareness of, and support for, literacy as a determinant of health and wellbeing. They also pointed out a need to increase awareness of literacy among service and health care providers. A series of information and awareness-building sessions were held as a result. Practitioners are now looking at their own practices and becoming agents of change.

A report about the study can be found at [www.nald.ca](http://www.nald.ca).

Linda Shohet, Executive Director, The Centre for Literacy of Québec, spoke about a needs assessment that was jointly conducted by The Centre for Literacy of Québec and the Department of Nursing at the McGill University Health Centre. The assessment found that the health education needs of some patients were not

being met. Researchers also worked with participatory-health education committees in three departments of the Montreal General Hospital. They surveyed patients, professionals, support staff, and family members.

The surveys revealed that patients and health care providers had different perceptions about health education needs. Another interesting finding, when health care providers encountered patients that they considered “hard to reach,” they simply taught them less. This finding raised ethical questions.

Patients were concerned about the lack of time available for patient education. “If you don’t speak up, you get left behind,” one survey respondent said. Patients also commented that either practitioners gave too little information, or gave too much information using scientific terms. Patients also said that they wanted the practitioners to be sincere and not to withhold information “to keep patients from worrying.”

The project team included an evaluator. The evaluator observed that most health care providers test their education materials on colleagues rather than patients. When they do test materials on patients, they go to patient committees, which are not representative of the so-called “hard-to-reach” groups.

Shohet discussed the variety of reasons that people may have problems with written materials, such as lack of access to education, visual impairment, learning disabilities, and use of a language other than English or French. Clarifying definitions and being precise are therefore important in healthcare.

The Centre for Literacy of Québec has assembled a proposal for a four-year project. The goal of the project is to create a massive professional development program based on research findings.

The Centre would like to see standard practices in place, including adaptations to address literacy issues. A few hospitals have patient education policies and standards, but they are the exceptions. Practices need to be addressed to the most excluded portions of the population. Audience segments have to be identified, and connections made between the personal needs of individuals and the ability of health care workers to respond.

A report of this study can be found at [www.nald.ca/litcent.htm](http://www.nald.ca/litcent.htm).

### **Adapting Health Canada’s Tobacco Package Warnings for Less Literate Canadians- Nancy E. Hughes**

Studies have shown that health-warning messages (HWMs) are the most economical and effective means of reaching Canadian smokers. The size and graphic nature of HWMs ensure that smokers are looking at the warning messages frequently throughout the day. Tobacco prevalence is dropping, only

one in five Canadians smokes, but those who still smoke are less inclined to quit. Among smokers, awareness of the health risks of smoking remains high.

Studies have shown a correlation between lower levels of education and smoking behaviour. Health Canada is looking at adapting its HWMs for smokers to address Canadians with lower literacy levels. In 2003, in partnership with Communications Canada, Health Canada studied various dynamics and perspectives related to messaging, including focus-testing their messages with a less literate audience. The results of the study demonstrated the importance of using familiar, everyday words and expressions, of choosing one term to describe something, and of ensuring consistent use of the chosen term. The study results also showed the significance of various other factors, including relevance of the message to its readers' personal experience, logical signification, previous knowledge, the capacity to put the message into practice, the power to exercise a certain control, and cognitive competencies.

If HWMs are based solely on the ability to reason and to establish a relationship between pieces of information, then cognitive barriers appear to make it impossible to communicate health risks to a literacy level 2 audience.

### **Implications pour la recherche et le transfert des connaissances en alphabétisation et santé en français – Pierre Joubert**

Cette séance était une table ronde animée par Pierre Joubert, à laquelle ont participé Luce Lapierre, Lucie Lemieux et Rodrigue Landry.

Dans son mot d'ouverture, l'animateur Pierre Joubert a fait remarquer que les enjeux de l'alphabétisation et de la santé dépeignaient de façon particulièrement convaincante la vulnérabilité sociale. Les enjeux types étaient les problèmes d'accès et la capacité du personnel soignant d'intervenir efficacement. L'un des buts de la table ronde était de trouver des moyens de résoudre ces problèmes dans le contexte francophone.

Les panélistes ont discuté de la difficulté pour les responsables des domaines de l'alphabétisation, de la santé publique et de la recherche de transférer dans la pratique les résultats d'études. Le débat a donné lieu à d'autres idées et à des stratégies d'intervention pour l'avenir.

Luce Lapierre a proposé que l'on oriente la recherche et les interventions en analysant l'accès aux systèmes de soins de santé complexes du point de vue des apprenantes et des apprenants adultes. Les programmes d'alphabétisation peuvent viser à améliorer le niveau de lecture de leurs bénéficiaires, mais la collectivité de la santé doit aussi faire plus d'efforts pour simplifier l'accès à ses services, les gouvernements doivent améliorer les services en français, et lorsqu'il communique avec des adultes faiblement alphabétisés, le personnel soignant doit être suffisamment averti des écueils dans la communication.

Lucie Lemieux a parlé de la hausse inquiétante des taux de décrochage au secondaire, un problème que l'on considère en Outaouais comme étant un risque pour la santé publique. On fait actuellement des efforts pour contrer cette tendance. On tente de comprendre par la recherche le cheminement des décrocheurs et des décrocheuses – les points-clés où les jeunes songent à abandonner l'école, décrochent pour de bon ou envisagent un retour aux études.

Il existe déjà des programmes pour la petite enfance à l'intention des jeunes enfants de familles défavorisées ou à faible revenu. Ces programmes aident à préparer les enfants à la réussite scolaire et réduisent le nombre de jeunes qui abandonnent prématurément leurs études secondaires.

Les taux actuels de décrochage et d'échec des élèves du secondaire peuvent s'expliquer de deux façons – d'une part, les programmes scolaires favorisent les élèves qui se dirigent vers l'université, et d'autre part, ils ne reconnaissent pas la valeur de la formation professionnelle. Pour redresser cette situation il faudrait offrir davantage de cours pouvant intéresser les élèves qui n'iront pas à l'université ou mener une campagne de sensibilisation à l'utilité des métiers spécialisés.

Rodrigue Landry a affirmé que les francophones du Canada avaient de la chance que le français soit une langue officielle, car il est parfois compliqué, pour des raisons politiques et pratiques, de faire de la recherche sur les minorités linguistiques. Les possibilités de ce statut officiel devraient être explorées, et il faudrait définir les responsabilités fédérales et provinciales de manière à ce que les francophones du Canada puissent exercer leurs droits et exprimer leurs préférences. Le Canada est encore loin d'avoir créé la synergie entre les différents secteurs et les différents ordres de gouvernement qui serait nécessaire pour renforcer la langue et la culture françaises.

Le débat qui a suivi les présentations a clairement fait ressortir que le personnel soignant ne devrait pas seulement penser au message à transmettre, mais à la capacité de la cliente ou du client de recevoir et de comprendre ce message. Il faudrait commencer à intégrer à la formation du personnel soignant l'apprentissage d'approches de communication efficaces et compréhensibles. Il devrait être pratique courante, durant les consultations, de demander aux patientes ou aux patients ce qu'ils ont compris et ce qu'ils vont faire.

Les panélistes ont rappelé à l'auditoire que les francophones du Canada ont du mal à accéder aux services de santé, non seulement en raison de leur faible niveau d'alphabétisation, mais des barrières géographiques et linguistiques. La préoccupation actuelle du gouvernement pour l'évaluation pourrait être l'occasion d'amorcer des recherches qui donneront des résultats concrets sur le terrain. De bons résultats montreront les avantages que comportent des collectivités, des institutions et des services francophones vigoureux.

La recherche a montré qu'une identité francophone forte et positive contribue au dynamisme de la communauté francophone. Selon les panélistes, ces résultats

pourraient orienter concrètement l'élaboration de stratégies à l'égard des problèmes d'estime de soi qui influencent les taux de décrochage.

Pour clore la séance, Pierre Joubert a indiqué qu'il faudrait résumer les résultats et les recommandations des études sous une forme que les responsables des décisions puissent lire, comprendre et appliquer rapidement et facilement.

### **Language, Literacy and Healthy Development: The Work of CPNP and CAPC Projects- Pamela Nuttall Nason & Pamela Whitty**

Pamela Nuttall Nason and Pamela Whitty presented their recently released study that examines literacy in the context of two federally-funded programs targeting parents and children: the Canada Prenatal Nutrition Program (CPNP) and the Community Action Program for Children (CAPC). In this published study, the researchers paid particular attention to format. Rather resembling an academic paper, the study report looks like a magazine. Text and language are accessible, and photographs within the report show resources produced by CAPC and CPNP programs across the country.

The survey on which the report was based had a response rate of 20%. An interesting survey finding was that literacy initiatives are sometimes embedded in programming without the service providers recognizing them as literacy activities. For example, one program noted that they did not assume that everyone could read; however, they did not necessarily ask about reading skill, they simply offered every participant help in completing forms. Clients brought in rental agreements, income tax forms, school registration documents, and financial aid forms.

Another example of literacy embedded within a program was a workshop in cooking and in reading recipes. Some programs also mentioned specific literacy activities such as book giveaways to children and celebration of National Literacy Day.

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.

### **Direct-to-Consumer Advertising: Challenging Health Protection in Canada- Martha Jane Paynter**

Martha Paynter presented research on direct-to-consumer advertising (DTCA). DTCA is prescription drug promotion through print and broadcast ads, primarily in magazines and on television. In Canada, the *Food and Drugs Act* prohibits DTCA. However, DTCA has become pervasive because of loopholes and lack of enforcement.

Paynter's research evaluated the current DTCA ban and proposed changes through Health Canada's Health Protection Legislative Renewal process and the *Health Protection Act*. Her methodology included microeconomic, bioethical, and gender-based analyses. The findings showed that consumer spending on prescription drugs is rising at a rate of approximately 21% annually in Canada, and that prescriptions are increasing by approximately 7%.

Paynter recommended improving enforcement of the DTCA ban, increasing penalties for infractions, improving the drug review process, securing equality of access to information, enhancing consumer health knowledge, and being sensitive to gender differences.

A participant suggested that Health Canada could deliver advertisements that encourage people to speak to a health care provider about their health conditions. Such advertising would focus on consumer empowerment. Another participant pointed out that society has increasingly looked to drugs for solutions rather than address the deeper issues of values, ethics, and lifestyle.

### **People Who Rate: Community Involvement in the Development of Health Education Materials and Messages- Elsie Petch, Norma Levitt & Al Levitt**

In this interactive workshop, Elsie Petch and Norma and Al Levitt described how they work with health information to create accessible text. They advocate for clear language and design in health policy.

Their literacy work began in 1989, after they learned that 50% of Canadians were not able to read or had difficulty reading. In South Riverdale, 20% of residents had not completed Grade 9. In comparison, the average in the city of Toronto was 10%. South Riverdale is also home to many immigrants whose first language is not English.

In 1988, the South Riverdale Community Centre developed a coordinated approach and services plan for English and Chinese seniors in the community. They started to use a new storefront location where health information could be distributed. Feedback from readers indicated that some pamphlets were understandable, but that many others were difficult to read. Pictures were confusing or unattractive.

Project funding from Health Canada enabled the Centre to work with 30 seniors to review and rate health information materials. The seniors had a range of literacy skills. They reviewed 300 pamphlets and videos. The conclusion was that many of the materials did not meet the group's health information needs. As others heard about the project, the group was invited to review more materials intended for seniors. Some of the first clients were the Ontario Ministry of Agriculture and Food, a chiropodist, and the Ontario Ministry of Health. Mary Breen, a well known writer of accessible health information, acted as a consultant to the group. Over time, the seniors became very adept at the

work. To maintain a critical stance, they also involved new people with no previous experience.

The Centre found that seniors were not the only people who needed clear health information. Other audiences included people who do not read, people with English as a second language, people who hear or see poorly or have memory problems, and people of all literacy levels. To actually use printed information, a reader must be able to “get beyond the text.” Sometimes cultural misunderstanding can be a barrier to comprehending a text resource.

Most health information pamphlets are prepared by professionals. They are not tested with the target population. This can be because of a lack of time, money, or both. Petch and the Levitts suggested that partnerships with the target populations are useful. Through these partnerships, writers can learn about the target population’s culture. Then, clear language materials can be shared and programming developed. Additional community members can be involved as projects progress. Reaching beyond the health community can be worthwhile.

Respect is important for all members of a group, because ownership results from full participation. To work with a community, use these guiding principles:

- Start with a simple plan
- Be flexible and pursue opportunities that arise
- Build in rewards for everyone
- Respect everyone’s contribution
- Incorporate agreed-upon suggestions

Petch and the Levitts spoke about the many benefits of groups, and the range of activities they can undertake.

- Groups can write articles for community newspapers.
- They can organize education sessions that encourage participation and peer learning. Clear language encourages participation.
- Groups can choose and distribute materials that are deemed to be “clear,” and they can develop others with community members.
- The South Riverdale group has even held clear language workshops for health providers.

Petch and the Levitts have contributed to the development of clear messages about health and related topics, while changing the “gloom and doom” view of aging to one of productivity and participation. The story is one of true empowerment. Norma Levitt explained that when the seniors are approached by an outsider who wants to make a presentation at the Centre, that person is asked to formally commit to a clear language format and an evaluation by the participants. Recently, a physician who presented at the Centre said that although he was responsible for the information, Norma had told him how to present it to the group!

During this workshop, participants were able to critique some written health-related materials and to discuss them with the presenters. Copies of the *Safe*

*Medication Card* developed by the South Riverdale seniors were distributed to all participants.

### **Implications for Canada of the Institute of Medicine Report *Health Literacy: A Prescription to End Confusion***

This panel addressed the implications for Canada of the Institute of Medicine (IOM) report on health and literacy in the United States. In her opening remarks, moderator Deborah Gordon El-Bihbety observed that *Health Literacy: A Prescription to End Confusion* represented a landmark in the study of a traditionally unappreciated area that presents hidden barriers to health. The shame and silence surrounding the issue has made the gap between knowledge and practice in health even wider for millions of individuals.

#### **1. Literacy and Health in the US and the results of the IOM report- Rima Rudd**

April 2004 was a shining moment for the study of health and literacy in America, said Rima Rudd, School of Public Health, Harvard University, because of the publication of three key U.S. reports: *Literacy and Health Outcomes*, *Health Literacy: A Prescription to End Confusion*, and *Literacy and Health in America*. Those reports moved the topic of literacy and health onto the U.S. agenda in an unprecedented way.

*Literacy and Health Outcomes* is 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 (NALS) and the International Adult Literacy Survey (IALS), 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 (HALS) that more accurately captures the complexity of the tasks that individuals are expected to perform with health-related information.

Rudd described the findings in two major areas of the IOM report *Health Literacy: A Prescription to End Confusion*. First, she praised the report for expanding the definition of literacy. The expanded definition acknowledges that literacy is always part of an interaction, and 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 the health area 50 years ago, but that is certainly no longer the case in contemporary

society. 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.

Second, the report recognizes that literacy always takes place in a context mediated by education, culture, language, and the communication skills of both the lay individual and the health practitioner. The burden of responsibility for effectively communicating information is a shared one. Arcane medical terms such as “nephrology” present unreasonable barriers to communication, and Rudd drew on that example to underscore the report’s finding that the U.S. health care system demands an unreasonably high level of literacy.

## **2. Literacy and Health in Canada- T. Scott Murray**

T. Scott Murray, Director General, Social and Institutional Statistics, Statistics Canada, presented a detailed analysis of Canadian literacy and health data. He noted that on average, health literacy levels in the U.S. adult population are slightly better than those in Canada. However, the Canadian level varies widely by province, with the level in Alberta being the highest and that in Québec being the lowest.

Murray pointed out that the Canadian data reveals an extraordinary correlation between levels of health literacy in the population and measures of self-perceived wellness. Past work on literacy has found that the educational level attained by an individual accounts for 60% of that person’s literacy skill level. Canadian data shows that this finding also holds true for health literacy.

Age becomes a factor in low levels of health literacy for two reasons: people tend to lose literacy skills as they age, and the senior population generally has a lower level of education. Another factor that Murray pinpointed for further discussion is the size of the area being surveyed. It affects the measurement of health literacy proficiency in the population. In urban areas, the proficiency is lower because of a high concentration of immigrants. In rural populations, the proficiency is lower because individuals are hard to reach with technologies.

These findings matter because the health literacy scores for specific populations affect where funding dollars are allocated first. A differential study of population health literacy assessment jointly administered with the United States could be very revealing, Murray suggested, if it sampled each of the domains that Rudd described in her recent research.

Murray ended his presentation by saying that he has no doubt that the conclusions and recommendations from the IOM report pertain to Canada too.

## **3. Implications for Canada- Irving Rootman**

Irving Rootman, Professor and Michael Smith Foundation Scholar for Health Research, University of Victoria, the final panellist, whole-heartedly supported

Murray's closing sentiment. Rootman asserted that the IOM's report will very likely have a spillover value, raising the public and political profile of literacy and health in Canada as has already happened in the United States.

Rootman's presentation then focused on the report's implications for Canada in four specific areas: theory, knowledge, action, and research.

He introduced these implications for theory:

- Health literacy work will expand to include consideration of contexts outside direct health care settings.
- The onus of responsibility will shift as an individual's skill level comes to be viewed as just one element in a complex, interactive process.
- Literacy is being recognized as the necessary foundation of health literacy.
- The education system, the health care system, and media culture are being identified as key areas for intervention.

He then highlighted these implications for knowledge:

- The report brings information together in a way that Canadian researchers can use as a basis for comparisons.
- Attention is drawn to the consequences of low health literacy in the United States, suggesting that a strong relationship may exist between low health literacy and poor health outcomes.
- The importance of contextual barriers that impede the successful communication of health-related information is underscored, one such example being the mismatch between the complex level at which health materials are written and the literacy level of the users.

In terms of action, Rootman again emphasized that the list of recommendations in the report applies equally in Canada.

As for the implications for research, Rootman said that the report had already become the basis for a National Institutes of Health application for health literacy research. The findings will no doubt also influence research policies in Canada for years to come.

### **Challenging the Concept of Health Literacy: Action Research at the McGill University Health Centre- Linda Shohet**

The Centre for Literacy held plain language workshops for 300 health care providers at the Montreal General Hospital between 1995 and 1998. While productive, these presentations highlighted the need for more work. Organizers submitted a funding proposal for a needs assessment, focusing on three medical units in the hospital: dialysis, hematology/oncology, and pre-operation.

Phase 1 consisted of a literature review and interviews with health care providers (mainly nurses), support staff, patients, and patient families and caregivers. Staff at the hospital had designated this segment of the patient population "hard to

reach". However, the study found that this term said more about the caregivers than it did about the clients. The ethics committee at the hospital had cautioned the research team that they might have problems in getting a response, but the researchers found the opposite. The researcher who interviewed patients often had quite long interviews with clients who felt that this person was the first one to actually listen to their health concerns.

Phase 2 of the project focused on participatory health measures. Writers and graphic artists developed 24 versions of three messages, which were then tested with patients and families to determine how understandable they were.

Phase 3 involved determining a conceptual framework and undertaking another literature review. In this literature review, researchers found that little evaluation existed for interventions involving clients with a less than Grade 9 education and non-speakers of English.

Phase 4 is in the proposal stage. The four-year plan that was developed from the earlier research is waiting to be funded. In the first year of the plan, more action research is intended. Then, information will be disseminated, materials will be published, and a common form will be developed for all print materials. Woven into those activities will be constant assessment with the client population. Earlier work found that health professionals often think that a resource is fine, when testing with clients shows otherwise. Earlier work also found that the term "literacy" carries baggage and preconceived notions that confuse health professionals.

Details of the project can also be found online at The Centre for Literacy ([www.nald.ca/litcent.htm](http://www.nald.ca/litcent.htm)).

## Recommendations and Actions Steps

PRACTICE/AWARENESS/EDUCATION/SKILL-BUILDING
---

### **Recommendation #1**

That CPHA/NLHP partner with the National Literacy Secretariat and Health Canada to disseminate knowledge and resources to literacy and health workers through a clearinghouse to include:

1. Collecting/housing resources for best practice in literacy and health, possibly through the National Adult Literacy Database
2. Promoting resources through literacy and health networks
3. Sponsoring an annual training institute for literacy and health workers to improve skills and knowledge and share best practices

### **Recommendation #2**

That the CPHA and the National Literacy and Health Program partners direct their provincial agents to contact literacy coalitions in every province and to link to health literacy programs being done now.

#### Possible Strategies

Eg1. Publish articles on key projects in professional journals with contact information

Eg2. Plan literacy and health workshop in conjunction with professional development workshops or other events

Eg.3 Invite speakers from literacy programs/projects to networking events of provincial and regional assoc.

RESEARCH
----------

### **Recommendation #3**

That CPHA and the NLHP seek funding from government and other sources to commission the Royal Society of Canada to conduct a study on literacy and health in Canada.

That the study follow the model of the Institute of Medicine Report on health literacy which included a testimony from community groups and key informants in the field.

#### **Recommendation #4**

That CPHA and the NLHP approach the Canadian Institutes of Health Research and the Social Sciences and Humanities Research Council to undertake a joint strategic initiative on literacy and health research.

This strategic initiative would include funding for projects, capacity development and infrastructure with the following priorities:

- Culture, literacy and health
- Evaluation
- Cost benefits of literacy and health efforts
- Role of technology in literacy and health

The evaluation component would support the following components:

- training on logic model of evaluation
  - mentorships with trained evaluators
- funds to carry out literacy and health project evaluation

PARTNERSHIP DEVELOPMENT / ENGAGEMENT
--------------------------------------

#### **Recommendation #5**

That the National Indigenous Literacy Association approach the First Nations and Inuit Health Branch, the National Aboriginal Health Organization and the Indigenous People's Health Research Centre to identify key people and methodologies that build on cultural practices, traditions and strengths to address health literacy of Aboriginal peoples in Canada

#### **Recommendation #6**

That la Fédération Canadienne de l'alphabétisation en français 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 Québec and other parts of Canada

#### **Recommendation #7**

That CPHA in collaboration with the National Literacy and Health Program partners work with the Canadian Ethnocultural Council to identify funding support for outreach to engage ethnocultural partners working in literacy and health and to identify opportunities for partnership.

#### **Recommendation #8**

That the Council of Ministers of Education and the Deputy Ministers of Health Joint Committee on Education and Health champion an inter-disciplinary approach to health and literacy programs which integrate parenting, nutrition,

literacy and community development such as the Healthy Living Manitoba model

**Recommendation #9**

That we invite the Minister State of Public Health to initiate an inter-departmental meeting between Health Canada and Human Resources and Skills Development Canada to discuss establishing an interdepartmental program to support literacy and health practice.

IMPLEMENT AND MONITOR RECOMMENDATIONS
---------------------------------------

**Recommendation #10**

That CPHA's National Literacy and Health Program and the Program Committee for this Second Canadian Conference on Literacy and Health review these and other recommendations put forward at the conference, develop an implementation strategy and monitor the implementation recommendations.

**Recommendation #11**

That CPHA's National Literacy and Health Program seek funds from the National Literacy Secretariat and other partners to monitor, assist and implement these recommendations and report back by November 2005 on a Literacy and Health Report card.