Health Literacy Project, Phase 1:
Needs Assessment of the Health Education and
Information Needs of Hard-to-Reach Patients

Part 1

Background Document on Literacy and Health

The Centre for Literacy of Quebec

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CONTENTS

Executive Summary

The purpose of this document is to establish the rationale for conducting a Needs Assessment regarding the information and education needs of hard-to-reach patients at the Montreal General Hospital, part of the McGill University Health Centre (MUHC). These hard-to-reach patients include those with low literacy, those who face language and cultural barriers, and those who cannot process health information because of physical or cognitive learning disabilities. The overall purpose is to improve the health information given to and health education process of hard-to-reach patients, as well as determine ways to improve how health care professionals communicate with such patients. The findings of the Needs Assessment will be used in planning a Health Literacy Centre at the hospital.

Section 1 of this document presents an overview of health literacy. The 1995 International Adult Literacy Survey (IALS) informs us that nearly half the adult Canadian population has some difficulty with reading materials encountered in everyday life. This has serious implications for the health of citizens, all of whom need to understand and use information on health and health care. Low-literate patients are confronted with health information, materials and procedures that are difficult or impossible for them to understand and apply. Research suggests that this can have both a direct and indirect negative impact on their health. The proportion of low-literate patients is higher among seniors who are also more frequent users of the health system and seem to have a higher need for medication. They are one among several groups of patients targeted as hard-to-reach. It is difficult to communicate effectively with these groups either through writing or orally. For these patients, health information and education are often communicated in ways that they cannot understand or use.

The health care system has responded in limited ways to this complex issue. One response has been to develop different kinds of tests to measure patient literacy, such as quick reading tests to indicate the grade level of patients. These tests do not measure comprehension and have a limited use. Another response has focused on the readability of health materials, and many studies have shown that these are too complicated for a large proportion of the general population. Many organizations and practitioners advocate the use of plain language in the production of health education materials. More effective oral communication is also advocated in working relationships between patient and health care professionals. Tips are given on how to talk to patients in ways to maximize understanding and effective learning. Limited attention has been paid to other strategies for more effective patient education such as health videos. For the most part, the focus in health education remains on use of plain language and ways to improve patient compliance. National accreditation processes in Canada and in the United States have recognized the importance of more effective communication with patients, but their requirements remain general and do not specifically address hard-to-reach patients. The mainstream literature offers limited discussion on the social impacts of health literacy, of how to move beyond written materials, or on strategies devised by hard-to-reach patients themselves.

Section 2 of the document attempts to move beyond the mainstream literature on health education. It critiques the tendency to favour plain language as the key strategy to address health literacy issues, and agrees with several recent researchers that the answer to such a complex social issue cannot be found in plain language alone. There is a need to look beyond written information and to understand the issues from the point of view of hard-to-reach patients. Community development approaches, participatory health education and education through drama are examples of avenues that may broaden health literacy practices. Unfortunately, these kinds of initiatives appear to be relatively rare in Canada.

This section describes a groundbreaking American field experience in Massachusetts that focused on the empowerment of literacy students. Although this study did not take place in a hospital but in a literacy centre, it offers some important findings. Another researcher from Australia presents a three-part concept of health literacy: functional health literacy, interactive health literacy and critical health literacy. Using these categories, most current practice can be labelled as interactive health literacy, that is, designed to help patients develop a better capacity to act independently, with stronger motivation and self-confidence. Critical health literacy that addresses the social and economic determinants of health is much less common. Finally, this section suggests that health and education groups, organizations and networks need to cooperate and develop partnerships at the local, provincial and national/international levels if we are to seriously tackle this issue.

Section 3 includes profiles of different health literacy initiatives in Canada, looking at programs and projects that have been or continue to be taking place. Information about current initiatives is not easily available. We present information on these initiatives as they describe themselves in public documents and in interviews. We have not evaluated or assessed them. We found one major hospital-based patient education program similar to what we are planning at the MGH (MUHC). Located at the Princess Margaret Hospital in Toronto, this program offers, among other components, a computer-based multimedia software program on cancer for patients and their families. Section 3 reflects a great diversity of research and practice in health education across the country. We have found a whole spectrum of health literacy initiatives, from health information in plain language to training workshops for health care workers to literacy training for substance abusers. Some community groups have worked on participatory health education/literacy practices and manuals. Others are focusing on building a province-wide information and advocacy network on health literacy. These initiatives, while exciting and innovative, remain relatively isolated and at times short-lived. Many are project-based and minimally funded. Many serve very small numbers.

We conclude that there is a need for large-scale commitment to health literacy across Canada, with long-term funding and wide-ranging sustained programming. Long-term partnerships need to be developed, linking health and education institutions, not only in a few communities, but across provinces as well. Large health institutions such as hospitals need to take on the issue of health literacy in order to communicate more effectively with hard-to-reach patients. The Needs Assessment leading to the planned Health Education Centre at the Montreal General Hospital (MUHC) represents an important opportunity to develop a solid model of health education that can be replicated elsewhere in Canada and beyond.

Section 1. Overview of health literacy

1.1 Low literacy in Canada and the USA

The International Adult Literacy Survey (OECD, 1995) provides comparable data on the literacy skills of adults from eight Western countries including Canada. IALS represents the notion of literacy (please see definition in annex 1) as a skill continuum divided into five levels:

Level 1: Individuals have great difficulty reading; they are generally aware that they have a problem.

Level 2: Individuals can read, but not well. They can only deal with material that is simple and clearly laid out. They often do not recognize their limitations.

Level 3: Individuals can read well but have some problems with more complex tasks. In many countries, this is considered to be a basic skill level. Some occupations require higher skills.

Level 4/5: Individuals can meet most reading demands. This level is considered a high level of literacy.

The IALS determined literacy levels by using real examples of varying complexity drawn from everyday life. The adults tested had to understand and use information from texts (Prose scale; news story, editorial, etc.), from forms (Document scale: job application, maps, tables, etc.) and from numbers (Quantitative scale: balance a chequebook, calculate a tip, etc.). About 22% of adult Canadians fall into level 1 and a further 26% are at level 2. Thus, nearly half of Canadians (48%) have difficulty with reading materials encountered in everyday life.

The IALS also indicates that literacy skills generally increase from east to west, with Western provinces having the most literate population in Canada. For all three scales (prose, document and quantitative), Quebec has the highest percentage of adults at level 1 and the lowest percentage at level 5. Respondents took the test in the official language of their choice. Those who took the test in English had overall better results than those who took the test in French:

	Level 1	**Level 2**	**Level 3**	**Levels 4/5**
English	19%	26%	31%	24%
French	28%	26%	38%	9%

The differences between language groups strongly relate to differences in educational attainment. Quebec youth in particular showed strong results. There are a large number of older Canadians with low skills: 53% of adults over 65 are at level 1 and 27% are at level 2. However, few young people aged 16 to 24 are at level 1. A large number of immigrants in Canada are at the lowest and highest levels. Compared to other countries, a larger proportion of immigrants in Canada are at levels 4/5. The IALS indicates a close relationship between education and literacy. The higher the level of educational attainment, the higher the literacy level. The study also makes linkages between literacy and training, employment, income, economic change, social transfers. It demonstrates that lower-skilled adults spend more time per day watching television, their main source of information.

The results of Canadians are similar to those of its southern neighbour: 23% of adults in the United States scored at level 1, while another 28% are at level 2, for a total of 51%. In the United States, the average reading level is at the 8th to 9th grade levels (between levels 2 and 3). About one in five adults read at the 5th-grade level and below (at about level 1) (Doak, et al., 1996).

The IALS is not universally accepted; some researchers question its methodology. Thomas Sticht, an international consultant in Adult Education, raises the problem of how to determine on a continuum a point or points that divide the continuum into various amounts of literacy. The IALS set a criterion of having an 80 percent probability of getting the average item at a given literacy level correct to be assigned to that level of skill. According to Sticht, this criterion is arbitrary and denies the skills adults actually have in performing tasks above the level to which they have been assigned (Sticht, 2000). He argues that with a criterion of 65% or 50%, the percentage of adults scoring at level 1 and 2 would drop dramatically. Some researchers thus question the percentage of individuals assigned to each literacy level. There is considerable debate in the United States about which standards should be used for national assessments.

The IALS does, nevertheless, allow us to say that regardless of the actual percentage there are a significant number of Canadians who experience difficulty with everyday reading. One can however question the IALS finding that individuals at level #2 often do not recognize their limitations. An alternative interpretation might be that they have found ways around their “limitations”. They are generally functional because they have developed strategies and support systems to help them work around their difficulties with reading and writing.

1.2 The links between health and literacy

How does this very brief portrait of literacy in Canada and the United States relate to the realities of patients and health care? Health education and promotion are primarily carried through print materials written at a tenth grade or higher reading level, readability levels that low-literate adults cannot comprehend. Most health materials are hard to read. They use terms, concepts and illustrations that are not familiar to lower skilled readers. Thus, for almost half the Canadian population, access to usable and relevant health information and health education is limited. This problem is aggravated by the fact that health education and health promotion have become increasingly important as chronic disease has become a major cause of sickness and death, and the locality of care has shifted to outpatient settings (Hohn, 1998).

There is abundant evidence to support the argument that low literacy has a major negative impact on health. The early research on health and literacy conducted by the Ontario Public Health Association found that persons with low literacy skills as less healthy due to a number of specific health and literacy linkages. Researcher Burt Perrin looked at direct and indirect effects of literacy on health (Perrin, 1998):

Direct effects of low literacy:

The direct impacts on health are attributable to the inability to access vital health information presented in print form. The following situations are cited:

- Persons with low literacy skills cannot read medication labels and sometimes take medication incorrectly. This applies to both prescription and over-the-counter medications.
- Persons with low literacy skills have problems to comply with medical directions (ex. a diabetic following a prescribed treatment).

- Persons with low literacy skills cannot prepare formula properly and may improperly feed infants.
- Persons with low literacy skills may not understand safety precautions in the workplace.

Furthermore, research in the United States has shown that:

- Persons with low literacy skills cannot read written instructions for preventative care, self-care and follow-up care after an illness or injury.
- Persons with low literacy skills have problems understanding appointment slips, informed consent forms, discharge information and oral instructions.

Perrin (1998) also explains the:
Indirect effects of low literacy:

- Persons with low literacy skills are more likely to live in low quality housing and in unsafe areas, with higher rates of pollution and environmental hazards. They are less likely to have safety features such as smoke detectors.
- Persons with low literacy skills are less likely to request care early in the course of their illness.
- Persons with low literacy skills smoke more, have poorer nutrition and exercise less.
- Persons with low literacy skills are less likely to have had a PAP test, to practice breast self-examination or a blood pressure check.

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).

According to a 1998 report by the Canadian Council on Social Development, between 22% and 50% of adults with lower levels of literacy live in low-income households, compared with only 8% of those with high-level literacy skills. Women with lower level literacy skills are twice as likely as men to live in low-income households (quoted in Norton and Campbell, 1998, p.6).

There is considerable research demonstrating the links between low literacy, poverty and ill health. Therefore, groups that most likely need health education and promotion the most are the groups least likely to benefit from the current practice (Hohn, 1998).

For the purpose of this document, we wish to use the term hard-to-reach patients, which is broader than low-literate patients. Hard-to-reach patients include low-literate patients, patients with learning disabilities and patients facing language and cultural barriers. High literate individuals can become low-literate patients because of cognitive or physical disabilities such as visual impairment, difficulties with oral processing, etc. Many disabilities can seriously diminish or block the capacity to read, understand and apply health education information. Language and cultural barriers can also cause health literacy challenges. Patients who do not have minimal language skills in English or French and who have another first language face serious challenges in processing and applying health information. Someone may be high literate in Chinese or Swahili, but low-literate in English or French. But an immigrant or a refugee may also be low-literate or illiterate in both mother tongue and English or French. In addition, some patients face cultural barriers, having views and beliefs about health very different from our North American views. All these factors directly affect the capacity to understand and use health information.

As noted above, written materials are often above the comprehension level of many patients. In 1995, a study of more than 2600 patients in the United States used a diagnostic test of functional health literacy (please see definition in annex 1). This test measured the patient's ability to understand and read medical instructions and health care information in the form of texts and numerical information. In the study, up to 33% of patients did not adequately understand instructions for a common radiographic procedure written at a fourth-grade level. From 24% to 58% did not understand directions to take a medication on an empty stomach. More than 20% of patients incorrectly answered questions regarding information on a routinely used appointment slip. In a more recent study, patients with low literacy skills suffering from diabetes and hypertension were unable to effectively control the physical manifestations of their illness even after receiving educational material and/or classes (Williams, et al., 1998).

Health care providers are concerned because patients who misunderstand their diagnosis and treatment plans usually exhibit poor compliance (Mayeaux, 1996). There are also legal implications and ethical issues. Case law examples have been collected on the issue of providing health care information and handling consent forms with low-literate patients (Brandes, 1996). Some health care professionals have been sued and found guilty of not having provided sufficient medical information in a manner that the patient could understand. These cases provide evidence that health providers cannot assume that because they gave information orally and handed out additional written information, the patient has understood what is needed.

1.3 A high-risk group: Low-literate senior patients

The IALS corroborates other research findings that literacy skills are lower among seniors who are also the most frequent users of health services (Walmsley, 1982; Williams, 1995).

Using IALS data, the Canadian Council on Social Development has demonstrated that seniors with low literacy skills are more likely to have health problems than are seniors with high literacy abilities (Roberts and Fawcett, 1998). They demonstrate that the combination of low literacy and chronic illness is common among the elderly. Many seniors take several different types of medication and the potential for medication errors is large among those who are least literate. Given the growing proportion of seniors in the Canadian population and the use of medication that increases with age, medication non-compliance is likely to increase (Roberts and Fawcett, 1998).

The ability of elderly health-care consumers to be active and effective participants in their own health care regimes is compromised if their health literacy skills are weak. Older low-literate women are at much greater risk of both breast and cervical cancer because they are less likely to undergo screening procedures and perform self-examination for breast cancer. Low-literate seniors are less likely to obtain health information from a wider selection of sources than their more literate counterparts, and a large number of senior citizens overestimate their literacy abilities.

1.4 Measuring patient literacy

How has the medical system responded to the difficulties of low-literate patients in accessing health information and health education? During the past forty years, in the United States, instruments have been developed to measure the literacy levels of patients. The focus has been on rapid estimates of adult literacy, which enable health care professionals to quickly assess literacy levels and adjust health information/education accordingly. Reading test instruments can provide a profile of the reading skills of a patient population or of individual patients.

One commonly used reading test is the Rapid Estimate of Adult Literacy in Medicine or REALM. It consists of three lists of increasingly difficult words to read. Each list contains 22 words taken from medical terms. The REALM can be administered in five minutes. Its results give a grade range estimate that generally indicates to health care professionals the appropriate level of health material. A longer version of the REALM test uses 125 common medical terms (Davis, et al., 1993). Another older reading test instrument is the Wide Range Achievement Test or WRAT. Its reading portion is similar to the REALM but it also includes portions that assess writing and numeracy skills. A third instrument is the Test of Functional Health Literacy in Adults or TOFHLA; this measures ability to complete basic reading and numeracy tasks required to function in the health care setting. The 22 minutes it takes to complete this test limits its use as a rapid screening tool.

Comprehension skill tests can include a Cloze test that may be used for patients who have a WRAT/REALM score at the 6th grade or higher. The Cloze test determines the fit between reader and material by having the reader fill in the blanks in a short passage dealing with medical information (Doak, et al., 1996, p.35).

1.5 The focus on plain language

An important and more common response of the medical establishment has been to evaluate the readability of health materials and to recommend the use of plain language. These materials include health pamphlets, booklets, basic medical instructions and self-care information. A large number of articles in American medical journals repeatedly confirm that health education material is written at a level far above average patient reading ability. A typical suggestion is that health education materials be written at three grade levels below the educational level of the target population. Researchers generally recommend that health materials be written at a 5th or 6th grade level.

The use of plain language in written health materials has been promoted as a tool for creating more open lines of communication between patients and the health care system. The National Literacy and Health Program of the Canadian Public Health Association (CPHA) has been a champion of plain language through its publications, conferences, training programs, directories, and by advocating plain language across the country. In 1999, it produced the Directory of Plain Language Health Information that gives guidelines on how to assess materials (the S.M.O.G. Readability Formula or Simple Measure of Gobbledegook) and how to produce plain language materials, and indicates where to find existing appropriate materials. CPHA has also produced, among others, a resource entitled: Creating Plain Language Forms for seniors: A Guide for the Public, Private and Not-for-Profit Sectors. Experience has shown that patients of all reading levels and all socio-economic levels prefer shorter pamphlets written in plain language. The work done by the CPHA appears to be paying off; more and more Canadian health education material is written in plain language. Still, much remains to be done. According to the CPHA, the use of plain language is uneven across Canada, within regions, and even within large health-care centres.

An evaluation model for health materials was developed in the United States: SAM or Suitability Assessment of Materials (Doak, et al., 1996, p.49). SAM lists factors to be rated: consent, literacy demand, graphics, layout and typography, learning stimulation and motivation, cultural appropriateness. For each factor, SAM assigns a numerical score, the weighting of which leads to a rating of superior, adequate or not suitable.

Many organizations, both in Canada and the United States, advocate the use of plain language in the production of health care materials and in the dissemination of public information in general. Studies in the United States and Britain have shown that plain language writing saves money. Many writers offer concrete and useful tips on how to present information, how to design visuals and how to choose appropriate language (for example, Doak, et al., 1996; Mayeaux, 1996).

The consensus is that to be effective, patient education materials should include short and simple information, be written in simple language, contain culturally sensitive graphics and focus on the desired behavior of the patient (Mayeaux, 1996).

1.6 Oral communication and more effective patient education

Researchers and practitioners recognize the need for more effective patient teaching. Apart from recommendations on written material, health literacy studies and manuals also recommend techniques to improve oral communication between hard-to-reach patients and health care professionals, although this is less common in the literature than information on plain language. These techniques typically include:

- Limiting teaching objectives.
- Giving many examples that have meaning to the patients.
- Demonstrating procedures such as measuring dosages and counting pills.
- Making learning participatory. Ask patients to restate instructions in their own words.
- Repeating the information several times.
- Organizing your instruction so the most important messages are presented both first and last.
- Including family members or other caregivers in the education process (Mayeaux, 1996).

The issue of training health care providers is also discussed. In some cases, practice is changing. For example, a model for teaching oral communication skills to health care providers who deal with low-literate adults was developed a few years ago in the state of Maine in partnership with their largest rural health centre delivery system (Plimpton, 1994).

The need to develop non-written means of communication, including methods of conveying information such as audiovisual materials and storytelling, is mentioned in the literature. Guides exist on how to assess and produce effective health education videos. According to Mayeaux, et al. (1996), combining easy-to-read written patient education materials with oral instructions in simpler language has been shown to greatly enhance patient understanding. They stress that adults learn best when information is relevant to their lives, when they know the purpose of the information in their lives, when they have a specific educational plan or program and when evaluative feedback is given. Motivation is also a key factor that may be enhanced by involving family members in the patient education process and giving feedback.

1.7 Communication and health organization accreditation

In the United States, the Joint Commission on Accreditation of Health Organizations (JCAHO), a private accrediting agency that inspects all licensed health care facilities and establishes minimum standards for hospitals and other health care institutions, now requires that instructions be given at a level understandable to the patient. JCAHO emphasizes affording each individual the care and attention that is necessary to his/her particular situation. This includes the recognition of the psycho/social, spiritual and cultural values that affect a patient's response to care given (Brandes, 1996). Hospitals and other health organizations are required to assess how well their patients understand their health care instructions and to provide education specific to the patient's assessed needs, ability and readiness (quoted in Mayeaux, 1996).

In Canada, hospitals and health care facilities are involved in the AIM (Achieving Improved Measurement) accreditation program of the Canadian Council on Health Services Accreditation. The basic principles of AIM are: client focus, quality improvement, teams, leadership, process and outcomes, recognizing the continuum of care and service provision (each health service organization must ensure that the client can easily access all the components of health care services), a population health approach and better measurement.

The AIM program calls on health teams to evaluate how AIM standards are being met through a process of self-assessment. The standards assess the quality of the services provided by the organization and incorporate the philosophy of quality improvement. Many of the AIM standards touch, directly or indirectly, on the issue of patient literacy. The standards focus on the need for patients and their families to be well informed and involved as active participants, and to demonstrate that they understand the information provided. Standards deal with the whole spectrum of health intervention: health prevention, promotion and early detection, assessment, integrating services with external partners, process used to initiate service, informed consent, developing a service plan, etc. The term patient literacy is not used, but rather client's abilities, clients with special needs, and client's level of education. The standards state that health information must be based on the client's and families' information needs, and that it must be easy to read and use. A separate section of the AIM standards checks that clients and families receive appropriate education and support regarding medication and other therapeutic technologies.

Section 2. Key issues to consider

Section 2 attempts to critique and move beyond the mainstream literature on health education and health literacy, looking at key issues that are relevant to our project.

2.1 The limits of assessing patient literacy

There are significant limits to assessing patient literacy. Most health provider are not trained to make this type of assessment, and even if they were, there is rarely sufficient time to go through actual tests. Direct assessment can be embarrassing and increase anxiety for the patient. Research has demonstrated that there can be a gap between level of instruction and functional literacy level. A patient's level of education is not always an accurate indicator of literacy level. As time passes, reading skills and the capacity to comprehend more complex written words diminish when there are few opportunities to use these skills. In fact, research on literacy in the United States tell us that many adults read 3 to 5 grade levels below the last level of education completed (quoted in CPHA, 1999). Also, some low-literate patients may claim to have a higher level of education than what was actually completed. In Canada, we could not find health forms that even asked patients information about their education.

In cases where tests are used, they also have limitations. A patient's ability to understand a word does not necessarily mean that she understands the significance of the instruction being provided. A patient may be able to read all the words in a sentence but not comprehend its full meaning. This is an important consideration when one employs tests, such as REALM, that only assess the capacity to decode but not comprehension skills. Patients are expected not merely to decode health information, but to comprehend and apply it by modifying their behaviour in day-to-day living.

2.2 Over-reliance on plain language

Many researchers question an over-reliance on plain language in health education to address the issue of low-literate patients. According to a Health Canada profile paper entitled *How does Literacy Affect the Health of Canadians?*

> Plain language is a useful step but not the answer. Presenting written health information in easy-to-read, rather than complex, technical language, is undoubtedly a useful step… Plain language is not the primary solution to addressing the health difficulties associated with literacy. As the CPHA has indicated, written information should be secondary to verbal communication and should only supplement the exchange between physician and patient. Personal contact between patient and physician is the best way to ensure the transmission of a message.
>
> (Perrin, 1998, p.16)

American researcher Marcia Hohn also criticizes the over-reliance on plain language but looks beyond the individual patient-physician relationship. She presents the issue in the context of community dynamics and group participation:

> The view of addressing the health education needs of low literacy groups through simply rewriting existing materials at a simpler language level is exceedingly limited. Information is only one piece of a process that needs to include community context, participation, and support. (Hohn, 1998)

Hohn's views on low literacy, health and empowerment are expanded in sub-section 2.4.

2.3 Beyond written material

As explained in section 1.6, many researchers argue for more effective patient education and focus on different strategies to achieve this, such as better oral communication between patients and health care professionals, training for health care professionals and developing non-written means of communication. Perrin argues for the need to make health information available other than via the written word. He explains that some people do not view written information as credible and prefer to obtain their health information through other means. Health information alone is not sufficient for individuals with low literacy skills who often feel powerless to make changes in their lives. Looking at the issue from a different perspective, Perrin presents alternative forms of health communications such as community development approaches and participatory health education (Perrin, 1998).

Community development approaches
Since low-literate individuals often get more of their health information from people surrounding them rather than from health experts, it makes sense to look at community groups and how established community networks, which already include hard-to-reach patients, can become involved in health literacy efforts. The literature suggests that health care professionals must change their role and act more as facilitators, working in partnership with others in the community to provide health information. There is a need to investigate community dynamics and to tap into existing community networks, peer groups, social support networks, etc. A US study conducted in 1994 showed that using a peer-helper approach and community volunteers was a more effective way to reach out to older, low-literate women regarding health than using traditional and educational approaches (cited in Roberts, 1998, p.18, see endnote).

Participatory health education
On occasion, literacy and public health programs have facilitated the participation of low-literate individuals in the process of reflection, discussion and action concerning health issues. This education process works from the bottom up, with the active participation of literacy students or patients within a group process. They identify the health issues that concern them, they explore them, they develop the content and the methodologies for sharing information, and they take action in the community. Health specialists play a different role, not as experts but as human resources who share knowledge with the group. This participatory process enables students/patients to gain confidence and to take more control over their health and their lives.

Drama
Another alternative way to transmit health information, raise awareness and communicate messages is through drama or popular theatre. Drama can represent an effective way for hard-to-reach patients to express their difficulties with the health care system and to investigate strategies to improve their situation.

Unfortunately, the Perrin paper does not present Canadian case studies of these alternative forms of health communication. Few concrete examples can be found in the literature. Our hypothesis is that while these are not very common, they do exist (please see more in Section 3).

2.4 Discrimination and learner/patient empowerment

One example of alternative forms of health education stands out in the American literature: the participatory action research facilitated by Marcia Hohn in Lynn, Massachusetts (1998). Massachusetts is a leader among the states in adult education and health education. In this project, within the context of an adult literacy centre called Operation Bootstrap, a multicultural team of literacy students facilitated by Hohn worked collectively through participatory processes to explore and learn about two major health issues. They identified three major problems with health education. First, print materials about health topics were too difficult. Second, even if the materials were written at appropriate literacy levels, they were insufficient by themselves in promoting active engagement likely to result in behaviour change. Finally, many health educators were ill prepared to do effective teaching with low-literate audiences.

One of the major issues identified by these students was discrimination, defined as the level of fears about being poorly treated in a social sense at health care facilities and not knowing their rights and responsibilities in seeking medical care (Hohn, 1998, p.48). According to Hohn, there is a fundamental need to provide a psychologically safe atmosphere for health teaching and learning where people's questions are respected and addressed. Inherent to this safe environment is the need to respect different cultural perspectives and different belief systems. Students must feel comfortable to tell their stories, ask questions and even challenge information. Low-literate groups must understand their rights and responsibilities in the health care system, and how to negotiate within this system.

While health care is significantly different in the United States and in Canada, some of these concerns apply to Canada. Hard-to-reach patients in Canada can also have difficulties navigating the health care system and can, in some instances, feel they are poorly treated. For many different reasons, their questions are often not being answered (possibly they do not ask the questions) and they do not have the self-confidence to go a step further and find the answers. These problems are multiplied in the case of patients from ethno-cultural communities who face language and cultural barriers.

Unlike the majority of available studies and research on health literacy, the Hohn study focused on the empowerment of low-literate individuals. Participatory health education goes beyond having a patient understand information on a disease or taking prescribed medication. The goal is to empower users of the health care system so they may gain control over their own lives in the context of participating with others to change their social and political realities.

Empowerment education allows people in group efforts to identify their own problems, critically analyze the cultural and socio-economic roots of the problems and develop strategies to effect positive changes in their lives and in their communities (Wallerstein, 1994). This approach is inspired by the work of Brazilian educator Paulo Freire. According to Wallerstein, field research has documented better physical and behavioural health outcomes from increasing participation and control in one's life (Wallerstein, 1994). People who live with low literacy, poverty and health problems may more frequently feel disempowered by attitudes and actions of people, groups and institutions that hold power in our society. Empowerment becomes the strategy to address the lack of control that characterized individuals in positions of perceived and actual powerlessness. This is achieved through greater participation in community actions, a stronger sense of community, vibrant social networks, promoting a belief in people that they can control their environment and through actual socio-economic changes.

According to Hohn, an empowering education process must include:

a) direct teaching by peers;
b) a safe and respectful atmosphere to ask questions and talk culture;
c) creative and inclusive methods.

The teaching and learning approaches need to be supported by simple, easy-to-read materials. The whole process must start from the reality of learners' lives, their issues, problems, challenges, cultures and aspirations. Involving participants in the development of learning materials is often used as a strategy. The final product reflects both the reality and the language of people in the community.

Hohn believes that learning must take place in three realms: the physical, the cognitive and the psychological-emotional, looking at the whole person. Students learn about their bodies and about health issues. They develop greater self-confidence and emotional strength. Students learn how their reality fits into the larger social context. Health as a topic provides tremendous energy, motivation, and a commitment for learning and improving literacy skills. Learning programs like this one can serve both the health and the language-literacy needs of adult literacy students in a process that is mutually reinforcing. (Hohn, 1998).

A thoughtful Canadian example of a participatory health education process comes from the Learning Centre Literacy Association based in Edmonton, Alberta. Following a series of participatory health literacy education workshops for women, the Centre produced *Learning for Our Health: A resource for participatory literacy and health education* (1998). This resource was written by and for women with the objective of empowering women. It puts participatory education in a larger context and analyses the links between health and literacy. This resource was extensively field-tested and is clear and well developed. A series of ten workshop plans are included. The topics are: stress, saying no, exercise, healthy weight, eating for our health, menopause, anger, STDs, living healthy on a low budget and living with welfare.

This kind of change linked to individual and community empowerment takes time. The student action health team of Operation Bootstrap started its work in 1994 and the intense involvement of Ms. Hohn lasted approximately two years. The experience of the women in literacy class in Edmonton showed that it took almost 20 weeks before some women began to speak with comfort and confidence (Norton and Campbell, 1998, p.16).

2.5 Beyond functional health literacy

Without becoming overly preoccupied with theories and definitions, it is useful to consider concepts that help us distinguish among different views on health literacy. This section summarizes the views of Australian researcher Don Nutbeam (Nutbeam, 1999) who argues that the traditional definition of health literacy (an individual's capacity to read and comprehend medical information and instructions) misses much of the deeper meaning and purpose of literacy for people. By facilitating access to information, literacy enables individuals to make informed choices, to influence events and to exert greater control over their lives. This expanded concept of health literacy, similar to Hohn's, has been used for some time in Australia. Nutbeam cites a government report that lists one of the three goals of health literacy as enabling people to take an active role in bringing about change in environments that influence their health.

He also notes that the World Health Organization (1998) asserts that health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment (p.49). Nutbeam classifies three levels of health literacy: functional health literacy, interactive health literacy and critical health literacy. The levels reflect increasing degrees of autonomy and personal empowerment. Following is a condensed version of this classification of health literacy:

Health Literacy Level and Educational Goal	**Content**	**Outcome: Individual Benefits**	**Outcome: Community and Social Benefits**
Functional Health Literacy: Communication of information	Transmission of factual information on health risks and use of health services.	Improved knowledge of health risks and health services, compliance with prescribed actions.	Increased participation in populations health programs (screening, immunization).
Interactive Health Literacy: Development of personal skills	As above, including opportunities to develop skills in a supportive environment.	Improved capacity to act independently, improving motivation and self-confidence to act on advice received.	Improved capacity to influence social norms, and interact with social groups.
Critical Health Literacy: Personal and community empowerment	As above provision of information on social and economic determinants of health, and opportunities to achieve policy and/or organizational change.	Improved individual resilience to social and economic adversity.	Improved capacity to act on social and economic determinants of health, improved community empowerment.

While this chart lays out distinct divisions, the reality of health literacy practice is often based on a mixture of two or all three concepts. These three concepts could be seen as three levels in a health literacy continuum. Also, it is worth noting that the literature does not reflect a debate concerning the different concepts of health literacy. According to Nutbeam, the interactive health literacy model is currently the dominant one, while critical health literacy remains the exception. He believes that helping people develop confidence to act through community-based educational outreach and achieve a better understanding of the political aspects of education will be central in achieving a shift towards critical health literacy.

2.6 Partnerships between health and literacy organizations

The term health literacy implies in itself a junction, a crossing of two sectors: adult education and health. In classroom practice, joining the two appears to bring about positive outcomes. Introducing health topics in literacy classes brings out potential for effective learning and retention. Health is a subject of study that draws learners' interest and is a vehicle for teaching basic skills. It is in fact a two-way process. Language and literacy development facilitates the dialogue about health, while the topic of health simulates the motivation for literacy learning (Hohn, 1998, p.111). Adult educators report that health units enhanced skills in areas of dialogue, discussion, vocabulary building, reading, language development and critical thinking (Rudd and Moeykens, 1999). This can also apply to learning outside a typical classroom in a literacy centre, for example in a hospital or community health centre. The experience of the women's literacy classes in Alberta however underlines the challenge of introducing specific reading and writing activities while maintaining a broader perspective on the health issue (Norton and Campbell, 1998, p.13).

At the organizational level, many argue that in order to achieve more effective health education, there is a need for enhanced cooperation and closer partnerships between the education and health sectors. Nutbeam mentions the key role of overt alliances between the health and education sectors at the local, national and international levels (Nutbeam, 1999). Health centres of all kinds and education organizations such as literacy centres and community organizations should define common goals and objectives, share resources, plan together and develop joint programming in health literacy. Both have much to learn from each other and could benefit from the partnership. Appropriate curricula and methodologies for low-literate patients could be shared with health care professionals while health education content and analysis of community health challenges could be shared with educators. Research findings in health education offer insights into what could be included in health literacy curriculum.

Partnerships between the health and education sectors are also needed at the decision-making level. In Canada, this jurisdiction resides mainly with provincial/territorial governments who are responsible for health and education. Appropriate policies and funding mechanisms could support local and regional partnerships in the field. It is important to underline the benefits of health literacy for public health as it represents a way to reach out to hard-to-reach groups and to improve health among the least healthy.

2.7 The potential role of support staff

Dr. Rima Rudd from the Harvard School of Public Health, a key researcher in the field, has worked with fellow researchers to conduct a qualitative study (unpublished) on navigation, looking at the barriers people encounter as they make their way into and through medical institutions. Researchers conducted walking interviews with adult basic education learners, using a talk-aloud protocol as they walked through hospitals. Among the findings were that many of the adult learners who served as informants noted that they felt somewhat uncomfortable in the larger, fancier hospitals. They looked for friendly faces.

Several adult learners seemed to look for people 'like them' when they sought help. This meant that, in several cases, the adult learners turned to hospital cleaning staff when they needed directions. The staff people were warm and friendly but they had not been oriented to the lay out of the hospital and so could not usually offer the needed information. Many key support staff, who serve as greeters, had not been oriented to the layout of the hospital. According to Dr. Rudd, hospitals have in general neglected the potential role of support staff in providing certain types of information to patients.

In other studies, Dr. Rudd gathered stories from adult learners about their encounters with receptionists. They corroborated testimony from adult learners in many parts of Canada and the United States.

Examples of these were collected and displayed on a "Learners' Wall" at the CPHA conference on Literacy and Health in May 2000 (Canadian Public Health Association, 2001, p. 10).

People described how, before they could see a doctor or nurse, they were handed forms to complete by receptionists who treated questions and requests for help with disdain. They cited responses such as: Can't you read? or I don't have time to fill out your form. The adult learners telling these stories reported feelings of anger and/or of mortification.

Section 3. Profiles of health literacy initiatives in Canada

Section 3 presents profiles of different health literacy projects and programs that have been, or continue to be, conducted in Canada. We are presenting information gathered from articles, Web sites, and phone interviews. Most of the information has been taken from written documents produced by the programs themselves. We have simply described these initiatives. We have not conducted any evaluation of our own, either formal or informal, and have not considered independent reviews or assessments in our creation of the following profiles.

3.1 National Initiatives

Literacy and Health for Life **National Literacy and Health Program** **Canadian Public Health Association**	
Start/End Date	1992 – ongoing
Goals	▪ To establish a framework for raising awareness about the links between literacy and health. ▪ To build commitment among 27 national health associations.
Objectives	▪ To establish links between national health associations and: 1) the federal government; 2) literacy organizations; and 3) provincial health associations. ▪ To coordinate action on literacy and health, and, thereby, contribute to improving the health system.
Methods/Activities	▪ Promotes and supports the use/creation of plain language material for use within partner organizations. ▪ Plans and coordinates research projects proposed and agreed upon by NLHP partners. ▪ Encourages partners to identify and communicate specific ways to promote literacy and health that are attractive and relevant to their members/clientele. ▪ Provides health professionals with resources to help them serve people with low literacy skills. ▪ Targets students in academic training programs, within the health disciplines represented by partner organizations. ▪ Provides a Plain Language Service to edit health information, and help health providers get their message across. ▪ Offers plain language and clear verbal communication workshops.
Source of Funding	The National Literacy Secretariat provided seed funding for the program's development over the first three years. Since then, the network has subsisted on project grants, donations, and on limited revenues generated from the sale of resources. Grants are generally obtained from the NLS, and (when appropriate) from various departments or divisions of Health Canada. The Plain Language Service is sustained by its own project revenues: ▪ Consultation/Revision work ranges in cost from $375 per day for non-profit and public health units, to $600 a day for private sector clients. ▪ Workshops are customizable, and cost $500 for half a day, or $1000 for a whole day. Expenses are not included in these fees.
Population Served	The program acts as a resource for health professionals and students affiliated with partner organizations across Canada.
Evaluation	Evaluations are conducted at the project level, but, as such, no evaluation of the NHLP has been carried out.
Annual Budget	No comprehensive budget is available, due to the wide range of funding sources.
Structure	The NLHP network is composed of: ▪ 27 national health associations make up the NLHP partnership, and govern its activities as a group. ▪ Project directors and administrative staff, whose numbers' vary depending on project allowances. The Plain Language Service, composed of: ▪ 1 full-time manager ▪ 2 full-time assistants; and ▪ Associates – most of them former nurses – who are called in as the volume of work fluctuates.
Contact	Andrew Aitkens (Project Director) Tel: (613) 725-3769 Email: nlhp@cpha.ca URL: http://www.nlhp.cpha.ca/

3.2 Provincial Initiatives

Health Literacy Network **BC Coalition of People with Disabilities (BCCPD)** **Vancouver, British Columbia**	
Start/End Date	December 2000- ongoing
Goals	To raise awareness of health literacy issues, by establishing a province-wide Network linking disability, health, literacy and community groups, individuals and health care professionals.
Objectives	▪ To gather and share information from members about useful publications, education programs, and other activities. ▪ To link members together, providing access to needed and available resources. ▪ To identify gaps in information, and understand the health information needs of BC residents. ▪ To act as a referral service for health care practitioners and consumers.
Methods/Activities	The Health Literacy Network is a new program of the BCCPD's Wellness & Disability Initiative/AIDS & Disability Action Program [WDI/ADAP]. By meeting with advocates, consumers and service providers, the HLN aims to: ▪ promote the Network concept at conferences, community events, and through the WDI/ADAP newsletter *TIPS for Living Well*; ▪ identify key health literacy issues in various disability communities; ▪ identify relevant health literacy initiatives; and ▪ identify plain language and alternative format resources, determining significant gaps in the available body of resources. Future activities include: a Health Literacy Newsletter for health care workers, community groups and consumers; and the creation of brochures about health literacy and plain language resources. The Network is also co-sponsoring a plain language workshop with Vancouver Hospital's Patient and Family Resource Centre in September. The WDI/ADAP/HLN Resource Centre offers: ▪ Research and reference services for people with disabilities, their families, caregivers and healthcare workers across Canada. ▪ A collection of health and wellness materials in reader-friendly formats, cassettes, captioned videos. large print and Braille. ▪ Access to the ADAP database, including material on sexuality, HIV, and prevention of STDs. ▪ Resource guides on specific health topics. ▪ Health literacy and plain language resources. The WDI Web site offers: ▪ Links to reader-friendly material on all aspects of health and wellness. ▪ Access to WDI research and reference service. The HLN's Web site is in development.
Source of Funding	The BCCPD is a federally-funded, registered charitable organization. ADAP/WDI is funded through the BC Ministry of Health and private donations.
Population Served	The WDI/HLN serves health practitioners, consumers and community groups throughout BC; and online visitors are well-served by the wealth of information available through the WDI Web site.
Evaluation	The WDI/ADAP/HLN Program has, thus far, been evaluated through its ongoing review of: ▪ information requests; ▪ Web site hits; ▪ responses to mail-outs; ▪ informal surveys of consumers, consumer groups, and service providers to determine health information needs and interests; and ▪ discussions with health care providers at conferences and community events. As the HLN Program is still developing, no formal evaluation has been implemented.
Annual Budget	The Wellness & Disability Initiative/AIDS & Disability Action Program share a yearly budget of $136,179.
Structure	▪ Full-time WDI/ADAP/HLN Program Director ▪ Part-time Health Literacy Network Coordinator ▪ Part-time WDI/ADAP/HLN Librarian
Contact	Deborah Prieur (Health Literacy Network Coordinator) Shelley Hourston (WDI/ADAP/HLN Program Director) Janet Freeman (WDI/ADAP/HLN Librarian) Tel: (604) 872-7241 Toll-Free 1-877-232-7400 Email: hln@bccpd.bc.ca URL: http://www.bccpd.bc.ca/wdi

3.3 Local/Institutional Initiatives

Health Communication Service **Centre for Health Information and Promotion** **The Hospital for Sick Children** **Toronto, Ontario**	
Start/End Date	In fall 2000 the Health Communication Service was created when the Centre for Health Information and Promotion (CHIP) took over the development of patient and parent education materials from the Hospital's Public Affairs department. The CHIP itself has been in operation since 1979.
Goals	▪ To facilitate family education and support at an individual level. ▪ To develop strategies that improve health behaviours at a population level. ▪ To provide leadership in health communication, promotion, evaluation and research interventions.
Objectives	• To create clear and relevant educational material. • To promote awareness of health literacy and information issues among hospital staff. • To educate and train hospital staff to account for literacy and other communication needs, in their written and spoken communication with patients and their families.
Methods/Activities	▪ Consultation services (mandatory by hospital policy) for hospital staff producing parent and patient information/education material. ▪ Plain language editing and design of new and existing resources to provide relevant information at a target, Grade 6 reading level. ▪ Liaising with in-house Graphic Centre on production. ▪ Copyright management. ▪ Field-testing of materials with sample/representative readers. ▪ Provision of materials through the hospital's Resource Centre.
Source of Funding	A National Post Endowment for Innovative Health Promotion, provided by the Black Family Foundation. Hospital departments pay for services provided on individual projects. The materials produced by the Health Communication Service tend to be highly unique in nature and content, and are made available for purchase upon publication.
Population Served	The service's clientele includes doctors, nurses, social workers, dieticians, and other health professionals working within the hospital. Patients and families are also served by the HCS, contributing valuable input during needs assessment and content development phases, and providing feedback during field-testing.
Evaluation	Clear measures for evaluating the Service's activities and performance have not yet been defined or examined. Every item submitted to the service, however, is closely reviewed to ensure that no appropriate alternatives exist and that the specific informational/educational needs of patients and parents are met.
Annual Budget	Not available.
Structure	▪ Two full-time communications consultants (backgrounds in communication, languages, and adult education in hospital/non-profit settings) staff the HCS. ▪ 17 CHIP staff members deliver a range of services including health information through the resource centre, health communication, promotion, evaluation and research interventions.
Contact	Liz Leake Tel: (416) 813-5118 Email: liz.leake@sickkids.ca URL: http://www.sickkids.on.ca/chip/default.asp

Health Literacy Activities at the
Herzl Family Practice Centre: Jewish General Hospital
Montreal, Quebec

Start/End Date	Investigations into literacy issues began in 1997, and are still ongoing.
Goals	To guide patient education needs at the Herzl Family Practice Centre.
Objectives	▪ To estimate the prevalence of low literacy among patients of the practice; ▪ To identify patients with a need for low-literate health education materials; ▪ To determine whether reading grade level was associated with perceived health; and ▪ To estimate reading grade level of educational materials already in use.
Methods/Activities *	1997 ▪ Over the space of four weeks, a patient reading-level assessment (using the REALM test) and an assessment of self-perceived health status (using the COOP/WONCA Health Status Scales) were performed on a random sample of 230 English-speaking patients. ▪ 9.3% of patients scored low on the test; for most, English was not their maternal language. ▪ A weak correlation existed between literacy level and health status, but was not statistically significant. ▪ Ultimately, the prevalence of low literacy among patients was shown to be lower than the national and provincial averages. 2000 ▪ Patient information brochures were developed in consultation with the National Literacy & Health Program's Plain Language Service, on the topics of "Hypertension" and "Anorexia/Bulimia".
Source of Funding	The Research and Development Fund of the Herzl Family Practice provided financing for the 1997 literacy and health survey, and for the development of brochures in 2000-01.
Population Served	Patients of the Herzl Family Practice Centre.
Evaluation	A report on the 1997 study is awaiting publication: *Literacy and Health in a Family Practice Centre.*
Annual Budget	$2000 was provided for the health and literacy survey; and $1000 has been put towards the creation of plain language brochures.
Structure	1997 Survey ▪ 1 Patient Education Coordinator; ▪ 1 hired technician, who administered the tests; ▪ 1 epidemiologist, who performed statistical analysis.
Contact	June Smith Tel: (514) 340-8253 Email: smithjuno@hotmail.com URL: http://www.jghfamilymedicine.mcgill.ca/default.html

Patient Education Mandate of the Lakeridge Health Corporation Oshawa, Ontario	
Start/End Date	Evaluation of the Corporation's educational program and services began midway through 2000.
Goals	▪ To make health care more accessible to residents of Durham region.
Objectives	▪ To standardize patient education programs and materials across five participating hospital sites.
Methods/Activities	▪ Assess staff awareness of health and literacy issues; and educate them with regard to the importance of clear written materials and verbal communication. ▪ Assessment of patient literacy levels using (most likely) the REALM tests. ▪ Development of guidelines/standards for the creation and evaluation of patient education resources, based on staff and patient assessments.
Source of Funding	Private funding - "Corporate Dollars" – must be secured for specific initiatives. The Ministry of Health provides limited financing contingent on a base amount being secured elsewhere.
Population Served	Patients and staff of the Lakeridge Health Corporation.
Evaluation	Currently still in the stage of assessing and promoting staff awareness of patient's informational and educational needs; and of measuring those needs.
Annual Budget	Approximately $25,000.
Structure	▪ 1 Patient Education Consultant ▪ A grassroots network of approximately 40 front-line "educators" – including nurses, physicians, housekeeping staff, etc. – to assist the consultant in her efforts.
Contact	Julie Clarke (Patient Education Consultant) Tel: (905) 576 8711 ext. 4324 Fax: (905) 721-4812 Email: jclarke@lakeridgehealth.on.ca

Participatory Education Project **Learning Centre Literacy Association** **Edmonton, Alberta**	
Start/End Date	1996 – 1997
Goals	• To integrate literacy development and health promotion in a single program of participatory education.
Objectives	• To develop a participatory education program with the aid of women clients of the Learning Centre Literacy Association. • To research the outcomes of women's participation in such a program. • To produce a resource book for facilitators in literacy programs, health centres and other community organizations.
Methods/Activities	• The women's health group was formed, and members attended weekly, two-hour workshops on identified topics of interest. • During workshops, the women discussed their experiences and shared their knowledge of the issues with one another. • Facilitators mediated the group's discussions, recruiting subject specialists when deemed helpful or necessary. • In a concluding session, participants' perspectives on the workshops were recorded, and developed into a photostory to inform others about the group's activities. • Publication of: *Learning for our Health: A Resource for Participatory Literacy and Health Education*.
Source of Funding	National Literacy Secretariat
Population Served	The women who participated in the group were regular clients of the Learning Centre Literacy Association, which is a community-based adult literacy and education centre.
Evaluation	The project's outcomes were evaluated in a paper by Tammy Horne, entitled: *Learning for our health: Outcomes for women in a participatory literacy and health education program.*
Annual Budget	The National Literacy Secretariat granted $58, 258 to conduct this project.
Structure	• Two professional educators, Mary Norton and Pat Campbell, coordinated and developed the program. • 11 women from the LCLA formed the health group, participating in the development process.
Contact	Mary Norton (Project Coordinator) Tel: (780) 429-0675 Fax: (780) 425-2205 Email: learningcentre@compusmart.ab.ca

Patient Education at the
Ottawa Regional Cancer Centre
Ottawa, Ontario

Start/End Date	Adaptation of patient information began in 1999 and is ongoing.
Goals	To provide the information and resources patients need to make informed choices and be active participants in their care.
Objectives	To produce patient information that is clear, understandable, and appropriate to their needs.
Methods/Activities	• The in-house creation/adaptation of plain language patient literature and educational resources, written at an intended Grade 6 reading level, e.g., the Centre's *Patient Information Booklet* (a patient orientation guide to the Centre's departments and services). • Review of existing patient information through the National Literacy & Health Program's Plain Language Service. • Staff education through plain language workshops facilitated by the PLS.
Source of Funding	The ORCC subsists on provincial funding, and assistance from Cancer Care Ontario.
Population Served	The Centre serves over 16, 400 patients from within the National Capital Region, the Ottawa Valley and the Outaouais, each year. There is no available record of the specific population served by plain language materials at the ORCC.
Evaluation	Patient information is evaluated and adapted as the need arises. An in-house evaluation of plain language activities has been conducted, but findings have not been made public.
Annual Budget	There is no specific budget for literacy activities. Materials are produced as needed with Education Department funds.
Structure	• 2 members of the Education Department received training in plain language techniques through the CPHA's National Literacy & Health Program. • 1 Nursing Education Coordinator (a shared position) • Library staff; and • Other staff members have attended NLHP workshops.
Contact	Jo-Ann Nicol Tel: (613) 737-7700 ext. 6981 Email: joann.nicol@orcc.on.ca URL: http://www.orcc.on.ca/

A Volunteer-Assisted, Computer-Based Patient Education Program
Princess Margaret Hospital
Toronto, Ontario

Start/End Date	1997: Development of OIES, in collaboration with Jack Digital Productions. 1999: Planning begins for the creation of an internal Patient Education Web site and several small Patient and Family Resource Centres. 2001: The new program/service is launched.
Goals	To empower patients and their families, by providing them with accurate, up-to-date information, in a language and format that are clear and understandable.
Objectives	To find a cost-effective and timely way to deliver a complex mix of interesting and high-quality information and expertise to a large and diverse audience.
Methods/Activities	▪ Development of the Oncology Interactive^{TM} Education Series (OIES): an interactive multimedia software program for patient education on cancer topics. ▪ Creation of the PMH Patient Education Web Site: a hospital-based intranet site. ▪ Creation of several Patient and Family Resource Centres in hospital waiting areas. ▪ Development of a training program for volunteers to support patients' and families' use of the Web site and OIES at different Resource Centre locations.
Source of Funding	The Princess Margaret Hospital Foundation provided seed money for the project, and is committed to its future support. Development of the OIES was funded by both the PMH Foundation and Jack Digital Productions.
Population Served	Over 9,000 new patients are assessed annually, and 1,000 patients come to PMH daily for outpatient treatments or follow-up. All have access to the Web site/OIES, and to volunteer services.
Evaluation	A full evaluation will be conducted in coming months, but increased use of the hospital's central *Patient and Family Support Centre*, or library, are an indication of the program's success. Traffic has increased from 8 to 10 visitors a day, to upwards of 50-100 a day; and several additional copies of CD-ROMs have had to be purchased.
Annual Budget	An estimated $ 300,000-400,000 including salaries. $ 600,000 was raised in the last year-and-a-half to develop the program's infrastructure, which includes: • A dedicated server to host the OIES and Web site ($20,000) • Computer equipment, including leased printers, for 15 (soon to be 18) Patient and Family Resource Centres • Desks, chairs, shelving, etc. • Purchase of books and resources ($20,000 plus) • Training of volunteers Individual *Resource Centres* cost from $2,500-$15,000 to develop, based on levels of donor interest.
Structure	▪ Staff: 1 full-time director, 1 full-time librarian/manager, 1 full-time secretary, and 2 education researchers. ▪ 1 central library and 14 *Patient and Family Resource Centres* located in waiting areas throughout the PMH. ▪ 29 volunteers trained to offer support and assistance.
Contact	Audrey Friedman Tel: (416) 946-4501, ext. 5340 Email: audrey.friedman@uhn.on.ca

Health Education in Plain Language Projects **Women's Network PEI** **Charlottetown, PEI**	
Start/End Date	The following projects began around the early 1990s.
Goals	The Network's defining purpose is to strengthen and support the efforts of PEI women to improve the status of women in our society.
Objectives	The Health Education in Plain Language project aims to develop plain language health education tools for adult learners, their families, and communities.
Methods/Activities	The development and publication, through project grants, of several plain language resources and workshop facilitation guides: ▪ *Partners for Health : Stories About Health* ▪ *Partners for Health :Helping Each Other* ▪ *Partners for Health : First Aid Kit* ▪ *The Relationship Book: A Resource of Social and Legal Information* ▪ *Beyond Prescriptions: Meeting your Health Needs* ▪ *Is It Hot in Here?: A Handbook for Menopausal Women and Their Families* ▪ *Curriculum Guide Book for Plain Language Health Resources* ▪ *The Health Board Game* The Network conducts half-day workshops on literacy and its effects on health, as well as "Train the Trainer" workshops for prospective workshop facilitators. Resources are publicized through the direct mailing of flyers.
Source of Funding	The National Literacy Secretariat and Health Canada have funded most of the above projects.
Population Served	▪ Resources are available for purchase from anywhere in Canada and beyond. Ordering information for resources is provided on the Web site. ▪ Workshops are available within PEI.
Evaluation	Since their original publication, most of the Network's resources have been re-evaluated and adapted in light of the group's greater understanding and experience with plain language writing and instruction. Feedback from evaluation forms has shown that resources are positively used in a far wider variety of ways and contexts than originally intended. There were no quarrels over price, but the Network reduced costs anyway.
Annual Budget	The average budget per project is estimated at between $20,000 - 25,000. Resources produced through projects are marketed and sold at rates sufficient to cover future editing, reprinting, shipping and handling costs. The average budget for such activities is maintained at approximately $2000 a year.
Structure	Projects are coordinated, and resources developed and published by: • Women's Network Staff; with the assistance of • Professionals within the community. • Steering Committees who oversee the development and progress of each project. Most of the Network's resources are distributed by Grass Roots Press.
Contact	Laurie Anne McCardle Tel: (902) 368-5040 Fax: (902) 368-5039 E-mail: wnpei@isn.net URL: http://www.wnpei.org

3.4 Literacy Programs in Health Settings

Action ABC **Montreal, Quebec**	
Start/End Date	Fall 1997 – ongoing
Goals	▪ To be a strong advocate, for students, of front-line literacy training. ▪ To teach basic literacy skills to individuals recovering from substance abuse and to psychiatric patients, enabling them to establish a viable, self-sufficient existence within the community.
Objectives	▪ To reintegrate these individuals into society. ▪ To provide effective literacy training in both group and individualized settings. ▪ To advance students a minimum of two standardized literacy levels. ▪ To prepare students for employment.
Methods/Activities	Students are taught: ▪ Reading, writing and comprehension skills. ▪ Basic keyboarding and word processing. ▪ Job-hunting and resumé writing skills. ▪ Basic numeracy skills and budgeting. ▪ Better understanding of medical procedures and prescriptions. Method: ▪ Benchmark testing. ▪ Group and individualized teaching. ▪ "Cognitive Enrichment Advancement": a meta-strategic approach to learning to learn (used by Correctional Services Canada).
Source of Funding	Not available.
Population Served	Action ABC has literacy programs in Montreal at: ▪ Jewish General Hospital – Herzl Family Practice Centre. ▪ The Montreal General Hospital - Addiction Unit ▪ Douglas Hospital - Crossroads In Toronto: ▪ The Centre for Addiction and Mental Health Yearly, over 200 patients/students are served at Action ABC's four branch locations.
Evaluation	A report, published in 2000 and entitled *Observations in the Field: Literacy and Substance Abuse*, found that over 60% of students progressed two standard literacy levels, and that over 40% left the program employed. No student leaves the program without a resumé. Constant evaluation is the essence of the program, and the group keeps very close track of its students' future performance.
Annual Budget	Not available.
Structure	▪ 7 professional educators deliver client services at the locations listed above. ▪ The curriculum incorporates materials developed by major Canadian school boards, and educational software developed by AutoSkill International, Inc.
Contact	Lisa Lucas (Director) Tel. (514) 235-7440 Email: lisa.lucas@sympatico.ca

Literacy Training at the
Carlington Community & Health Services
Ottawa, Ontario

Start/End Date	The centre has been offering literacy classes for 10 years: the first four in a stand-alone community gymnasium, before moving the program to the Community & Health Services building.
Goals	Through its literacy and other programs, the CCHS seeks to promote the social, economic, physical, mental and environmental health of the community and its members.
Objectives	▪ To provide individualized literacy training to low literate members of the community, preparing them for employment and raising their self-esteem. ▪ To render such training in a supportive, convenient, and accessible manner.
Methods/Activities	A professional literacy trainer conducts full-morning classes, four days a week. ▪ Classes are multi-level, so students progress at their own level and pace. ▪ Students with health concerns and related information needs are easily referred to other departments of the Community & Health Services. Since the centre is located outside the immediate community, daily transportation and childcare services are provided as most cannot afford them.
Source of Funding	The Ottawa School Board pays the literacy trainer's salary. For many of the students, attending literacy classes qualifies them for childcare support under the Ontario Works program. Students have opted to pool these funds to finance the centre's childcare service. The centre fundraises to maintain the transportation service.
Population Served	The student population is always in flux, but there are approximately 15 adults enrolled in the course at any given time. The majority tend to be women, and most are unemployed with children.
Evaluation	Evaluation information to come.
Annual Budget	The transportation and childcare service runs on an average $3,000-$4,000 annually. The literacy trainer receives an average salary, commensurate with her hours, trainers' skills and responsibilities.
Structure	▪ One professional literacy trainer; ▪ Several volunteers who assist the trainer and students in the classroom; ▪ An average of 15 students – the classroom's capacity - enrolled at any given time; ▪ Two primary education students, who oversee child care; and the ▪ Bus driver, who makes 6 daily rounds of the community.
Contact	Anne Joyce (ABE Program Coordinator & Social Worker) Tel: (613) 722-4000 Email: ajoyce@carlington.ca.hc.org URL: http://www.uottawa.ca/associations/clinic/carlington_e.html

3.5 Upcoming Research

Health Literacy in Rural Nova Scotia
St Francis Xavier University
Antigonish, Nova Scotia

Start/End Date	April 2001 to March 2003
Goals	▪ To study the experiences of a rural Nova Scotia population in order to better understand the interface of literacy and health. ▪ To provide a basis for improving public policy and programs to enhance the capacity for health of less literate adults living in rural northeastern Nova Scotia.
Objectives	This research project will address the following questions: ▪ What are the factors that influence the ways less literate adults living in northeastern Nova Scotia access and act upon health information and services; and ▪ What strategies for change will build upon existing capacities for achieving health?
Methods/Activities	Using an ethnographic methodology, data will be collected from three different focus groups through: 1) interviews with less literate adults; 2) interviews with key informants; and 3) group interviews with health and literacy practitioners. Each interview will be structured using a four-stage process that will: 1) engage subjects in discussion regarding literacy and health issues based in their experience; 2) analyze the issues; 3) reflect on the meaning of their experiences; and, finally, 4) suggest ways of taking action.
Source of Funding	This project is being made possible through a "Strategic Research Grant," provided by the Valuing Literacy in Canada Program: a Strategic Joint Initiative of the Social Sciences and Humanities Research Council (SSHRC) and the National Literacy Secretariat.
Population Served	Residents of rural northeastern Nova Scotia are the intended subjects of this research. The Atlantic provinces have the highest low-literacy rates in Canada (Statistics Canada, 1996), and it is challenging to meet the needs of several culturally diverse groups living in this region of Nova Scotia. Participants in the partnership development workshops identified, for example, unique literacy and health issues that face people living in Mi'kmaq communities, in isolated rural Black communities, and in Acadian communities.
Evaluation	The extent to which the community-based organizations are successful in using the research to address programs and policies will be an indicator of the effectiveness of this collaborative research initiative.
Annual Budget	**Year 1** **Year 2** **Totals** $ 49,700.00 $47,700.00 Note: A $5,000.00 SSHRC-NLS Partnership Building Grant sponsored workshops in November 2000 to involve literacy and health practitioners, and adult learners in exploring the links between literacy and health in two countries in northeastern NS.
Structure	A multidisciplinary research team with expertise in adult literacy education, community health nursing and nutrition, is working in partnership with community members knowledgeable of local literacy and community health issues. The research team consists of: ▪ Doris Gillis, Assistant Professor in the Department of Human Nutrition (Principal Investigator); ▪ Allan Quigley, Professor and Chair of the Department of Adult Education (Co-investigator) ▪ Donna Gallant and Sharon Dublin, Assistant Professors in the Department of Nursing (Collaborators); and ▪ One experienced research assistant. The community-based partnership is composed of the following organizations: The Antigonish County Adult Learning Association, the Antigonish Town and County Community Health Board, Public Health Services of the Eastern Region, and the Richmond County Literacy Network.
Contact	Doris E. Gillis (Principal Investigator) Tel: (902) 867-5401 Fax: (902) 867-2389 Email: dgillis@stfx.ca

3.6 The Current Project

Towards the Creation of a Patient Education Centre **The Montreal General Hospital (McGill University Health Centre) and** **The Centre for Literacy of Québec** **Montreal, Quebec**	
Start/End Date	Groundwork for this project began in 1995, with a series of professional development workshops at the Montreal General Hospital. Phase 1 – the needs assessment project – was developed in 1999. Implementation of this phase began in 2000, and is expected to conclude in June 2001.
Goals	To create a Health Literacy Centre at the MGH (MUHC), in partnership with the Centre for Literacy of Quebec.
Objectives	▪ To provide effective, culturally appropriate support and resources for low-literate patients and their families/caregivers; ▪ To help health professionals develop skills, strategies and tools in order to communicate effectively with low-literate and other “hard-to-reach” patients; ▪ To gather and disseminate information and findings concerning health literacy.
Methods/Activities	An independent consultant, contracted by the Centre for Literacy: ▪ Conducted a review of past and current health literacy initiatives in Canada; ▪ Prepared a *Background Document on Health and Literacy*; ▪ Conducted interviews and focus groups with hard-to-reach patients, their families, support staff and health-care professionals at the MGH (MUHC); and ▪ Prepared a final report on the results of the Needs Assessment, including recommendations regarding three pilot Health Education Centres.
Source of Funding	Health Canada granted $30,000 to cover the costs of preliminary research and perform a patient needs assessment; and $2000 was fundraised by the Centre for Literacy to augment this amount.
Population Served	The proposed Health Literacy Centre would provide resources for low-literate, or otherwise “hard-to-reach” patients, and training for health professionals at MGH (MUHC).
Evaluation	Self-evaluation has been ongoing through a Steering Committee, and all activities have been closely monitored by the hospital’s Ethics Committee, and by an external evaluator.
Annual Budget	The proposed Health Literacy Centre's annual budget has yet to be determined
Structure	▪ One project director; ▪ One independent consultant/researcher; and ▪ A steering committee composed of various health professionals, literacy specialists, one patient advocate, a medical librarian, and an external evaluator.
Contact	Linda Shohet (Project Director/Director of the Centre for Literacy) Tel: (514) 931-8731, ext. 1415 Fax: (514) 931-5181 Email: literacycntr@dawsoncollege.qc.ca URL: http://www.nald.ca/litcent.htm

3.7 Background Initiatives

Professional Development Workshops at The Montreal General Hospital Montreal, Quebec	
Start/End Date	1997 – 1999
Goals	To promote awareness of, and educate health professionals about, the links between literacy and health.
Objectives	To provide health professionals with: ▪ Communication strategies for effective patient education. ▪ Tools for assessing patient education materials. ▪ Techniques for assessing patients' and their families' ability to access health education material. ▪ Information about past and current methods of patient education.
Methods/Activities	Workshops • Language, Communication & Health Care: A Practical Workshop – November 28, 1997; • Brown Bag Lunch Session: Can Patients Understand Our Instructions? – February 5, 1999; • Brown Bag Lunch Session: Health, Literacy and Community – November 19, 1999. Annual public displays of health and literacy information have coincided with International Literacy Day and/or National Nurses Week.
Source of Funding	The National Literacy Secretariat funded these activities through The Centre for Literacy of Quebec's Community Outreach Project. The Montreal General Hospital (MUHC) contributed in kind, providing the space and many valuable staff hours.
Population Served	Health professionals at the Montreal General Hospital, as well as public health educators, literacy teachers and program coordinators.
Evaluation	Workshop participants were asked to fill in evaluation forms following each workshop. Positive feedback from these workshops initiated the current project to establish a Health Literacy Centre at the Montreal General Hospital (MUHC).
Annual Budget	The Community Outreach Project receives approximately $1000 annually.
Structure	Workshops were coordinated by The Centre for Literacy of Quebec, in collaboration with Nursing Staff Development at the MGH.
Contact	Linda Shohet (Director of the Centre for Literacy) Tel: (514) 931-8731, ext. 1415 Fax: (514) 931-5181 Email: literacycntr@dawsoncollege.qc.ca URL: http://www.nald.ca/litcent.htm

Travelling Resource Trunk
Health, Communication, and Literacy
The Centre for Literacy of Quebec

Start/End Date	Spring 1998 – ongoing
Goals	To improve understanding and promote awareness among health care providers of low-literate patients' health information needs.
Objectives	To develop a health and literacy resource, for use in training environments and public health education organizations. To select and acquire: ▪ Sample consumer health education materials; ▪ Research articles; and ▪ Information about plain language.
Methods/Activities	▪ Several health and literacy organizations were contacted; ▪ Samples of health information and educational materials created by these organizations were requested; and ▪ Permission was asked to include these materials in the trunk. ▪ Upon receipt, resources were classified by type; and ▪ A plan was developed to publicize the new Travelling Resource Trunk on International Literacy Day.
Source of Funding	The National Literacy Secretariat.
Population Served	The Travelling Resource Trunk is available to health and literacy workers and professionals throughout Quebec and Canada.
Evaluation	Borrowers of the Health, Communication, and Literacy trunk are asked to evaluate its contents; and to describe how the resources were employed and to what benefit.
Annual Budget	The Centre's Health, Communication and Literacy Project spends an average of $1000 per year, and is part of the Centre's greater Community Outreach Project.
Structure	The resources were found and acquired by the Centre for Literacy's Resource Librarian, in consultation with the Montreal General Hospital's Nursing Library.
Contact	Claire Elliott (Resource Librarian) Tel: (514) 931-8731, ext. 1415 Fax: (514) 931-5181 Email: literacycntr@dawsoncollege.qc.ca URL: http://www.nald.ca/litcent.htm

Health, Communication, and Literacy: An annotated bibliography
The Centre for Literacy of Quebec
Montreal, Quebec

Start/End Date	The first edition of the bibliography was published in 1995, and the second in 1998.
Goals	To make the professional literature on health and literacy available in a single, annotated document.
Objectives	To identify and select relevant writings on health and literacy, including: research articles; consumer health education materials; assessment tools; information about plain language; and links to important Web sites. Topics covered include: Assessment, the Elderly, Empowerment, Maternal Child Health, Patient Education, and Plain Language.
Methods/Activities	A student enrolled in the Nursing Program at Dawson College was contracted to find the above resources; and was assisted in this by the Centre's Resource Librarian. The Centre's staff was responsible for formatting and publishing the final document.
Source of Funding	The research component of this project was funded by Canada Post; and additional money was fundraised (through such events as a Golf Day for Literacy) to cover the costs of publication.
Population Served	The bibliography was intended primarily as a research tool. Its resources, however, are equally invaluable to literacy teachers and tutors, as well as health care providers and educators.
Evaluation	Users of the bibliography (as of the Centre's many other resources) are asked to share any feedback with the Centre; and to describe how the resource was used, and to what benefit.
Annual Budget	Canada Post granted $700 to develop the bibliography.
Structure	▪ Project Director ▪ Nursing student from Dawson College ▪ The Centre for Literacy staff.
Contact	Claire Elliott (Resource Librarian) Tel: (514) 931-8731, ext. 1415 Fax: (514) 931-5181 Email: literacycntr@dawsoncollege.qc.ca URL: http://www.nald.ca/litcent.htm

Conclusion

As was explained in Section 1, the International Adult Literacy Survey (IALS) found that nearly half the population of adult Canadians has difficulty with reading materials encountered in everyday life. This has an important impact in the health sector as low-literate patients encounter information, material and procedures that are difficult or impossible to understand and apply. This can have a negative impact on their health, both directly and indirectly. Seniors in particular represent a high-risk group. To the large groups of low-literate patients, we add patients who face cultural and language barriers as well as patients who cannot process health information because of physical or cognitive disabilities. We group these patients under the term “hard-to-reach”, as it is more difficult to communicate with these patients.

The general response of the health care system has been to develop literacy tests to measure patient literacy, to assess the readability of health materials and to advocate the use of plain language in the production of health education materials. More effective oral communication has been advocated between patients and health care professionals. The focus in health education remains on individual lifestyles and behavioural changes that are dictated from the top down (Rusek, 1996 quoted in Hohn, 1998, p. 14). The literature offers limited information on the social implications of health literacy and on strategies devised for hard-to-reach patients. We critique the tendency to give prevalence to plain language as the key strategy to address health literacy issues. Community development approaches and participatory health education are potential avenues that broaden health literacy practices and move them beyond the current focus on written information.

The diversity of health literacy initiatives and approaches in Canada is impressive. But while exciting and often innovative, these initiatives remain relatively limited. They are, for the most part, isolated from each other and at times short-lived. There appears to be very few health literacy programs in Quebec and Atlantic Canada. There is no national umbrella organisation linking these initiatives and providing a forum for sharing and networking. There is no established source of funding that could enable the development of new and larger health literacy projects and programs. There are few hospital-based patient education programs in Canada, and even less that focus on the needs of hard-to-reach patients. But we know from our research that the lack of health literacy programs and the lack of appropriate patient education have a negative effect on the health of thousands of Canadians. Our project at the Montreal General Hospital (MUHC) appears to be breaking new ground. It attempts to look at the issue for a new perspective, that of hard to reach patients, and to answer an apparent gap in the practice of patient education. It is starting from the information and education needs of hard-to-reach patients in order to design appropriate and effective information and education programs for these patients and their families.

These following points, among others, help us define the focus of our Needs Assessment:

1. Plain language is a useful and important first step, but health literacy is much more than plain language. It is necessary to look at oral communication with health care workers and other alternative sources of health information.
2. Linking health education to community resources and initiatives outside the hospital and using participatory methodologies of learning are two important strategies to communicate with hard-to-reach patients and practice effective health literacy.

3. Hard-to-reach patients should (must?) have an important voice in the project, from expressing their needs during the Needs Assessment process to, later on, deciding aspects of the planned Health Literacy Centre. They must feel safe and secure when expressing their views, and feel that their voice is important and respected.
4. Critical health literacy takes time.
5. Health literacy practice in Canada is very diversified and there is no easily available compilation of current practices. We have not yet found an initiative that has a similar approach to our project.

Our Needs Assessment will look at patient needs in all spheres of health education: written information, oral communication with health care workers, health videos and other sources of health information. It will investigate how hard-to-reach patients learn best. It will give a voice to hard-to-reach patients, their families, support staff and health care workers. It will explore what health care workers know about health literacy and what are their most pressing training needs. It will reach out to health care workers outside the hospital. It will facilitate the discussion around the planned Health Literacy Centre, allowing for patients and others to express their preferences about the *what* (type of health information) and the *how* (teaching and learning process, learning tools, methodologies, etc.). Informants will be encouraged to imagine beyond what is common practice and formulate innovative ideas about the planned Centre.

There is a need for large-scale commitment to health literacy across Canada, with long-term funding and wide-ranging programming. Long-term partnerships need to be developed, linking the health and education sectors across the provinces. Large health institutions such as hospitals need to recognise the issue of health literacy and change the ways health information is provided in order to communicate more effectively with hard-to-reach patients. There appears to be a serious “gap” in the way health information and education is currently provided in the health system for a large group of patients. The Needs Assessment leading to the planned Health Literacy Centre at the Montreal General Hospital (MUHC) represents a very important step towards developing a model of patient education that can be replicated elsewhere in Canada and beyond.

APPENDICES

Appendix 1. Research by Sharon Brez

Brez's *Adult Learners' Perspectives on Screening Reading Ability for Patient Teaching* (1995) reports the findings of a study designed to investigate low-literate adult patients' reactions to literacy screening in hospital settings. As one of the first, and few, pieces of research to examine the needs and concerns of patients, Brez's study explores health education issues from a very unique perspective.

A qualitative, case-study design was employed for this study, and a sample of eight, English-speaking adults, enrolled in a college-based literacy program, was deliberately selected on the basis of recommendations made in the literature. Data was collected through semi-structured interviews, participant observation, and the administration of the REALM test in a simulated screening situation.

Participants' responses to interview questions, and the researcher's observation of patients' reactions to the REALM test, served to identify five major themes. These themes represented certain core issues of concern to the study's participants, and formed the basis for a conceptual model of the factors influencing patients' reactions to literacy screening. These were:

1. The risks of illiteracy exposure, and ways of minimizing exposure of low literacy skills.
2. The risks to health of non-disclosure during hospital stays/visits.
3. The perception of hospitals as "special" environments, where personal matters might be discussed, with an expectation of sensitivity and confidentiality.
4. The generally supportive responses of participants' towards the concept of literacy screening for patient teaching.
5. The mixed reactions of participants to literacy screening using the REALM tool.

The conceptual model derived from these themes was compared with other, established, decision-making frameworks, and found to correlate well with them. Brez's findings were also consistent with results anticipated by previous research in the field.

Based on her study's findings, Brez makes the following recommendations for future practice:

- Patients should be assured of privacy and confidentiality, and these assurances should be strictly respected.
- Patients should be clearly advised of the intended purpose of literacy screening.
- Literacy screening should only be administered by those trained in communication skills and building therapeutic relationships.
- Signs of diminished self-esteem – including changes in body language, tone of voice, and verbalization – should be closely monitored.
- Health care professionals should follow through on their responsibilities to provide appropriate/alternative learning opportunities.

Appendix 2. Research by Rob Sarginson

The study Literacy and health: A Manitoba perspective (1997) is an action research that explores health literacy issues in rural/northern areas populated by First Nations. Using data provided by the Manitoba Centre for Health Policy and Evaluation of the University of Manitoba, areas of Manitoba were compared according to health and the literacy levels of their residents. It was possible to draw these conclusions:

1. Instances of disease and epidemic increase markedly in areas in which the literacy rates are low.
2. Violent death is more prevalent in low-literate areas than elsewhere in Manitoba.
3. Hospital usage by children is highest in low-literate communities.

These conclusions apply most of all to the Thompson and Norman areas in northern Manitoba, where there is a large native population. According to Sarginson, overcrowding, poor quality housing, impure sources of water, uncertain hygienic procedures, and questionable infant and toddler nutrition combine to create a health time bomb on the reserves. There are direct links between these factors and the realities of poverty, youth unemployment and single parent female households. He predicts that health costs for reserve populations will explode in the near future without immediate intervention. He notes that the northern reality of long-distance medicine (rare face-to-face contacts between doctor and patients, patient consent forms administered orally, forms signed during emergencies, reliance upon written instructions in post-hospital recovery) amplifies the challenges faced by low-literate patients.

Sarginson strongly advocates the investment in literacy programming, and argues it is much cheaper than medical care, hospital stays, physician visits and transportation. He says that preventing just one AIDS case would save more money in one year than the cost of a dozen part-time literacy programs across the North. Furthermore, once adults can read well, they can acquire other marketable skills and training. He also recommends:

- using plain language in government publications;
- strengthening linkages between literacy programs and community health projects;
- re-instating the Rural Literacy coordinator; and
- maintaining long-term commitments to literacy.

Appendix 3. Definition of Terms

Literacy:

> It is the ability to understand and employ printed information in daily activities, at home, at work and in the community to achieve one's goals, and to develop one's knowledge and potential.

As defined in Appendix D of Health Canada. Health Promotion and Programs Branch. Policy Development and Coordination Division. Report of the August 1997 roundtable on literacy and health, December 1997, p. 16.

Functional literacy:

> The ability to use reading, writing, and computational skills at a level adequate to meet the needs of everyday situations.

From Williams, Mark V, Parker, Ruth M., Baker, David, and Nurss, J.R. Inadequate Functional Health Literacy Among Patients at Two Public Hospitals. In JAMA, December 6th, 1995.

Health literacy:

> The ability to use written materials to function in health care settings and to maintain one's health and the skills needed to advocate for and request needed clarification.

From Rudd, Rima E. and Moeykens, Barbara. Adult educators perceptions of health issues and topics in adult basic education programs. NCSALL (National Center for the Study of Adult Learning and Literacy) Report no.8, August 1999, p. 1.

Functional health literacy:

> Ability of patients to complete successfully basic reading and numeracy tasks required to function adequately in the health care setting (for example, read and understand prescription bottle labels, appointments slips, complete financial eligibility requirements).

From Williams, Mark V, Parker, Ruth M., Baker, David, and Nurss, J.R. Inadequate Functional Health Literacy Among Patients at Two Public Hospitals. In JAMA, December 6th, 1995.

or

> Ability to apply literacy skills to health-related materials such as prescriptions, appointment cards, medicine labels, and directions for home health care.

Taken from Nutbeam, Don. Literacies across the lifespan: Health literacy. Literacy and Numeracy Studies. Vol 9 No.2 1999.

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