
# Family Literacy and Health

Developed by the

**Centre for Family Literacy**

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and
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# Introduction

*Well, I was stupid, like, to stuff like that. OK, you would take a book and you would try to read about emphysema and cancer and all of that. Sometimes there are words there and if you broke it down in your own way - but it may not mean that at all…I went to the library, and little pamphlets that you get at the doctor's office about it - I found out on my own. Now you don't like to ask, what do you think they are saying? That happens and then they know that you don't have enough schooling to understand whatever they are saying. You don't like to say, well I haven't got that much schooling; what does this mean? …They don't use plain words.*

*People don't realize when a person is sick, they change their moods. Such as my husband; he could be happy right now and in two minutes he could be just the opposite. There was never nobody to come in and say, "Well now, you take an hour off." I had nobody. … You know, there should have been somebody come out and sit me down and say, "This is what it is," and explain more to me than they did.*

*"Written information is not enough. There has to be personal contact. It has to be explained, and people's questions have to be answered."*

*Health Literacy in Rural Nova Scotia Research Project (2004)*
*Taking Off the Blindfold: Seeing How Literacy Affects Health, A Discussion Paper*

## Purpose of This Module

Communication gaps between health care providers and people with limited literacy or English language skills create a major barrier to improving health outcomes for a large percentage of Canadian families. In order to respond to the heartfelt plea above and answer "people's questions," both family literacy and health practitioners need to work together to develop strategies for improved communication.

Until recently, both research and practice in the fields of health and literacy have remained quite separate, and much of the focus on "health literacy" for adults with literacy challenges has been on plain language. However, as both health and literacy practitioners become increasingly aware of the complex impacts of one domain upon the other, there is growing interest in exploring the more profound relationship between the two and promoting partnerships that integrate "health **and** literacy."

## 1. The Objectives of this Module are:

- To explore the relationship between health literacy and family literacy
- To look at ways that health and family literacy practitioners can work together to address common issues
- To establish a shared framework for bringing about positive changes in practice that will promote health literacy among Canadian families

Although we have included some of the linguistic and cultural barriers that affect the health literacy of immigrant families, we have not addressed the literacy and health needs of the Aboriginal population, African Canadians, or other population groups with unique needs. The culture and identity issues that impact on the health of these families merit a dedicated study and report undertaken with researchers and writers from those distinct culture groups. Likewise, although we recognize the tremendous challenges to health literacy faced by families with physical or mental barriers that require specific supports, such as the blind, deaf, or mentally ill, it is beyond the scope of this module to address those special issues. It is our hope that this more general discussion will serve as a starting point for broader and deeper dialogue.

## 2. Development of this Module

The *Family Literacy and Health* module was developed by the Centre for Family Literacy in Edmonton working closely with la fédération canadienne pour l'alphabétisation en français (FCAF).

It was prepared by a team of anglophone and francophone practitioners working together to address literacy and health issues among a range of populations in Canada. Parts were written in French and parts in English, then both sections were combined, translated and revised to form both an English and a French version. The specific issues of Francophones living in minority situations in Canada are addressed in the French language version available through la fédération canadienne pour l'alphabétisation en français (FCAF).

## 3. Target Clientele of this Module

*Family Literacy and Health* is designed in particular for practitioners in the areas of health and family literacy. Because those working with families in the fields of health and literacy represent such a broad spectrum of practices, we realize that there may be gaps in the information presented. Those using the module for professional development purposes are invited to add specific information or delivery strategies that best suit their needs. It is exactly this inclusive and participatory approach that we

would like the module to support. We hope that *Family Literacy and Health* provides a solid starting point from which we can begin to work together towards a common goal – the health and well-being of Canadian families.

**3.1 Health practitioners** include all professionals who interact with families around issues relating to their health and well-being. Given the broad perspective of health in use today (see Definitions in Section 1), these practitioners include everyone from swim coaches to medical specialists. Health is supported in any community by a broad range of practitioners, including:

- Health educators
- Nutritionists, dieticians
- Medical doctors, nurses, nurse practitioners, midwives, lab technicians
- Public health services and educators
- Health librarians
- Dentists and dental assistants
- Pharmacists
- Chiropractors, physical therapists, occupational therapists, kinesiologists, message therapists
- Naturopathic and holistic health professionals
- Consultants on specific conditions or situations, from diabetes counselors to lactation specialists
- Psychologists, psychiatrists, counselors, social workers and other mental health professionals
- Early interventionists; speech language pathologists
- Family resource centres
- Gerontologists, Personal Support Workers, Activity and Recreation Aides and others working in long term care
- Recreation instructors/leaders
- Social and human service organizations
- Spiritual care workers

**3.2 Literacy practitioners** include professionals who facilitate learning for families with literacy or language challenges. Again, these may vary from community to community, and can include but are not limited to:

- Adult literacy practitioners
- Family literacy practitioners
- Librarians
- Teachers
- Early Childhood Educators
- Family Resource Centre staff
- Youth Centre staff
- Women's Centre staff
- Community literacy volunteers

### 3.3 Learning Outcomes Targeted by the Module

On completion of the training, participants will be able to:

1. Understand the relationship between literacy and health

   a. Understand health determinants and how they contribute to the health status of families

   b. Understand literacy as a key determinant of health that has both direct and indirect effects on the health of family members

2. Identify the challenges that many Canadian families face in relation to literacy and health

3. Identify ways that they can contribute to improving health literacy levels among all members of client families

4. Understand the importance of cooperating with practitioners from other sectors in order to increase health literacy in their communities

5. Take concrete action to contribute to increasing literacy and/or health literacy in an effort to make a difference in their communities

6. Identify options for adding to their knowledge about family literacy and health.

### 3.4 Approach of the Module

This module was developed as a component of *Foundations in Family Literacy,* a resource for family literacy practitioners that integrates the complex range of knowledge and skills required by those working with families for whom literacy may be a barrier. It embraces a participatory approach to family literacy that builds on family and community strengths and fosters a respectful and equal relationship between practitioners and family members. The goal is to support families in their efforts to effect positive changes within the context of their own communities and realities.

# 1. Definitions and Basic Premises

In order to understand the important connections among literacy, family literacy, and health, it is essential to explore the common definitions and language of these inter-related concepts. Because both the fields of family literacy and health literacy are still emerging, and because concepts like health and literacy are constantly evolving, the definitions and basic premises that inform those fields and concepts are consequently subject to change.

The purpose of this section is not to explore all current definitions or underlying premises, but rather to present those that are most generally accepted at this time and which are, in our opinion, of greatest use in increasing understanding among family literacy and health practitioners. The first step towards working together is speaking a common language.

### 1.1 What is Family?

Throughout this module, as in all modules of *Foundations in Family Literacy*, family is defined in the most inclusive sense of the term. It encompasses significant others and extended family/community members, whenever relevant, and includes any enduring relationship that connects members of different generations through shared emotional commitment and mutual support.

The Vanier Institute of the Family defines family as "*any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement and who, together, assume responsibilities for variant combinations of some of the following: physical maintenance and care of group members, addition of new members through procreation or adoption, socialization of children, social control of members, production, consumption, distribution of goods and services, and affective nurturance – love."* http://www.vifamily.ca/about/definition.html (2007)

While family is defined differently by different cultures, it is usually the primary system of support for its members. Adult family members are the ultimate decision makers for services and supports for their children and/or themselves.

### 1.2 What is Community?

"Communities, like families, come in all different shapes, sizes, colours, configurations and locations. Communities can be geographical such as a neighbourhood, town, or city, or can be based on mutual interest or involvement such as in a neighbourhood

school, workplace, cultural group, advocacy group, and so on. Community can also refer to the ways that people interact with one another and with other communities and institutions: 'a strong community,' 'an isolated community,' an 'at risk community'" (Centre for Family Literacy, 2002, 7-3). We are all a part of several communities defined by our location, our culture, our professions, our interests, our relationships, etc.

### 1.3 What is Culture?

Broadly defined, culture refers to the values, beliefs, language, ways of thinking, communicating and behaving, art and artifacts, expectations, and lifestyle of a group of people. These cultural attributes are derived from shared familial, ethnic, socio-economic, religious, or professional connections or experience. It is important to remember that we all tend to think, act and communicate from the perspective of the culture groups to which we belong. As family literacy or health care professionals we have our own distinct culture, which includes language, ways of thinking and communicating, and expectations concerning behaviour. We must work diligently to avoid seeing and judging others and their behaviours through our own cultural filters or expecting that "other" cultures should necessarily do all the adapting to our expectations and ways of communicating.

### 1.4 What is Literacy?

The traditional definition of literacy is considered to be the ability to read and write, or the ability to use language to read, write, listen, and speak. In modern contexts, the word refers to reading and writing at a level adequate for communication, or at a level that lets one understand and communicate ideas in a literate society, so as to take part in that society.

The United Nations Educational, Scientific and Cultural Organization drafted the following definition:

> Literacy is the ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts. Literacy involves a continuum of learning to enable an individual to achieve his or her goals, to develop his or her knowledge and potential, and to participate fully in the wider society.

*UNESCO, 2003*

However, this focus on written literacy does not take into account the diverse ways that people communicate information, develop their knowledge and potential, or achieve their goals in oral and non-mainstream cultures. Nor does it take into account the range of skills required in a technological society geared for people to take increasing control of their own needs and services – from navigating the maze of options on touch-tone phones to internet banking to online education to internet sources of family health information.

In a 2004 position paper, UNESCO explored the diversity of purposes for literacy, stating:

"*People acquire and apply literacy for different purposes in different situations, all of which are shaped by culture, history, language, religion and socio-economic conditions. The plural notion of literacy latches upon these different purposes and situations. Rather than seeing literacy as only a generic set of technical skills, it looks at the social dimensions of acquiring and applying literacy. It emphasizes that literacy is not uniform, but is instead culturally and linguistically and even temporally diverse. It is shaped by social as well as educational institutions: the family, community, workplace, religious establishments and the state*."

http://unesdoc.unesco.org/images/0013/001362/136246e.pdf

As Rootman and Ronson point out, the definitions of literacy may always be a moving target. For this reason, we have moved towards a notion of "multiple" or "plural" literacies. "*People have begun speaking in terms of 'literacies' not 'literacy' and promoting 'media literacy,' 'computer literacy,' 'health literacy' and the like, instead of a discrete concept of something one either has or does not have . . .. New technologies, bilingualism, multiculturalism and the renaissance of Aboriginal culture in Canada have pushed the meaning of literacy beyond reading, writing and numeracy skills in one official language*" (2003).

Paulo Freire, the Brazilian literacy educator, believed that the central concern of education was not simply to teach learners how to *read the word*, but rather to help them *read the world* through reflection and dialogue (Freire,1972). This early focus on "**critical literacy**" as an essential tool for all people has perhaps even more important implications today. Critical literacy is almost a survival skill in a world bombarded by media messages, an array of choices from food to medical treatments, and the increasingly sophisticated strategies of big business to sell its products or services. Critical literacy skills need to be a part of any programs that support the literacy development or health care needs of families.

## 1.5 What is Family Literacy?

Denny Taylor, who first coined the term "family literacy" in 1977, acknowledges the difficulty in defining it: "*No single narrow definition of family literacy can do justice to the richness and complexity of families and the multiple literacies, including often unrecognized local literacies, that are part of their everyday lives*" (1997).

For this reason, we will offer for discussion a number of definitions regarding family literacy and family literacy programs. These statements, some of which are used so widely that it is difficult to pinpoint their origin, highlight approaches generally regarded as promising practices in the field among Canadian practitioners.

- Family literacy encompasses the ways parents, children, and extended family members use literacy at home and in their community. Family literacy occurs naturally during the routines of daily living and helps adults and children "get things done" (International Reading Association).

- In its broadest sense, family literacy encompasses both the research and the implementation of programs involving parents, children, and extended family members and the ways in which they support and use literacy in their homes and in their communities. http://www.ed.gov/pubs/FamLit/need.html

- Family literacy is an approach to literacy development that recognizes and supports the family as a "learning unit." It builds on families' strengths and connections in the context of the culture and community in which they live and learn.

- "Family literacy programs differ from traditional adult literacy programs in that they are designed to maximize the probability that adults who receive literacy education will actually succeed in transferring aspects of their new beliefs, attitudes, knowledge, and skills intergenerationally to their children" (Sticht, 1995).

- Family literacy programs coordinate learning activities among different generations in the same family with the goal of helping both adults and children reach their full personal, social, and economic potential.

## 1.6 What is Health?

The Ottawa Charter for Health Promotion defines health as "a resource for everyday life, not the objective of living" that emphasizes social and personal resources as well as physical capacities. The Charter identifies a number of fundamental prerequisites for health that include peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity. "Health is created by caring for oneself

and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members" (World Health Organization, 1986). http://www.who.int/hpr/NPH/docs/ottawacharterhp.pdf

This is the basis for a "population health" approach, which aims to improve the health of entire populations, or sub-populations, and to reduce health inequities among population groups. A population health approach recognizes the range of social, economic and physical environmental factors that contribute to health, which has also been defined as "the capacity of people to adapt to, respond to, or control life's challenges and changes" (Frankish et al., 1996).

According to this comprehensive perspective, health is "created and lived by people within the settings of their everyday life; where they learn, work, play and love" (World Health Organization, 1986). The family environment is an important setting in which all members learn, work, play and love.

The Health Literacy in Rural Nova Scotia Research Project found that there is considerable variation in how individuals define health for themselves and their families. While many participants applied a strict physical interpretation and considered themselves healthy as long as they were experiencing no serious illness or "aches and pains" at the moment, others spoke about factors they could control - such as eating habits, physical activity levels, smoking, etc. - that directly affected their current and future physical health status. Some, however, saw health in much broader terms and regarded "being healthy" as being able to cope with life's circumstances, "keeping your family motivated to be able to deal with issues; being able to enjoy life." The report from this project defines health as "a state of physical, mental and social well-being. When an individual is healthy, he or she can identify and achieve goals, satisfy needs, and cope with change" (Gillis and Quigley, 2004).

It is interesting to note that current definitions for concepts of literacy, family literacy, and health are surprisingly similar and - not surprisingly - interdependent.

### 1.7 What is Health Literacy?

There is still considerable confusion about the evolving concept of health literacy, although it was first used in health education about thirty years ago. Only recently, with the recognition of its significant personal, social, and economic implications, has it become a serious field of study.

Several definitions currently exist for health literacy. The Expert Panel on Health Literacy (Canada) states:

> Health literacy is the ability to access, understand, evaluate, and communicate information in order to promote, maintain and improve health in a variety of settings across the life course.

*CPHA, 2007*

There is considerable overlap between this definition of health literacy and definitions of literacy in general, as understanding, appraising, and communicating information are essential skills required for all types of literacy.

When faced with complex information and treatment decisions, patients may be required to:

- locate health information
- evaluate information for credibility and quality
- analyze relative risks and benefits
- calculate dosages of medicine or portions of food
- interpret test results and decide between treatment options

In order to accomplish these tasks, individuals need a high degree of literacy and oral language skills. They need to be able to articulate their health concerns and describe their symptoms accurately, ask pertinent questions, understand medical advice or treatment directions, and be able to make informed decisions.

Health literacy, then, requires a complex group of reading, listening, analytical, and decision-making skills, as well as the ability to apply these skills to health situations.

> The U.S. Institute of Medicine accepts the following definition of health literacy:
>
> *The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*.

*IOM, 2004*

What is missing in the above discussions of definition, however, is the notion of collective responsibility for health literacy. It is extremely important to avoid placing the full onus upon the individual to make sense of the system rather than on the system to make itself comprehensible and accessible to all Canadians. While the vocabulary of health care and the Canadian health care system can be confusing to even mainstream educationally advantaged adults, for those with limited literacy or language skills the system can be incomprehensible.

Irving Rootman reports that the IOM has developed a **"***framework for health literacy that identifies three major areas of potential action: the health system, the education system, and culture and society. The framework also suggested that health contexts interact with individual factors to produce health outcomes. In other words, the committee suggested that health contexts, including public health, bear as much or more responsibility for addressing health literacy as individuals who are affected."* (Rootman,2004).

Keeping this framework clearly in mind, we can then define health literacy as an **"*opportunity for practitioners and policy makers from the fields of health, literacy, and other sectors to work together to address the health concerns of people limited in literacy, and the literacy concerns of people experiencing poor health*"** (Gillis and Quigley, 2004).

### 1.8 What are Health Promotion, Population Health, and Health Education?

**Health promotion** is the process of enabling people to take control over and improve their health (WHO, 1986).

**Population health** is an approach to health promotion that addresses the entire range of factors that determine health and, by so doing, affects the health of the entire population (PHAC).

**Health education**, considered a specific strategy within the broader concept of health promotion, focuses on changing health-related behaviours of individuals.

In a health care world where chronic illness has replaced acute infectious disease as the major cause of sickness and death, health education and health promotion have an increasingly important role to play. A growing body of evidence about what makes

people healthy was outlined in the Government of Canada's Report, *A New Perspective on the Health of Canadians* (1974). This document has helped build Canada's international reputation as a leader in the field of health promotion. It established a framework of key factors that seemed to determine health status: lifestyle, environment, human biology and health services. Since then, evidence has continued to mount and the framework has been refined and expanded.

A population health approach, which aims to improve the health of the entire population and reduce health inequities among population groups, supports a broad and multi-faceted view of health that links a person's health status to the complex interactions among physical, social, environmental, cultural and behavioural factors (PHAC). These combined factors, known as "Determinants of Health," strongly influence individual, family, and population health status at every stage of life.

### 1.9 The Determinants of Health

"Why is Jason in the hospital?
Because he has a bad infection in his leg.
But why does he have an infection?
Because he has a cut on his leg and it got infected.
But why does he have a cut on his leg?
Because he was playing in the junk yard next to his apartment building and there was some sharp, jagged steel there that he fell on.
But why was he playing in a junk yard?
Because his neighborhood is kind of run down.
A lot of kids play there and there is no one to supervise them.
But why does he live in that neighborhood?
Because his parents can't afford a nicer place to live.
But why can't his parents afford a nicer place to live?
Because his Dad is unemployed and his Mom is sick.
But why is his Dad unemployed?
Because he doesn't have much education and he can't find a job.
But why ...?"

*Toward a Healthy Future: Second Report on the Health of Canadians*
http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/determinants.html

### Income and social status

According to the Second Report on the Health of Canadians, only 47% of Canadians in the lowest income bracket rate their health as very good or excellent, compared with 73% of Canadians in the highest income group. Low-income Canadians are more likely

to die earlier and to suffer more illnesses than Canadians with higher incomes, regardless of age, sex, race and place of residence. Health status improves at each step up the income and social hierarchy.
http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/determinants.html

Why are higher income and social status associated with better health? If it were just a matter of the poorest and lowest status groups having poor health, the explanation could be things like poor living conditions. But the effect occurs all across the socio-economic spectrum. Considerable research indicates that the degree of control people have over life circumstances, especially stressful situations, and their discretion to act are the key influences. Higher income and status generally results in more control and discretion. A number of recent studies show that limited options and poor coping skills for dealing with stress increase vulnerability to a range of diseases through pathways that involve the immune and hormonal systems.

Studies suggest that the distribution of income in a given society may be a more important determinant of health than the total amount of income earned by society members. Large gaps in income distribution lead to increases in social problems and poorer health among the population as a whole. The healthiest populations are those in societies that are prosperous and have an equitable distribution of wealth.

It is interesting to note that the 1996-97 National Longitudinal Survey of Children and Youth found that many immigrant and refugee children were doing better emotionally and academically than their Canadian born peers, even though far more of the former lived in low-income households. The study suggests "poverty among the Canadian-born population may have a different meaning than it has for newly arrived immigrants. The immigrant context of hope for a brighter future lessens poverty's blows; the hopelessness of majority-culture poverty accentuates its potency" (PHAC).

**Social support networks**

Support from families, friends and communities is associated with better health. Effective responses to stress and the support of family and friends seem to act as a buffer against health problems, while social isolation has a negative impact on health. Lack of literacy in itself can be a source of stress, social isolation and marginalization. Along with the stresses that accompany limited employment opportunities/income and trying to cope in an increasingly information dependent world, there is the stigma and constant fear of being “found out.”

### Education and literacy

Health status improves with each level of education, which in turn is generally tied to socio-economic status. Effective education for children and lifelong learning for adults are key contributors to health and prosperity for individuals, and for the country. Education equips people with knowledge and skills for problem solving, provides more opportunities for income and job security, and gives people a sense of control over life circumstances - key factors that influence health.

### Social environments

Social stability and strong communities can help reduce health risks. Studies have shown a link between low availability of emotional support, low social participation, and mortality (whatever the cause). Family violence has a devastating effect on the health of women and children in both the short and long term.

### Employment/Working conditions

Unemployment is associated with poorer health. People who have more control over their work circumstances and fewer stressful job demands are healthier and often live longer than those involved in more stressful or riskier work and activities.

### Geography

Whether people live in remote, rural communities or urban centres can have an impact on their health and their access to health services.

### Physical environments

Physical factors in the natural environment (e.g. air and water quality) are key influences on health. Factors in the human-built environment such as housing, workplace safety, community and road design are also important influences.

### Healthy child development

The effect of prenatal and early childhood experiences on subsequent health, well-being, coping skills and competence is very powerful. Early child development influences health throughout the life span. Factors that influence child development include healthy birth weights, positive parenting, and safe, friendly neighbourhoods. Experiences from conception to age six have the most important influence of any time in the life cycle on the connecting and sculpting of the brain's neurons. Positive stimulation early in life improves learning, behaviour and health into adulthood.

### Health services

Health services, particularly those designed to maintain and promote health, to prevent disease, and to restore health and function contribute to population health. Many low- and moderate-income Canadians have limited or no access to recreational programs or health services such as eye care, dentistry, mental health counselling and prescription drugs.

### Biology and genetic endowment

People's genetic endowment contributes to their predisposition to certain diseases. Biology influences their response to sources of stress, such as viruses or emotional strain.

### Personal health practices and coping skills

People's knowledge, behaviours and abilities to handle outside influences and stressors affect health. Coping skills, which seem to be acquired primarily in the first few years of life, are also important in supporting healthy lifestyles. These are the skills people use to interact effectively with the world around them, to deal with the events, challenges and stress they encounter in their day-to-day lives. Effective coping skills enable people to be self-reliant, solve problems and make informed choices that enhance health. These skills help people face life's challenges in positive ways, without recourse to risky behaviours such as alcohol or drug abuse. Research tells us that people with a strong sense of their own effectiveness and ability to cope with circumstances in their lives are likely to be most successful in adopting and sustaining healthy behaviours and lifestyles.

### Gender

Gender refers to the array of society-determined roles, personality traits, attitudes, behaviours, values, relative power and influence that society ascribes to the two sexes on a differential basis. Many health issues are a function of gender-based social status or roles. Among populations where gender limits access to education and control over their own lives and sexuality, women are vulnerable to violence, exploitation, unwanted pregnancies, lone parenthood, low income, and sexually transmitted infections. Measures to address gender inequality and gender bias within and beyond the health system will improve population health (PHAC, 2006). In addition, men and women have different health concerns at different ages.

### Culture

Belonging to a particular race or ethnic or cultural group influences population health. Dominant cultural values contribute to the perpetuation of conditions such as marginalization, stigmatization, loss or devaluation of language and culture and lack of access to culturally appropriate health care and services.

For many populations the cultural expectations, traditions and beliefs about health may directly conflict with mainstream Canadian health expectations.

Sources for information on Determinants of Health: Public Health Agency of Canada, 2006
http://www.phac-aspc.gc.ca/media/nr-rp/2006/2006_06bk2_e.html
http://www.phac-aspc.gc.ca/canada/regions/ab-nwt/pdf/resources/Determinants_colour_e.pdf

For more information on how these factors affect health please refer to the PHAC website: http://www.phac-aspc.gc.ca/ph-sp/phdd/determinants/

## 1.10 The Literacy Challenge

> Education is closely tied to socio-economic status, and effective education for children and lifelong learning for adults are key contributors to health and prosperity for individuals, and for the country. . . Because initiatives to ensure access to effective education for children and youth and opportunities for lifelong learning must be part of an effective population health strategy, the involvement of the education sector is essential.

*Strategies for Population Health: Investing in the Health of Canadians, 1994*

The reality is that those likely to benefit most from health education and promotion are also the least likely to access and use it. Health education initiatives and approaches have generally assumed a fairly high degree of literacy. This assumption often results in poor or inappropriate communication strategies on the part of health care practitioners, thereby limiting the capacity of those with limited education and/or language skills to gain the knowledge they need to engage in preventive health practices. The major challenge, then, is to identify effective means of working with low literacy populations around health issues so that the health status of all Canadian families is improved.

## Promising Practice

Develop partnerships between health care and family literacy practitioners to better improve the health capacity of those with limited literacy or English language skills.

***Can you identify initiatives in your community that illustrate the implementation of this promising practice?***

# 2. Making the Connection: Literacy and Health

**Gerald's Story**

(*Health Literacy in Rural Nova Scotia Research Project*, Antigonish, 2004)

Gerald is a man in his mid-60's who lives in a rural trailer park with his wife and their 16 year-old grand-daughter. The trailer itself is ramshackle, with poor doors and windows through which the cold winter wind blows quite freely. His school attendance was sporadic, and he finally quit altogether in Grade 4.

*Back then, that was in the 30s and 40s, and there wasn't too much money coming in. I lived on a farm and I had 12 kids in the family, so you only go to school once or twice a week… if you went then… See, I was the oldest in the family and the rest of them were younger than I was.*

He didn't learn to read while at school because he went to a one-room school with about 30 children at different levels, and the teacher *only had certain ones that she would teach. The rest of them were just sitting there*. He sums up his current literacy level as follows: *Well, I can't read and I can't write. I can just sign my own name. That is about it.*

Gerald is diabetic, has high blood pressure, and crippled hands. He began working in the woods at age 16 and injured himself almost immediately. His hands became more crippled as the years went by, and soon he couldn't use a power saw at all. As working in the woods was his only source of income, and he was not educated enough to get any other form of employment, he ended up on a disability pension at an early age. About 25 years ago he discovered that he had diabetes when he "started passing out and having blackouts." He still feels quite tired and run-down.

*I should be on the needles by rights*. *I don't figure I could be able to afford it ... To be on medicine like that and stuff, you stay on until you can't get the money to buy it…. I can't get enough to get the food I am supposed to get. You need a lot of certain stuff*…. *I get the cheap stuff…and whatever is the cheapest. I don't get no quality stuff. Certain things I have to eat… like low fat and not too much sugar and stuff like that…. Like after a while you just forget about your diet and you eat a little more of this and a little more of that.*

He goes on to say that the Diabetic Clinic tries to help him as much as they can, but *by the time you get out of the hospital* (clinic), *you forget it…… I don't imagine there is too much they could do…if you can't read.*

Although he has never told them at the Diabetic Clinic that he doesn't know how to read, he suspects they've figured it out. This is embarrassing to him.

*And even your own people don't know you can't read… and you don't even tell your own… If you asked one of my brothers and sisters if I could read, they would probably say, "Oh yea, he can read."*

When asked how his situation would change if he knew how to read, Gerald replies, *Well, first getting the trailer fixed and going to the board* (re: tenant issues*) and all that…. and knowing what you are doing. …. I would be looking up a lot of things--diabetic stuff*.

Gerald admits that he wishes someone would *"help me a little bit."* However he also comments that Y*ou don't know what you want… so how are they going to help you?.. You feel uncomfortable and you don't know what to ask for… See we are kind of like blind folded…. just like you are in the dark… A lot of people, you know, can't read.*

His advice to others is, *Go to school and get your reading so you can help yourself…. You ought to be able to learn how to read and write in this world or you are done for.*

When asked if he is interested in a program that will help him learn to read and write, he replies, *If you can't read and write how can you get in touch with them? They tell you to come to a certain office in a certain place…. You wouldn't know how to get there.*

Nothing - not age, income, employment status, educational level, and racial or ethnic group - affects health status more than literacy skills.

That's why clear communication between patients and health care providers is critical.

*Ask Me 3 ;*http://www.askme3.org/

### 2.1 Measuring the Literacy of Canadians - International Adult Literacy and Skills Survey

The International Adult Literacy and Skills Survey (IALSS, 2003) reported that 41.9% of Canadians aged 16 and over have literacy skills below Level 3, the international standard of literacy needed to function effectively in a modern society and economy.

The survey was done across nationally representative samples of 16-to 65-year olds from six participating countries (Bermuda, Canada, Italy, Norway, Switzerland, and the United States). IALSS builds on its predecessor, the 1994 International Adult Literacy Survey (IALS), which was the world's first internationally comparative survey of adult literacy.

In Canada, more than 23,000 individuals aged 16 and over from across the 10 provinces and three territories responded to IALSS. The survey was conducted in either English or French. Of those who responded, 3,400 were Aboriginal Canadians; 2,600 were established immigrants (10 years + in Canada); 1,200 were recent immigrants (less than 10 years in Canada); 3,500 were Francophones outside of Quebec; and 3,500 were youth 16-24. They spent an average of two hours answering questions

which consisted of common questions seeking demographic information (such as education, occupation, income and engagement in adult learning and community activities), as well as tasks to determine proficiency levels at work, and in the community across four domains, as follows:

***Prose literacy*****:** The knowledge and skills needed to understand and use information from texts including editorials, news stories, brochures and instruction manuals.

***Document literacy***: The knowledge and skills required to locate and use information contained in various formats, including job applications, payroll forms, transportation schedules, maps, tables and charts.

***Numeracy*****:** The knowledge and skills required to effectively manage the mathematical demands of diverse situations.

***Problem-solving***: Involves goal-directed thinking and action in situations for which no routine solution or procedure is available.

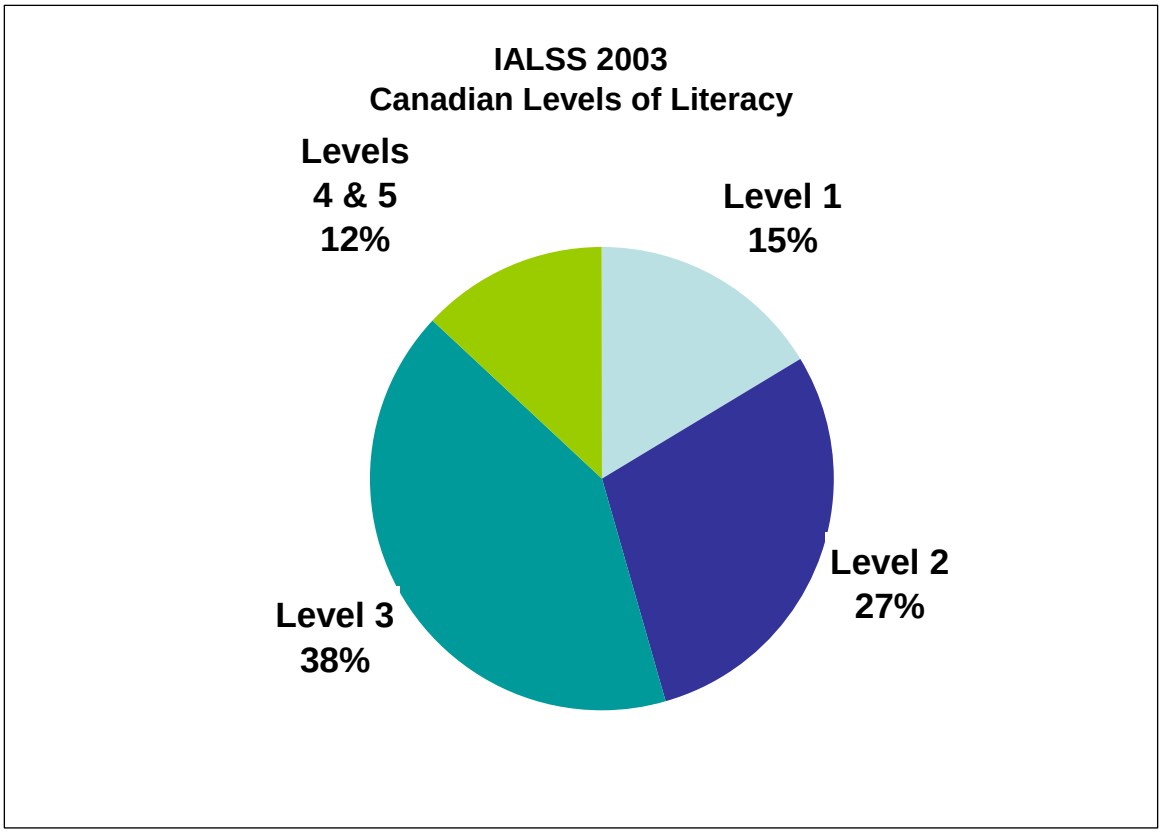
Each type of literacy was scored on a numerical scale from 0 to 500. According to that scale, the Organisation for Economic Co-operation and Development (OECD) defines the levels of literacy as follows:

- Level 1(0-225) *Very poor literacy skills*. An individual at this level may, for example, be unable to determine from a package label the correct amount of medicine to give a child.

- Level 2 (226-275) *Capacity to deal only with simple, clear material involving uncomplicated tasks.* Although people at this level have developed coping skills to deal with everyday life, their limited literacy skills make it hard to conquer challenges such as learning new job skills or interpreting print in unfamiliar contexts (e.g. health information).

- Level 3 (276-325) *Adequate to cope with the demands of everyday life and work in an advanced society.* Roughly denotes the skill level required for successful high-school completion and college entry. People at this level can read well, but have problems with complex tasks.

- Levels 4 and 5 (376-500) *Strong skills*. An individual at these levels can process information of a complex and demanding nature.




**The OECD considers Level 3 the international standard of literacy needed to function effectively in a modern society and economy**.

While most people have some literacy skills, "*a very high proportion — nearly half of adult Canadians — have literacy skills which are sufficiently limited to affect their ability to function in society. These people are especially vulnerable to changes in circumstances or contexts*" (Perrin, 1999), which could include changes in job requirements, health status, or family situation.

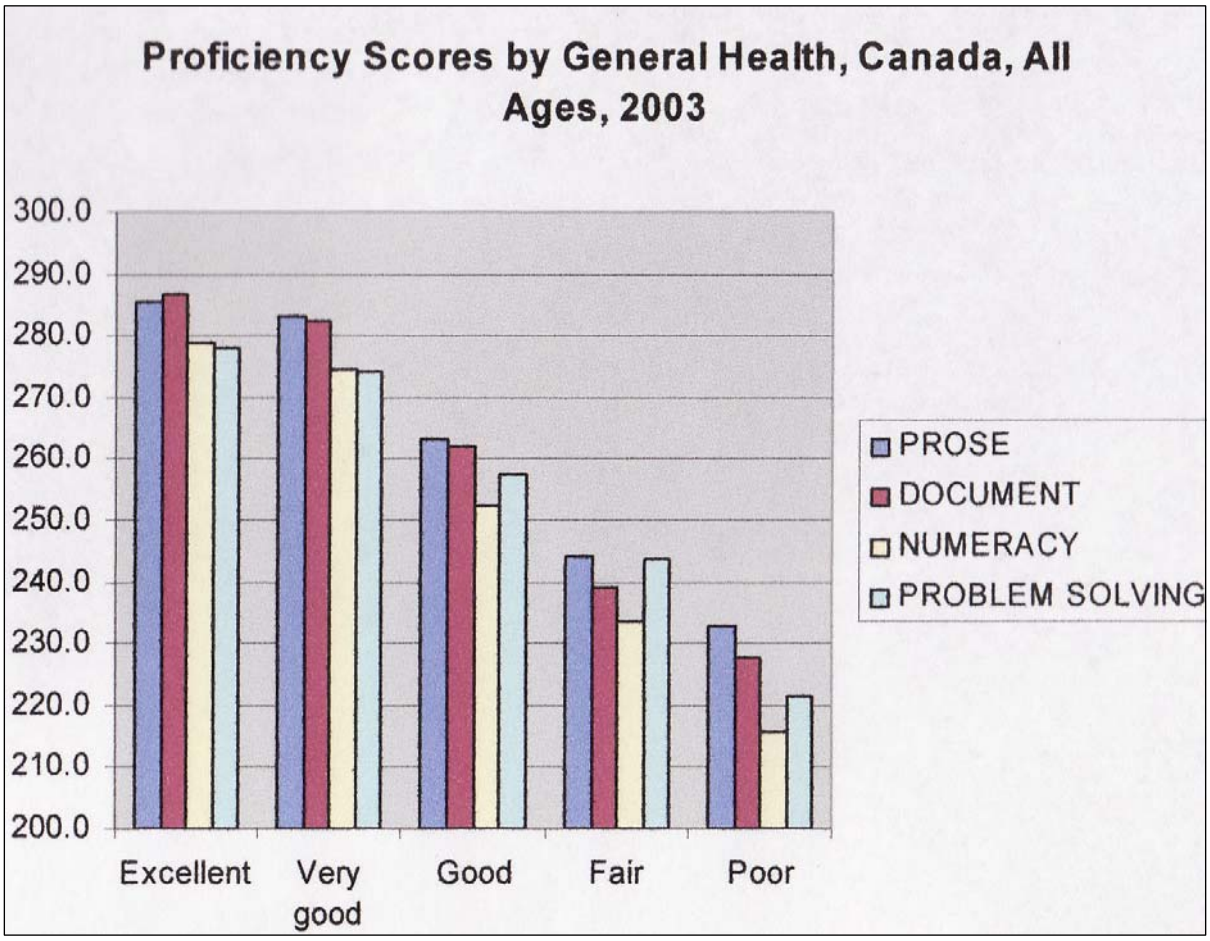
## 2.2 Literacy as a Determinant of Health

> Low literacy levels have a major negative impact on health. In fact, literacy is one of the major influences of health status. However health is defined or measured, people with limited literacy skills are worse off than others with higher literacy skills. Literacy is a major factor underlying most other determinants of health.

Perrin, *How Does Literacy Affect the Health of Canadians (1990)*

It is important to recognize the difference between “health literacy,” which is a discrete concept and “health and literacy,” which implies the correlation between the two domains. Research evidence points increasingly toward the existence of an important link: the higher one's literacy level, the better one's health and vice versa. One of the first major studies concerning the connection between literacy and health in Canada was the OPHA research study (1989), co-sponsored by OPHA (Ontario Public Health Association) and Frontier College. A summary of those findings concludes that:

One of the most commonly used indicators of health is self-rated health status. The 2003 IALSS survey indicated a significant relationship between literacy scores and self-perception of health. The table below demonstrates the decline in health that accompanies lower levels of literacy proficiency as defined by the OECD numerical scale.




*CCL, 2006*

While literacy skills as measured in the IALSS survey are different from health literacy skills, which were also measured on the latest survey, they are linked. Many individuals

with low literacy skills also have limited health literacy skills. Although a person's health literacy skills may vary depending on the situation, their literacy skills tend to remain stable unless some intervention occurs such as attending adult literacy programs (CPHA, 2006).

The inference from these observations is that increasing people's literacy levels (including oral language skills) will improve people's overall health. This highlights the importance of literacy, family literacy and early childhood programs as well as initiatives in health promotion and health education, all of which help to increase overall literacy levels (O'Neill, Dupéré, Pederson and Rootman, 2007).

### 2.3 Direct and Indirect Effects of Literacy on Health

> The effects of low literacy on health can be either direct or indirect. Although we are used to thinking about the more obvious direct effects, continuing research suggests that the most serious impacts of low literacy on health status are the indirect ones. Literacy problems affect health in less direct ways by reducing access to well-paid employment and hence increasing the likelihood of poverty and its related stresses, and by diminishing self-esteem and self-confidence.
>
> *Perrin, 1998*

The effects of literacy, low income, poverty and health are interdependent and self-perpetuating in a number of ways. For example, literacy or education level can have a direct impact on a family's income, which in turn has a direct impact on housing conditions and nutrition level. As a result, when children go to school undernourished they may have difficulties in concentrating, which then impacts on their ability to develop literacy skills.

However, the OPHA research study reports that: "*A number of statistical analyses which have controlled separately for the effects of education and of income indicate that while both are associated with ill health,* ***lack of education is the predominant factor***." (emphasis in original)

#### 2.3.1 Direct effects

People with low literacy levels:

- have greater difficulty finding and understanding health information
- have problems complying with treatment instructions
- make more errors with regard to taking or administering medications, mixing infant formulas, etc.

- may not understand safety precautions in the workplace, resulting in more workplace accidents
- have problems understanding appointment slips, informed consent forms, discharge information and oral instructions
- have more difficulty communicating with health practitioners

Some researchers have found that people with low literacy skills access health care at more advanced stages of disease (Bennett et al, 1998), are less likely to use preventative services, have less knowledge about disease, medication and protocols for asthma, hypertension and diabetes (CPHA, 2006; Williams et al, 1996, 1998), are more likely to be hospitalized (Baker et al, 1998) and have difficulty managing chronic diseases. Although chronic diseases are the leading cause of death in Canada (CPHA, 2006), many are preventable. An increase in health literacy could result in an increase in preventative measures and a decrease in risk behaviours for chronic disease. Literacy programming is cheaper than all types of medical care, increases self-reliance rather than dependence (Sarginson, 1997), and could result in better health for families and substantial cost savings for the health care system.

### 2.3.2 Indirect effects

As important, although often not as obvious, are the **indirect** effects of limited literacy or language skills on health. People with low literacy levels are more likely to have **socio-economic challenges** that affect their physical and social environments, which in turn impacts negatively on their health. Low literacy skills in our society often translate into low employability and low income. This in turn restricts the capacity of families to obtain adequate housing, good nutrition, and appropriate cultural and recreation pursuits; it also undermines confidence and self esteem, leading to physical and mental problems associated with poverty, dependency, and socio-cultural alienation (Pacific Region Medical Services Branch, 1996).

People with limited literacy skills tend to be under a higher degree of **stress** than those with higher skill level. They are more likely to have limited self-confidence and to feel vulnerable, which is probably a fairly accurate assessment of their reality. They <u>are</u> more vulnerable. The OPHA research study cites evidence documenting that unemployment, under-employment and poverty, coping with unsafe and insecure living and working conditions, and dealing with the uncertainty and lack of control over one's life are extremely stressful situations. People living in such conditions not only encounter more stressful events, they have fewer resources to be able to cope with stressful situations when these do occur.

There is substantial evidence from Canada's major survey of health status as well as from numerous other sources that literacy is also closely related to **healthy lifestyle practices**. People with limited literacy levels are more likely than others to take part in a wide range of unhealthy lifestyle practices, such as smoking, poor nutrition, infrequent physical activity, lack of seatbelt use or wearing of bicycle helmets, and less prevalence of breast feeding. They are also less likely to ever have had a blood pressure check or to be aware of the importance of healthy lifestyle practices.

People with limited literacy skills also tend to have **limited prior knowledge of health and health concepts and terminology.** As a result, there is ample evidence that even verbal information, from health care practitioners or others, is frequently not understood.

### 2.4 The Need for Partnerships and Collaborations

A population health approach focuses on root causes and prevention, and calls for "shared responsibility and accountability for health outcomes with multiple sectors whose activities directly or indirectly impact on health or the factors known to influence it. This requires partnerships, inter-sectoral cooperation, and community participation" (PHAC).

A family literacy approach also focuses on root causes and prevention. Promising practices in family literacy include taking a holistic, multi-disciplinary approach to working with the complex issues that affect the health and well-being of our families and communities. Family literacy is, above all, an inter-generational approach that addresses a wide range of learning needs across the lifespan. To be effective, it, too, requires partnerships, inter-sectoral cooperation, and community participation:

> "[Family literacy] programs depend on the collaboration and synergy created by like-minded people, from a variety of sectors within the community, each with its own knowledge, insights, experience, and resources, to reach a common goal - - providing opportunities for individuals and families to learn, grow, develop, and prosper. … If, as literacy practitioners, we can become literacy resources to our communities, we have the potential to create literacy-friendly and literacy-rich communities so that everyone will recognize the importance of literacy to the healthy development of individuals, families, and communities."

*Foundational Training in Family Literacy, 2001*

## 2.5 What is Collaboration?

The term “collaboration” has become something of a buzzword and the philosophical foundation of most family literacy and population health initiatives. As professionals in those fields, we are working our way together towards effective collaborations that will maximize our collective resources in order to better support the inter-related needs of Canadian families. The development of effective collaborations is an arduous endeavor and, like all worthwhile relationships, collaborations require continual care and attention.

Collaboration is defined as exchanging information, altering activities, sharing resources, and enhancing the capacity of another for mutual benefit and to achieve a common purpose.

The willingness to enhance the capacity of another organization requires sharing risks, responsibilities, and rewards, all of which can increase the potential of collaboration beyond other forms of organizational activity.

Because we live in a very individualistic and competitive society, collaboration also represents a change in values and beliefs about the nature of our relationships, both organizational and personal.

*Himmelman, 1992*

## Promising Practice

Practitioners from the fields of literacy, health and health literacy can work together to:

- Better understand how a family's educational, cultural, and environmental circumstances affect literacy, health literacy and long-term health status
- Work towards improving access to appropriate health care information and services for **all** families, including those who experience linguistic, educational or cultural barriers
- Make families aware of practices that support long-term health and help them to identify ways to enhance their current literacy and health literacy levels
- Provide increased, more coordinated and more accessible opportunities for families that maximize resources and minimize duplication
- Collaborate with rural providers of crucial services to bring as many services as possible to families at one site – one-stop centres with which family literacy programs are connected
- Make a concerted effort to partner with private businesses and industries for money, equipment, supplies, and volunteers
- Share staff members across agencies, to share expertise, especially where individual agencies cannot afford full-time staff.

***Can you identify initiatives in your community that illustrate the implementation of these promising practices?***

# 3. Family Literacy, Health, and the Community

**Stephanie's Story**

(*Health Literacy in Rural Nova Scotia Research Project*, Antigonish, 2004)

Stephanie is a woman in her mid-40's who lives with her husband of 21 years and her 13 year-old daughter. She is planning on separating from her husband and moving to the city with hopes of opening a small food service outlet. Stephanie dropped out of school at the age of 15, and has since made several attempts to upgrade her education. Her memories of her childhood school years are painful, as she remembers being totally ignored by the teachers. She was immediately placed in an "adjusted" class, where she was bored and frustrated and never taught to read.

*I kind of block school. I don't know what happened. I thought I was doing good, like when I was in Primary and stuff, and I passed on to Grade 1… and then I ended up going into an adjusted class. I guess I was kind of quiet as a child. ...My mom was very into teaching us about people, because she didn't have very much education and all she had was her life skills…. We had nothing, but we had each other. … love was the thing that makes you healthy. Music makes you healthy. You know I grew up with…just a happy environment keeps you healthy.*

Stephanie's mother, despite her limited education, tried unsuccessfully to advocate for her daughter's schooling.

*Well, my mom she wasn't that alert to education because she only had a grade two herself. ... She used to get involved and she used to tell them, hey, I can't do it, so can you please give her extra help or something, but nobody was there to hear it. Like they just weren't listening… Society, I think, labeled us. … Yea, there was hungry days, and maybe that accumulated to the quietness in class, I don't know. But whatever it was, I think they should have taken the time out to figure it out.*

At age 16, Stephanie taught herself to read, saying to herself*:*

*Ok, enough is enough. Like get off this pity trip and teach yourself. …..*(Now*) I am a very good reader. I find it hard sometimes, like if I am under pressure I can't spell properly. Like I can spell, but if I feel like I am under pressure it won't come out. It won't come out of my brain only because the lack of confidence I have in myself… Sometimes well, mentally wise sometimes, because of the education thing where I am fighting with that and stuff, I sometimes get lost there and I lose my self-esteem and that is not healthy because when you do that… well, I smoke my cigarettes and drink my coffee and I do all the stuff I am not supposed to be doing. Physically I am very healthy. I have only ever been in the hospital once and that was for appendicitis.*

When asked to talk about a time in her life when she had to deal with a health issue, Stephanie immediately responded*, "Ok, my marriage",* and told of nine years of living in total isolation with an abusive husband.

*And him and I kind of both leaned on one another because we were both sick at the time. He was an alcoholic and I was kind of like a co-dependant. Mentally I was lost. I didn't know where I was at and I didn't know my feelings… When you are lost in that aspect you might as well be a plant without your roots, because you are kind of stuck… like 4-wheeling in the woods. Like I had such a horrific nine years that I don't even, I mean you never talk about it…That is a lot of women's problems today is that they are ashamed to speak out….I really didn't get help. I never went to a psychologist or anything. …Sometimes you get so isolated that you can't get help…. I think the rural areas are the worst…. And how can you get out of that until you just find it in here… in yourself… to do something about it. No outsider could have come in and helped me…. I think I would have come around sooner if I would have had somebody that wasn't judgmental…. But again that is the community thing. You need a strong community for that…… It is the one you are having a coffee with and the one that is there, not somebody that has got a book in her hand and is coming in and saying, "Well, I am here to help you, dear," and then go… and you never see them again.*

In speaking of what could help her or others in her situation, she answers without hesitation:

*I think it is community and education is the whole…that is the whole survival of life… . It all boils down to an education. Like that is my whole problem…. Like, that is my whole thing. I don't lack courage. I don't lack self-respect. Like I have all that… it is just the education. I want to find out how to get an education. That is my main goal in life. … I am thinking, ok where do I fit in? Like you never knew where you fit in.*

### 3.1 Cultural Norms and Change

The array of values and norms of a society influence in varying ways the health and well-being of individuals and populations. … Some persons or groups may face additional health risks due to a socio-economic environment, which is largely determined by dominant cultural values that contribute to the perpetuation of conditions such as marginalization, stigmatization, loss or devaluation of language and culture and lack of access to culturally appropriate health care and services (PHAC).

Although literacy skills play a key role in an individual's ability to understand, access, or act upon health care information and services, cultural barriers compound the situation. The health of an individual is often dependent upon their place in the community – where they "fit in." The response of society to marginalized populations - the poor, the physically or mentally challenged, the mentally ill, people of racial or ethnocultural minorities - can have significant implications for health and well-being (Health Canada, 1999). As a civil society we must work towards acceptance and inclusion of diversity to ensure the health and well-being of all Canadians.

Language, literacy, lifestyle and self-care practices that affect health are intimately connected to culture and community. The food we eat, our attitudes towards drugs and alcohol, our gender roles, the way we nurture our children, whether or not we are likely to breast feed, our expectations regarding education and employment and our recreational activities are all transmitted to us through our culture and community. We learn from each other and the collective knowledge and practices of a community are transmitted culturally from generation to generation. For people with lower literacy skills, almost all information including health information is relayed through modeling and word of mouth.

Changes in values and norms require a change in attitude of the prevailing culture. Shifts are often brought about through deliberate educational campaigns or through the messaging of the media and popular culture. For example, in the area of health over the past twenty years we have seen dramatic shifts in attitudes towards smoking, breastfeeding, wearing of seatbelts and bicycle helmets, drinking and driving, drinking while pregnant, domestic violence, physical activity, and nutrition, to name just a few. However, most of this messaging is aimed at the mainstream population. Communities across Canada differ widely both in their exposure to and acceptance of new attitudes. Information alone will not bring about change where cultural entrenchment is strong or it is in conflict with prevailing community attitudes.

Although the tendency in the field of health literacy is to focus on a person's ability to read and comprehend instructions, awareness of the cultural factors that shape health literacy is fundamental to effecting positive changes in outcomes. It is important for both literacy and health practitioners to understand the beliefs, expectations, and behavioural norms of the communities in which they are working if they expect health information to be acted upon. Barriers to "compliance" are very often cultural rather than personal. Medical, lifestyle or dietary recommendations are less likely to be followed if they are contrary to the traditions of a community or culture.

**"***People use collective beliefs, customs, world-views, and social identity in order to interpret and act on health information*" (Zarcadoolas et al, 2006).

People will only act on information if they understand it, if it comes from a trusted source, if it is relevant to them at the time, if it suits their culture, values, and beliefs, and if it is within their means – if they have the capacity and support - to do so. Information alone is not useful when either the will or the ability to act on that information is lacking.

### 3.2 Cultural Competency

*Lia Lee was a three-month-old Hmong child with epilepsy. Her doctors prescribed a complex regimen of medication designed to control her seizures. However, her parents felt that the epilepsy was a result of Lia "losing her soul" and did not give her medication as indicated because of the complexity of the drug therapy and the adverse side effects. Instead, they did everything logical in terms of their Hmong beliefs to help her. They took her to a clan leader and shaman, sacrificed animals and bought expensive amulets to guide her soul's return. Lia's doctors felt her parents were endangering her life by not giving her the medication so they called Child Protective Services and Lia was placed in foster care. Lia was a victim of a misunderstanding between these two cultures that were both intent on saving her. The results were disastrous: a close family was separated and Hmong community faith in Western doctors was shaken.*

*American Medical Student Association*, http://www.amsa.org/programs/gpit/cultural.cfm

The above situation could have had a more positive outcome if the cultural literacy of the family and the cultural competence of the medical practitioners had been at a higher level. The impact of cultural knowledge and communication on family health is as basic in importance as the understanding of oral or written information. Cultural competency enables professionals, agencies and systems to work effectively in cross–cultural situations.

Cultural competence is the ability of organizations and practitioners to recognize the "*cultural beliefs, values, attitudes, traditions, language preferences, and health practices of diverse populations, and to apply that knowledge to produce a positive health outcome. Competency includes communicating in a manner that is linguistically and culturally appropriate*."

*http://www.health.gov/communication/literacy/quickguide/factsbasic.htm*

### 3.2.1 The cultural competency continuum

Like all competencies, cultural competency is a continuum that involves developing awareness, knowledge and skills over an extended period of time.

According to Terry Cross et al (1989), there are six possible levels of cultural competence, from negative to positive:

1. Cultural destructiveness - blatant attempts to destroy the culture of a given group; there is also an assumption that one group is superior to another

2. Cultural incapacity - lack of capacity to be responsive to different groups that is not intentional but born out of ignorance (e.g., not recognizing when mistreatment is due to cultural differences thereby perpetuating its occurrence)

3. Cultural blindness - belief that culture is unimportant in relation to the way groups act or react; fosters the assumption that people are all basically alike, so what works with members of one culture should work with members of all other cultures

4. Cultural pre–competence - movement toward cultural sensitivity; individuals actively pursue knowledge about differences and attempt to integrate this information into service delivery

5. Cultural competency - involves actively seeking advice and consultation and a commitment to incorporating new knowledge and experiences into a wider range of practice; acceptance and respect of differences, continual self-assessment, attention to dynamics of differences, and continual expansion of knowledge about the target group are important factors of competency

6. Cultural proficiency - pro-actively regarding cultural differences and promoting improved cultural relations among diverse groups; individuals in this category are specialists in developing culturally sensitive practices

It has been suggested that, at best, most agencies providing services to children and families fall between cultural incapacity and cultural blindness on the continuum (Cross et al., 1989).

Family literacy and health practitioners are at various stages along the continuum and should constantly strive to increase their own cultural competency. The first step is to examine their own assumptions, expectations and communications regarding literacy and health and to understand that these arise from the norms of their own particular socio-economic and professional culture.

The **National Center for Cultural Competence** at Georgetown University's Centre for Child and Human Development has recently published *A Guide for Advancing Family-Centered and Culturally and Linguistically Competent Care*. Its intention is to "promote cultural and linguistic competence as essential approaches for practitioners in the elimination of health disparities among racial and ethnic groups." It can be found at: http://www11.georgetown.edu/research/gucchd/nccc/documents/fcclcguide.pdf

You can also complete an online **Cultural Competence Health Practitioner Assessment (CCHPA**). This self-assessment tool can be found at: http://www11.georgetown.edu/research/gucchd/nccc/features/CCHPA.html

### 3.3 What Groups Have Health Literacy Challenges?

Health literacy issues affect a vast majority of people regardless of their formal schooling, language or culture. People in general often have difficulty analysing and applying complex and often conflicting information on health management, including preventative health strategies, the safe use of medications or various medical and non-medical treatment options.

In the 2007 report on the State of Learning in Canada, *No Time for Complacency*, the Canadian Congress on Learning states that more than half (55%) of Canadians aged 16 to 65 do not have levels of health literacy adequate to read nutrition labels, follow medication directions, understand safety instructions, or make informed and adequate choices for healthy living.

Naturally, some populations are more vulnerable than others in this regard. Low health literacy affects a broad range of people, including those who:

- are not fluent in English or French
- have low literacy skills in their first language
- do not use verbal language (deaf-mute) or written language (blind, indigenous or Aboriginal peoples)
- have cognitive and/or mental disorders
- are excluded from, or live outside of, a social network to use for information, support or the fostering of ties
- are ashamed of revealing their limitations with regard to reading.

Specific groups in Canada who may lack the language skills needed to deal with health information include people with very low incomes, older adults, Francophones, Aboriginal people, and recent immigrants with low levels of formal education and a foreign mother tongue (*CCL, 07*).

### 3.3.1 Aboriginal peoples

The prevalence of major chronic diseases (including diabetes, heart problems, cancer, hypertension and arthritis/rheumatism), infant mortality rates and suicide rates are significantly higher in Aboriginal communities than in the Canadian population as a whole (Second Report on Health of Canadians, 1999). It is important that these challenges be addressed in a culturally appropriate way that respects the diversity of Aboriginal communities, their understanding of health and their traditional approaches to healing. The Aboriginal perspective views everything in nature as connected, and it is necessary to acknowledge this philosophy when defining Aboriginal health literacy or addressing lifelong learning needs. This holistic attitude supports health as an approach to life that includes healthy relationships, healthy nutrition, language instruction, ceremonial practices, and family literacy (Antone and Imai, 2006). The medicine wheel of Aboriginal people includes four parts: mind, body, heart, spirit. When all four parts are healthy, and the community is healthy, then the Aboriginal person is considered healthy.

Aboriginal health issues are so important, pressing, and culturally unique that they require a module and workshop of their own. However, the holistic framework that underpins the notion of Aboriginal health is a model well worth exploring by other communities in Canada.

### 3.3.2 Recent immigrants

Immigrants comprise a significant segment of Canada's population. Over the last two decades, immigration trends have changed considerably with the majority of new immigrants now coming from non-European countries. Approximately one in nine people admitted to Canada in 1997 were refugees. One in five children in Canada are either immigrants or the children of immigrant parents (Health Canada, 1999).

The limited English literacy skills of many recent immigrants create a barrier to accessing health care information and services. Despite generally higher education levels, they tend to score lower on the IALSS survey of literacy skills than native born Canadians. This is not surprising since the test can only be taken in English or French. Among immigrants, limited literacy skills are more prevalent in women than men and younger immigrants tend to have higher literacy skills than older immigrants, despite their length of stay in Canada (Literacy Ontario, 2000).

Experiences unique to immigrants may be significant determinants in the health of this population, at least in the short term. Often immigrants leave behind family, friends, and social support systems. They frequently give up careers and comfortable incomes.

Refugees may have experienced violence/torture, deprivation and extended poor living conditions. They may be affected by poverty, discrimination, and new pathogens (Health Canada, 1999).

In addition, research at the Canadian Institute for Health Information suggests that the stress of immigrating to Canada may lead to poorer health. While the majority of immigrant women surveyed in 2001-2002 reported that they were in good to excellent health for the first two years after arriving in Canada, after 10 years in the country they were 30 per cent more likely to report fair or poor health compared to Canadian-born women. Despite Canada's public health care system, language barriers may prevent immigrants from accessing it. This compounds the effects of relocation stress, loss of social supports, changes in diet and lifestyle, reduced income, etc.

### 3.3.3 Older adults

Health literacy is particularly low among seniors. More than 80% of Canadians 65 and older scored at Levels 1 & 2 on the IALSS study (Statistics Canada, 2005). This is particularly significant in light of the increasing proportion of senior citizens; researchers suspect that health literacy declines with age. Older adults with low literacy skills experience a "double jeopardy, " as many also have vision and/or hearing difficulties and suffer from chronic diseases. Older adults who have lower literacy levels have more and longer hospitalizations than older people who have higher literacy levels (Rootman and Ronson, 2003). They also take medications more frequently or are responsible for some other form of self-care that requires understanding and using information correctly. In addition, there is a shift towards home-based care, which requires family members to understand information regarding the care they need to provide.

### 3.3.4 Rural residents

The Health Literacy in Rural Nova Scotia Research Project explored the links between literacy and health from the perspective of people living in rural communities. Several major themes emerged: social isolation; limited employment opportunities; lack of transportation; limited access to education, recreation, health care, and social support services. All of these are linked to health outcomes. At the same time, it was noted that "*small communities are often close and supportive, which can lessen the negative impact of limited literacy on health"* (Gillis and Quigley, 2004).

A Manitoba study on health and literacy in that province found that rural Manitobans are hospitalized 46% more than their urban Winnipeg counterparts. Rural residents with

limited literacy skills are disadvantaged because they need reliable transportation to access both literacy and health services that are usually not found in close proximity to them. Individuals who live on reserves are also at greater risk. "*Lower incomes, poorer nutrition, inadequate housing, overcrowding, and higher rates of single parent families all serve to set the stage for poorer levels of health compared to urban Manitobans*" (Sarginson, 1997).

Rural areas struggle with issues related to isolation which impacts availability of services, scarcity of resources, isolation of professionals, and attracting and retaining qualified professional staff. In remote areas, transportation becomes a key determinant of both health and literacy. The economic expense and travel-time required to access health services, especially for services like emergency evacuation, are part of the reality of the North. At the same time, access to education programs is equally limited. *"With isolation comes lack of transportation, and lack of transportation becomes lack of knowledge*" *(Gillis & Quigley, 2004).*

Rural programs supporting the health and literacy of families may be able to address the impact of isolation by expanding the scope and depth of partnerships, collaborations, and community involvements so that as many services as possible are provided at one site – one-stop centres with which family literacy programs, health services and related supports are connected.

### 3.4 Supporting Health Literacy

In a rapidly changing society that places escalating demands for health literacy on all families, it is the responsibility of practitioners to make sure that those demands are not unreasonable or unattainable. Health literacy refers to the interaction of individuals and families with the systems that are intended to support them. It is essential to keep in mind that those with the highest health and health literacy needs are often the members of our communities who also experience the greatest barriers to accessing information, services, and the conditions that nurture health and well-being.

*Social stability, recognition of diversity, . . . and cohesive communities provide a supportive society that reduces or avoids many potential risks to good health* (PHAC).

## Promising Practice

Both health and family literacy practitioners work together to:

- reach underserved populations who may not seek out health or literacy support
- assess health and literacy needs in a timely way and make appropriate referrals
- enable communities to explore issues of concern to them in ways appropriate to their culture, needs, and learning styles.

***Can you identify initiatives in your community that illustrate the implementation of these promising practices?***

# 4. Health Literacy and the Family

**Marc's Story**
(*Health Literacy in Rural Nova Scotia Research Project*, Antigonish, 2004)

Marc is an Acadian man in his mid-thirties who lives alone. He has a son who is in the custody of his ex-wife, and his greatest wish is that he could spend more time with him. Marc's first language is French and he believes that this has contributed to his difficulty in school, where he has only gone as far as Grade 6.

*What happened was I never had any help at home to help me finish my French, so I never got to learn to read and write the French. I never had anyone home to help me with my English, so I never got to read and write the English.*

Marc was earning a good living fishing until he badly injured his arm. His doctor repeatedly told him that it was just a sprain and that he should keep working. The pain finally got so bad that the skipper of his boat contacted the doctor and insisted that Marc be sent to a specialist. The specialist told him that the arm had been badly broken and that he could no longer fish.

*I didn't have to take the doctor's word for it…. I wouldn't have these problems if I had education, because I could have helped myself. I would have known what to do.*

With no education, his employment options were extremely limited. When his Workmen's Compensation was cut off he had to rely on social assistance.

*I was used to working hard, because I had no education when I was growing up and I was used to working hard. I was making good money and I was making a good living and I was not worried because there was always work out there. When you are healthy and you got your arm, it is not a problem. …I had a job, I was doing it well, I didn't need education to do it, but then I lost my arm. Then after that I needed education all of a sudden. …. I wanted to work. I am not the kind of guy that can stay home and watch TV. That is why I have problems with my nerves, that is why I have a lot of frustration in me. I have nothing to do. … If I had a job and could work everyday, I would be happy. Even just enough to get by, just enough to support myself and my son…. Just like a normal person, just enough for my car and room and board, enough to support my son to go to college.*

In an attempt to better his position, he enrolled several times in literacy programs, but found them frustrating because they were not on-going.

*I have been taking literacy courses over the past few years. …You get started in your literacy course and you do fairly well and you get in good spirits about what you are doing and learning and it helps a lot and you feel proud. And when you go to the next level the next year, there is none…. and it is discouraging, because you forgot already*

*what you learned instead of keeping on going and refreshing your memory. . I don't really find that you have a fair chance. It is like counting from 1 to 10 every year: you get sick and tired of it, you want to get to 15, 20, 25.*

Marc feels isolated and believes that also aggravates the situation.

*I always found you needed somebody at home to help you out. I am alone and I have no one to help me out... I try to learn different ways of doing it by myself … Just trying so hard and trying to figure out ways, because I am tired of being illiterate… When me and the ex left each other, I didn't know how to pay the power bill. I had to learn that on my own. My father is dead, my mother is on her own, and I have been left back by myself-- and now I am supposed to raise my son. But really it is like the job was not finished for me being raised properly.*

Marc's motivations for learning to read are to get a good job so he can afford to have his son visit him more often and to be able to help his son with his homework.

*It makes me feel bad that if my son was with me now in full custody, I wouldn't be able to help him with his homework. That really bothers me…It makes you feel like a failure when you can't provide what you want for your kids*…

Marc feels as if life is one big Catch-22, and, as he puts it:

*It is a lot of hurt…Really, you can't blame anybody. But I don't blame myself, because I have tried every corner there was to go to to help myself. …. You know, they say life is what you make it, but that is not true as far as I am concerned. I tried to make my life a lot different and I couldn't do it all because of these reasons. Life is what you* ***try*** *and make it, but it doesn't mean it is going to come true…If you were me, how could you make it better? That is my question to you? How could you make your life better if you were me?*

The family constitutes a context of informal education, a base from which members seek formal education, and should provide a supportive environment for learning. Literacy has a dramatic effect on the dissemination of ideas and the ability of families to adopt new approaches, technologies and forms of organization conducive to positive social change. Often affected by early school leaving or dropping out, literacy is a prime conditioner of the ability of families to adapt, survive and even thrive in rapidly changing circumstances....

*U.N. Statement on Family Literacy, Sticht, 1995*

Family literacy programs support the education of families in the broad and inclusive sense of the term presented in Section 1.1. The dynamics among all people who constitute any family group have a significant impact on the health, learning, and well-being of each of its members. Each family member has a unique role and influence in the family that needs to be supported.

### 4.1 The Role of Women

For a variety of social, economic and cultural reasons, women and their children are the primary participants in family literacy programs.

Although some have suggested that this focus on women unfairly places the onus of responsibility for family education on the mother, it also has a number of benefits for women, families, and society as a whole. In 2004 position paper, UNESCO reported:

> "Gender-based discrimination remains one of the most intractable constraints to realizing the right to education" (Dakar Framework for Action, § 40). Analysis of figures from the past 30 years reveals the persistent disparity between literacy rates for women and for men. Eliminating this disparity, which itself perpetuates sexual discrimination, is imperative for realizing education for all. Levels of female literacy tend to accompany lower rates of infant mortality and maternal mortality in childbirth, better children's health, higher school enrolment rates among girls, and even lower fertility rates. Beyond these general positive effects and the particular instrumental advantages of literacy, its intangible benefits – self-awareness, self-esteem and self-determination – may accomplish even more for gender equality. These intangible benefits allow women to assess their own situations critically in the light of broader horizons and new possibilities. As a social event, participating in literacy provides women with a forum to share their experience of male and female gender roles, to develop new insights and knowledge, and to support each other in bringing about beneficial change.

*UNESCO, 2004, p.23*

Women's schooling is associated with much of the world's improvement in child survival and maternal and child health since 1960; this association is widely interpreted as demonstrating a cause and effect relationship between formal education and health (Rowe et al, 2005).

In a paper developed for UNESCO, Tom Sticht looks at the effects of parent's education (in particular, mother's education) at different phases of child bearing and schooling. He uses this information to make a strong case for education programming aimed at women that provides "double duty dollars" (Sticht, 1999). Family literacy programs that

use health information as a curriculum resource seem to fit this prescription for effective programming that does, in Sticht's words, "Teach the mother and reach the child."

**Some effects of higher levels of mothers' education at different phases of child bearing and schooling**

| Phase of child bearing/schooling | Effect of higher levels of mothers education |
|---|---|
| Before pregnancy | Higher economic productivity; better personal health care; lower fertility rates: smaller families |
| During pregnancy and at birth | Better prenatal care; more full term births; higher birth-weight babies; fewer learning disabilities |
| Before going to school | Better health care; better development of language, cognitive, and literacy skills; better preparation for schoolwork |
| During the school years | Higher participation rates in the schooling process; better management of homework; better advocacy for children's education and negotiation of school/child conflicts; higher academic achievement by children |

*Sticht, T. & McDonald, B. Teach the Mother and Reach the Child: Literacy Across Generations; International Bureau of Education, 1990. (ERIC Document # ED321063)*

Because women are traditionally the primary caretakers of the family's health, and the mother's level of education is a significant indicator of family health, it is absolutely essential to focus more educational resources on women.

Family literacy programs provide:

- an ideal opportunity for women to increase their own education, skills, and self-efficacy
- an effective means of integrating health information, issues and resources into a literacy curriculum for parents, so that family health status is improved.

## 4.2 The Role of Men

Although women have traditionally been the primary focus of family literacy programs, efforts are increasing to encourage men to attend. Involving fathers and other male family members in the family literacy program reinforces the importance and relevance of the program for the entire family and encourages active participation. In many cultures, fathers assume responsibility for their children's education, suggesting that it is crucial to have fathers involved when children, as part of a family, are being provided an educational program (FiFL, Chapter 8, 2008). In addition, there are many single parent families headed by men and some two-parent families with two dads.

The roles that both men and women play in a family are determined by a variety of factors, including cultural expectations. When those expectations change as a result of immigration, there is a risk of significant pressure to either adapt or adopt new roles. This can create considerable tensions within a family. Men sometimes feel threatened when their wives begin to increase their education and their independence. The facilitators of a family literacy program at an immigrant serving agency in Calgary (Hoffart & Clark, 2007) find that acculturation for the entire family is less difficult when the fathers are involved. When fathers are engaged it helps ensure that the family's involvement and learning in a program is supported by the head of the household. It also provides an opportunity for family members to talk through important issues in a neutral and non-threatening environment, learn new information together concerning family education and health, practice new strategies together, and have fun together (FiFL, Chapter 8, 2008). In this way, chances of applying new information and strategies at home are often improved.

## 4.3 Health Challenges for Families

Family and community structures are as diverse in Canada as our ethnic and cultural backgrounds. Family groupings might include - but are certainly not limited to - nuclear families, families who have chosen not to have children, families with same-sex parents, families where grandparents are raising their children's children, homeless youth and adults who develop their own "families" and support systems on the street or in shelters, and cultures and communities who collectively take responsibility for their own members as an extended family.

It is important for practitioners from the fields of literacy and health to take the plurality of families into account in order to effectively support the literacy and health needs of all Canadians. Although many of the issues are the same for all groups, they all also have distinct needs and perspectives that arise from their varied structures, settings, internal

and external dynamics, cultures and languages, socio-economic level, and beliefs and practices with regard to education and health, to name only a few.

The challenges in relation to health and literacy not only vary widely from family to family, but they change over time. Some families may be dealing with the addition of a new child and the steep learning curve that entails; some may be struggling with an adolescent who seems to have a substance abuse problem; some may be trying to understand and cope with the chronic care needs of a family member with physical or mental challenges; some may be experiencing a medical crisis and the confusion that comes with navigating a complex and unfamiliar medical system; some may be learning how to manage a chronic disease and the consequent changes in family lifestyle; some may be caretakers for elderly family members with multiple health challenges and medications to sort out and attend to; while others may be trying to figure out how to keep their family healthy while living under the oppressive conditions of poverty.

For all families, health challenges and priorities follow their life experiences closely, both what they are living through now and what challenges they anticipate for the future. Some priorities are common to many families, while others are shared by a relatively small number of families. What all families have in common, however, is that when concerns arise regarding the health of a family member, that member's health becomes a priority and the focus of the family's energy and resources.

The various phases and challenges of the family life-cycle provide family literacy and health practitioners an opportunity to reflect on how both learning and health needs change over the years. The phases also assist with understanding how the various members of the family are called upon to assume caregiver roles, with the responsibility always being passed on to the strongest members.

### 4.4 Growing Requirements of the Health System

In looking at the range of concerns and issues faced by families over the course of their life-cycle, it is easy to see that many Canadian families may be further challenged by our society's ever-increasing demand for stronger literacy skills. It is known that:

- Our health care system is increasingly oriented toward health promotion and disease prevention, which requires individuals and families to play a greater role in managing their health.

- People need to care for their loved ones at home more frequently. It is essential that caregivers know what to do and how to proceed.

- Knowledge and communication modes are evolving rapidly. Families need to stay abreast of new developments in health, which is not a simple task for many people, particularly vulnerable populations (e.g., weak readers, immigrants, senior citizens, minority Francophones).

### 4.5 Independence: A Basic Need of Families with Regard to the Health of their Members

With the growing emphasis on personal responsibility for health, achieving independence in relation to one's health and the health of one's family members becomes the ultimate objective of health literacy. To develop this health-related independence, it is also necessary for people to seek to improve their literacy levels.

It is expected that families will increase their independence with respect to:

- Prevention, e.g., maintaining a healthy lifestyle and safe home and workplace environment
- Disease management in the current context of a health care system based on high technology, information and home/self-care
- Health promotion among all family members

All the above are influenced by the literacy levels of the family members.

Families want and need the best possible opportunities and life chances for all their members. If, as the Ottawa Charter for Health Promotion (1986) states, “health is a resource for everyday living,” then it is time to ensure that resource is available equally to every Canadian.

## Promising Practices

A number of national programs and resources have been implemented to meet the health literacy priorities of families across the life span. These include:

- Community Action Program for Children (CAP-C) – Public Health Agency of Canada (PHAC)
- Canada Prenatal Nutrition Program - PHAC
- National Literacy and Health Program - CPHA (Canadian Public Health Association)
- National Collaborating Centre on Determinants of Health - PHAC
- Canadian Council on Learning Knowledge Centre on Health and Learning
- Expert Panel on Health Literacy – CPHA

***Can you add to this list?***

# 5. Key Issues for Health Literacy

**Mary's Story**
(*Health Literacy in Rural Nova Scotia Research Project*, Antigonish, 2004)

Mary is a 68 year-old woman who lives in a rural area with her 40-year old son: *He has to stay with me to drive me around.* She has brought up 15 children.

*I had 14 of my own, and one of my daughters had a little baby boy and the welfare was going to take it, and I said no. I have got a piece of bread for one, I can have it for another one. So I took him.*

Mary quit school in Grade 7, as she found the experience both painful and humiliating. Because she was a slow learner from a poor family, kids called her names and taunted her about the clothes she wore and what she brought for lunch.

*So I said to myself, well if I am stupid and I am retarded and I don't know nothing, why should I go and take the teacher's time up?*

She considers herself generally healthy, except for *a headache now and again… my nerves, when I get excited, they kind of go. I mean when my husband was sick they started to go bad.*

Her husband died of emphysema a couple of years ago, and that experience was extremely difficult for her on a number of levels. Her family suffered further financial difficulties because of his extended illness, and this increased her own stress level.

*It is hard… very, very hard. You have got to squeeze. You have got to buy a lot of yellow labels. …You …have to think, 'Well, I am going to see the doctor and he is going to give me this big prescription. Have I got money to pay for it?' Because some pills… it costs. My husband had these pills -- $98 per week. And that came out of Canada Pension Old Age. You take out the medication and you don't have much left.*

She also had difficulty understanding the information she was receiving. *They use words that are 12 inches and you are sitting there, hmm…now what is this*? Although a nurse came in and she found that useful in providing medical care for her husband, she also realized that it wasn't supporting her needs as the constant caretaker of a very sick man.

*People, they don't realize when a person is sick… they change their moods. Such as my husband - he could be happy right now and in two minutes he could be just the opposite. There was never nobody to come in and say, well now you take an hour off. I would come in town and I used to have to run to get my stuff all done to be home with (my husband). … I had nobody. My kids… but there was nobody to come in and talk to me or make me a cup of tea, you know what I mean?*

Mary's stress was amplified by the fact that she had no idea what was going on with her husband.

*I thought emphysema was something you go to the drug store and get some pills. They never explained that is was a dead disease….. But I got mad one day and I asked. I said, 'What in the hell is this? Is he going to get better or is he going to get worse?' I wanted to know, you know, because I had to balance myself. … You got to get yourself prepared for loss. It is not just, 'That is it,' … and that's it! … Well, I was stupid… like to stuff like that. Ok, you would take a book and you would try to read about emphysema and cancer and all of that. Sometimes there are words there, and if you broke it down in your own way… but it may not mean that at all.*

Mary began going to her local Women's Resource Centre and found the kind of support she was looking for.

*That was a beautiful program. We would come here once a week and we would talk, like, how you would try to help each other. .It was nice. It was for us women that were all like in the same bracket. … I think there should be more support groups because you can talk about a lot, and people may have more trouble than I would. We could settle it out with each other.*

### 5.1 The Role of Family Literacy and Health Care Practitioners

Fifty-five percent of Canadians have a level of health literacy that creates difficulties for them in navigating the health care system, reading medicine labels and health care information, or taking action to prevent disease (CPHA, 2006). By improving the health literacy levels of all Canadians, these difficulties can be alleviated. Health literacy levels can be improved if practitioners from both the health and literacy sectors understand the interconnections between their fields and work together to address common issues.

Until recently, the worlds of health and literacy have been quite separate. In general, health care practitioners have only begun to realize that a population with good literacy skills may have greater capacity for accessing and using health information and health services than one with low literacy skills. The shift to a population health approach with its emphasis on health determinants has resulted in a more comprehensive view of health and the conditions required to achieve and maintain it. While it is not necessary for health professionals to be literacy experts, it is important to understand that the reading and comprehension abilities of many adults fall well below the level at which most health care information is written or communicated. Approaching their practice through a literacy lens would likely make the transmission of information much clearer

(McKinney and Kurtz-Rossi, 2006). These professionals can also work at finding plain language health information, improving their own communication skills when interacting with low literate individuals, and taking into account the context of the client (Rudd, 2002). Was there a shared communication so that it was apparent that the person understood, or was the information only presented to the client? Can the individual act on the information given? If not, what supports might be required? These are issues that health care practitioners need to consider in order to interact effectively with families.

Likewise, literacy workers need to work collaboratively with health practitioners to support health literacy in families and communities. Health and health literacy are significant but often overlooked or misunderstood issues that have a significant impact on the effectiveness of adult and family literacy programs. Most literacy programs experience difficulties with attendance, and it is often issues created by a complex mix of health determinants that cause learners to miss classes or ultimately drop out of programs. Attendance issues not only affect the learning of the individuals involved but also undermine the cohesion of the group. An understanding of health and its determinants from a broader perspective than colds and flu will help literacy practitioners recognize and address a range of health and health literacy issues that affect their participants and their programs. This shift in perspective also encourages consultation with practitioners from health care and/or related fields and promotes solutions that are collaborative and more effective.

Addressing health related questions and concerns within family literacy programs is a good adult education strategy that focuses on the needs and interests of participants. Although they should constantly be striving to improve their own health literacy, literacy practitioners do not need to become experts in health. They do, however, need to work collaboratively with health practitioners who can provide information and support for family literacy programs. Family literacy practitioners, already used to addressing a range of client issues, are in an ideal position to assist families in finding, understanding and evaluating relevant health information and services. They can also work with families to help them better communicate their needs and wants to medical personnel and to increase control over their own health and self-care.

### 5.2 What Does it Take to be "Health Literate?"

Because so much health information is available in various media including the internet, television, newspapers and magazines, as well as through a variety of health care practitioners, it is difficult and sometimes impossible for families to decipher what is

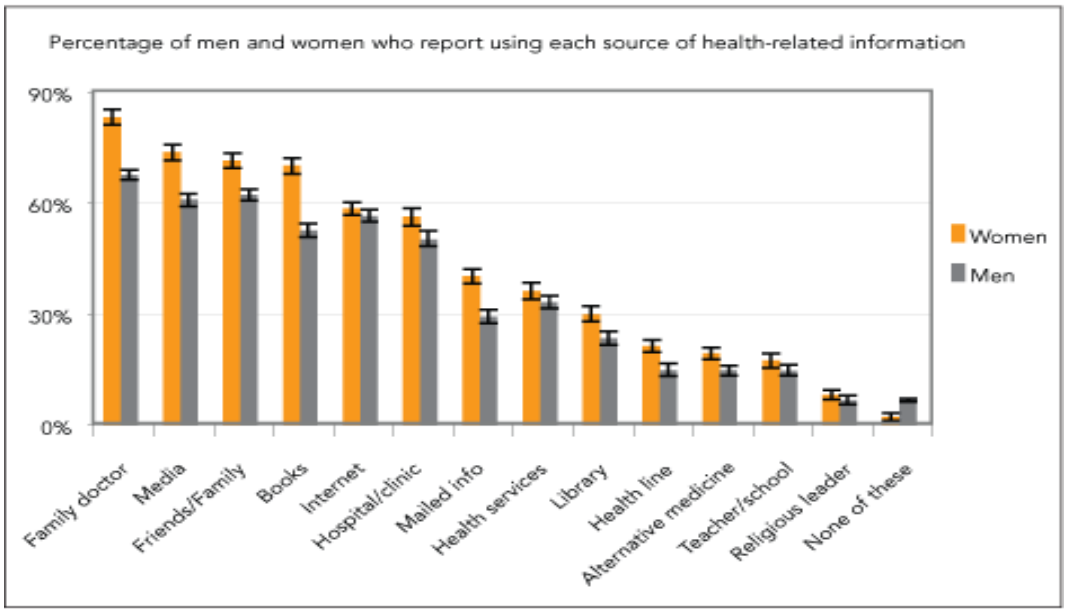
important in making healthy choices. Whether or not individuals have high or limited literacy skills, four key processes are involved in health literacy that include:

- Accessing information
- Understanding information
- Evaluating information
- Communicating information

### 5.3 Accessing Information

How do individuals find the right health care professional or service? How does a person find any information on a specific health subject, let alone ensure that this information is valid and current? Individuals need to have high health literacy skills to know where, how, and what health services they require. They also need to understand that some beliefs they have regarding health and healthy practices are not in fact healthy and may actually harm their families. If they don't know who or when to consult, they may continue to practice detrimental health behaviours.

There are many sources of health information including doctors, pharmacists, public health nurses and other health care professionals, television, the internet, health lines, books, magazines, friends and family, community programs, etc.




*CCL, Survey of Canadian Attitudes Toward Learning, 2006*

While the internet is playing an increasingly important role in providing Following a 2006 survey on Canadian Attitudes Toward Learning, the Canadian Congress on Learning (CCL) reported that family doctors were the most frequently cited source of information, followed closely by media, friends and family, books and the internet. Individuals with limited literacy skills frequently use medical services for less severe medical issues because they do not know or understand how to access information in other ways and need to talk to someone directly about their concerns. People with low literacy skills report that they prefer receiving health information in a familiar environment directly from someone they trust. Having messages repeated on a number of occasions helps them remember the information (CPHA, 2006).

When communications with doctors are not comfortable or comprehensible, individuals with low literacy skills often depend on television and radio (including infomercials), family and friends. These sources can be biased or dubious, resulting in health care decisions made on the basis of unreliable or inappropriate information.

### 5.3.1 The internet as a source of health information

The internet has become such a common source of information for the general public that it is changing the way professionals interact with clients. Many doctors are beginning to assume that their clients have done a degree of research on their particular condition and are therefore speaking and making medical decisions from a more informed perspective than in the past.

The 2005 Canadian Internet Use Survey shows that more than two-thirds of Canadian adults used the internet for personal activities over the past year. Internet access rises with educational level: from 49% of adults with only a high-school education to 80% of adults with at least some post-secondary education. Younger adults also reported the highest rates of internet use.

While the internet is playing an increasingly important role in providing health and medical information to Canadians, this source is not readily available to those with literacy or language barriers and those who do not have easy access to internet services (the homeless, those living in poverty or in very rural locations, and many seniors to name a few).

In addition, it seems reasonable to assume that many people access and attempt to use health information from the internet without the literacy, health literacy or critical literacy skills required to synthesize and analyze vast amounts of complex and often contradictory information.

There are a number of internet resources for the general public on how to evaluate information found online. The National Library of Medicine has a 16-minute tutorial on Evaluating Internet Health Information that can be found at: http://www.nlm.nih.gov/medlineplus/webeval/webeval_start.html

### 5.4 Understanding Health Information

As a consequence of the multiple sources of health information, the information overload is confusing and often contradictory. More than half of Canadians surveyed reported that they receive contradictory information from different sources (CCL, 2006). Families with limited literacy skills often don't have the health literacy skills necessary to understand and critically analyze health information and then make an informed choice as to whether to act or not act on it (Rudd, 2002).

Many factors may contribute to difficulties in understand health information and instructions, including hunger or fatigue, low literacy levels, lack of familiarity with the health or medical terms used, culture bias, emotional distress, information overload, and having a first language other than English. Multiple factors can be present at the same time for marginalized families, compounding their difficulties with both learning and health. For example, although most parents want their children to be healthy and successful, many children attend school without having had a nutritionally adequate breakfast. When individuals are tired or hungry, their ability to focus and to understand is lessened (Brown and Dryden, 2004). This is one of the major reasons why "Breakfast for Learning" programs have begun all over Canada. "*Developing healthy eating habits at an early age is critical to the future health and well-being of Canadians. In addition, good eating is essential to ensuring children have the energy they need to get the most out of their school day" (*Canadian Living Foundation, 2007). Many low literate parents do not have the health literacy skills necessary to understand that sending children to school inadequately fed limits their children's ability to learn. Low literate parents also tend to have less money available to purchase nutritious foods like milk, whole grain cereals and fresh fruits even if they understand the differences and benefits of nutritious foods versus less-nutritious foods.

How information is understood and acted upon depends upon the context of the individual receiving the information. This variable is always changing and is influenced by many factors. Emotional distress or anxiety can hinder a family's chances of understanding health information. When a person is distressed, the body and brain are in a temporary state of chemical imbalance. This is unhealthy and limits the ability to understand information (Thwaits, 1999). Frequently, people access the health care system when they are sick and therefore already emotionally distressed. Although

health care practitioners may provide a lot of information, individuals may only remember or understand a portion of it. Low health literacy skills compounded by emotional distress present a situation in which little health information has actually been communicated (CPHA, 2007).

It is not only those with limited literacy skills who struggle with understanding the health care system; even health care professionals who are sick struggle with the many choices needed to understand and receive the best treatment options (CPHA, 2006). Specialized terminology is seldom encountered until patients or their families find themselves in a new and often stressful medical situation. Since much medical information is transmitted to low literate individuals by friends and family members who are themselves overwhelmed by the medical terminology used, it is not surprising that many individuals receive incorrect or incomplete health information.

### 5.5 Evaluating Health Information

Health literacy, like all skills, exists on a continuum and evolves over one's lifespan. It is impacted by health status, demographics, culture, sociopolitical, and psychosocial factors (Zarcadoolas et al, 2006). Health decisions are made on the basis of the information available and how that information fits with personal circumstances at the time. A health literate person is able to adapt and apply existing knowledge and skills to new health situations as they arise (Zarcadoolas et al, 2006). For example, if a mother's first child developed asthma early in life and she discovered that the asthma was linked to milk allergies, she will be cautious about placing her second child on a milk-based formula, will ask appropriate questions, and will make decisions accordingly. The health literacy skills of this mother will have increased because of her experiences with her first child, and she can then use this knowledge to better care for her family.

Individuals with low literacy often depend on the judgment of others to help them evaluate information and make decisions about their health care. This is problematic when the health literacy level and knowledge of friends and family are also low.

It is important for people to feel comfortable in approaching professionals for reliable information on health care issues that concern themselves or family members. In many cases, those with limited literacy skills feel a sense of shame about their situation, which may decrease their ability to express concerns or ask questions of well-educated professionals. This embarrassment as a result of low literacy skills directly impacts access to vital information necessary to making appropriate health care choices (Rudd et al, 1999). If individuals feel comfortable receiving information from health or literacy professionals, and get support in assessing and applying it to their own circumstances,

they will be in a better position to make good health care decisions for themselves and their families that are in line with their cultural beliefs and life circumstances.

There are some excellent resources available to guide people in getting and evaluating essential information when visiting health care providers. The *Ask Me 3* Program sponsored by Partnership for Clear Health Communication in the U.S. provides information on health literacy and improving client-practitioner communications for both providers and patients. (http://www.askme3.org)

Literacy Partners of Manitoba has developed a plain language publication, "Going to the Doctors" (2005), for people who do not feel comfortable with their literacy skills. It suggests a number of simple strategies for ensuring that communications with health care practitioners address their questions and concerns about their condition, treatment options or follow-up instructions. One of these strategies, a **Health Visit Prompt Card** that helps people "remember things to say and ask" during a health visit, can be found in the Appendix at the end of this module or at: http://www.plainlanguage.mb.literacy.ca/resource/GoingtotheDoctor.pdf.

### 5.6 Communicating Health Information

The extent to which health information is accessed, understood and evaluated is dependent upon how it is communicated**.** In Section 1.4, we discussed the concept of "multiple" or "plural" literacy and its importance in a culturally and linguistically diverse country like Canada. Culture and language also affect how people communicate, understand, and respond to health information. Cultural bias, or interpreting and judging information based on one's own cultural understanding and expectations, has a significant impact on many of the distinct populations that make up Canada. Often when health care professionals give advice, they do not take into consideration the language and culture of the families in their care (CPHA, 2006) but communicate instead from the perspective of their own distinct medical culture and language.

Increasing cultural competency among professionals as discussed in Section 3.2 is essential to increasing both understanding and the ability to act upon health care information. Cultural competence allows literacy and health care practitioners to recognize and address communication problems that might arise as a result of a client's cultural beliefs, practices, language, or literacy skills (Centre for Health Care Strategies, 1998).

The use of medical jargon compounds the communication challenges for clients with limited literacy or English language skills. Often they do not ask for further explanation

because they assume that they “should” understand and are reluctant to divulge their own “ignorance.“ As a result, health care practitioners may be unaware that their clients have not understood the information, instructions, or treatment options presented to them. This confusion leads to increased stress for patients and their families.

The health care system needs to acknowledge that many families do not feel empowered to take control over their lives and their health and at times are afraid or embarrassed to ask questions (Health Canada, 2003). It is the responsibility of health care professionals to ensure that clear communication has taken place: that is, that all parties concerned have heard and understood each other and are able to act on the basis of the information communicated.

**Tips for recognizing and supporting clients with low literacy skills can be found in the Appendix.**

Many studies have focused on the need to write promotional materials, signage, medical instructions and other written documentation in clear language, but alternative modes of communication must also be implemented to ensure that all families are able to understand and act on the health information presented to them. Most people with limited literacy skills prefer and respond better to face-to-face communications.

When communication is effective and supports for acting upon information are in place, families are in a much better position to make good health care decisions. Family literacy programs and practitioners are an important link in the chain of support for families with literacy barriers.

## Promising Practice

Practitioners from the fields of family literacy and health recognize and respect the knowledge and expertise of the other and work together to:

- develop alternative strategies to provide clear and culturally appropriate information and support to families
- improve communication between health providers and patients with marginal English literacy skills
- share referrals and resources
- integrate services to provide on-going support for families health and learning needs.

***Can you identify initiatives in your community that illustrate the implementation of these promising practices?***

# 6. Working Together for Healthy Families and Communities

The health and quality of life of our families and communities depend largely on the collective abilities of policy makers and practitioners to work together towards (a) a common awareness of the health and literacy challenges experienced by **all** Canadian families, (b) a shared vision of possible solutions, and (c) a commitment to implement those solutions.

The Canadian Public Health Association (CPHA) established an Expert Panel on Health Literacy in the spring of 2006 to investigate and recommend ways to improve health literacy in Canada. In 2008, the Expert Panel published findings from a National Symposium on Health Literacy. Below are some of the key elements of those findings, which serve as an excellent summary of the principles and approaches advocated in this *Family Literacy and Health Module.*

The following principles are fundamental to the pan-Canadian health literacy strategy:

- health literacy is an issue of social equality
- solutions are embedded in existing structures
- literacy begins early in childhood and is strengthened over time
- adult literacy learners are engaged in the development of solutions
- diverse needs and cultures are recognized and respected

Make health and education sensitive and responsive to language, culture and health literacy.

Establish literacy as a national priority, with health literacy as part of that agenda.

Develop programs that enable priority populations to make better use of health services.

Encourage and support health practitioners and professionals to be agents of change

Canadian Public Health Association (2008). *Priorities for Action: Outcomes from the National Symposium on Health Literacy*

This final section focuses on actions that individuals, their families and the various practitioners and managers in the community might undertake to support development of health literacy. Many of these ideas for actions are based on research in the area or on efforts already underway in selected communities. Some strategies have been evaluated and their effectiveness demonstrated, while others likely require additional research to prove the extent to which they are in fact useful.

It is to be noted that the possible solutions proposed here are neither exhaustive nor necessarily applicable to all settings. It is up to families, practitioners and managers familiar with their environments to choose the strategies that appear to best meet requirements with regard to health literacy.

Prior to proceeding with any strategy, practitioners are encouraged to ask themselves the following four questions:

1. Who are the practitioners in the community working with families, and what roles can they play with respect to developing people's health literacy?
2. How can we work together to create healthy families and communities?
3. What do we need in order to improve our health literacy programs and policies? How can we meet these needs?
4. How can we provide tangible support to families in becoming more independent in relation to their health?

### 6.1 Parents and the Family

As already discussed, development of health literacy begins within the family and in the context of the broader framework of culture, community and society in general. However, whenever families face barriers that accompany limited literacy skills in English or French, the development of health literacy usually requires support. Parents want to know, and deserve to know, how to best nurture positive growth in their children and promote health and well-being for their entire family.

There are numerous challenges that parents face in developing their family's health literacy and supporting positive health practices. Examples are provided below of possible solutions that parents and families might adopt to meet the various challenges

identified. However, it must be remembered that parents who face language or literacy barriers may not be able to follow the recommended strategies as effectively as other parents with higher literacy levels and will require more support; the same applies to other factors identified as health determinants (see Section 1.9 for a list of health determinants).

| Challenges for Parents and Families | Possible Solutions |
|---|---|
| Information about health received from health care providers conflicts with traditional or cultural beliefs | Talk to a trusted and respected contact person in the community, particularly one in the health field (and of similar cultural background if at all possible)<br><br>Invite the contact person to visit the family<br><br>Be open to new information; discuss new information with other family and community members |
| Gaining access to the information, services and support they need | Seek support from other people in the community (e.g., community nurse, social worker, literacy practitioner)<br><br>Inquire at the children's school or contact the staff at the local community centre<br><br>Find out about the services available in the family's first language |
| Understanding written information on health, health promotion and disease prevention | Participate in a family literacy or adult education program to improve reading and writing skills<br><br>Talk about reading and writing challenges with a health care practitioner<br><br>Ask the health care practitioner to give a verbal explanation of information provided in writing |

| | |
|---|---|
| Being uncomfortable taking part in conversation with a doctor due to the complexity of the language used<br><br>*Note:* People with lower literacy levels often have limited health-related knowledge and vocabulary | Write down or memorize health questions before going to an appointment<br><br>Ask the health care practitioner to repeat or speak more slowly<br><br>Ask for written information in the family's first language, or ask for a health care practitioner who speaks that language<br><br>Bring along an interpreter, a friend or family member, or a trusted person from the local community<br><br>Take conversation courses in English as a second language |
| Understanding or implementing the necessary treatment and care for family members with a chronic condition | Ask the health care practitioner to draw up a list in plain, concise language of instructions for care and medications<br><br>If certain care or procedures are required, ask for a demonstration and an opportunity to practise until comfortable with all tasks |
| Maintaining the health of the family's children | Attend community workshops on useful topics, such as healthy eating, physical activity or positive discipline<br><br>Talk as a family about healthy food choices and safety guidelines, such as wearing a helmet when using a bicycle |
| Navigating through the health care system | Ask for assistance in filling out forms<br><br>Ask for an advocate to provide support navigating the system |
| Making important decisions about self-care and treatment of illnesses | Ask the health care provider to thoroughly explain the benefits and drawbacks of all treatment options<br><br>If the options are not clear, ask for additional time to reflect; seek out other health care providers if necessary<br><br>If possible, read about the topic, or ask a friend or family member to read some information for you |

## 6.2 Family Literacy Practitioners

The literacy development of families impacts upon every other area of their lives: health, employment options, economic status, social status, and life-long learning opportunities. The role of family literacy practitioners is to support learning among all members of the family that will contribute to that family's well-being. Participatory approaches to literacy development stress situating literacy in a meaningful context in people's lives. Of primary importance to almost all families is that their members are healthy and thrive. Incorporating health and health literacy into the curriculum - for both adults and children - is an effective way of developing family literacy and health at the same time.

In addition, recruitment and retention of participants is more successful when the focus of the program is relevant and important to the participants' lives.

Family literacy practitioners usually work with several family members together and develop a trusting relationship with the families in their programs. For these reasons, they are often aware of family challenges and concerns and can act as a liaison between families and health care services and providers. Family literacy programs and practitioners can also provide support for accessing and using health information and resources. In addition, family literacy program participants often form close and supportive bonds. Group discussions around health topics such as nutrition, childcare, maintaining health of family members, and specific health topics of interest to group members can have a significant impact in this peer-supported environment.

| Challenges for Family Literacy Practitioners | Possible Solutions |
|---|---|
| Taking into account participants' needs in a range of areas, including health and literacy | Incorporate a module on health into a family literacy program; many family literacy programs or models exist that include learning activities to address this issue<br><br>Have participants share experiences with health and/or health literacy issues; discuss what all participants can do to improve the quality of life of their families<br><br>Invite contact persons working in health care to talk about topics of interest to participants<br><br>Distribute plain language information on health topics and discuss as a group or individually, as appropriate |
| Being knowledgeable about literacy and health | Receive training, do reading and share information with other literacy workers or health care practitioners on the topic |
| Making contact with the most vulnerable client groups with regard to health literacy | Invite current participants to share information with one another<br><br>Network with health care practitioners to identify vulnerable individuals, and then find interesting ways to get them to participate, e.g., family activity or celebration, pizza party<br><br>Remain visible in the community, especially in locations frequented by target client groups |

### 6.3 Health Care Practitioners

All health care practitioners - doctors, nurses, pharmacists, nutritionists, psychologists, counsellors, recreation staff and all those working in fields that support the health and well-being of Canadians - need to be aware of the issues experienced by clients in relation to literacy and particularly health literacy. In addition to enhancing their own cultural competence in this area, there are a number of ways that health practitioners

can work with family literacy programs and practitioners to support the health literacy of families. These include providing information that can be used for family literacy curriculum, visiting programs to facilitate discussions on various health related topics, and developing programs that can be used in family literacy settings.

For example, *Nobody's Perfect* is a parenting education and support program for parents of children from birth to age five. It is designed to meet the needs of parents who are young, single, socially or geographically isolated or who have low income or limited formal education. Based on principles of adult education, it starts with personal interests, builds on what parents already know, and actively involves participants in the learning process. It also builds networks among parents and encourages them to see one another as sources of advice and support. Developed by Health Canada in partnership with the four Atlantic provinces, *Nobody's Perfect* was introduced nationally in 1987 and updated in 1997. The program is available in both English and French. Further information can be found at: http://www.phac-aspc.gc.ca/dca-dea/family_famille/nobody_e.html.

*Wiggle, Giggle & Munch: A physical activity and nutrition program for preschoolers and their parents,* was designed for families who face multiple barriers by the Healthy Lifestyles Committee of the Downtown Parent-Child Coalition in Winnipeg. It was created to promote physical activity and healthy eating from an early age by providing participants with experiences and tools to make both a part of daily living. Order forms for the handbook can be found at: http://communities4families.ca/WGMHandbookOrderForm-apr07.pdf.

Research in the area of literacy and health has provided a number of ideas for meeting the needs of a range of clients, some of which are included below. Practitioners are invited to consider the possible effectiveness of these strategies in their specific settings and to add further challenges and/or solutions they have experienced.

| **Challenges for Health Care Practitioner** | **Possible Solutions** |
|---|---|
| Health care practitioner not aware of the close relationship between literacy levels and health | Take part in training on the topic; explore resources and tools in the area of literacy and health<br><br>Consult with a literacy or family literacy centre or practitioner in your community |

| | |
|---|---|
| | Discuss the issue with work colleagues; ask about their experiences and strategies |
| Practitioner not familiar with a client's literacy level<br><br>***Note:*** **Although there are a number of standardized tests available for determining literacy or health literacy levels (such as REALM - Rapid Estimate of Adult Literacy in Medicine), their use is controversial and should be considered carefully. Literacy testing may limit or prevent individuals with low literacy from seeking advice from health practitioners.** | Be aware of vulnerable groups for low literacy or health literacy<br><br>Be familiar with signs for recognizing low literacy levels (Appendix)<br><br>Pay attention to body language, questions asked, and tone used for any signs of discomfort or difficulty in understanding<br><br>Provide clear communications to all |
| Client exhibits challenges with oral communication | Listen and encourage dialogue. Try to gain an understanding of what the client knows. Check the client's degree of understanding regularly by asking if you have been clear<br><br>Use plain language, avoid medical jargon and do not give too much information all at once<br><br>Find other means to support oral communication, such as concrete examples from the client's daily life, visualization and translation of information, models, dramatization, illustrations, plain-language documents or multimedia |

| | |
|---|---|
| Client has challenges with written information<br><br>*Note*: More than one-quarter of people have difficulty understanding text written at higher than a fifth grade level | Ensure that the client feels comfortable asking for clarification or additional information<br><br>Prepare and adapt informative materials based on principles of simple writing (which still does not mean that all clients will understand them); invite clients who are weak readers to take part in preparing these materials<br><br>Have materials translated into clients' first language; take clients' cultural context into account in translation<br><br>Partner with family literacy instructors in the goal of sharing information and resources and working together to achieve fully literate communities |
| Interacting with clients who have difficulties with the written language | Establish effective and appropriate communication based on trust; believe what the client says<br><br>Demonstrate discretion and tact: take care not to embarrass clients by treating them in a manner that might draw attention to their problem; assure them verbally of the confidential nature of your interactions with them<br><br>Show compassion: avoid using blame, as any number of factors can limit individuals from making wise decisions about their lifestyles<br><br>***Remember that people with low literacy levels may ****<br><br>- Have difficulty talking about their health problems or may not understand the importance of talking about them with a healthcare practitioner<br><br>- Not provide many details on their conditions or may assume that the practitioner can guess or should know what is wrong<br><br>- Have difficulty expressing themselves because their health-related vocabulary is limited |

| | |
|---|---|
| | - Agree indiscriminately with anything they are asked to do, with no understanding or intention of follow-through<br><br>- Lack confidence due to negative experiences in relation to healthcare services<br><br>***Source**: Kazap, 2006. |
| Client needs to complete a questionnaire to assist the practitioner in arriving at a diagnosis | If it is suspected that a client is a weak reader: complete the questionnaire orally rather than having the client complete it in writing; if uncertain of the client's literacy level, ask whether the client prefers to answer the questions orally or fill out the form in writing |
| Client shows difficulties cooperating with treatment | Ensure that clients understand their plan of treatment and its importance<br><br>Explain clearly to clients any potential adverse affects of their medications and how to respond.<br><br>Ask clients what might prevent them from following the prescribed treatment to the letter (lifestyle, family obligations or circumstances), and adjust the treatment if necessary<br><br>*To improve cooperation with treatment:*<br><br>- Take care to maximize access to services: extended business hours, transportation, on-call service<br><br>- Offer efficient service: appointment system with limited wait time, prompt administration of laboratory tests<br><br>- Provide effective health education programs for families to promote understanding and self-care<br><br>- Contact clients for follow-up |

| | |
|---|---|
| Client needs to modify behaviours with negative impact on his or her health<br><br>The distribution of printed materials can never replace interactive instruction and learning | - Provide health education<br><br>- Foster a relationship of trust with client learners<br><br>- Use both oral and written communication, adapting content to clients' culture and living context<br><br>- Assist clients in managing their own health and understanding the relationship between their health status and prescribed treatment<br><br>- Use written materials on the prescribed treatment that are adapted to clients' level of reading skill, written in plain language, illustrated and presented in relation to daily life<br><br>- Practise self-care until clients are comfortable with it, as this improves their performance<br><br>- Arrange for group support, which appears to facilitate learning |
| Client does not arrive for appointments | *Reflect on the barriers faced by the client in gaining access to services and information:*<br><br>- Does the client need someone to provide additional support, e.g., make appointments, come to appointments with the client, call the client to remind him or her about the appointment?<br><br>Does the client need help with transportation or child care? Arrange for these services by partnering with other community organizations |

| | |
|---|---|
| Client has challenges understanding information and following recommendations of health care practitioner | How well do you know the client?<br><br>Take the following factors into account that might influence a person's ability to understand information and follow the recommendations of a health care practitioner: cultural context, languages spoken/understood, beliefs, socio-economic situation, living conditions, etc.<br><br>If necessary, arrange for a cultural or linguistic interpreter |
| Health care practitioner needs support from other practitioners (health or literacy) to meet clients' needs | Partner with family literacy programs and/or other organizations working with parents and families; determine the roles and responsibilities of each partner in helping to establish fully literate, healthy communities<br><br>Network with other health care practitioners to improve clients' access to information and services |

**The Appendix at the end of this module contains tips for recognizing and supporting clients with low literacy or low health literacy skills.**

## 6.4 Strategies for Policy and Decision Makers

The report from the Health Literacy in Rural Nova Scotia Research Project, *Taking Off the Blindfold: Seeing How Literacy Affects Health* (2004), lists priority actions for communities to improve health literacy. These actions were identified by a group of participants at a round-table discussion and come directly from their experience and needs. Although the research in question focused on the needs of rural communities, the solutions proposed could be of use to literacy and healthcare managers in a variety of communities. While many health literacy needs are specific to particular environments, many are quite universal and simply human.

*Note*: This list has been adapted from the Health Literacy in Rural Nova Scotia Research Project for the purposes of this module.

**Promotion and Awareness**

- Raise community awareness about the importance of literacy as the responsibility of all and a health and wellness determinant
- Provide more information to practitioners working with families about issues related to literacy levels
- Develop strategies for health and literacy promotion taking into account the specific needs of various client groups
- Raise funds to allocate to disease prevention and health promotion

**Access to Programs**

- Identify ways to reduce barriers preventing access to literacy programs
- Ensure that programs are accessible (e.g., schedule, transportation, child care) and flexible and meet the needs of a broad range of people with regard to learning and daily life

**Access to Information**

- Increase access to health-related information for all
- Follow guidelines for simple writing in drawing up pamphlets or booklets for use by families
- Take families' first language into account: produce information in French as well as in any other languages spoken in the community
- Ensure that all information and services are offered to people actively rather than waiting for people to seek them out
- Create informal settings where families can have access to information or interact with a contact person

**Support for Families**

- Implement and promote the use of support persons in navigating the healthcare system, for example, cultural or linguistic interpreters for immigrants, Aboriginals or Francophones

**Recruitment**

- Make an extra effort to reach those who are isolated or marginalized

**Partnering, Networking**

- Enhance networking among practitioners; coordinate literacy and healthcare services to increase their effectiveness
- Support and highlight the essential role of community organizations in offering services relating to health and literacy
- Examples of strategies for strengthening ties among partners:
    - Focus/discussion group on health and literacy
    - Sharing of information and resources
    - Creation of new partnerships and solidification of existing partnerships between the domains of health and family literacy and among decision-makers, managers and practitioners

## 6.5 How To Find Health Care Services and Practitioners

Some provinces have established toll-free telehealth lines that offer a variety of services to help people find appropriate health support and information. Services may include providing advice and information about health symptoms and concerns, answering questions about healthy lifestyles and nutrition, and helping callers decide when to see a health professional. In addition, there are provincial online health sites.

## Provincial and Territorial Telehealth Lines

**B.C.**

*B.C. Nurseline*
Within Greater Vancouver: **604-215-4700**.
Toll-free elsewhere within B.C.: **1-866-215-4700**.
Deaf and hearing-impaired toll-free throughout B.C.: **1-866-889-4700**

**Alberta**

*Health Link Alberta*
Calgary Health Region: **403 - 943-5465**
Capital Health Region: **780 - 408-5465**
or Toll-Free: **1-866-408-5465**

**Saskatchewan**

*HealthLine Saskatchewan*
**1-877-800-0002**
TTY access: **1-888-425-4444** for those with hearing and speech difficulties

**Manitoba**

*Health Links Manitoba*
Winnipeg: **788-8200**
Rural and northern areas: **1-888-315-9257** (toll-free)

**Ontario**

*Telehealth Ontario*
**1-866-797-0000**

**Nova Scotia**

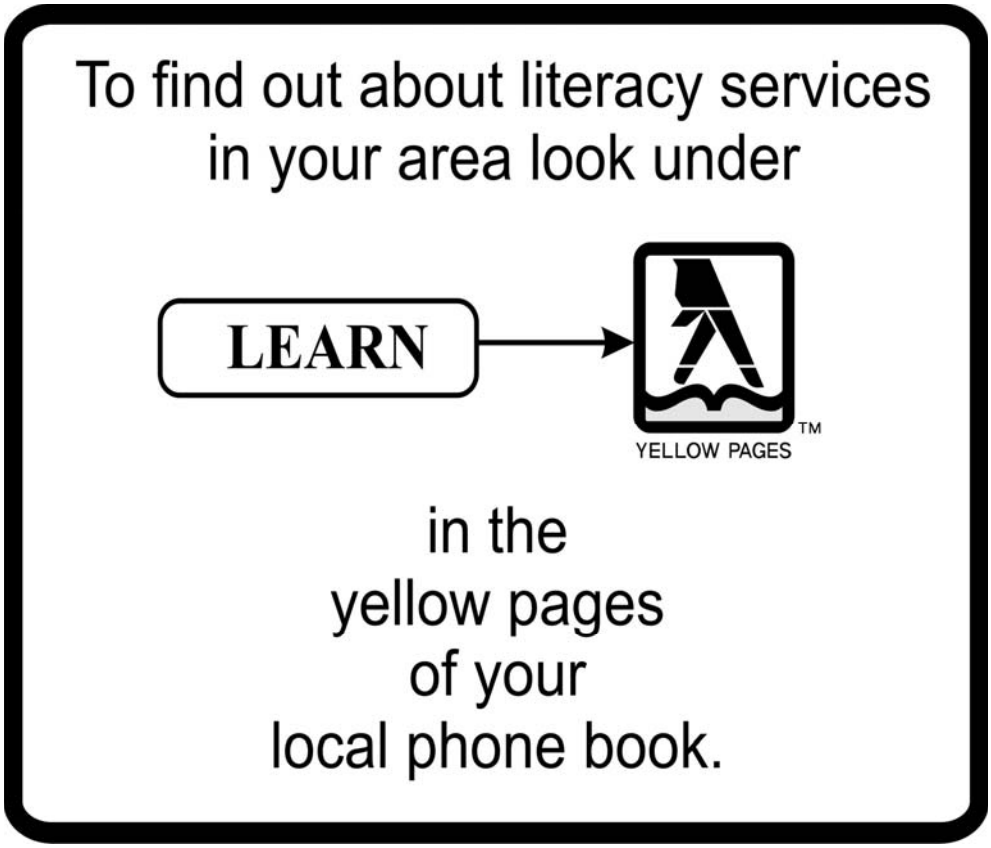
*Nova Scotia TeleHealth Network*
**1-800-889-5949**

**Northwest Territories**

*Telehealth Line*
**1-888-255-1010**
TTY access: 1-888-255-8211

More may now be available, and some provinces or territories have regional or local telehealth lines. **Can you add to this list?**

**How to Find Literacy Services and Practitioners**



# Recognizing and Supporting Clients with Low literacy and/or Health Literacy Skills

People with low literacy skills have developed many coping mechanisms over the years, so that it may be hard to detect whether they can read, write, or fully understand oral communications. Many with low health literacy skills will appear in control on the surface but are missing critical information to manage their condition effectively. The following are indicators that your client may have limited literacy skills.

## Possible Signs of Low literacy and/or Low Health Literacy Skills

**When asked to fill in a form:**

- Client asks to take the form home to complete; possible reasons include forgotten glasses or not having the time to complete it at the moment
- Client gets agitated or irritated and refuses to write anything
- Client has brought a relative or friend who completes the form

**When given a document to read:**

- Client looks at paper for a length of time and then hands it back
- Client asks that the important parts be read to them, explaining that they are too tired, sick, don't have time, have forgotten their glasses, etc.
- Client brings a relative or friend who reads the form to them

**When information is being explained orally:**

- Client nods head but avoids eye contact
- Client interrupts or responds off topic
- Client doesn't ask questions
- Client looks to an accompanying friend or relative to repeat information or to answer questions

## Tips for Improving Communications with Adults Who Have Low literacy and/or Health Literacy Skills

- Do not assume that adults can read and write well; check to make sure, e.g., ask if they would like some assistance in filling out forms. Be aware that people are embarrassed if they don't understand and may pretend rather than admit their difficulties.

- Sit down (rather than standing) to achieve eye-level with your client

- Practice clear oral communication techniques - step by step instructions stated slowly (not loudly) and repeated as necessary; request that clients paraphrase or repeat important information

- Ask, "Was there anything that wasn't clear?" and provide an opportunity for questions

- Ask open-ended questions

- Limit technical language' avoid jargon and acronyms

- Use body language to support what you are saying

- Draw pictures, use posters, models or physical demonstration

- Become familiar with literacy programs for referral purposes - both adult and family literacy programs

- Provide alternate forms of communication in addition to written, e.g., videos, tapes, etc.

- Use plain language techniques when preparing written materials:
    - Lots of white space
    - 12 font size
    - Point form where possible
    - Short sentences; reduce jargon and long words
    - Use lower case, not all capital letters
    - Address readers directly
    - Use active not passive voice
    - Use graphics as well as print where possible

- Use colour to highlight important deadlines on forms or correspondence, or colour code information as appropriate

# *Health Visit Prompt Card*

### My rights

I can expect
- to be told what's happening to me
- to have my questions answered in words I can understand
- to know the possible treatments, and to say yes or no, and to change my mind
- to be treated with dignity, kindness and respect at all times
- to know that my health information will not be shared with anyone without my agreement

### Planning before your visit to a doctor

1. Think of what you want to talk about before you go. You can take someone with you to help you talk to the doctor.
2. Write 2 or 3 words that will remind you what you want to ask.
3. Ask the most important things first.
4. Tell the doctor as much as you can about what's bothering you.
5. Know what medicine you are already taking (including aspirin and cough syrup, etc.)

### At the end of your visit

*You might say: Doctor, I just want to make sure I understand. Then ask these questions:*

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?
4. Will I get better? How long will it take?

*Write down the answers.*

### If you still don't understand...

*You might*
- say: "This is new to me. Will you please explain that to me again?"
- ask: "What does that mean?" " I don't understand that word."
- ask for a picture of the medical problem.
- ask him/her to write things down.
- bring someone to the next visit.
- call Health Links and ask them to explain (786-8200, 1-888-315-9257)

### Questions about medicine

1. What is the name of this medicine? Can you write it down for me, please?
2. What will it do for me?
3. Are there any problems that the medicine might cause?
4. How much does it cost?
5. Are there other medicines or treatments that might help me with this problem?
6. When should I take the medicine?
7. How should I take the medicine?

### My medicine list

*Write down what you need to take. The doctor or pharmacist can help you cross the name off when you no longer take the medicine.*

| Date | Name of drug | Reason |
|---|---|---|
| _____ | _____ | _____ |
| _____ | _____ | _____ |
| _____ | _____ | _____ |

### Important phone numbers

Dr. _____ _____

Dr. _____ _____

Dr. _____ _____

Pharmacist _____

Emergency 911 or _____

Other _____

### Health Visit Prompt Card

Literacy Partners of Manitoba ...your literacy link

***This card can help you remember things to say and ask during your health visit.***

For help with reading and writing, phone the **LEARN line: 947-5757 or 1-866-947-5757**

This card has been produced by Literacy Partners of Manitoba
947-5757 1-866-947-5757 www.mb.literacy.ca literacy@mts.net

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