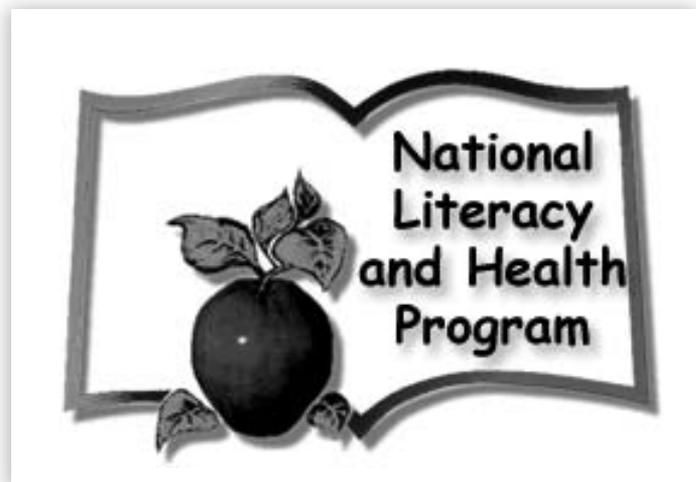


Toward an Agenda for Literacy and Health Research in Canada

by **Irving Rootman, Deborah Gordon-El-Bihbety, Jim Frankish, Heather Hemming, Margot Kaszap, Lisa Langille, Darryl Quantz, and Barbara Ronson**

In 1992 the Canadian Public Health Association established the National Literacy and Health Program (NLHP). This program is considered a model for raising awareness, exploring issues, developing resource materials and building partnerships in this field. It has led to Canada being recognized as an international leader in the field of literacy and health. However, our track record in research in literacy and health has been less than exemplary. Very few Canadian papers on this topic have been published in the peer-reviewed literature and there have been few systematic evaluations of interventions. Thus, there appears to be a need to develop a program of research in Canada to support programmatic and policy initiatives in literacy and health.

This paper reports on the National Literacy and Health Program's consultations with educators, health professionals, community workers, policy-makers and researchers from across Canada. The process began with a needs assessment to review the gaps and priorities for literacy and health research in Canada, and identify the barriers and opportunities for building capacity to do research. The second part of this process was a national workshop, during which the participants were asked to help develop a framework for future literacy and health research in Canada. This paper presents the outcomes of this consultative process. We hope that this information will stimulate educators, service providers, academics and policy-makers to become involved in research and action related to literacy and health.



Needs Assessment

The objectives of the needs assessment were to identify (1) gaps in knowledge, (2) current and proposed initiatives, and (3) resources and opportunities for research in literacy and health in Canada. To accomplish these goals, we undertook an environmental scan of Canadian documents on literacy and health initiatives, research and programs. The environmental scan was followed by a consultation with forty-eight practitioners, researchers and policy-makers, who we surveyed face-to-face, by telephone, or by e-mail. Finally, we held four focus groups involving a total of thirty-three people in Vancouver, Toronto, Ottawa, and Wolfville. Participants were chosen based on their involvement and/or interest in literacy and health issues. The following outlines our findings.

What research is needed

Participants identified a wide range of needed research in the area of literacy and health. Initial responses from participants often focused around defining what we mean by *literacy* and *health literacy*. Most people said that a clearer conception of these terms and their usage was a necessary step, especially if we want to facilitate collaboration between diverse sectors. Another key theme was the need for better understanding of the relationship between literacy and health for diverse populations such as urban/rural, Aboriginal, diverse ethnic and language groups, different age groups, disease and risk specific groups, the disabled, and the mentally ill. Again, people felt that this work could benefit from a clearer concept of the terms around health literacy.

Another recommendation was that research should be conducted within established conceptual models such as the health-belief model, or the precede-proceed model. Research should also follow the common language from the maturing fields of population health and health promotion. For example, several participants called for linking literacy and health to the determinants of health. Some also said we need a better understanding of how health impacts literacy and learning, as well as how literacy impacts health. Some people suggested that literacy program providers and learners in particular could benefit from a better understanding of how medications and chronic illness affect concentration, and thus learning.

Several people noted that cost-benefit and economic impact analyses would help build the case for work in the area of literacy and health. Respondents called for a better understanding of the impact of literacy on health, economics and poverty. They also suggested that we need research that generates testimonials, case studies, and fact sheets which would influence policy-makers, practitioners and potential volunteers.

Finally, respondents stressed the need for research to enhance health care providers' capacity to improve health, particularly among patients with limited literacy skills. They also stressed the need for research on ways that literacy program providers and learners could help minimize the negative health impacts of low literacy and negative learning impacts of health problems.

Barriers to research

People identified a number of barriers to research in literacy and health. The most common was funding and resources. Other issues were: unclear terminology; the fragmentation of interested individuals, groups and organizations; uncertainty about where this kind of research fits in traditional jurisdictions and departments; the lack of a common language and infrastructure across sectors; no recognition of the need for this kind of research; the stigma attached to low literacy and how difficult it is to reach this population; how difficult ethics-review requirements for research are; the programs being unstable and inconsistent; the emphasis on treatment over prevention; various countervailing political and corporate influences and agendas; the lack of experts and mentors in the field; how few grants administrators are familiar with the field; the vast size and diversity of the country; and the overwhelming workload faced by many service providers in the field.

Research Questions

At the national workshop in 2002, participants identified the following eight themes.

Understanding the issue

- (1) How is literacy related to mental, spiritual, physical and emotional health?
- (2) What impact do literacy skills have on how people access and use health promotion, prevention and treatment?
- (3) How is literacy related to the determinants of health?

Building the case

- (4) How does literacy affect how people access and use health services?
- (5) How is literacy related to health status and medical outcomes?
- (6) What are the legal implications of literacy issues?

Making a difference

- (7) What literacy interventions are the best practices and approaches?
- (8) How can we influence, develop and evaluate policy related to literacy and health?

A theme that came up repeatedly was the concern that funds for research would take precedence over funding for programming.

How to address the barriers

In terms of opportunities and solutions, respondents suggested getting all interested parties in the same room, involving learners, advocating for a provincial as well as a national agenda, tapping into the good will of seniors and the enthusiasm of teenagers, and adopting an agenda for literacy and life-long learning. They also suggested a number of potential partners including business, the media, ethno-cultural organizations, Aboriginal groups, family literacy programs, public schools, Departments of Education and Public Health and the health care system.

National Workshop

In October of 2002, the National Literacy and Health Program organized a national workshop to develop consensus about policy issues and research questions in Canada. The objectives were to identify six to eight literacy and health research themes, to develop a series of research questions focused on the themes, and to identify priorities for literacy and health research. Participants included thirty-two leaders in research, policy and practice from across Canada. We used the results of the needs assessment as a framework for our discussions and activities.

Eight themes emerged and participants identified a number of key questions related to each of the themes. Participants suggested that four areas of research should take priority: evaluating interventions, conducting cost/benefit analyses, studying the impact of literacy and life-long learning on health, and studying literacy and health within the unique circumstances of different communities, including Aboriginal, francophone, culturally diverse and other marginalized groups across the country.

SOURCES:

Statistics Canada/OECD (2001). *Health in the Information Age: Final Report of the International Adult Literacy Survey*. Ottawa, ON: Statistics Canada.

Implications and Future Direction

At the end of the workshop, participants recommended several steps to disseminate the work of the consultation, as well as to initiate work around the themes, issues and questions that emerged from the process. The final report of this process and the contact list were posted on the NLHP web site, and distributed widely to participants and others. Participants also recommended that people be encouraged to submit literacy and health research project proposals to the Canadian Institute of Health Research (CIHR). They also suggested that we work to encourage the CIHR to develop a future strategic initiative on literacy and health research. Some participants wanted the workshop to lead to a compendium of resources and policies related to literacy and health. They felt that the inventory of projects begun in the environmental scan should be completed and continually updated. Many people were interested in continuing to develop awareness of literacy and health issues—some felt that this was “at least as important as more research.” Participants strongly recommended continuing to build new partnerships, for example between researchers, hospital workers, and unions. They also called for the support and training of new researchers, and encouraged future opportunities, like conferences, to bring literacy and health partners together.

The authors are in the process of implementing these recommendations. We welcome your support in this work. Further information and a copy of the final report and other resources are available on the National Literacy and Health Program web site (www.nlhp.cpha.ca). ■

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