

# **Retrospective Evaluation of the National Literacy and Health Program**

## ***Final Report***

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For the National Literacy and Health Research Project Team***

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# Retrospective Evaluation of the National Literacy and Health Program

## *Final Report*

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### **I. Background**

Literacy is an important determinant of health. Literacy also affects other factors that determine health such as income, access to jobs, education and social supports. Almost half of Canadians have low literacy skills, and these Canadians are more likely to have poor health than those with higher levels of literacy. They are more likely to be living with chronic diseases such as diabetes, heart disease and cancer. As well, they are more likely to have an early death.

Health literacy is a new concept that links our level of literacy with our ability to act upon health information and, ultimately, to take control of our health.

Canadian interest in literacy and health can be traced back to the mid 1980s. Key developments during that time included a series of large-scale surveys carried out by Southam News (1987), Statistics Canada (1992), and HRDC/Statistics Canada (1994 and 1997). The Ontario Public Health Association and Frontier College also jointly undertook pioneering research in the late 1980s and early 1990s in order to understand the links between the two areas.

In 1991, the Canadian Public Health Association (CPHA) approached the National Literacy Secretariat (NLS) with a proposal to raise awareness among health professionals about the link between literacy and health. In 1992, CPHA's *National Demonstration Project on Literacy and Health* received approval and ten national health associations were invited to participate. Based on the success of this early initiative, CPHA approached NLS with a proposal to build long-term, self-sustaining commitments to the literacy agenda among its national partners and extend the partnership to other national health associations. Funding for this proposal was approved, and in 1994, the *National Literacy and Health Program (NLHP)* was officially underway with 12 national partners.

## II. This Report

In January 2004, the Canadian Public Health Association and the National Literacy and Health Program Steering Committee commissioned Rick Wilson Consulting Inc. to conduct a retrospective evaluation of the *National Literacy and Health Program*. Ongoing direction, advice and support to this process are being provided by the National Literacy and Health Research Project Team.

The study was designed to answer the following questions:

- ▶ What is the National Literacy and Health Research Program?
- ▶ What are its principal goals and objectives, and how does it go about systematically contributing to these goals and objectives?
- ▶ What key activities have been undertaken and what key outputs have been produced over the past ten years of its existence?
- ▶ What have been the key documented impacts of these activities and outputs, individually and collectively?
- ▶ To what extent has the program succeeded in making progress towards its stated goals and objectives?
- ▶ What is the evidence base upon which these questions are being addressed, including gaps and limitations, if any?
- ▶ What are the major recommendations for the program itself in general, and for further research in particular, to answer the above questions?

### **III. Methodology**

In consultation with the National Literacy and Health Research Project Team and CPHA program staff, the following steps were undertaken:

- ▶ Development of an agreed upon evaluation plan and evaluation protocol, specifying key evaluation questions, indicators and data sources to be examined and/or developed as part of the evaluation. This evaluation protocol is included as Appendix A.
- ▶ Development of an agreed upon program “logic model” specifying key program components, activities, outputs, impacts and desired long-term outcomes.
- ▶ Data/information collection consistent with the requirements outlined above.
- ▶ Development of a draft report for comment and review by the National Literacy and Health Research Project Team and CPHA program staff.

#### **Data Sources**

This retrospective evaluation is informed primarily by three complementary sources of information/data collection: (1) interviews with project staff; (2) identification and review of key documents, and (3) a key informant survey.

The retrospective evaluation process began with the identification and review of key documents related to the last ten years of program implementation. CPHA program staff participated in the selection of relevant documents and the consultant reviewed the selected documents as background to this report. Additional reports and documents were collected and reviewed by the authors to supplement program records. These included early reports prepared by Frontier College, research reports, web sites, and conference proceedings. Partner web sites and documents provided during consultations were also reviewed. Additionally, attempts were made to retrieve funding proposals, and project reports and evaluations to the extent possible, as well as to identify all relevant outputs and products produced and disseminated over the lifetime of the program.

Ongoing liaison and interviews were carried out with program staff to identify and respond to information gaps, and to reconstruct, to the extent feasible, key factors and milestones in the evolution of the initiative.

Key informant interviews were held with 18 representatives from program partners and funder representatives as recommended by the National Literacy and Health Research Project Team. A copy of the interview protocol is included in Appendix B, and a list of key informants is provided in Appendix C.

Efforts were also made to identify secondary data sources that might help to address progress towards desired long-term outcomes. Regrettably, despite the fact that there has been a considerable recent upsurge in interest and research on determinants of health such as education and income, and in spite of the known powerful relationships between literacy and these

determinants, the research team was unable to identify any follow-up surveys to complement the baseline surveys on literacy and health mentioned earlier.

## **Limitations**

There are many important limitations to consider in carrying out a retrospective evaluation, particularly over a period of ten years, and this evaluation is no exception.

First, the program has been funded predominantly by a series of relatively short-term grants and contracts since its inception. In that regard, it has not been guided by a formal ten-year plan and accompanying global evaluation infrastructure, since reporting requirements have been predominantly short term and project specific. As well, given the reliance upon short-term funding, the program has evolved and needed to demonstrate considerable flexibility to respond to the evolving opportunities and priorities of funding agencies.

Consistent with the above, information collection and reporting on specific projects has been guided by the requirements of the funding agencies, which too have evolved over time. Collection of information on these projects has also been inhibited by the limited amount of funding dedicated to evaluation and to the development of evaluation capacities for the program.

Program implementation has varied over the years in the CPHA and partner organizations. *NLHP* start-up included a full-time coordinator position that was highly involved and effective in developing resources, partnerships and program profile. Reorganizations moved this position to a Director of National Programs and a dedicated project coordinator position was not maintained.

Staff turnover levels over a ten-year period are also significant. As a result, gaps in knowledge and information provided have occurred. Similarly, reviewing ten years of documentation has been a difficult process. Although hundreds of files have been reviewed in this study, gaps in files and information have been encountered. Many documents are simply no longer available.

Necessarily, there have been multiple changes in the external environment over the ten-year time frame, and these have had a deleterious impact on efforts to evaluate the program as well. These changes have had important implications not only for CPHA and the *NLHP*, but also for program partners. The *NLHP* was designed to work on the basis of “empowerment of intermediaries”. Partnerships were formed with major health professional organizations with program components such as training workshops, education and awareness resources delivered through their communication vehicles (i.e., newsletters, conferences) and services (e.g., plain language services offered to partners). The changing environment and reduced resources have led to cost-recovery requirements for many program services, and problems for partner organizations in justifying free newsletter inserts and other similar awareness programs.

Similarly, partner organizations have undergone multiple reorganizations over ten years and informants indicated a renewed emphasis on cost efficiencies, reduced budgets and so forth, impacting on the priority that could be given to this issue. Ongoing staff turnover in partner organizations has also inhibited the key informant segment of this evaluation. Informants range

from having one- to two-weeks' experience on the job, to others with many years of experience in the field of literacy and health.

Changes in the external environment also have implications for the question of attribution. Although this evaluation has been able to document many impressive program accomplishments, and to a lesser degree some important changes in the orientation of partner organizations and in the field of literacy and health, direct attribution of these changes to the *NLHP* itself remains problematic as many other factors may have played a part.

Finally, the evaluation has been constrained by limitations in the resources available to develop new information sources to address important gaps in the information base. For example, while it might have been desirable to carry out a survey (or set of surveys) of health professionals to document changes over time, the resources to do so simply have not been available to the program. As such, the evaluation has relied predominantly on existing information, secondary data (of which there is a paucity) and limited key informant surveys.

Despite these important limitations, evaluation of the ten-year experience of the *NLHP* remains a worthwhile undertaking. Important questions like: what has the *NLHP* produced and accomplished to date, what are the major gaps in our knowledge and where should the program go in the future must be informed by the best information available — as well as a consideration of its limitations. In that regard, documentation of existing information about the program, as well as the limitations to that information both are integral to creating a stronger program and to overcoming these limitations in the future.

## IV. The National Literacy and Health Program: An Overview

From relatively modest and circumscribed beginnings, supplemented by an ongoing series of funded projects, the *NLHP* has evolved into a relatively comprehensive program. The *current* logic model for the *NLHP* is shown as Figure 1 on page 10. It is this logic model which informs our description of the program, as well as the reporting of evaluation results. It is important to note that the program, particularly in its early stages, was not guided by such a formal model, and that the current model reflects the evolution of the program over the ten-year period. Certain aspects of the program, such as the development of national literacy and health program partnerships have existed since the inception of the program, while emphasis on several other elements has been somewhat more recent. Some milestones in literacy and health in Canada are illustrated in Figure 2 on page 11.

### **Funding**

We have not been able to reconstruct a funding and expenditure profile for this initiative based on existing information.

### **Goals**

The *goals* of the *NLHP* include *contributing to* the following valued long-term outcomes:

- Raising awareness among health professionals about the links between literacy and health;
- Building commitment to literacy as a critical determinant of health; and
- Establishing literacy partnerships within and outside of the health field.

Consistent with the problems associated with attempts at direct attribution discussed earlier, the objective of this report is to assess whether and/or the extent to which activities undertaken by the *NLHP* have contributed toward these objectives.

The *NLHP* approaches these objectives predominantly via an “empowerment of intermediaries” programming model through building and nurturing partnerships, and equipping them through resource development and dissemination, promotion (e.g., conferences; newsletters), and responding to information requests and projects.

The *NLHP* consists of five interrelated components: (1) development of literacy and health partnerships; (2) projects; (3) health professional education; (4) provision of services; and (5) research, policy and advocacy. Because the program components are interrelated, many projects, activities and outputs contribute to more than one of these components. Nevertheless, the major activities, outputs and intended impacts of each of these streams are summarized briefly below.

### **1. Development of Literacy and Health Partnerships:**

The major *intended impacts* of this component include: the development of strong and committed partnerships; and increased collaboration and coordination of literacy and health initiatives. *Key activities* include promoting links between literacy and health; promoting plain language and clear verbal communication; and identifying health communication projects and initiatives through the development and use of health resources, published articles, workshops and project participation.

## **2. Projects:**

The *NLHP* carries out a broad array of projects that contribute to each of the aforementioned components, as well as special projects on new or emerging issues related to literacy and health. These are discussed separately in the next section of this report.

## **3. Health Professional Education:**

The major *intended impacts* of this component include increasing awareness of literacy and health; improved verbal and print communication; improved adherence to health instruction and reduced safety risks. This is approached through the development and dissemination of *outputs* such as presentations, resources, conferences and workshops.

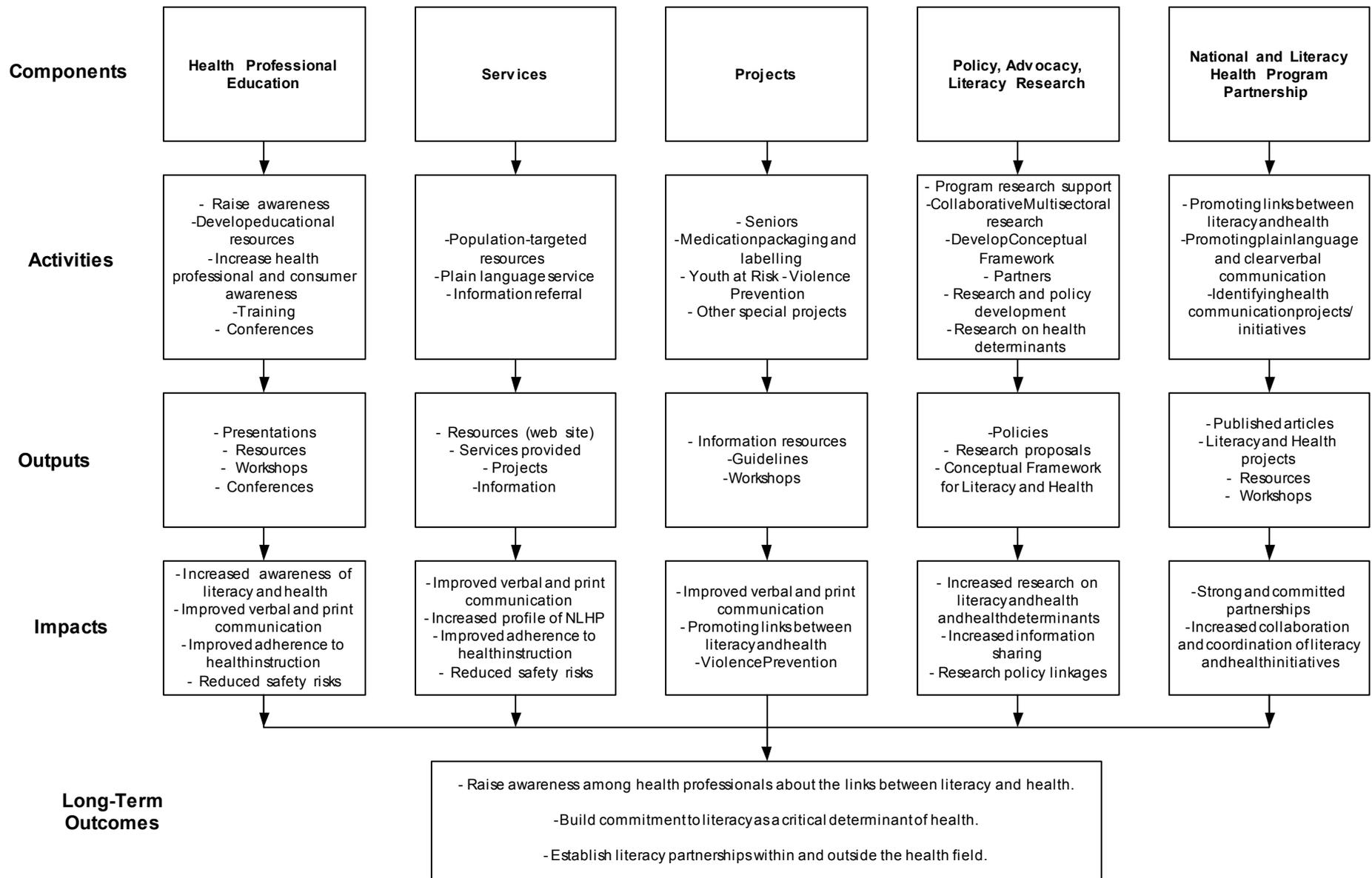
## **4. Services:**

The *NLHP* develops and disseminates a range of services, including population targeted resources, a plain language service, and an information referral service, as well as a web site. The *intended impacts* of this component include improved verbal and print communication; improved adherence to health instruction and reduced safety risks, as well as increasing the profile of the *NLHP*.

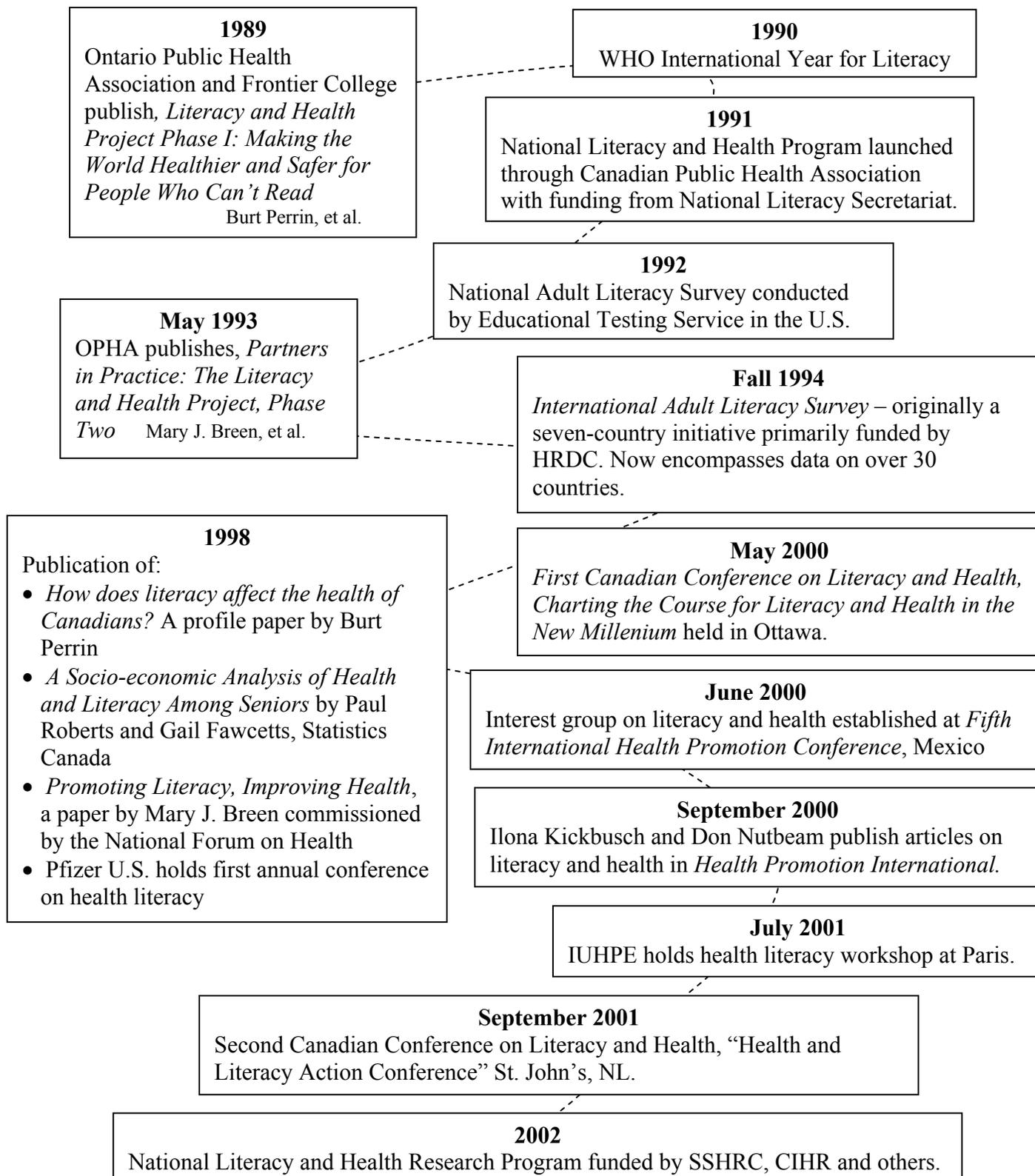
## **5. Policy, Advocacy and Literacy Research:**

The *intended impacts* of this component relate to promoting increased research on literacy and health and health determinants; increased information sharing and increased research-policy linkages. This is accomplished through conceptual frameworks, research proposals and policies related to literacy and health.

# Figure 1: National Literacy and Health Program Logic Model



## Figure 2: Milestones in Canadian Literacy and Health Research and Practice



## **V. The National Literacy and Health Program: Key Activities, Outputs and Accomplishments — 1994 to 2004**

In this section, we review some of the major activities, outputs and accomplishments of the *NLHP* over the past ten years. During the early years of the initiative, considerable effort was devoted to developing and nurturing partnerships and creating awareness. More recently, the efforts appear to have shifted toward carrying out specific projects in collaboration with partners. Although we summarize these findings on a component-by-component basis, it must be emphasized that many of these activities are incorporated into *projects* that span a number of the component areas.

### **1. Development of Literacy and Health Partnerships:**

The initial *NLHP* began with ten partner organizations (*Demonstration Phase*, 1992), expanded to 12 partner organizations in 1994, and now involves the following twenty-five organizations:

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

Partnerships are at the core of the success of the *NLHP*. Partner organizations contribute to the success of the initiative in the following ways:

- ▶ Raising awareness of the issue of literacy and health within their own organizations;
- ▶ Raising awareness of the issue among members of their organizations; (through secondary distribution of resources, materials and services);
- ▶ Participation in steering committees and advisory committees;
- ▶ Participation in projects as partners, reviewers, workshop participants, and as links to the broader public health community;
- ▶ Primary and secondary (linkage to memberships) consumers of resources and services produced under the *NLHP*;
- ▶ Policy development, advocacy and research.

Unfortunately, no formal records have been kept of partnership activities. Nevertheless, through a process of file review and interviews with project staff and key informants, a number of examples have emerged of the types of benefits of this collaboration. These are discussed in subsequent sections of the report.

Similarly, to the best of our knowledge, there has been no formal partnership evaluation undertaken over the ten-year course of the *NLHP*. This is problematic since it would be useful to know such things as:

- Is this the optimal mix of partners?
- Why do some organizations join the *NLHP* and others not?
- What can be done to enhance the effectiveness and the efficiency of the partnership?

## 2. **Projects:**

A wide and impressive array of projects has been undertaken by the *NLHP* in collaboration with partner organizations. Since many of these projects span several of the other program components, they are summarized briefly here, together with information regarding evaluations. In most cases, evaluations were “process only” with partner organizations involved in reviewing/evaluating materials and participating in/evaluating workshops. Information on recent distribution statistics (excluding downloads) is provided as well. However, it is important to note that this excludes “secondary distribution” via partner organizations through their memberships.

- ▶ ***Easy Does It! A Health Communication Training Package:*** A package/resource developed to help health professionals and providers serve clients with low literacy skills more effectively. The resource kit included three components: (1) a training manual, (2) a video entitled “*Face to Face*”, and (3) a CD-ROM game entitled, *Plain Word*. It was developed over two years and offers an introductory section that establishes the links between literacy and health, provides effective communication tools, and discusses professional liability issues such as informed consent.

**Dissemination:** All *NLHP* partners committed to promoting the resource through ads and articles in their communications with members, as well as at conferences. The program prepared an article, ads and poster sessions for use by partners, and the article was also published in *Health Promotion in Canada*. The program distributed complimentary copies to 130 health professionals, associations, voluntary organizations and literacy

groups. In addition, over 4,000 order forms were sent to health professional associations, health units, health departments and Medical Officers of Health.

**Dissemination:** 1999 to present: 347 English; 30 French  
Plain Word Game: 302 (? English only)  
CD- ROM: 135 (? English only)

**Evaluation:** Process only. “The components of *Easy Does It* were reviewed by a number of the partners in the *NLHP*. The reviews were overwhelmingly positive.”

- ▶ ***Working with Low literacy Seniors: Practical Strategies for Health Providers:*** A complementary package to the above resource, this guide focuses on the needs of low literacy seniors within the health system. It provides communication techniques which help health providers serve this target group.

**Dissemination:** 1999 to present: 211 English; 34 French

**Evaluation:** Process only. No data available.

- ▶ ***Creating Plain Language Forms for Seniors:*** The *NLHP* has worked with seniors, banks, insurance companies and health sector organizations to revise forms that are typically filled out by older adults into plain language.

**Dissemination:** 1999 to present: 362 English; 34 French

**Evaluation:** Process only. No data available.

- ▶ ***Plain Language Service:*** The goal of this project was to develop national and health focused plain language services within the CPHA and the *NLHP* by providing a plain language assessment or revision for health-related materials; providing plain language workshops to train health professionals in plain language and verbal communications techniques, and developing a directory of plain language health resources available in Canada and the United States for use by health providers (*Directory of Plain Language Health Resources*).

**Dissemination** (Plain Language Services): “Between November 1997 and October 2000, 105 health-related organizations contracted with CPHA’s Plain Language Service (PLS) to have a total of 195 documents assessed or revised into plain language. The true success of this service is evidenced by the continuation of the PLS into its fourth year based on revenue generated from year three.”

**Dissemination:** 1999 to present: unknown

**Dissemination:** *Directory* - 1999 to present: 148 English; 17 French

**Evaluation:** Process only. “The success of the PLS was reviewed in three different ways: review of operations; volume; and unsolicited comments.”

- ▶ **Medication Package and Labelling:** This was a two-year project to enhance seniors’ independence and well-being with partners in the public, not-for-profit and private sectors. The project created guidelines and recommendations on designs for patient information materials. The project involved consultations and focus groups with seniors and pharmacists, Guidelines were produced, and a symposium was held with 23 delegates participating. The project resulted in 400 copies being produced and the guidelines being incorporated in the *Canadian Drug Regulatory Framework*.

**Dissemination:** 1999 to present: 17 English; 0 French

**Evaluation:** Process only. No data available.

- ▶ **Youth at Risk - What the Health:** The goal of this project was to provide a health curriculum that could be used by literacy workers. Conducted in partnership with Frontier College, workshops were held with youth in five cities across Canada and a resource was developed to improve youth health literacy in many settings where young people gather. The workshops involved over 150 youth across the country and resulted in a unique literacy and health resource that increased awareness for health professionals, literacy practitioners, youth workers and educators. The resource package contains stories, discussion questions, activities and information on a number of topics such as prejudice, drug abuse and self-esteem. The project involved consultations with youth in the identification of topics and the development of content.

**Dissemination:** 2,000 English and 500 French copies of the *What the Health* resource package were distributed to 1,300 community centres, CLSCs, school boards, literacy groups and youth programs across Canada.

**Dissemination:** 1999 to present: 142 English; 98 French

**Evaluation:** Process only. “The workshops with youth provided an opportunity for participant feedback...selected sections of the document were reviewed and were also focus-tested with youth. And, eight evaluations were also received on the English resource.”

- ▶ **M.O.V.E.: Mind Over Violence Everywhere:** This project was designed to increase awareness and understanding on how violence affects health among youth between 16 and 24 years with low literacy skills. The project involved both youth and those who provide youth services in developing and disseminating (via workshops) creative materials on safety and violence prevention.

**Dissemination:** Unknown

**Evaluation:** Process only. “The learning materials were focus-tested with youth... input was obtained from literacy workers...and evaluation forms were distributed to Advisory Committee members requesting their feedback on the process.”

- ▶ ***Charting the Course for Literacy and Health in the New Millennium:*** This project involved the *First National Conference on Literacy and Health*, and a resource (proceedings) document to serve as an information resource on literacy and health in Canada.

**Dissemination:** Unknown

**Evaluation:** Unknown

- ▶ ***National Literacy and Health Research Program: Needs Assessment and Environmental Scan:*** The objectives of this study were to identify: (1) gaps in knowledge in literacy and health research in Canada, (2) current and proposed initiatives in literacy and health in Canada, and (3) resources and opportunities for research in literacy and health. This study also produced an inventory of researchers across Canada interested in literacy and health, an inventory of Canadian publications on the topic, and a revised conceptual framework.

**Dissemination:** Unknown

**Evaluation:** Unknown

These projects provide the substantive base for the products and services that have been produced and disseminated under the *NLHP*. The program provides these products and services as resources to promote awareness of the links between literacy and health, and to help health professionals serve clients with low literacy skills more effectively.

### **3. Health Professional Education:**

Although no comprehensive listing of partner activities exists in this area, it is clear from file reviews and related documentation that all partner organizations have participated to varying degrees in raising awareness of the issue of literacy and health and educating health professionals about the issue. The majority of organizations have included exhibits and/or presentations at their national conferences, include literacy and health information on their web sites, and include links to the CPHA Literacy and Health Program site.

The following describes some highlights of processes and activities undertaken by partners over the last ten years:

- The Canadian Medical Association has acted as a sponsor for two conferences, held plain language workshops and participated on the Advisory Committee for the *First National Conference on Literacy and Health*.
- The Canadian Nursing Association has included literacy materials in its newsletters and other communication vehicles, and also provided a half-page article on literacy and health in their school package.
- The Canadian Pharmaceutical Association's 1995 *Pharmacy Awareness Week* featured a clear verbal communication 'tips' kit in their promotional booklet.
- The Canadian Dental Assistants' Association included inserts in their journals on a regular basis, as well as e-mail notices to members.
- The Canadian Optometrists Association held a *Vision Awareness Week* and developed a specific literacy-related initiative that included free eye exams for low literacy children. Free eyewear was provided to 15,000 low literacy learners.
- The Canadian Association of Obstetricians and Gynecologists has placed *NLHP* ads in its electronic newsletter.
- The Canadian Psychiatric Association included articles on literacy and health in their journal and newsletters.
- The Canadian Association of Occupational Therapists, in addition to developing a position statement on the issue, has also included literacy presentations in their national conference, and incorporated literacy ads and articles in their student newsletters and e-mail bulletins to members.
- The Canadian Physiotherapy Association has been involved in supporting *NLHP* conference organization, has developed a position statement on the determinants of health that includes literacy, and has attended international conferences, meetings and events as a representative of the *NLHP*.
- The Canadian Pediatric Society has held workshops on Plain Language.
- The VON has included program links and references on their web site and has distributed *NLHP* booklets and resources to its members.

In addition, a review of the projects described earlier demonstrates that *NLHP* partners have been actively involved in contributing to the professional integrity of products and services produced under the auspices of the *NLHP* and as primary and secondary distribution nodes for these products and services.

That being said, to the best of our knowledge no systematic evaluation has been carried out on the desired impacts of these activities, specifically: increased awareness among health

professionals of the issue of literacy and health; improved verbal and print communication; and improved adherence to health instruction.

#### **4. Services:**

The *NLHP* has produced an abundance of resources and provided a Plain Language Service to support literacy and health. In partnership with health organizations, the program has provided information and mechanisms to support literacy and health services. As noted in the recent *Literacy and Health Environmental Scan and Needs Assessment Report*, “The most widespread work related to literacy and health has probably resulted from a new emphasis on ‘plain’ or ‘clear’ writing considerations in the development of health education materials. CPHA’s encouragement of this work through various publications (e.g., *Easy Does It!*; *Working with Low Literacy Seniors*; *Creating Plain Language Forms for Seniors*) and through their work in establishing and maintaining 27 national partner organizations, can be credited for much of the ‘flurry of activity’ in this area over the past decade.”

Central to activities in this area is the Plain Language Service offered through CPHA. The program focuses on promoting health information in plain language and clear verbal communication between health professionals and the clients they serve. The service was used by 105 organizations for 195 documents between 1997 and October 2000. The service was marketed and promoted to national voluntary organizations and health and social service organizations. In addition, information letters/packages have been sent to a variety of health-related organizations and private sector companies. Plain Language Workshops were held at CPHA National Conferences, as well as the May 2000 *National Literacy and Health Conference*. The project produced a *Directory of Plain Language Health Resources in Canada and the United States*.

Service volumes resulted in financial self-sufficiency being attained in Year 4 of the project and the need to sub-contract work to meet demands. Unfortunately, no utilization data are available for the Plain Language Services pursuant to its move to a cost-recovery format. Also, despite the availability of a client list, there have been no systematic evaluations of the perceived or the actual cost effectiveness of the service in its present form.

#### **5. Policy, Advocacy and Research:**

In the earlier stages of the *NLHP*, advocacy and policy development activities appear to have focussed on creating awareness of the issue of literacy and health within partner organizations, and on advocating for organizational policies and activities that reflected the importance of this issue. There are a number of examples of such activities:

- The Canadian Association of Occupational Therapists has developed a position statement on Literacy and Health that was approved by their organization and posted on their web site.
- The Canadian Physiotherapy Association has developed a position statement on the determinants of health that includes literacy.

Regrettably, there have been no systematic surveys of the policies of member organizations related to literacy and health.

Similarly, although research has been carried out within the *NLHP*, it has been focussed predominantly on development and testing (and to a lesser degree, evaluation) of resources and services.

More recently, however, there has been a strong upsurge in activities in these areas, as reflected in four specific initiatives.

- ▶ ***The First Canadian Conference on Literacy and Health:*** This groundbreaking national conference was held in May 2000, and involved a diverse array of stakeholders including: health professionals, government representatives, researchers and academics, literacy providers, health administrators, policy makers, representatives of pharmaceutical companies, and adult learners. The conference focussed upon five broad themes:
  - Making health services and health information easy to use for all Canadians;
  - Looking for ways to improve the training of health professionals;
  - Learning more through research;
  - Learning from learners; and
  - Building literacy and health partnerships.

The conference proceedings, *The Captain's Log: Charting the Course for Literacy and Health in the New Millennium*, provides an important national input to deliberations related to policy, research and advocacy in this area.

- ▶ ***National Literacy and Health Research Program Needs Assessment and Environmental Scan:*** In April 2002, a group of researchers led by Dr. Irving Rootman was funded for three years by the Social Sciences and Humanities Research Council to develop a national program of research in literacy and health for Canada in partnership with CPHA. Among other things, they proposed to: establish an advisory committee; conduct an environmental scan and needs assessment; organize a think tank and workshop; submit research proposals; develop a web site and electronic newsletter; evaluate the *NLHP* and their own efforts to establish a research agenda; and develop a plan for sustaining the research program over the long term.

The objectives of the environmental scan were:

- To identify gaps in knowledge in literacy and health research in Canada;
- To identify current and proposed initiatives in literacy and health in Canada;
- To identify resources and opportunities for research in literacy and health in Canada.

Forty practitioners, researchers and policy makers involved in literacy and health were interviewed by telephone or face-to-face, and eight were surveyed by e-mail. Four follow-up focus groups were held at different locations across the country and a national workshop was held to consider the findings and to finalize a national research agenda.

The needs assessment concluded that, “Canada has an abundance of literacy and health projects, but relatively little research...There are pockets of very promising work being done across the country, but huge gaps in between with very little knowledge of what is being done elsewhere and what works best.” The report provides much of the foundation for building a national research agenda relating to literacy and health.

- ▶ ***Retrospective Evaluation of the National Literacy and Health Program:*** The *NLHP* is clearly the largest program related to literacy and health in Canada. As such, an evaluation of its activities, accomplishments, impacts and limitations constitutes another important contribution toward the development of a national agenda for research and practice in Canada.
  
- ▶ ***Second Canadian Conference on Literacy and Health: Staying the Course: Literacy and Health in the First Decade.*** This conference, scheduled for October 2004, will provide a national forum to discuss what is being done to improve the health of Canadians with low literacy skills and identify what needs to be done to build:
  - A stronger social foundation where Canadians are literate, healthy, and able to reach their full potential in our new economy;
  - A healthier population with fewer people living with avoidable diseases;
  - A more sustainable health system where all Canadians can access services and receive quality care that is sensitive to language and culture;
  - A culture of life-long learning where children arrive at school ready to learn and where youth and adults can access education and training.

This conference builds upon the *First National Conference on Literacy and Health* by offering opportunities to build new partnerships in literacy and health; share knowledge, skills and practical tools; and identify future actions for all participants in practice, policy and research.

## VI. The National Literacy and Health Program: Key Impacts and Outcomes — 1994 - 2004

The *goals* of the *NLHP* include *contributing to* the following valued long-term outcomes:

1. Establishing literacy partnerships within and outside of the health field.
2. Raising awareness among health professionals about the links between literacy and health;
3. Building commitment to literacy as a critical determinant of health.

In this section, we look at progress toward these goals through a combination of aspects of the information reported earlier supplemented by key informant survey results. As well, we report suggestions made by key informants regarding future directions for the *NLHP*. In that regard, it should be emphasized at the outset that there are some important caveats governing the information reported in the key informant surveys. In particular, many of the key informants were relatively new to the field of literacy and health. While they could comment on the current situation within their organizations, they felt constrained in commenting about the situation of partner organizations, and especially about attributing changes to the *NLHP* itself.

### **1. Establishing literacy partnerships within and outside the health field:**

In previous sections, it was noted that the *NLHP* has succeeded in establishing partnerships among 25 organizations. There is also evidence (albeit not fully systematic) that partners have actively contributed to the *NLHP* in a number of important ways, including but not limited to the following:

- Participation in steering committees and advisory committees;
- Participation in projects as partners, reviewers, workshop participants, and as links to the broader public health community;
- Primary and secondary (linkage to memberships) consumers of resources and services produced under the *NLHP*;
- Policy development, advocacy and research.
- Raising awareness of the issue of literacy and health within their own organizations; (see next section)
- Raising awareness of the issue among members of their organizations; through secondary distribution of resources, materials and services (see next section).

Unfortunately, to the best of our knowledge, there has been no formal partnership evaluation undertaken over the ten-year course of the *NLHP*. This is problematic since it would be useful to know such things as:

- Is this the optimal mix of partners?
- Why do some organizations join the *NLHP* and others not?
- What can be done to enhance the effectiveness and the efficiency of the partnerships?

Moreover, during the course of the key informant surveys, several partners commented on changes in their internal and external environment that are impacting upon the nature and extent of their involvement in such partnerships. Free space in publications cannot readily be assumed; payment for plain language services has become more difficult; maintenance of internal capacities are under more pressure; partners are being asked for more rationale of what benefits they receive from the *NLHP* partnership and are looking for renewed direction and focus.

## **2. Raising awareness among health professionals about the links between literacy and health:**

There is evidence from the key informant surveys of increased awareness of the links between literacy and health among partner organizations. Fifteen of the 18 respondents “strongly or somewhat agreed” with the statement that, “as an organization we have increased our knowledge and awareness of literacy as a critical determinant of health”. No respondents disagreed with this statement, although three chose not to respond to the question.

Similarly, 14 of 18 respondents “strongly or somewhat agreed” with the statement that, “as an organization we have increased our knowledge about what services, resources, programs and policies can be developed in relation to literacy and health” — with four choosing not to respond to the question.

Although respondents were understandably reluctant to attribute these changes directly to the *NLHP*, there is evidence that the *NLHP* did make a contribution to increased awareness, although the magnitude of this contribution is impossible to ascertain.

When asked “What would you say is the single most important contribution of the Literacy and Health Initiative to changes in this area?”, respondents repeatedly cited increased awareness:

- “Health care professionals’ awareness of literacy issues and their responsibility to provide clear communication and respect patient rights in that area.”
- “Raising awareness amongst health care professionals has been the major contribution of the *NLHP*. No other mechanism exists and no one would be talking about literacy and health without the program.”
- “Increased awareness of literacy and health among health professionals and the public.”
- “*NLHP* did raise awareness of literacy as a determinant of health.”
- “Resource tools and information have been useful.”

- “Providing information to organizations ensuring the importance of clear and precise language to communicate with patients.”
- “CPHA has taken a leadership position on this issue which was needed or the issue would have fallen by the wayside.”
- “The *NLHP* put the issue on the radar screen and provided an interface between the professional organizations and the CPHA.”

### **3. Building commitment to literacy as a critical determinant of health:**

There is substantive evidence from the key informant surveys of an increased commitment to literacy as a determinant of health among partner organizations. Thirteen of the 18 “strongly or somewhat agreed” with the statement that, “as an organization we have increased our commitment to literacy as a critical determinant of health”. One respondent strongly disagreed with this statement, while four others chose not to respond to the question.

Similarly, 13 of the key informants “strongly or somewhat agreed” with the statement, “as an organization, we have increased our capacity to address issues related to literacy and health”, while five others chose not to respond to the question.

#### ***Directions for the Future:***

Informants offered a wide range of suggestions for the future direction of the program in response to the question, “What do consider to be the most important things that must be done to build upon this initiative?”. These included:

- “The program could be ‘widened’ to include learners, moving beyond just health care workers to ensure patient rights.”
- “Need a program leader, identifiable contact point and champion to keep profile.”
- “Need to evaluate their services especially in Plain Language Program.”
- “Need to revisit partnership from perspective of both sides — what do partners get out of national network and what does the network get out of partners?”
- “Need an improved link between the colleges, universities and the *NLHP* to create more awareness among students and integration with curriculums.”
- “Need to increase program profile and find ways to develop a more creative role for the network.”
- “Improve, update and inform partners of all literacy and health resources available.”
- “Need clearly set goals on how each partner can contribute.”

- “Renew focus on immigrant/cultural groups as a primary catalyst for literacy and health.”
- “More health professionals are aware of literacy as a determinant of health. What do they do about it? What is the applicability to health professionals?”

## **Conclusions**

Research conducted for this study has led to the following conclusions:

- ▶ The program has made significant accomplishments in establishing partnerships and using those partnerships to increase the awareness among health professionals of the links between literacy and health.
- ▶ The program has produced useful resources and services to facilitate increased health professional awareness of the links between literacy and health.
- ▶ The program has identified literacy as a determinant of health.
- ▶ More research is needed to identify the following:
  - Actual awareness levels and practices for health professionals in literacy and health.
  - Identification of Best Practices in literacy and health.
  - Effective literacy and health policies.

## **Recommendations:**

- ▶ The national *Literacy and Health Research Program Needs Assessment and Environmental Scan* offered a series of research-related recommendations. These are important to the continued development of the program and their implementation is supported by this study.
- ▶ The program should undertake a systematic strategic review and forward planning exercise involving all the partners. The NLHP should focus in the near future on the establishment of a planning framework and strategic goals to support a renewed role in policy and research. At the same time, the program should revisit its past goals in the context of this report and any new research related to health professional awareness and practices.
- ▶ A systematic prospective evaluation of the National Literacy and Health program should be undertaken if the program is continuing.
- ▶ The *NLHP* partnership has proven to be a valuable mechanism for the development and dissemination of literacy and health resources and information. It should continue, but needs renewed direction to:
  - Continue dissemination of literacy and health information to health professionals and literacy workers.
  - To support development and implementation of literacy and health policy initiatives by governments, professional organizations, voluntary associations and the private sector.

- To support research initiatives by providing a mechanism to contact/survey health professionals and literacy workers.
- The *NLHP* needs to plan for improved services/programs to integrate literacy and health concerns with college and university programs for health professionals. New mechanisms and goals should be developed in collaboration with ongoing research. Literacy and health needs have moved from awareness to implementation based on sound research evidence.

## **Appendix A**

### **Evaluation Protocol**

**National Literacy and Health Program**

**Evaluation Protocol**

**June 9, 2003**

*Draft for Discussion*

## Introduction

This document describes the development of a protocol to conduct a *retrospective evaluation* of the National Literacy and Health Program. The protocol includes the following elements:

- A logic model of the program
- Questions to be answered by the evaluation
- A recommended research design
- Data collection instruments and procedures

The protocol has been developed by RW Consulting in consultation with the Investigators for the National Literacy and Health Research Project and the Evaluation Committee of the National Literacy and Health Program.

## Background

The Canadian Public Health Association's (CPHA's) National Literacy and Health Program (NLHP) promotes awareness among health professionals of the links between literacy and health. People with low literacy skills may not understand what health professionals tell them. They may not be able to read health information. Some may not use health services, except in an emergency.

CPHA's National Literacy and Health Program provides resources to help health professionals serve clients with low literacy skills more effectively. The program focuses on health information in plain language and clear verbal communication between health professionals and the clients they serve. The National Literacy and Health Program has been in existence for ten years, and works with twenty-seven national health association partners to raise awareness about literacy and health.

The National Literacy and Health Program projects included:

- *Charting the Course for Literacy and Healthy in the New Millennium: The First Canadian Conference on Literacy and Health.*  
This event took place in May 2000, and the conference report is now available.
- *Medication Packaging and Labelling* is a project to develop a set of Guidelines on using plain language and good design in prescription medication packaging and labelling.
- *M.O.V.E.* (Mind Over Violence Everywhere)
- *Canadian Literacy and Health Research Program*

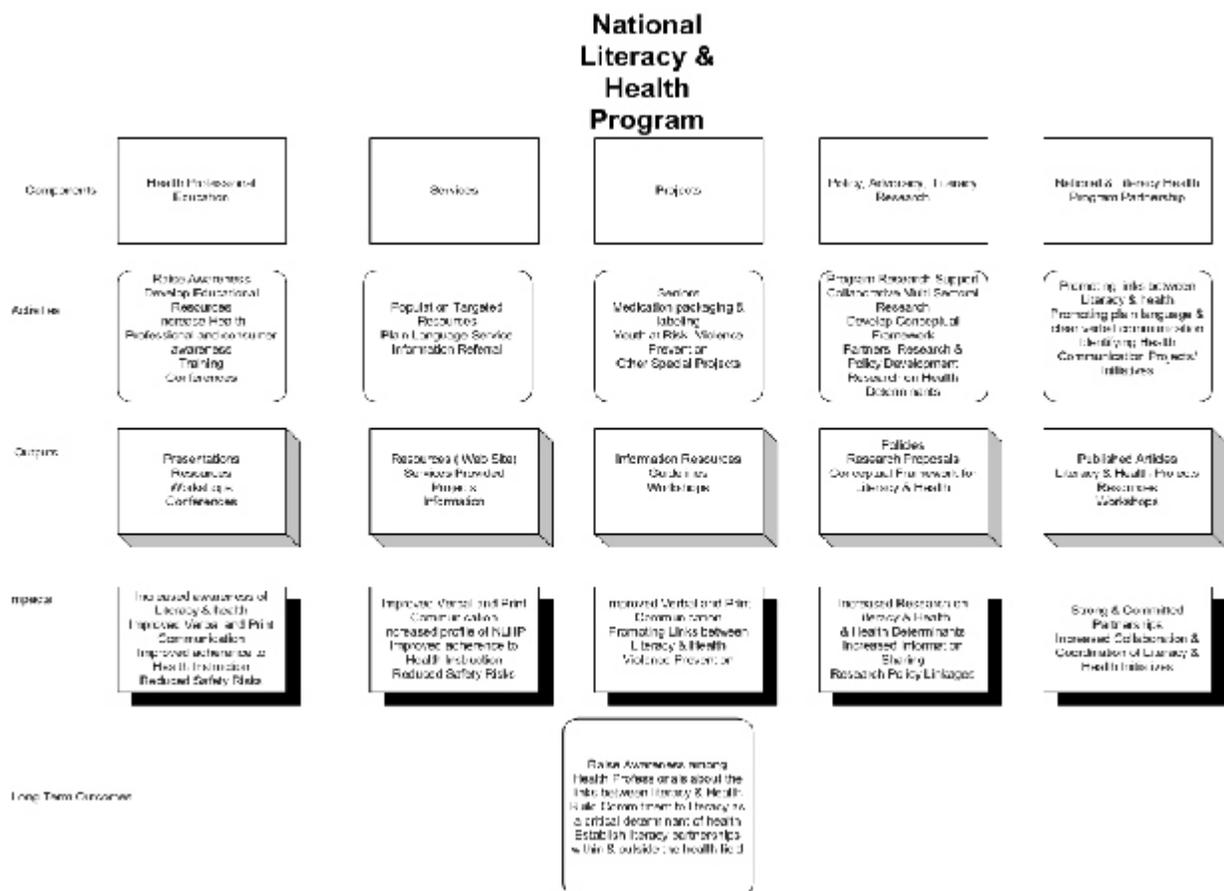
The following publications have been developed by the National Literacy and Health Program:

- *Easy Does It!* – A training package for health care professionals, providing information, tips and techniques to improve the way they communicate with their patients. The complete

package includes a manual, a training video (Face to Face) and a game on CD-ROM, (plain•word)<sup>TM</sup>.

- *Working with Low-literacy Seniors* – Focuses specifically on the senior segment of the population, giving practical strategies for health providers serving these Canadians, and a bibliography of resources.
- *Creating Plain Language Forms for Seniors* – A guide for the public, private and not-for-profit sectors on the design and plain-language wording of forms intended to be used or completed by seniors.
- *What the Health!* – A literacy curriculum for youth containing stories, exercises and information to help them take action towards a healthy lifestyle.
- *Captain's Log: Charting the Course for Literacy and Health in the New Millennium* – Reports on the First National Conference on Literacy and Health held in May 2000.

## National Literacy and Health Logic Model



## **Questions to be answered by the evaluation**

The key long-term outcomes for the National Literacy and Health Program were defined as follows:

1. Raise awareness among health professionals about the links between literacy and health
2. Build commitment to literacy as a critical determinant of health
3. Establish Literacy and Health partnerships within and outside the health field

In this context and in recognition of the retrospective nature of the evaluation process, the following evaluation questions are proposed:

- Has the National and Literacy and Health program increased awareness among health professionals about the links between literacy and health? What evidence can be demonstrated of the changes in awareness over the last ten years (baseline and present)?
- What evidence can be demonstrated of commitment to literacy as a critical determinant of health? Health professionals? NGOs? Public? What has been the contribution of the National Literacy and Health Program?
- Have Literacy and Health partnerships been established within and outside the health field? Are they effective partnerships? What has been the contribution of the National Literacy and Health Program?

## **Component Potential Indicators and Information Sources**

The National Literacy and Health Program has been identified with the following program components:

- Health professional education
- Services
- Projects
- Policy, advocacy, literacy research
- National Literacy and Health Program partnerships

The activities and outputs for these components are identified in the Logic Model on page three of this document.

## **Process Evaluation**

The table below provides summary indicators related to an operational/process evaluation for the National Literacy and Health Program:

<b>Component</b>	<b>Process/Output Indicators</b>	<b>Information Collection</b>
Health professional education	# presentations given # and nature/characteristics participants in presentations # workshops produced # and nature/characteristics of workshop participants # workshop participants satisfied with workshop # reporting follow-up action to workshop # resource materials produced # and nature/characteristics of resource recipients # resources recipients satisfied with resource materials # conferences attended	Document review (CPHA and partners' statistical records) Key Informant Interviews
Services	# resource information materials produced # and nature/characteristics of resource/information materials recipients Use/hits on web site # of projects created # of services provided # of services received # of clients # of repeat clients	Document review (CPHA and partners' statistical records) Key Informant Interviews
Projects	# project-related information resources produced # project-related information resources distributed # resources recipients satisfied with resource materials # project-related workshops held # and nature/characteristics of workshop participants # workshop participants satisfied with workshop # reporting follow-up action to workshop Level/Nature of partner "in-kind" contributions	Document review (CPHA and partners' statistical records) Meeting Minutes Key Informant Interviews Project Evaluation Reports

<b>Component</b>	<b>Process/Output Indicators</b>	<b>Information Collection</b>
Policy, Advocacy, Literacy Research	# policy recommendations developed # policy recommendations adopted by policy makers # of literacy and health research proposals developed # of literacy and health research proposals approved # of literacy and health research citations # of researchers working on literacy and health Level/Nature of partner “in-kind” contributions	Document review (CPHA and partners’ statistical records) Meeting Minutes Key Informant Interviews Project Evaluation Reports
National and Literacy Health Program Partnership	# of literacy and health partnerships # of joint partner projects implemented # of partners # of jointly-sponsored resource materials produced # of jointly-sponsored workshops held # of jointly-sponsored articles produced Level/Nature of partner “in-kind” contributions	Document review (CPHA and partners’ statistical records) Meeting Minutes Key Informant Interviews

**Impact/Outcome Evaluation**  
*Health Professional Education*

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Collection Methods</b>	<b>Comments</b>
Increased awareness of literacy and health	Level of awareness among health professionals Male/Female (1994) Level of awareness among health professionals Male/Female (2004)	Document review (1994) - Surveys, etc., research Surveys - health professionals (2004)	Secondary analysis of literacy and health research Key informant interviews Focus groups/surveys of selected health professionals and recipients of program materials	Baseline data may utilize literacy and health “Start Up” documents Costs involved in Focus groups, surveys, key informant interviews - (2004)

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Collection Methods</b>	<b>Comments</b>
Improved verbal and print communication	Self-reported levels of knowledge and awareness of health-related verbal and print education Communication materials (1994) Self-reported levels of knowledge and awareness of health-related verbal and print education Communication materials (2004)	Document review Secondary Research Analysis (1994) - Surveys, etc. research Surveys - Health professionals (2004) Focus groups Informant opinion	Secondary analysis of literacy and health research Key informant interviews Focus groups/surveys of selected health professionals and recipients of program materials	Baseline data may utilize literacy and health “Start Up” documents Costs involved in Focus groups, surveys, key informant interviews - (2004)
Improved adherence to health instruction	Perceived levels of adherence to health instruction (Health professionals) - (1994) Perceived levels of adherence to health Instruction (Health professionals) - (2004)	Secondary research analysis (1994) - Surveys, etc. research Survey/focus groups of health professionals and patients - (2004)	Secondary analysis of literacy and health research Design of survey/focus groups for health professionals/patients	Baseline data may utilize literacy and health “Start Up” documents Costs involved in Focus groups, surveys, key informant interviews - (2004)
Reduced safety risks	Levels of perceived safety risks (1994) Levels of perceived safety risks (2004)	Secondary research analysis (1994) and (2004)	Secondary analysis of Literacy and Health Research Reports National Surveys	Baseline data may utilize literacy and health “Start Up” documents

*Services*

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Collection Methods</b>	<b>Comments</b>
Improved verbal and print communication	Self-reported levels of knowledge and awareness of health-related verbal and print education Communication Materials (1994) Self-reported levels of knowledge and awareness of health-related verbal and print education Communication Materials (2004)	Document review Secondary research analysis (1994)- Surveys, etc. research Surveys - Health professionals (2004) Focus groups Informant opinion	Secondary analysis of literacy and health research Key informant interviews Focus groups/surveys of selected health professionals and recipients of program materials	Baseline data may utilize literacy and health “Start Up” documents Costs involved in Focus groups, surveys, key informant interviews - (2004)
Increased profile of NLHP	Levels of awareness of NLHP among health professionals, government, private and voluntary sector (1994) and (2004)	Document review Secondary research analysis (1994)	Surveys - Health professionals (2004) Focus groups Informant interviews	Baseline data may utilize literacy and health “Start Up” documents Costs involved in Focus groups, surveys, key informant interviews - (2004)
Improved adherence to health instruction	Perceived levels of adherence to health instruction (1994) Perceived levels of adherence to health instruction (2004)	Secondary research analysis (1994) - Surveys, etc. research Survey/Focus groups of health professionals and patients (2004)	Secondary analysis of literacy and health research Design of survey/focus groups for health professionals/patients	Baseline data may utilize literacy and health “Start Up” documents Costs involved in Focus groups, surveys, key informant interviews - (2004)

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Collection Methods</b>	<b>Comments</b>
Reduced safety risks	Levels of perceived safety risks (1994) Levels of perceived safety risks (2004)	Secondary research analysis (1994) and (2004)	Secondary analysis of literacy and health research	Baseline data may utilize literacy and health “Start Up” documents

*Projects*

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Collection Methods</b>	<b>Comments</b>
Improved verbal and print communication	Self-reported levels of knowledge and awareness of health-related verbal and print education Communication Materials (1994) Self-reported levels of knowledge and awareness of health-related verbal and print education Communication Materials (2004)	Document review Secondary research analysis (1994)-Surveys, etc research Surveys - Health professionals (2004) Focus groups Informant opinion	Secondary analysis of literacy and health research Key informant interviews Focus groups/surveys of selected health professionals and recipients of program materials	Baseline data may utilize literacy and health “Start Up” documents Costs involved in Focus groups, surveys, key informant interviews - (2004)
Promoting links between literacy and health	Perceived levels of awareness among health professionals on links between literacy and health (1994) and (2004)	Document review Secondary research analysis (1994) - Surveys, etc. research Surveys - Health professionals (2004) Focus groups Informant opinion	Secondary analysis of literacy and health research Key informant interviews Focus groups/surveys of selected health professionals and recipients of program materials	

***Policy, Advocacy, Literacy Research***

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Collection Methods</b>	<b>Comments</b>
Increased research on literacy and health and health determinants	# of research projects Literacy and Health (1994) # of research projects Literacy and Health (2004) # of citations on research Literacy and Health (1994) # of citations on research Literacy and Health (2004)	Document review Secondary research analysis (1994) Document review Secondary research analysis (2004)	Document review Key informant interviews	CPHA Literacy Secretariat Records will be reviewed
Increased information sharing	Levels of perceived information sharing (1994) Levels of perceived information sharing (2004)	Key informants	Key informant interviews	
Research policy linkages				

***National Literacy and Health Program Partnership***

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Collection Methods</b>	<b>Comments</b>
Strong and committed partnerships	Levels of information sharing among partners Levels of resource sharing among partners # of joint projects among partners Partners' perceived benefits of partnership arrangements	Partners' information	Survey of literacy and health partners Key informant interviews	Need for third-party information collection (objectivity)

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Collection Methods</b>	<b>Comments</b>
Increased coordination and collaboration of Literacy and Health initiatives	Levels of information sharing among partners Levels of resource sharing among partners # of joint projects among partners Partners' perceived benefits of partnership arrangements	Partners' information	Survey of literacy and health partners Key informant interviews	

***General Long-Term Outcomes – Potential Indicators and Information Sources***

<b>Results</b>	<b>Indicators</b>	<b>Information Sources</b>	<b>Comments</b>
Raise awareness among health professionals about the links between literacy and health	Levels of awareness professionals about the links between literacy and health 1994-2004	Document review Key informant interviews/surveys	
Build commitment to literacy as a critical determinant of health	Funding levels literacy programs 1994-2004	Document review Key informant interviews	
Establish literacy and health partnerships within and outside the health field	# of partnerships within and outside the health field 1994-2004	Key informant interviews	

**Evaluation Implementation Plan Process**

The recommended approach involves multiple sources of evidence including as a minimum the following:

- Review of partner-relevant existing documents (proposals, statistical records, etc.)
- Key informant interviews with partner representatives and others
- Focus groups/surveys of health professionals and other recipients of program products
- Analysis of research reports, surveys and other relevant documents.

## **Document Review Process**

This will focus on reviews of Literacy and Health partner statistical records (distribution, etc.), proposals and other documents as appropriate.

- Development of protocol for document review process
- Approval of protocol
- Selection of documents for sample of indicators
- Application of analysis to identified documents 1993 onwards
- Application of analysis to new documents (2003-04)
- Preparation of summary analysis report

## **Focus Group/Key Informant Interviews**

This will supplement record review and offer health professional and selected recipients of resource materials and other program products to provide qualitative information on the program. Key informant partner interviews are especially important given the retrospective evaluation approach

- Decision on method by Evaluation Working Group
- Development of Focus Group/Key Informant protocol
- Select informant/focus group participants
- Convene focus groups – hold key informant interviews with partner health professionals
- Preparation of summary analysis report

## **Secondary Research Analysis**

This will involve a literature/research review of reports, surveys and other materials to identify baseline data for program commencement, as well as the current “state” of program outcomes.

- Hire researcher(s)
- Identify appropriate data sources
- Conduct review
- Compile and analyze data
- Prepare summary report

## **Final Evaluation Report - Presentation of Results**

This report will enable consolidation of all information from the above processes.

- Analyze and consolidate summary reports from all above processes
- Prepare consolidated summary report
- Present results to Working Group and researchers

## **Appendix B**

### **Key Informant Interview Protocol**

# Literacy and Health Questionnaire

**Draft, 16 Feb. 2004**

You are being invited to participate in a study entitled Retrospective Evaluation of the National Literacy and Health program being conducted by Irving Rootman, who is the principal investigator for the project. Dr. Rootman is a Professor at the Centre for Community Health Promotion Research in the Faculty of Human and Social Development at the University of Victoria and you may contact him if you have further questions by calling (250) 472-4102. He can be reached by email at [irootman@uvic.ca](mailto:irootman@uvic.ca)

The research is being funded by the National Literacy Secretariat and administered by the Canadian Public Health Association.

The purpose of this research is to study the National Literacy Program and its attainment of its intended outcomes:

- Raise Awareness among Health Professionals about the Links between Literacy and Health
- Build commitment to Literacy as a critical determinant of Health
- Establish Literacy and Health partnerships within and outside the health field

**Name of Respondent:** \_\_\_\_\_

**Organization:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## **I. Your/ Your Organizations Involvement in Literacy and Health.**

We would like to begin with a few questions about the involvement of you and your organization in the Literacy and Health Initiative.

1. Are you currently involved in the issue of literacy and health?
2. When did you first become involved in this issue?
3. Is your organization currently involved in the issue of literacy and health?
4. What are the main activities in which your organization is currently involved in relation to literacy and health?
5. To the best of your knowledge, when did your organization (use name of organization) first become involved in the issue of literacy and health?
6. Over the past 10 years, would you say that your personal involvement in this issue has... increased, decreased, or remained about the same?

{Probe: How? Why?}

7. To the best of your knowledge, would you say that the involvement of your organization (use name of organization) has increased, decreased, or remained about the same?

{Probe: How? Why?}

8. To what extent do you attribute these changes to the Literacy and Health Initiative ... Would you say, "A great deal, somewhat, not very much, or not at all?"
9. What impact, if any, would you say that the Literacy and Health Initiative has had on your personal involvement in this issue?
10. What impacts, if any, would you say that the Literacy and Health Initiative has had on the involvement of your organization in this issue?
11. Can you provide some specific examples?

## II. Partnerships.

1. Is your Organization currently involved in any partnerships related to literacy and health?
2. To the best of your knowledge, when did your organization first become formally involved in a partnership?
3. Which of the following sectors are currently involved in your literacy and health partnership?
  - Health Professional
  - NGOs
  - Community Groups
  - Other sectors \_\_\_\_\_. (Specify)
4. To the best of your knowledge, has the number of your partnerships increased, decreased or remained about the same over the period of your involvement?
5. To what extent do you attribute these changes to the national literacy and health initiative?
6. What is the nature of the involvement of your organization in this partnership?
  - As a sponsoring organization
  - As a member of a Steering Committee
  - As a partner who provided information to the project
  - As a partner who provided time, staff, space, materials?
  - As a partner who facilitated access to special populations?
  - Other \_\_\_\_\_.
7. To what extent has the involvement and commitment of your organization to this/these partnerships increased or decreased over the past few years?
8. To what extent do you attribute these changes to the national literacy and health initiative?

## **Impacts and Outcomes:**

These statements refer to the benefits that your organization, your partners and/or your clients have received from participating in the Literacy and Health Initiative. For each statement, we would like to know whether you... “Strongly agree, somewhat agree, somewhat disagree or strongly disagree”.

1. As an organization we have increased our *knowledge and awareness* of literacy as a critical determinant of health.
2. Our partners have increased their *knowledge and awareness* of literacy as a critical determinant of health.
3. What is your reason for this conclusion?
4. As an organization we have increased our commitment to literacy as a critical *determinant of health*.
5. Our partners have increased their commitment to literacy as a critical *determinant of health*.
6. What is your reason for this conclusion?
7. As an organization, we have increased our knowledge about what services, resources, programs or policies can be developed in relation to literacy and health.
8. Our partners have increased their knowledge about what services, resources, programs or policies can be developed in relation to literacy and health.
9. As an organization, we have increased our capacity to address issues related to literacy and health.
10. Our partners have increased their capacity to address issues related to literacy and health.
11. We believe that the population that we serve receives better services related to literacy and health.
12. Our partners believe that the population that they serve receives better services related to literacy and health.

## **Summing Up:**

1. What would you say has been the single most important contribution of the Literacy and Health Strategy to changes in this area?
2. What do consider to be the most important things that must be done to build upon this initiative?

## **Appendix C**

### **List of Key Informants**

## Literacy Interviewees:

**Ms. Millicent Toombs**

Senior Project Manager, Office for Public Health  
Canadian Medical Association

**Ms. Jane MacDonald**

Gov't & Public Relations Manager  
Canadian Nurses Association

**Cheryl Teeter**

Director of Education  
Canadian Healthcare Association

**Doris Mirella**

Director of Communications  
Canadian Centre for Optometrists

**Ms. Janet Becigneul**

Media Relations Manager  
Canadian Pharmacists Association

**Ms. Judy Lux**

Canadian Dental Hygienists Association

**Dan Morier**

Translator, Communications Specialist  
Society of Obstetricians & Gynaecologists of Canada

**Francine Knoops**, CPA Director of Professional and Public Affairs

Communication Officer  
Canadian Psychiatric Association

**Ms. Wendy DesBrisay**

Executive Director  
Movement for Canadian Literacy

**Ms. Ranjana Chopra**

Director of Communications  
Canadian Association for Community Care

**Melanie Hall**

Senior Writer-Editor  
Canadian Dental Association

**Ms. Darene Toal-Sullivan**

Director of Professional Practice  
Canadian Association of Occupational Therapists

**Elizabeth Moreau**

Director of Communications & Public Education  
Canadian Paediatric Society

**Ms. Jennifer Stevens**

Communications Manager  
Victorian Order of Nurses

**Ms. Emily Saunders**

Projects Administrator  
Canadian Dental Assistants Association

**Wendy Zatylny, Director Stakeholder relations**

Canada's Research-Based Pharmaceutical Companies

**Ms. Judy King**

Canadian Physiotherapy Association  
Physiotherapy Programme  
University of Ottawa

**Ms. J. Woolfrey (Janice Sonnen)**

Program Manager  
Canadian Institute of Child Health

## **Appendix D**

### **PLS Clients and Projects**

## Plain Language Service (PLS) Clients and Projects

### Canadian Health Network

Plain language revision of *48 Frequently Asked Questions (FAQs)*

- Ten FAQs on immunization
- Ten FAQs on relationships
- Ten (Nine FAQs and one glossary) on complementary and alternative health
- Five FAQs on schizophrenia
- Six FAQs on accident prevention
- Two FAQs on nutrition
- Five FAQs on workplace situations
- Translation coordination of some FAQs into plain language French version.

### Health Canada (HC)

Therapeutic Products Programme

- Plain language revision of *Scientific Issues Raised by Xenotransplantation*
- and *Ethical Issues Raised by Xenotransplantation*
- Coordination of translation into French for both documents
- Coordination of Clear Design for both documents
- Plain language revision of documents for regional forums, questionnaire for Public Advisory Group and plain language version of web site for Xenotransplantation project
- Focus testing of questionnaire for Public Advisory Group

Radiation Protection Bureau

- Plain language revision of four information bulletins on *Sun Safety*

Policy and Major Project Directorate

- Plain language editing of an abridged version of the report *Toward a Healthy Future*, for inclusion in the Canadian Journal of Public Health

Centre for Chronic Disease Prevention and Control

- Plain language revision of two pamphlets for breast cancer

Tobacco Control Programme

- Plain language revision of quit smoking guide *12 Steps to Staying Quit*

#### Product Safety Bureau

- Plain language revision of six safety bulletins about hazardous symbols, utility lighters, stationary activity centres, pool safety, ozone generating devices, winter sports and cooking fires
- Plain language revision of seven safety bulletins about bunk beds, curtain and blind cords, lighters and matches, children's sleepwear and candles
- Coordination of translation into French of all bulletins
- Focus tested all bulletins with adult learners and reported on test findings

#### Division of Aging and Seniors

- Plain language revision and clear graphic design assessment of the publication entitled *Medication Matters*
- Plain language revision of two brochures on *Sleeping Pills* and *Tranquillizers*

#### Family Violence Prevention Unit

- Plain language revision of booklet entitled *Financial Abuse of Older Adults*

#### Public Involvement Process on Xenotransplantation Project

- Plain language revision of Questionnaire
- Coordination of focus testing of Questionnaire
- Plain language revision of key issues document
- Plain language revision of material for plain language section of web site
- Plain language revision of the final report

#### First Nations Inuit Health Branch

- Plain language revision of Oral Health Prevention Kit
- Plain language revision of *Fetal Alcohol Spectrum Disorders (FASD) Program Guidelines, The Funding Application Process*
- Plain language revision of Canadian Prenatal Nutrition Program handbook

#### Canadian Mental Health Team

- Plain language revision of 4 public service announcements about the tragedy of September 11, 2001 and subsequent events.

#### **National Ovarian Cancer Association**

- Plain language revision of information about symptoms, diagnosis, treatment and statistics on ovarian cancer for web site

#### **Ottawa Regional Health Institute**

- Plain language revision of a decision aid questionnaire entitled *Breast Screening Decision Aid for 70 Years +*
- Translation coordination of document into French
- Plain language revision of a decision aid questionnaire entitled *Making Choices: Life Changes for Lowering Your Risk of Heart Disease and Stroke*

### **Canadian Breast Cancer Initiative**

- Plain language revision of nine *Guidelines on Breast Cancer Treatment*
- Plain language revision of one *Guideline on Breast Cancer Treatment*
- Coordination of translation into French for all ten Guidelines
- Clear graphic design

### **Canadian Cancer Society**

- Plain language revision of the brochure entitled *Listen with Your Heart*

### **Savattuq Inc.**

- Plain language revision of 13 *Fact Sheets* and a *Glossary on Cancer*
- Plain language revision of *Personal Health Journal*

### **Hospital for Sick Children (HSC)**

Plain language revision of 15 documents:

- four on breast feeding, hypospadias, exercise testing and pain management
- one pamphlet on *What is Kawasaki Disease* for HSC's web site
- one CD-ROM on Asthma for HSC's web site
- nine information documents for parents, including subjects such as anorexia, diabetes, and speech and hearing development, milestones of speech development, use of car seats for special needs/premature infants, mental illness in youth, and eating disorders.

### **Ontario Residential Care Association (ORCA)**

- Plain Language revision of *Mandatory Standards* for the web site

### **Manitoba Public Health Communicable Disease Control Unit**

- Plain language revision of Pentacel fact sheet
- Plain language revision of Pneumococcal Vaccine Fact Sheet
- Plain Language revision of fact sheets on Malaria and Mefloquine

### **Treasury Board**

- Plain Language Assessment of English and French Blue Pages Telephone Directory

### **Mount Sinai Hospital**

- Plain language revision of three fact sheets:
  - *Understanding Drug-Resistant Germs*
  - *VRE Fact Sheet for the Client at Home*
  - *MRSA Fact Sheet for the Client at Home*

### **Department of Foreign Affairs & International Trade**

- Clear language editing of selected chapters and assessment of the Youth International Internship Program's *Passport* binder

### **Canadian Haemophilia Society**

- Clear Design of *Parents' Handbook*
- Plain Language revision of four chapters of the *Parents' Handbook: Home Infusion, Clotting Factor, Family Perspectives and Heredity*
- Plain language revision of the document entitled *Von Willebrand Disease*
- Plain language revision of brochures entitled *Desmopressin and Amicar and Cyklokapron*
- Coordination of translation of the above documents into French
- Plain language revision of a book entitled *HIV and Safer Sex*
- Translation coordination of the above document into French

### **Northern Alberta Comprehensive Hemophilia Centre**

- Plain language revision of *Central Venous Access Device - Home Care Guidelines*

### **Canadian Ethnocultural Council**

- Plain language revision of three fact sheets: *Questions to Ask Your Doctor, Questions to Ask Your Pharmacist* and *Safe Drug Use: A Guide for Seniors*

### **The Arthritis Society**

- Plain language revision of *Living Well with Rheumatoid Arthritis*
- Plain Language revision of *Basic Facts on Rheumatoid Arthritis for AS's web site*

### **Aboriginal Healing Foundation**

- Plain language revision of *Program Handbook 2000* and *Ethics Guidelines*
- Coordination of translation into French for both documents

### **Ontario Breast Screening Program**

- Plain language revision of two pamphlets on breast density
- Plain language revision of three form letters
- Plain language revision of pamphlets entitled *Breast Tenderness* and *Skin Breakdown Under the Breasts*
- Plain language revision of a guidebook entitled *Breast Assessment: A Woman's Guidebook*
- Plain language revision of OBSP website
- Plain language revision of OBSP authorization form

### **Canada's Research-Based Pharmaceutical Companies**

- Plain language revision of *Code of Marketing Practices*
- Plain language revision of a pamphlet and medicine record entitled *Knowledge is the Best Medicine*

### **Canadian Pediatric Society**

- Plain language revision of a varicella pamphlet for series *Getting Your Shots*

- Plain language revision of five immunization pamphlets for the same series

#### **Eastern Pediatric Group - Diabetes**

- Plain language revision of booklet *Take Charge* for parents of children with diabetes

#### **Canadian Council on Social Development**

- Plain language revision of a report entitled *Computers and Adult Literacy*

#### **Canadian Diabetes Association**

- Plain language assessment of two pamphlets: *Well and Alive at 45+* and *Staying Healthy with Diabetes*
- Translation of the consent form for flu shot into French

#### **Victorian Order of Nurses Canada**

- Plain language revision of the *Informed Consent for the Flu Shot* form
- Plain language revision of VON Canada's *Client Bill of Rights and Responsibilities*
- Translation coordination of form into French
- Plain language revision of a bulletin

#### **Ottawa Regional Cancer Centre**

- Plain language revision of Centre's patient information booklet
- Plain language revision of the updated/expanded version of the booklet
- Coordination of translation into French

#### **CancerCare**

- Plain language revision of brochure *Are you age 50 or older? Ask your doctor for a colorectal cancer test – it could save your life!*

#### **McNeil Consumer Healthcare**

- Plain language revision of a pamphlet entitled *Living Well with Osteoarthritis*

#### **North Lanark County Community Health Centre**

- Plain language revision of the Centre's *Public Information Pamphlet*

#### **Community Care Access Centre**

- Plain Language revision of two pamphlets entitled *General Information about CCAC* and *What Clients Need to Know About CCAC*
- Plain language revision of two brochures
- Coordination of translation into French
- Clear graphic design of all pamphlets

#### **Canadian Liver Foundation**

- Plain language revision and graphic design assessment of an information sheet on *Hepatitis C*

**Al Ritchie Health Action Centre**

- Plain language revision and graphic design assessment of the Centre's pamphlet entitled *Baby's Best Start Program*

**Haldimand-Norfolk Regional Health Department**

- Plain language revision of five patient information pamphlets
- Plain language and graphic design assessment on a *1999 Calendar*

**Canadian Dental Association**

- Plain language revision and graphic design assessment of booklet *First Teeth* and graphic design assessment of prototype pamphlet entitled *You and Your Dentist*
- Plain language revision of the booklets *Dental Materials* and *Dental Care for Seniors*

**University of Alberta Medical School**

- Plain language revision of a patient education booklet on Anesthesia

**Canadian Dental Assistants' Association**

- Plain language revision and clear graphic design of a brochure entitled *Dental Assisting*

**Novo Nordisk Canada Inc.**

- Plain language revision and graphic design assessment of booklet entitled *NiaStase*

**Ferring Pharmaceuticals**

- Bedwetting Tear Sheet
- Assessment and development of a questionnaire for pamphlet entitled *Induction of Labour*

**Lavender Ink**

- Plain language revision of a brochure entitled *Quality Screening Mammography: Making an Informed Choice*

**Leeds, Grenville and Lanark District Health Unit**

- Plain language revision of a pamphlet entitled *Coping with a Disaster*

**Canadian Red Cross**

- Language assessment of the document *Chapter 2 - The Emergency Medical System*

**Royal Architectural Institute of Canada**

- Plain language revision of the pamphlet *Choosing a Career as an Architect*

**Somerset West Community Health Centre**

- Plain language revision of *Mariposa* newsletter

### **Canadian Pharmacists Association**

- Plain language revision of the booklet entitled *Am I Getting The Best Benefit From My Medication?*
- Plain language revision of patient information sheet entitled *How to Use Emergency Contraceptive Pills*

### **Society of Obstetricians and Gynaecologists of Canada**

- Plain language revision and clear graphic design of the booklet *Hormone Replacement Therapy*
- Plain language revision and clear graphic design of five booklets on labour and childbirth for a series called *Bringing Baby Safely Into the World*

### **New Brunswick Department of Health and Community Services**

- Plain language revision and graphic design of a brochure entitled *Diarrhea and Vomiting Discharge Instructions*
- Coordination of translation into French

### **Banfield-Seguin**

- Plain language revision of the brochure entitled *Services for Canadian Business Clients* (on behalf of the Export Development Corporation)
- Language assessment of a pamphlet and medicine record entitled *Knowledge is the Best Medicine*

### **Manitoba Heart and Stroke Foundation**

- Plain language revision of a brochure entitled *Hearts are for Life*

### **The Ottawa Hospital**

- Plain language revision of the Ottawa Hospital Patient Information Handbook

### **Regional Sexual Assault Treatment Centre**

- Plain language revision of a poster for rape drugs

### **Ferring Inc.**

- Plain language revision of patient information sheet for Pentasa® Tablets
- Plain language revision of patient information sheet for *Minirin® Tablets Patient Information*

### **TrainCan**

- Plain language revision of a food safety manual *BASICS.fst Food Safety Training in Canada*

### **Becton-Dickinson**

- Plain language revision of a patient guide to the BD Posiflow IV Access Device

- Plain language revision of an aseptic information sheet *Keep your syringe and needle free from germs!*

#### **Canadian Food Inspection Agency**

- Plain language revision of 30 safety fact sheets

#### **Jewish General Hospital**

- Plain language revision of two pamphlets entitled *So I have "a problem"* and *Are you at risk?*

#### **National Voluntary Organization**

- Plain language revision of a presentation *Towards A Framework Of Competencies For Leadership In The Voluntary Sector*
- Plain language revision of documents for roundtables including *Backgrounder, Inventory on Policy Capacity/Partnership, Building/Collaboration, Definitions, Frequently Asked Questions*

#### **Correctional Services of Canada**

- Plain language revision of CSC Safer Tattooing Initiative

#### **ALTANA Pharma Inc.**

- Plain language revision of a consumer information document for ALVESCO™

#### **University of Ottawa**

- Plain language revision of information on Rheumatoid Arthritis Treatment

#### **City of Ottawa**

- Plain language revision of a guidebook entitled *Low Birth Weight, Learn the facts, Together we can make a difference*

#### **Ontario Public Health Association**

- Plain language revision of a document entitled *Parent Media Resource Calendar*

#### **Finance Canada**

- Plain language revision of two brochures *Do You Need a Personal Bank Account?* and *How to Cash Your Government of Canada Cheque for Free*

#### **Canadian Public Health Association (CPHA)**

##### Canadian Immunization Awareness Program (CIAP)

- Plain language revision of a story on immunization
- Feature on influenza
- Clear language revision of the Canadian Health Network's Resource Mapping Project Final Report on *Immunization in Canada*

- Plain language revision of *Vaccination Information on the Internet, Can you trust what you read?*

#### Youth at Risk Project

- Research and development of ten original health fact sheets for the project entitled *Developing a Health Literacy Curriculum for Youth at Risk*
- Plain language revision of final Mind Over Violence Everywhere resource

#### Canadian HIV/ AIDS Clearinghouse

- Plain language revision of five *Frequently Asked Questions* about HIV/AIDS
- Plain language revision of a pamphlet entitled *Pregnancy and HIV* and a manual entitled *CANNET Manual*
- Plain language revision of two pamphlets on facts about HIV and AIDS

#### Canadian International Immunization Initiative (CIII)

- Plain language revision of a pamphlet entitled *Disease Knows No Borders*

#### Health Effects of Climate Change

- Plain Language revision of one insert document for the Canadian Journal of Public Health entitled “Seeing Through the Haze, Climate Change, Air Pollution and Your Health” for the Roundtable on Health and Climate Change project

#### Medication Packaging and Labelling Project

- Plain language revision of terminology for commonly used medication phrases
- Plain language revision of patient information section of Compendium of Pharmaceuticals and Specialities (CPS)
- Plain language assessment of final report for this project

#### Anti-Bullying Best Practices

- Plain language revision of *Safe School Student Survey* for Parents, Teachers and Students

#### The Health Effects of Air Pollution

- Plain language revision of 5 brochures and a Frequently Asked Question document on the health effects of air pollution

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

- Plain language revision of Conference Abstracts
- Plain language revision of the Preliminary Program