

Literacy and Health Project

PHASE ONE

**Making the World Healthier
and Safer for People
Who Can't Read**



ONTARIO PUBLIC HEALTH ASSOCIATION
L'ASSOCIATION POUR LA SANTÉ PUBLIQUE DE L'ONTARIO

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**[Note: This electronic version does not contain
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printed version.]**

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The Literacy and Health Project

Making the World Healthier and Safer
for People Who Can't Read

Phase One

A WORD ABOUT WORDS AND PHRASES

Throughout this document, we have tried to be very careful in our use of certain words and phrases when referring to people and how well they read, write or use numbers.

In part, we have taken this care out of respect for people who have trouble reading, writing or using numbers. For this reason, we have not used such words as “illiterates.” We do not believe words which describe conditions or abilities should be used to identify people. We prefer phrases which recognize that people are people, not conditions.

We are also concerned that our use of such words as “skills,” “levels,” or “abilities” may be confusing to the reader. Our experience with this project has taught us that people who currently have trouble reading, writing or using numbers do have the ability to develop these skills. Their problems result more from a lack of opportunity to learn, than an ability to learn.

Finally, we have done our best to avoid discussions which end up “blaming the victim” - implying that an individual is responsible for his or her problems. The issue involved in the relationship between illiteracy and health are far too complex simply to blame the individual or the system. We must collectively discover ways in which individuals, organizations and society can act responsibly.

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I. PREFACE

The Literacy and Health Project asked three central questions:

- What is the relationship between literacy and health?
- What is being done to ensure that people who do not read, write or use numbers well live healthier and safer lives?
- What should be done in the future to “make the world healthier and safer for people who can’t read?”

The Project has discovered a clear relationship between literacy and health. We have found that people with low literacy skills are more likely to be in worse health than people who are literate. We also discovered that many people do not know about the extent of illiteracy in Ontario and Canada, or of the impact of illiteracy on health.

Through our research and consultations across the province, we have received tremendous support for a range of actions to deal with the issue of health and literacy.

The information in this report describes Phase One of the Project. We start with Plain Language summaries of the report. The findings of our research help develop a greater understanding of the issue. Based on this understanding, we call for commitments and action in three areas:

- achieving literacy and health for all
- making environments healthy and safe
- ensuring equitable access to vital information.

The recommendations at the end of this report prepare the groundwork for the next phase of the Literacy and Health Project. We encourage people to use this document to raise awareness and develop specific plans of action within their organizations and communities.

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II. THE SUMMARY REPORT

Everyone needs to be able to read and write. However, in Canada, thousands of people cannot read or write or use numbers very well. For many of these people, their reading problems can lead to health problems.

The Literacy and Health Project:

The Literacy and Health Project was set up to find out how reading and health problems are connected. We called the project “Making the World Healthier and Safer for People Who Can’t Read.” People from Frontier College and the Ontario Public Health Association worked together on this project.

This report is about the first part of the project. We decided to talk to a lot of people who know about these problems. We also decided to read as much as we could about the issue.

Who We Talked To:

We talked to people from many different backgrounds, including:

- teachers, coordinators and students in literacy programs
- social workers
- people who work with the government
- public health nurses, doctors and druggists.

The Questions We Asked:

When we talked with these people, we wanted to get answers to these questions:

- Are people who cannot read as healthy as people who can read? If not, why not? In what ways are they not healthy?
- Do health workers, such as doctors and public health nurses, know that many people can’t read? Do they understand that not being able to read can cause problems?
- Is most health information heard to read? If it is, how do people who can’t read well get health information?

- What is being done about these problems?
- What should be done about these problems?

We talked to people all across Ontario. We wanted information about how reading problems can lead to health problems. In each area we visited, people told us their stories and discussed their ideas with us.

In November, 1988 we held a meeting for people from all over Ontario. We spent two days talking about the health problems of people who can't read very well.

What We Found Out:

1. Health information is hard to read.

We found that people who can't read well have a hard time getting the information they need. Most health books and pamphlets are written for people with a lot of education.

2. People with reading problems have more health problems.

We found out that people who can't read well have more health problems than those who can read. We wanted to know why.

Some health problems are clearly caused by reading problems. For example:

- Many people can't read the directions on medicines. This can result in problems such as using the wrong medicine or taking too much medicine.
- Many people make mistakes because they cannot read the instructions on packaged food. For example, if baby formula is not mixed the right way it can cause serious health problems for babies.
- Many people can't read the written instructions they get from their doctors or nurses. This can affect how they cope with an illness, or how well they recover after an operation.
- Many people are hurt at work. This is often because they cannot read the warning signs or the safety information.

People with reading problems have certain kinds of health problems more often than people who read well. For example, people with less education don't use seat belts regularly. They don't exercise regularly. They also

smoke more. They don't eat well. They tend to live in places that are less healthy. They tend to work in jobs that are more dangerous.

People who don't read well tend to be poorer. It is much harder to live in a healthy way if you are poor. Good food and good, safe housing are expensive.

We need to prevent these and many other health problems. People who can't read well have the right to be healthy and safe. They have the right to information and services that will help them be healthy and safe.

What Happens Next?

We decided to try to make these things happen:

- We need to make sure everyone has a chance to learn to read and write.
- We need to make sure everyone is healthy, and able to live and work in safe and healthy places.
- We need to make sure that everyone has all the information they need. With more information, people can start making good, safe, decisions about their lives. This means that information must be presented in many different ways. Some people will want written information. Others will want tapes or videos. All of this information must be developed with the people it is meant for.

Who Needs To Do What?

Many things need to be done by many different people. Some of these things can be started right away. Other things will take much longer.

1. People in the government need to work on these problems.

Here are some of the things government people need to do:

- Make people aware of how many people in Canada can't read well. People need to know there is a problem.
- Make the schools better so everyone can learn to read. Make the schools better so everyone can learn the skills they need to get good jobs.

- Offer many different kinds of classes for adults. Make sure these classes let adults learn when they want, where they want, how they want, and what they want to learn.
- Make sure that all Canadians have a healthy, safe place to live, and enough money to live on.
- Make sure that all Canadians have good changes at getting jobs that are safe and healthy.
- Make sure that information about how to be healthy and how to avoid getting hurt is easy to read.
- Make sure health information can be understood by anyone who needs it. Make sure workers have job safety information.
- Support and fund community groups because these groups can have very good effects on people's health.

2. *Community groups need to work on these problems.*

- Let people know that people who can't read well have more health problems.
- Make sure people can get information in different ways.
- Make sure people understand information when they get it.
- Make sure that all the information they give out is readable and useful to anyone who needs it. To do this well, people who can't read well must help write the material.
- Work with government people to do something about these problems.

3. *The Literacy and Health Project needs to keep track of what is being done.*

Here are some of the things which people working on this project need to do:

- Make sure health workers understand that there are many people who can't read well.

- Send out the information from the project. This information should go to people across the country.
- Work together with other people who are trying to do something about these problems.
- Work with people who work for the government and organizations to do something about these problems.
- Start working on some of the biggest problems where people need information. For example, a group could work on making sure that all drug labels are as readable as possible. Or, another group could work on making sure workplaces have readable information about safety.

RAPPORT SOMMAIRE

Tout le monde a besoin de savoir lire et écrire. Pourtant, au Canada, des milliers de personnes ne savent ni lire ni écrire, ni faire du calcul. Pour beaucoup de ces personnes, les problèmes de lecture peuvent mener à des problèmes de santé.

Le Projet Alphabétisation et Santé :

Le Projet Alphabétisation et Santé a été lancé pour nous permettre d'apprendre comment la lecture et les problèmes de santé sont reliés. Nous avons intitulé le projet «Rendre le monde plus sain et plus sécuritaire pour les personnes qui ne savent pas lire» Des gens du Collège Fontière et de l'Association pour la santé publique de l'Ontario travaillent ensemble à ce projet.

Pour la première partie du projet, nous avons décidé de parler avec des gens qui connaissent bien ces problèmes. Nous avons également décidé de lire le plus possible sur la question.

Avec qui avons-nous parlé ?

Nous avons parlé avec toutes sortes de personnes, y compris:

- des intervenantes et des intervenants en alphabétisation, des coordonnateurs et des coordonnatrices, et aussi des personnes inscrites dans des programmes d'alphabétisation
- des travailleuses sociales et des travailleurs sociaux
- des gens qui travaillent pour le gouvernement
- des infirmières de la santé publique, des médecins et des pharmaciens

Quelles questions avons-nous posées ?

Quand nous avons parlé avec ces personnes, nous avons cherché à obtenir des réponses aux questions suivantes:

- Est-ce que les personnes qui ne savent pas lire sont en aussi bonne santé que celles qui savent lire? Sinon, pourquoi pas? De quelle façon est-ce qu'elles ne sont pas en bonne santé?
- Est-ce que les médecins, les infirmières et les autres intervenantes en soins de santé sont au courant que beaucoup de gens ne savent pas lire? Est-ce qu'ils comprennent que ne pas savoir lire, cela peut mener à des problèmes de santé?

- Est-ce que la plupart de l'information sur la santé est difficile à lire? Si oui, comment est-ce que les gens qui ne savent pas très bien lire peuvent obtenir de l'information sur la santé?
- Qu'est-ce qui est fait pour essayer de corriger ces problèmes?
- Qu'est-ce qui devrait être fait pour essayer de corriger ces problèmes?

Nous avons parlé avec des gens de toute la province de l'Ontario. Nous voulions de l'information qui explique comment les problèmes de lecture peuvent mener à des problèmes de santé. Dans chaque région que nous avons visitée, les gens nous ont raconté leurs problèmes à eux et ont partagé leurs idées avec nous.

En novembre, nous avons tenu une réunion où nous avons invité des gens de tout l'Ontario. Nous avons passé deux jours à parler des problèmes de santé qui se posent pour les personnes qui ne savent pas très bien lire.

Ce que nous avons découvert :

1. L'information sur la santé est difficile à lire.

Nous avons appris que les personnes qui ne savent pas très bien lire ont de la difficulté à obtenir l'information dont ils ont besoin. Le plupart des livres et des dépliants sur la santé sont écrits pour les gens qui ont beaucoup d'instruction.

2. Les personnes qui ont des problèmes de lecture ont davantage de problèmes de santé.

Nous avons appris que les personnes qui ne savent pas très bien lire ont davantage de problèmes de santé que celles qui savent lire. Nous avons voulu savoir pourquoi.

Pour certains problèmes de santé, il est clair que ce sont les problèmes de lecture qui en sont la cause. Par exemple :

- Beaucoup des gens ne savent pas lire le mode d'emploi des médicaments. Ils courent alors le risque de prendre le mauvais médicament ou d'en prendre trop.
- Beaucoup des gens font des erreurs parce qu'ils ne savent pas lire les instructions sur les paquets de nourriture. Par exemple, si le lait en poudre pour bébés n'est pas mélangé

comme il faut, il peut causer de graves problèmes de santé pour les bébés.

- Beaucoup des gens ne peuvent pas lire les instructions qu'ils reçoivent du médecin ou de l'infirmière. Cela peut affecter leur attitude envers la maladie, ce qu'ils font pour guérir et comment ils se remettent de la maladie.
- Beaucoup de gens ont des accidents du travail. Souvent, c'est parce qu'ils ne savent pas lire les avertissements et l'information sur la sécurité.

Les personnes qui ont des problèmes de lecture ont, plus souvent que les gens qui lisent bien, des habitudes qui peuvent mener à des problèmes de santé. Par exemple, les personnes qui ont moins d'instructions n'utilisent pas la ceinture de sécurité régulièrement. Ils ne font pas des exercices régulièrement. Ils fument plus. Ils ne mangent pas bien. Ils vivent souvent dans des endroits qui ne sont pas aussi sains. Et ils font souvent un travail plus dangereux.

Les personnes qui ne savent pas bien lire ont tendance à être plus pauvres. Il est beaucoup plus difficile de vivre une vie saine quand on est pauvre. La bonne nourriture et les bons logements sécuritaires coûtent cher.

Nous devons faire quelque chose pour prévenir ces problèmes de santé et beaucoup d'autres. Les personnes qui ne savent pas très bien lire ont le droit d'être en bonne santé et de vivre en sécurité. Elles ont droit à l'information et aux services qui les aideront à rester en bonne santé et à vivre en sécurité.

Qu'est-ce qui se passe maintenant?

Nous avons décidé d'essayer d'accomplir trois choses:

- Nous assurer que tout le monde a la chance d'apprendre à lire et à écrire.
- Nous assurer que tout le monde est en bonne santé et peut vivre et travailler dans des endroits sains et sécuritaires.
- Nous assurer que chaque personne a l'information dont elle a besoin pour prendre de bonnes décisions, des décisions sûres, concernant sa vie. Cela signifie que l'information doit être présentée de plusieurs façons différentes. Certaines personnes voudront de l'information écrite. D'autres voudront des cassettes audio ou vidéo. Toute cette information doit être rédigée avec l'aide des gens à qui elle s'adresse.

Qui doit faire quoi?

Il y a beaucoup à faire, et il faut beaucoup de personnes différentes pour faire. Certaines de ces choses peuvent être commencées tout de suite. D'autres prendront beaucoup plus de temps.

1. Les gens du gouvernement doivent se pencher sur ces problèmes.

Voici certaines choses que les gens du gouvernement doivent faire :

- Faire comprendre au monde combien il y a de personnes au Canada qui ne savent pas bien lire. Il faut que les gens comprennent qu'il y a un problème.
- Améliorer les écoles pour que tout le monde puisse apprendre à lire et s'équiper des aptitudes nécessaires pour obtenir de bons emplois.
- Offrir plusieurs sortes de cours différentes pour les adultes. S'assurer que ces cours permettent aux adultes d'apprendre quand ils veulent, où ils veulent, comme ils veulent et ce qu'ils veulent.
- S'assurer que toutes les Canadiennes et tous les Canadiens ont un logement sain et assez d'argent pour vivre décemment.
- S'assurer que toutes les Canadiennes et tous les Canadiens ont la possibilité de trouver un emploi qui ne met pas en danger leur santé et leur sécurité.
- S'assurer que l'information qui explique comment être en bonne santé et comment éviter les accidents est facile à lire.
- Appuyer et financer les groupes communautaires car ces groupes peuvent avoir une très bonne influence sur la santé des gens.

2. Les groupes communautaires doivent se pencher sur ces problèmes.

Voici certaines choses que les groupes communautaires doivent faire :

- Faire savoir au monde que les gens qui ne savent pas bien lire ont plus de problèmes de santé.

- S'assurer que les gens peuvent obtenir de l'information de plusieurs façons différentes.
- S'assurer que les gens comprennent l'information qu'ils reçoivent.
- S'assurer que l'information qu'ils distribuent est facile à lire et qu'elle est utile pour toutes les personnes qui en ont besoin. La meilleure façon de la faire, c'est de demander à des personnes qui ne savent pas très bien lire d'aider à écrire l'information.
- Travailler avec les gens du gouvernement pour corriger ces problèmes.

3. *Le Projet Alphabétisation et Santé doit se tenir au courant de tout ce qui se passe dans ce domaine.*

Voici certaines choses que les gens qui travaillent à ce projet doivent faire :

- S'assurer que tous les intervenants en soins de santé comprennent qu'ils y a beaucoup de personnes qui ne savent pas très bien lire.
- Envoyer de l'information sur le projet à des gens à travers tout le pays.
- Travailler avec d'autres personnes qui essaient de faire quelque chose pour corriger ces problèmes.
- Travailler avec le gouvernement et avec les organismes intéressés pour corriger ces problèmes.
- Pour commencer, s'attaquer à quelques-uns des plus grands problèmes où les gens ont besoin d'information. Par exemple, un groupe pourrait travailler à s'assurer que toutes les étiquettes sur les médicaments sont très faciles à lire. Un autre groupe pourrait s'assurer qu'il y ait de l'information claire et lisible sur la sécurité dans les lieux de travail.

III. THE PROJECT

INTRODUCTION

24% illiteracy rate It is estimated that 24% of adult Canadians require assistance to read, write and use numbers well enough to meet the literacy demands of today's society.¹ Some cannot read or write at all. Excluded from this survey were people under 18, residents north of the 60th parallel, transients, members of the armed forces, natives living on reserves and anyone living in an institution, such as a prison, hospital and nursing home. If immigrants who speak neither of the two official languages are also excluded, the illiteracy rate of native-born Canadians is still 22%!

health and safety People need to be able to receive and understand information about their health and safety. Not understanding information may adversely affect a person's health.

With this in mind, the Ontario Public Health Association (OPHA) and Frontier College developed the Literacy and Health Project entitled "Making the World Healthier and Safer for People Who Can't Read."

Three government departments funded the project: the Ontario Ministry of Skills Development (Community Literacy Program Unit), the Ontario Ministry of Health (Health Promotions Branch); and Secretary of State (National Literacy Secretariat).

PROJECT OVERVIEW

major health issues This nine month exploratory project, set out to explore a number of specific topics. We wanted to identify the major health of people with low literacy skills. We wanted to establish a network of organizations and individuals from a variety of disciplines and interest areas, such as

network literacy, health, social services, medicine, business and government. Our

set of strategies ultimate goal was to develop a set of strategies dealing with the literacy and health relationship.

The Project steering committee developed a work plan and research strategies to meet the project's stated goals. The members of this committee were Peter Elson, OPHA Executive Director; Ron Labonte (who replaced Carol Farkas), OPHA Board Liaison; Bruce Kappel, Frontier College Program Manager; Salli Abbott, Project Manager; and Burt Perrin, Research Coordinator.

RESEARCH PHASE

The purpose of the research was to document the relationship between literacy and health. We explored questions such as:

- poorer health?** • do people with limited literacy skills have poorer health as a result? In what ways? Why?
- awareness?** • How do people with limited reading ability obtain their information about health? How appropriate are health and medical services information for them? How aware are health and medical workers of health problems associated with illiteracy?
- solutions?** • What are the potential solutions and means of addressing these problems?

From June to September 1988, information was collected from several sources to answer these questions.

Observations of Community Organizations about Health and Literacy Problems:

A questionnaire was sent to a variety of contacts in Ontario including public health units, community health centres, district health councils, community literacy groups and others asking about their familiarity with health problems related to illiteracy, as well ideas for solutions.

- health problems and approaches** The response was overwhelming, both in quality and quantity.² Many respondents had personal experience with health problems related to illiteracy and were very appreciative of the opportunity to express their thoughts on the subject. They offered many specific examples of health problems and approaches which have been tried to overcome them.

Literature Review:

- information statistical data** We conducted a comprehensive review of published and unpublished information from Canada and abroad. We also reviewed statistical data about health status from surveys and other sources.³

We uncovered much relevant information from a variety of sources. However, the information was scattered, and little systematic attention had been paid to the relationship between health and literacy. In some cases, sources containing relevant data (e.g. some surveys of health status) had not considered the use or implications of their data with literacy.

To the best of our knowledge, this study represents the most comprehensive examination to date of the relationship between literacy and health.

Case Studies:

We conducted three case studies at different sites in Ontario. One was with a rural multi-service centre, one with a community health centre, and the third with a literacy program. The purpose was to investigate some of the issues we had identified elsewhere in a small number of settings. These involved group and individual interviews with people associated with each site, including staff and learners where possible.

Key Informant Interviews:

We conducted a number of interviews with knowledgeable people throughout Canada and beyond - individuals or researchers personally familiar with the area or who could refer us to other persons or to relevant documentation.

There was a high degree of consistency in the information gathered. The responses to the letters and case studies largely confirmed the statistics and research findings reported in the literature we had examined.

CONSULTATION PHASE

The presentation and discussion of the research findings began in October, 1988. The consultation process involved regional workshops across Ontario, a two-day provincial workshop and a strategy meeting.

Regional Workshops:

During October, 1988 regional workshops were conducted in Hamilton, Ottawa, Toronto, Thunder Bay, Sudbury, Kitchener-Waterloo and London. The objectives of the workshops were to:

**clarify and expand
research
observations

solutions

build a
constituency**

- clarify and expand upon the research to date
- identify specific examples and observations of literacy-related health issues
- identify current and potential solutions
- build a constituency for on-going action

There were approximately fifteen participants at each workshop representing people working in the literacy, health, pharmaceutical and social service fields. These individuals were selected on the basis of their understanding of the connection between literacy and health and their involvement with the issue. Some participants had completed the research questionnaire. Others were new to the project.

Although each regional workshop used the same format, there were some differences in the dialogue. For discussion purposes, the workshops focused on four sets of issues:

- drug use
- use of services and information
- parent and child health
- environmental health and safety

broader social context

Some participants took the discussion to a much broader social context - making connections between illiteracy and poverty, inadequate housing and unemployment. Some participants were more active in the community than others in tackling the literacy-related health issues.

Provincial Consultations:

development of strategies

On November 28 and 29, 1988 in Toronto a provincial consultation took place. Sixty individuals from the literacy, health and social service communities, as well as representatives from the federal and provincial governments were brought together. The first day was spent reviewing the research findings and devising strategies to deal with specific issues. The second day involved looking at the issues in a larger social context. This led to the development of strategies with the aim of improving the situation in a concrete way.

Strategy Meetings:

**synthesizing information
areas for action
recommendations**

The Project steering committee took on the task of synthesizing all the information gathered throughout the research and consultation processes. Areas for action and recommendations with accompanying strategies were drawn from the data gathered. This information was sent to a strategy team, made up of eleven interested individuals who had participated at one of the regional workshops and/or at the provincial consultation. The strategy team met on February 17th, 1989 to consolidate the recommendations and establish a structure to move the project forward into its next phase.

Special Populations:

The consultation process made it clear that certain groups - such as Natives, franco-Ontariens, people with disabilities, senior citizens and immigrants - have unique concerns about literacy and health and require focused attention. We propose in Phase Two to sharing with each group the information gathered and to provide support so they can deal with their own issues and circumstances.

ENDNOTES

1. Southam “Literacy in Canada” Survey, 1987.
2. We received a total of 107 responses to our initial mailing of 368 letters. This represented a response rate of 18% from community groups and 65% from public health units.
3. A complete list of papers and documents reviewed is contained in the Bibliography.

IV. RESEARCH FINDINGS

WHAT IS ILLITERACY?

comprehension

The concept of literacy is relative. Literacy exists in degrees. There is no distinct cutoff point between literacy and illiteracy. Literacy involves more than simple reading (or decoding) of words. It includes skills of comprehension, understanding and verbal reasoning ability.

The research of Eisemon¹ and others has indicated understanding of literacy is further influenced by one's familiarity with the context or "prior knowledge" of an area. For example, a report about immunization may be incomprehensible to a person with no prior knowledge about microorganisms. This broader view of literacy has implications both for the presentation and understanding of health information.

"basic illiteracy"/ "functional illiteracy"

"Basic illiteracy" is the total inability to read or write. More common is "functional illiteracy" - a lack of sufficient reading, writing and numeracy skills to get by in everyday life. The concept is intentionally relative - the knowledge and skills an individual must possess to be able to cope are related to the demands of a particular society or community. These demands can and do change. With the shift away from a manufacturing to

information-based economy

an information-based economy, increasingly higher levels of reading, writing and numeracy skills are required even for many entry-level jobs.

The Southam *Literacy in Canada* study, completed in 1987, measured literacy ability through the use of reading assessment tasks. According to Southam, 24% of Ontario adults are functionally illiterate. 20% of Canadian-born Ontarians (excluding all immigrants) are illiterate.

However, few direct measures of literacy are available. Functional illiteracy is most commonly defined by the UNESCO guideline as less than grade 9 education. According to this criterion, 19% of Ontario's adults are functionally illiterate.

The Southam study identified "false illiterates" - persons who were functionally literate but with less than grade 9 education - as well as "false literates" - persons who were not functionally literate even though they had more than grade 9 education. While grade level is not always useful for determining the literacy level of a given individual, it only slightly underestimates, by about 5%, the literacy rate of a community or society. In spite of its shortcomings, grade level is still a useful indicator. Literacy has been assessed using the grade level method in most of the research studies reported in the literature.

Our study focused on illiteracy rather than on the inability to speak or read English and French. Two other issues are related and important.

- We also found that people such as immigrants, illiterate only in their mother tongue, had similar health problems.
- Written and oral communication which fail to take into account the cultural or sub-cultural background of the intended audience also contribute to a failure in understanding.

LITERACY AND HEALTH STATUS

The initial purpose of this study was to identify specific health hazards that result from a limited ability to read. Our findings demonstrate that virtually all health-related aspects of people with limited literacy skills are worse than for others.

poorer self-reported health status

One of the most commonly used indicators of health is self-reported health status.² The Health Promotion Survey found that 27% of those with elementary school education or less rated their health as fair or poor. For those with some high school only 17% reported their health as fair or poor. For those who had graduated

from high school, the figure dropped to 9%; some post-secondary education - 8%; community college completed or a university degree - 6%. Very similar findings of self-rated health have been found in other surveys.

greater activity limitation

Another measure of health is activity limitation.³ 26% of persons with elementary school or less reported an activity limitation, compared to 16% for those with some high school and 11% for those with a university degree.

higher rate of accidents

Some activity limitation is the result of an accident. We found that people with limited education also have a higher rate of accidents, not only at the workplace but also at home and in the community.

Many other factors in addition to illiteracy or limited education are also associated with poor health. These include age, income and environmental concerns. To what extent might the health effect associated with illiteracy and education level actually be a result of one or more of these other factors? To what extent might illiteracy result from poor health, rather than the other way around?

illiteracy major variable affecting

A variety of studies have explored the relative contribution to health of a wide range of variables, and all have shown that literacy or education is the major variable affecting health. To give one example, Leigh

examined some 20 other factors and concluded that: “Years of schooling persists as a predictor of good health regardless of which other variables enter the equation or in what manner health is measured.”⁴

Particularly dramatic is a report of the World Bank on the effects of education on health.⁵ *The report indicates that literacy is the most important variable associated with mortality, even more so than income and food intake!*

HOW IS ILLITERACY RELATED TO POORER HEALTH?

Does illiteracy lead to poorer health? It is clear there is no simple answer to this question. The nature of the impact is complex. It appears that illiteracy has an indirect affect on the health as well as a more pronounced direct affect. Some of these factors are discussed below.

DIRECT IMPACT OF ILLITERACY ON HEALTH

In the literature we surveyed, there is limited information indicating the direct impact of illiteracy on health. On the other hand, the responses of community health and literacy workers to our questionnaire, as well as the case studies we conducted, enabled us to identify numerous examples of health problems, often severe enough to require hospitalization, directly related to illiteracy. The following are specific examples of the types of problems reported.⁶

Incorrect Use of Medications:

lack of understanding inability to read

Just about half of the respondents to our questionnaire indicated an experience with incorrect use of medications, or a lack of understanding instructions about proper use of medications. This involved both prescription drugs as well as over-the-counter (OTC) medications. Errors due to an inability to read instructions have resulted in overdoses and in mixing up different medications. Some of these errors were serious:

Inappropriate administration of medication - both OTC and prescription. Clients go by colours and are confused if brand changes and pills change colour. Can't read directions, so underdose or overdose with adverse effects.

Geriatric patient admitted to hospital with overdose of sleeping medication - couldn't read English or mother tongue and couldn't differentiate medications or remember when to take them - an accidental overdose.

Client with epilepsy couldn't distinguish medication - thought they were all vitamins and couldn't understand why she was taking them.

Not Following Medical Directions

We were given a number of examples of persons who would not comply with medical directions, due to inability to read written instructions or because verbal instructions were not presented in a way in which they could be understood. Examples we were given included:

**lack of compliance
lack of comprehension**

Diabetics who were not following prescribed treatment, who were not taking insulin, or who could not read food labels in order to avoid foods containing sugar.

Surgical procedures and test results may be poor or faulty because of incorrect patient preparation – instruction sheet too difficult to follow and not comprehended or complied with.

Forty-eight year old man had coronary condition – couldn't read instruction sheets re special medical procedures given by doctor.

Family discontinued use of contraceptive practices – no understanding of concept and couldn't read instructions/literature.

Errors in Administration of Infant Formula

misuse

13% of the respondents to the questionnaire spontaneously identified misuse of infant formula:

Unable to read directions on baby formula.

Mothers not diluting concentrated formula and others diluting ready-to-feed formulas – babies at risk.

Illiterate couple with bottlefed baby. Baby was “fussy” as father changed formula and gave baby almost undiluted carnation milk and then changed to whole milk – changed formula four times. Baby became very dehydrated and had to be hospitalized.

Young student in literacy group was about to give newborn baby Enfalac straight out of the can because she couldn't read instructions to mix it with water.

Safety Risks:

**inability to read and
comprehend safety warnings**

These include the inability to read and comprehend safety warnings, particularly at the workplace. While no quantitative evidence about the incidence of accidents in

which illiteracy has been a direct cause is available, some examples serve to illustrate problems which have arisen. The Advisory Council on Occupational Health and Occupational Safety cites the following examples:

A worker who was unable to read was newly recruited to a construction site and was asked to obtain boots for the worksite. The boots purchased outwardly resembled those worn by other workers but, having no steel plate insert, subsequently played a part in an injury to the worker's foot.

A worker was injured when handling chemicals that had safety instructions on the label, which he was unable to read.

A pictorial instruction material demonstrating "how not to" carry out a task was interpreted as a "how to" instruction and the result was an increase in accidents.

But not all safety risks are in the workplace. One respondent to the questionnaire gave the following example:

One learner had her child taken away from her because her baby became ill after playing in polluted water. The Children's Aid accused the mother of neglecting to read the warning signs posted in the area. The mother was too ashamed to say that she couldn't read.

INDIRECT IMPACT OF ILLITERACY ON HEALTH

Health problems such as those indicated above, resulting directly from an inability to read, are significant and dramatic. However, a striking finding from our research is that these direct impacts represent just the tip of the iceberg.

It is apparent from the research and our own data that the major impact of illiteracy on health status occurs indirectly. For example, as Leigh has indicated, "Evidence from two national surveys indicates that the indirect dominate the direct effects ... In terms of statistical significance, smoking, exercising and choice of occupation appear to be very important intervening variables between schooling and health."

greater indirect impact

Illiteracy leads to poor lifestyle practices, stress, unhealthy living and working conditions, and results in lack of access to health information and to inappropriate use of medical and health services. It also frequently results in unemployment and in poverty. These factors,

in turn, have major detrimental impacts on health, as briefly outlined below.

Healthy Lifestyle Practices

unhealthy lifestyle behaviours

People with limited literacy skills are more likely than are others to take part in a wide range of unhealthy lifestyle behaviours, and less likely to engage in preventative measures.

For example, people with limited literacy, in comparison with other:

- smoke more
- have poor nutrition
- drink more coffee
- are less likely to engage in regular physical activity
- do not use seatbelts
- among women, are less likely to practice breast self-examination and to obtain pap smears
- are less likely to ever have had a blood pressure check
- are less likely to have a fire extinguisher, smoke detector, or a first aid kit at home

These findings are consistent across a wide variety of surveys and research studies. They have been confirmed by respondents to our own survey. In addition to risky

lifestyle behaviours in a number of situations, people with limited literacy skills are also less likely to be aware of the importance of healthy practices.

Indeed, as Canada's Health Promotion Survey and other major surveys have found, about the only major risk factor where people with limited literacy were not worse off was with respect to drinking. People with higher levels of education drink more in total, are more likely to drink to excess and to drive after drinking.

The impact of these risk factors on health is well documented. Some researchers feel that the unhealthy lifestyle practices, and failure to practice preventative medicine, may be one of the major reasons for the poor health status of people with limited literacy skills.

avoid "blaming the victim"
limited opportunity

When considering the lifestyles of people with limited literacy, one should be careful to avoid "blaming the victim". For many reasons people with low literacy have limited opportunity to make informed choices about their own lifestyles.

Literacy and Poverty:

The impact of poverty on ill health has received considerable research attention and is well documented.

health inequalities
die younger
ill more often
fewer years of life that are disability free

The Black Commission in the United Kingdom documented health inequalities among people of low income. There has been considerable documentation in Canada as well of health inequalities among the poor. For example, a background study for the Social Assistance Review Committee (SARC)⁸ documented the relationship between poverty and health status, presenting evidence that poor people die younger, are ill more often and have fewer years of life that are disability free.

higher mortality and morbidity

The National Anti-Poverty Organization, in a review of community-based literature, found "an inexorable link between low income and higher mortality and morbidity" and a surprising consensus that health inequalities created by poverty result from hunger/malnutrition, unhealthy environments, and from stress. Labonte⁹ has also explored some of the mechanisms whereby lower socio-economic status leads to poor health.

education is basic prerequisite

To what extent are health problems attributable to illiteracy rather than to low income and poverty? While the lack of education and literacy skills is not the only reason for poverty, it clearly is the major factor. Education is a basic prerequisite in most cases to enable a person to obtain employment and sufficient income to avoid or to escape poverty.

**low-paying, low-skilled,
marginal jobs**

Over half of all social assistance recipients in Ontario are functionally illiterate. Only 40% of Ontarians with less than grade nine are employed, 55% are not even in the labour force. And those functionally illiterate people who are employed are more likely to be working in low-paying, low-skilled, marginal jobs with poor job tenure. These and other factors have led the Social Assistance Review Committee to conclude that “a basic level of literacy and numeracy is a prerequisite for almost any job.”¹¹ This is backed up by Rea, who states: “Quite simply, it will be considerably more difficult for an illiterate or semi-literate to find gainful employment in an increasingly information-based economy.”¹²

Not only are literacy skills required to obtain almost any job which would pay enough to permit a person to live above the poverty line, but many training programs have educational prerequisites of grade 10, 11 or 12. Thus functionally illiterate persons cannot even qualify for admission to training programs, including the Employment Support Initiatives Program of the Ministry of Community and Social Services. These are specifically designed to assist social assistance recipients in acquiring skills to achieve independence.

We do not intend to minimize the direct influences of poverty itself on ill health. On the contrary, poverty directly affects health in many ways. It is clear that the effects of illiteracy, poverty and health are related and interdependent. To a large extent poverty results from illiteracy and limited education, and so do the health problems associated with it.

Stress and Low Self-Esteem:

Both the literature review, our questionnaire and case studies highlight the connection between illiteracy, stress, and ill health.

high level of stress

less self-confidence

People with limited literacy skills tend to be under a high level of stress and to have less self-confidence. It is difficult to function in a world where the ability to read is taken for granted and a requirement for many basic day-to-day activities. One must “make do” without information available to those with better literacy skills. This leads to frustration, anger, and feelings of shame. People with low self esteem also find it more difficult to seek and find employment or to socialize with others. This leads to even greater stress and increased risk of health problems.

vulnerability

lack of control

Inability to read well enough to meet society’s literacy demands results in feelings of vulnerability and lack of control over one’s life. This vulnerability is very real. Jobs which are open to people with limited literacy skills

generally are of low status and of limited tenure, and give employees little say over working conditions. And people on social assistance are perceived by society – and often by themselves – as having given up their independence. Resulting poverty brings on additional stress. The National Anti-Poverty Organization has identified stress as the major health hazard affecting people living in poverty.

Dangerous Work Environments

more occupational injuries

jobs more hazardous

While conclusive data is not available, it appears that people with limited literacy skills have a higher than average rate of occupational injuries. This appears to be mainly because the types of jobs open to them are more likely to be hazardous. A disproportionate number of persons who are functionally illiterate are employed in primary, resource and construction industries. Accident rates in these industries are well above the average across all workplace settings.

In addition, much information about occupational health and safety is available only in written form.¹³ One study of literacy students¹⁴ found that:

- almost all participants had the need to read material related to occupational health and safety and that all had experienced some difficulty in doing so

- most ignored instructions they could not read
- only about one-half had been provided with oral explanations of jobs

Furthermore, people with limited literacy skills are less likely to be aware of the existence of dangers at the workplace and of their rights under occupational health and safety legislation. If they are aware, workers are unlikely to be in a position to assert their rights.

As the Advisory Council on Occupational Health and Occupational Safety indicated:

Practical difficulties in finding and obtaining employment, fear of losing one's job if lack of literacy is discovered, limited job options and lack of confidence can be expected to inhibit the illiterate worker from speaking out and from effectively participating in the resolution of health and safety problems in the workplace. Those who are functionally illiterate tend to be operating from a position of social and economic disadvantage, and the "stigma" associated with illiteracy may cause the illiterate to hide an inability to read, write or comprehend material or to fail to seek help.

presence of hazards insufficient or inappropriate instruction or training	The available evidence, as Ramirez ¹⁵ suggests, is that it is the job and not the worker who is dangerous. As the Advisory Council indicated: "The cause lay rather with the presence of hazards in the workplace and/or insufficient or inappropriate instruction of training."
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Access to Health Information

Reading Information

inaccessible	A great deal of health information is in written form and hence inaccessible to people with limited literacy abilities. This includes information from health and social services organizations, as well as from the popular press and other sources.
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major vehicle used	The written word is the major vehicle used by health agencies for transmitting information about health care and health lifestyles. Thus this information is inaccessible for people who cannot read.
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simplified language	There has been increasing recognition within the health community that much of the written material available may be overly complex, and should be prepared using more simplified language. This developing interest in readability will expand the accessibility and usefulness of written materials to many people.
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However, many others still cannot or will not read any written information, no matter how simplified the language.

Understanding Information

translation not readily understandable

There are increasing attempts to provide translations of a number of brochures into other languages. However, we have been told that many of these translations are overly complex in the language to which they are translated and hence are not readily understandable.

adapt rather than translate

Much health information, in whatever form, may be culturally inappropriate. Material needs to be *adapted* rather than translated for it to be meaningful and understandable.

use of complicated symbols

Use of symbols has sometimes been suggested to communicate with people who have limited reading skills. However, many symbols are also incomprehensible. Generally the more abstract a symbol is, the less likely it will be understood. As with words, the meaning of a symbol to an individual is related to previous experience with the symbol and the context in which it applies. For these reasons, it appears that symbols may be even less meaningful for people with limited literacy skills than for others.

limited vocabulary

Literacy involves not just the simple decoding of written words. More importantly, it involves comprehension and

limited prior knowledge of health

understanding. If health messages of any form are to be understood, basic principles of communication must be followed. This involves adapting messages to fit the context of the person's life, and may involve checking the actual knowledge acquired. People with limited literacy skills tend to have a limited vocabulary and limited prior knowledge of health.

Unless these factors are taken into account, even verbal directions from health practitioners to people with limited literacy are frequently impossible to understand. Written materials are also used frequently by health practitioners as backup or reminders to verbal directions. For people who cannot read, this is not an option open to them.

misinformation

As a result, it is hardly surprising that many people with low literacy skills have a limited understanding of health issues, and often acquire considerable misinformation. To be sure, the impact of health information on actual health behaviour and on health status has not been well evaluated. But health promotion efforts have been credited with recent improvements in health practices among the general population. For example, information on smoking has decreased the numbers of smokers and nutrition information has improved dietary practices. To the extent that written health information has value, then the inaccessibility of this information to persons with limited literacy can only have a negative effect on their health.

Lack of Use or Inappropriate Use of Medical and Health Services:

locating health services

There is considerable documentation that many people with limited literacy skills don't know where to go for health services. Many people don't know what community or health services are available. If they do know which services exist, they don't necessarily know how to get access to them. We heard of examples of people who did not have OHIP – some could not fill out the necessary forms to qualify, some didn't know about the premium assistance plan, while some were not aware of OHIP at all.

One case reported to us (through our questionnaire) concerned a young boy who fell and cut his forehead near the eye. His mother was new in town, did not know where the hospital was located, and was unable to use the telephone book. As a result, the boy did not receive immediate attention and almost lost his eye. Others may be afraid or embarrassed to ask for help. As one health worker indicated in her response to the questionnaire:

Clients' self-consciousness about not knowing how to read is a major problem. They are shy about asking the doctor or social worker to explain to them the instructions on prescriptions, the terms of their ailments... They prescribe over-the-counter medication for themselves based on the recommendations of friends.

keeping track of appointments	Illiteracy also leads to inappropriate use of medical services and care. For example, people with limited literacy skills sometimes have difficulty keeping track of appointments or following directions. In at least one case of which we were made aware, surgery had to be postponed because of a patient could not read the hospital's pre-admission directions.
following directions	
neglect preventative care	Some people over-react to perceived health problems, and others make unnecessary use of hospital emergency services. But in many other cases, people with limited literacy skills, for a variety of reasons, neglect preventative care and wait to seek medical help until a health problem has reached a crisis stage. As Leigh ¹⁶ has indicated, education enables wise use of medical care.
	Compliance with medical directions may be poor among people with limited literacy skills. This is partly because of the inability to read or understand written instruction sheets or prescriptions. More often, it is a result of lack of understanding of verbal directions, due to the failure of medical workers to present information and direction so that it can be understood.
AWARENESS OF THE HEALTH PROBLEMS RESULTING FROM ILLITERACY	
lack of awareness	Many people within the public health and literacy communities are aware of the potential impact of illiteracy on health. The response to our questionnaire from public health units indicated that many public health workers are aware of the problem, and have thought about it and are struggling to deal with it. Many public and community health workers gave us specific examples of literacy-related health problems, and approaches they have taken to attempt to combat these.
feelings of isolation	However, these same respondents indicated that they feel isolated. They appreciated the opportunity to talk about their encounters with illiteracy. For many, this was their first opportunity to discuss the topic. Others felt that they were one of a very few that understood the nature of the problem.
few understand problem	But many others – 20% of those who responded to the questionnaire, and probably many of the others who

chose not to – indicated that they are not aware of the relationship, if any, between literacy and health. This was reflected in:

- an interest in knowing more about the literacy and health issue
- an admission that little thought had been given to the issue
- outright denial that illiteracy could lead to health problems
- one respondent who claimed that health problems were not a function of illiteracy, but rather of *lifestyle*.

It appears that most people do not understand the full extent of illiteracy in our society. A survey by Westmount Research¹⁷ found that only 11% of Canadians were able to estimate correctly how many people are lacking in literacy skills. While there is no data about awareness among health workers, all indications are that they similarly fail to comprehend the magnitude of the literacy problem.

One of the top three suggestions among respondents to our questionnaire was to enhance awareness of health care professionals about the problems of illiteracy and how they should respond.

Awareness of What To Do:

disguising illiteracy recognizing illiteracy

Many people who cannot read go to considerable effort, for good reasons, to disguise their illiteracy from everyone, including health workers. In response to our survey, many health workers indicated the need for training about recognizing in a tactful manner when illiteracy is a factor, and how to respond appropriately.

Some medical and health workers disclaim any responsibility on their part.¹⁸ It is apparent that most professionals in the health area are simply not aware of the problem of illiteracy or the fact that many persons disguise their inability to read or to understand. Nor have they considered that “lack of compliance” may be no more – and no less – than the inability to read or to understand complex verbal directions.

THE CHALLENGES

People with low literacy skills face a number of challenges:

- **opportunities** Many recognize that they do not read well enough to understand a great deal of information that is important to them, and they want to learn to read

better. *Canadians should have the opportunity to learn to read better.*

able to get and use information

- While some people have low literacy skills, they still must have access to vital information. *Regardless of whether or not people can read well, they should be able to get and use information that is important to their health and safety.*

need healthy and safe environments

- Limited options make it difficult for people with low literacy skills to use the information they do possess. For instance, someone who knows how to eat well still has trouble doing so if there is not enough money to buy food. *Regardless of how well people read, and how much information they have, they should be able to live, learn, and work in environments which promote their health and safety.*

ENDNOTES

1. See T.O. Eisemon, *Benefitting from Basic Education, School Quality and Functional Literacy in Kenya*, (Oxford Pergamon Press, 1988).
2. The question used on the Health Promotion Survey was: “In general, compared to other persons your age, would you say your health is excellent, very good, good, fair or poor.”
3. The question asked on the Health Promotion Survey was: “Are you limited in the kind or amount of activity you can do because of a long-term physical condition or health problem?”
4. J.P. Leigh, “An Empirical Analysis of Self-reported, Work limiting Disability,” in *Medical Care*, (1985: 23,4), p. 318.
5. See S.H. Cochrane, D.J. O’Hara and J. Leslie, *The Effects of Education on Health* (Washington, D.C.: The World Bank, 1980), Working Paper No. 405.
6. All quotations in this section are from the responses to the questionnaire, unless otherwise indicated.
7. J.P. Leigh, “Direct and Indirect Effects of Education on Health,” in *Social Science Medicine* (1983: 17,4).
8. See M. Harding, “The Relationship Between Economic Status and Health Status and Opportunities: A Synthesis” (Toronto, Ontario: The Ontario Social Assistance Review Committee, 1987).
9. H. Echenberg, National Anti-Poverty Organization, “Working Summary of Community-based Literature on Health Inequalities” (Ottawa, Ontario Health Service and Promotion Branch, Health and Welfare Canada, 1987).
10. R. Labonte, “Concepts, Research and Strategies Related to Social Support and Surplus Powerlessness (*Heart Health Inequalities Workshop Report*, December 3, 1987).
11. Report of the Social Assistance Review Committee, *Transitions* (Toronto: Ontario Ministry of Community and Social Services, 1988).
12. B. Rea, *Adult Literacy and the Workplace* (Interim Report: Phase II, 1986).
13. The new Workplace Hazardous Materials Information System is just one example.

14. The quotations on this page are taken from The Advisory Council on Occupational Health and Occupational Safety, *Seventh Annual Report* – April 1, 1984-March 31, 1985 (Toronto: Ontario Ministry of Labour).
15. See R. Ramirez, “The Relationship between Illiteracy and Accident Occurrence.” Proceedings of the 10th World Conference on the Prevention of Occupational Accidents and Diseases (1983), pp. 165-66.
16. See J. P. Leigh, “Direct and Indirect Effects of Education on Health.”
17. Canadian Business Task Force on Literacy, *Literacy Public Opinion Survey*, (Toronto: Westmount Research Consultants Inc., 1986).
18. The questionnaire responses and the case studies suggest the presence of viewpoints such as:
 - “It’s a job for the education sector, not for health workers.”
 - “If people don’t understand what I say, it’s not my problem – I don’t have time to explain everything in simple language.”
 - “It’s the job of the health educator – not for me to worry about.”However, it is.

V. RESPONDING TO THE ISSUE

Three types of action are required to address the different kinds of relationships between literacy and health and the various challenges that people with low literacy skills face. These three crucial areas of action are:

- a commitment to achieve literacy and health for all
- a commitment to make environments healthy and safe
- a commitment to ensure equitable access to vital information

coordinated and complimentary action

These commitments cannot occur in isolation of each other. Action must be coordinated and complimentary in order to make the world healthier and safer for people who can't read.

A COMMITMENT TO ACHIEVE LITERACY AND HEALTH FOR ALL

All Canadians need to read, write and use numbers well enough to meet the literacy demands of today's society. People need to have control over and improve their health. Particular attention should be directed to increasing the ability of Canadians to understand information which is important to their health and safety.

The research and consultation process purposefully did not address issues related to improving the quality of the public school and health care systems in Ontario. But what became very clear during the process was that both need improvement.

teaching people to read

Many respondents to our questionnaire, as well as researchers in the area, have said that the best way of addressing the health problems associated with illiteracy is by teaching people to read. A number of medical economists, including Slater and Carlton, indicate that "Each additional dollar spent on education reduces mortality more than each additional dollar spend on medical care."

A commitment to literacy means at least two things:

effective and useful education

- Making sure that young people learn to read, write and use numbers. This means ensuring all children receive an effective and useful education.

provide opportunity

- Many adults have never had an appropriate opportunity to become literate. Action must be taken to provide that opportunity. Today, about

24% of adult Canadians are not able to read, write, and use numbers well enough to meet the literacy demands of today's society. A commitment to moving from this situation to one of a literate Canada is critical. It will take time.

A commitment to achieve health for all means:

- reduce health inequalities**
 - Finding ways to reduce inequalities in the health of people in different income groups, geographic groups (including rural and urban disparities), and cultural backgrounds. Searching for health policies and actions which can reduce health inequalities is a major challenge.
- prevention**
 - Finding new and more effective ways of preventing the occurrence of injuries, illnesses, chronic conditions and their resulting disabilities. Prevention involves identifying the factors which cause a condition, and then reducing or eliminating them.
- enhancing people's ability**
 - Enhancing people's ability to manage and cope with chronic conditions, disabilities and mental health problems. The challenge is to provide the skills and community support needed to improve the quality of life.²
- community support**

Barriers:

Many people with low literacy skills want to improve their skills but are unable or unwilling to do so for a number of reasons. For these same reasons, people with low literacy skills may or may not take advantage of the health care system available to them.

- The accessibility of programs and services in communities at times and places and with the supports required. Many communities do not have literacy programs. Many literacy programs are not able to respond to the demand. People who are working and raising families often do not have sufficient time to engage in ongoing education programs. Adults with child care responsibilities often require child care supports.
- learning styles and preferences**
 - The learning styles and preferences of individuals vary considerably. Frequently, available literacy programs offer only one approach. The program is not accessible if this approach does not match the learning style of the individual.
- stigma of illiteracy**
 - The stigma of illiteracy. We know from the Southam Literacy Survey that many adults who have low literacy skills will not take advantage of

programs. In part, this is because people are embarrassed or feel badly about themselves because they cannot read, write or use numbers well enough. There are other reasons. Clearly, many people believe they have developed other ways of coping which, they feel, means they do not have to develop their own skills. They rely on other people and other methods to get the information they need.

Strategies:

The implications of these factors are far-reaching. The following strategies suggested by participants in the research process, the regional workshops and the provincial consultation:

- increasing the capacity** • Increasing the capacity (the size and number) of literacy programs to respond to the number of people who want and need support.
- expanding the range of settings** • Expanding the range of settings in which literacy programs are available in each community, so that individuals can take advantage of opportunities in environments which are more responsive to their preferences. A diverse range of settings would include community programs with a range of affiliations and locations.³ Individuals would have choices of individual or group tutoring in places which are convenient and comfortable for them.
- expanding the range of approaches** • Expanding the range of approaches to literacy which are available in each community. A diverse range of approaches would include curriculum-based and individual and/or family-based. It would also include approaches which help learners focus on a broad range of topics so they can be better informed about specific matters such as a new work responsibility, a child's health, their legal rights, and so on.
- expanding the supports and opportunities** • Expanding the supports and opportunities available to individuals so they can move in and out of education programs throughout their lives. There are many different types of supports which are required, ranging from child care to the ability of an individual to attend programs which are close to home or work. Financial assistance would support individuals to further their education while they continue to meet their other obligations at home or work, or so they can be relieved of those responsibilities for periods of time.
- “watchdog” role** • A committee on literacy and health needs to be formed to take a leading “watchdog” role. Developing a READ Team that would help groups

	Review, Evaluate And Develop appropriate materials and programs for people with low literacy skills.
literacy criteria	<ul style="list-style-type: none"> • Government and foundation grant and contribution programs need to incorporate specific criteria ensuring that literacy has been considered.
alternative means of communication	<ul style="list-style-type: none"> • Guidelines need to be established for creating readable and useful information and for encouraging alternative means of communication other than print.
lifelong learning	<ul style="list-style-type: none"> • The creation of a major shift in the education system to allow for lifelong learning. This would establish a drop-in/drop-out philosophy allowing people to acquire the skills they need when they need them.
increasing the awareness	<ul style="list-style-type: none"> • Increasing the awareness among health, medical and social service workers of the incidence of illiteracy and how it can affect the health of a large number of people. The existing health care system in many respects perpetuates rather than attempts to minimize the systemic barriers resulting in unequal health services and unequal health outcomes.
reduction of health inequalities	<ul style="list-style-type: none"> • A commitment by the health and medical communities to the reduction of health inequalities. This requires action on the individual level, for example in the provision of appropriate and culturally sensitive health services for disadvantaged people, including people with limited literacy skills.
re-directing the philosophy	<ul style="list-style-type: none"> • Re-directing the philosophy of the medical model from curing people to preventing illness and promoting health and safety. A re-aligning of funding would need to occur to reflect the prevention and promotion orientation. This in turn has implications for restructuring the way health services are organized and provided and for changes in health priorities.
recommended changes in health services	<p>Limitations in our current approach to health care have been well documented. So have needed changes. For example, three major reports on the health care system in Ontario have recommended major changes in the manner in which health services are provided.⁴ Health and Welfare Canada's framework for health promotion, <i>Achieving Health for All</i>, is also dedicated to the reduction of health inequalities. The Ontario Public Health Association recently identified the reduction of health inequalities [as] a priority.</p>

non-medical interventions

healthy public policy

making workplaces safer

improving living conditions

Health inequalities such as those identified in this report, arising from illiteracy as well as from other socio-economic factors, can only be eliminated through concerted action by all sectors of society. While the health consequences of illiteracy may be medical in nature, resulting in increased mortality and morbidity, the solutions for the most part require non-medical interventions. Action is required in the development of healthy public policy, making workplaces safer, improving living conditions, ensuring the delivery of education for all, and along other fronts.

For this to happen, commitment to action is needed by politicians, all levels of government, business and labour, the media, and the public. Any remedies which do not involve a major commitment and action across many different fronts would only involve tinkering, and are unlikely to make any major impact on existing inequities in health status.

A COMMITMENT TO MAKE ENVIRONMENTS HEALTHY AND SAFE

being able to act on information

Having information is one thing. Being able to act on that information is often quite another thing. During the consultation process, the following example was presented related to this issue:

We all know that to fight a cold you should go to bed, drink plenty of fluids, and take aspirin. Now a kid living on the street can understand this perfectly well. The problem is that he does not have a bed, can't rest because he has to spend so much time just surviving, and has no money to buy aspirin. The cold is probably going to turn into something much more serious until he has what he really needs – a decent place to live, an income, and enough security that he can rest.

Making environments healthy and safe is not just an issue of providing what is needed. People can act in unhealthy and unsafe ways in perfect environments. *The point here is that it is very difficult for people to be healthy and safe in unhealthy and unsafe environments.*

public policy process

Just as the project did not explore the complex issues and strategies related to improving the quality of the public school and health care systems in Ontario, it did not take an in-depth look at all the strategies required to make environments healthy and safe. Currently, the public policy process in Ontario is involved with numerous studies related to strategies in critical areas:

- decent and affordable housing
- safe work environments and practices

- access to quality medical care
- adequate income for those requiring assistance
- environmental quality (air, water, and so on)
- the organization and delivery of human services

**environments
favourable to safe and
healthy practices**

Actions and policies related to achieving literacy and health for all and ensuring equitable access to information in the context of health and safety are ineffective if the environments in which people spend their time are not favourable to safe and healthy practices and lifestyles.

Strategies:

From the research findings and the provincial consultation, a number of strategies were suggested.

**improving living
conditions**

- Many of the negative health consequences for people with limited literacy abilities result from poverty. Improving their living conditions and level of income will assist in combating these health problems.

**implementation of SARC
recommendations**

- The Social Assistance Review Committee (SARC) thoroughly investigated problems of people living in Ontario on social assistance, and among the working poor. As part of its investigation, the committee considered the effects of illiteracy as well as health problems of the poor. It made 274 recommendations for reform of the present system.
- Implementation of these recommendations can go a long way towards overcoming the health problems associated with poverty.

**more accessible safety
information
responsibility of employer**

- A major factor affecting the health of persons with limited literacy is that those jobs which are open to them tend to be dangerous. More accessible safety information in other than a written form will help to some degree. The responsibility of the employer must include testing for the actual receipt and understanding of safety knowledge, rather than the mere provision of materials. But for any substantive changes in the reduction of workplace injuries, there is need for a greater commitment to making the workplace safer.

**A COMMITMENT TO ENSURE EQUITABLE ACCESS TO
INFORMATION**

It is important to ensure that all Canadians receive, understand and are able to use information related to their health and safety.

**information is understandable
and useful**

**social and cultural factors
incorporated**

“Equitable access” means that vital information is adapted to individuals in ways which ensure the information is understandable and useful to them regardless of their literacy skills and learning styles. Equitable access also means adapting information to take into account other social and cultural factors – including language, gender, age, socio-economic status and cultural background.

This means recognizing and responding to a number of facts:

- Written information – labels, instructions, information pamphlets, books, posters, etc. – must be readable, useful, and geared to people who have trouble reading. *But this cannot be the only strategy.*
- Information can and should be presented in a wide variety of ways:

Written words, symbols, spoken words, information that is given in public or private information that is presented personally, through audio-visual means, by written materials; information that comes from a professional, a community authority figure, a neighbour or fellow worker; information that we have to go and get or that comes to where we are; information that is adapted to a variety of languages and cultures.

- People, regardless of how well they can read, respond differently to information presented to them. *If the same information is to reach different people, it is vital that this information be presented in a variety of ways.*
- And finally, the critical issue is comprehension. *Regardless of how information is presented, it is very important that we find out if individuals have understood it.*

Strategies:

The consultation process identified four major components that must be considered to ensure equitable access to information and corresponding actions to be taken:

1. Awareness

**extent and nature of
problem**

The public, professionals, and organizations must become more aware of the nature of the problem of

**actions required
obligations**

literacy and health, the kinds of actions that are needed and the obligations of many parties to take action.

Awareness of the extent and nature of the problems associated with illiteracy is a prerequisite for action by the health community. Many of the respondents to our questionnaire pointed to the need for increased awareness and education among health, medical and social service workers. The two most important areas they identified are:

- To increase awareness about the incidence of illiteracy and how it affects the health of a substantial proportion of the population.
- To assist health workers, through training and other means, in recognizing when illiteracy may be a factor and how to deal with the problem tactfully and effectively while maintaining the dignity of the person.

A number of specific suggestions about how to accomplish the above were provided. These included:

- awareness-raising workshops
- consultations
- skill-training sessions showing health workers how to communicate clearly
- interaction between health professionals and literacy workers

Given that 25% of the adult population is functionally illiterate, health workers such as pharmacists should assume, unless they have reason to believe otherwise, that their clients cannot understand written instructions. Verbal explanations should be given as a matter of course. The recipients of information should be asked if they understand the information given to them.

During the provincial consultation, the following opportunities to raise people's awareness of literacy-related health problems were identified:

- health, medical and social service professional training programs
- professional and organizational conferences
- organizational in-service training opportunities
- the public school system
- inter-agency and social planning council
- the media.

2. *Community Involvement*

One of the effects of illiteracy is a lack of control over one's life. This feeling of helplessness produces stress, and in turn health problems.

work in partnership
community development
popular education
use existing social networks
peer groups
key neighbourhood contacts

One potential approach to combating health problems associated with illiteracy is to work in partnership with people who have limited literacy skills to help them help themselves. A variety of community development and popular education approaches can permit active and meaningful involvement of learners. These approaches can also include working together with existing social networks in the community, including a wide range of organizations such as literacy groups, women's groups, anti-poverty organizations and others.

People who do not read have other ways of acquiring information. These include peer groups, as well as key neighbourhood contacts, who may be a local point for the provision of information to others. (A helpful strategy for health education is to make use of these existing social networks.)

People for whom the information is intended must be involved in the design, production, distribution and evaluation of the information to be provided. This would ensure that vital information can be adapted, received, understood and used by people, and more specifically by people with low literacy skills.

community review teams

Community review teams – comprised of professionals and consumers – could also be developed to review and evaluate health, medical and social service information available, and encourage the development of appropriate information by and for that community. They would list resources available through agencies, government and other community groups that are appropriate for people with low literacy skills. In doing so, this team would link up with existing resource centres.

3. *Multiple Communication Strategies*

To ensure that information is accessible to the variety of individuals who require it, many types and styles of communication strategies must be employed to adapt any single piece of information.

**use non-written forms
of communication**

For those who cannot understand the written word, it is necessary to use non-written forms of providing health information. The most common approaches we heard about include the following:

- use of pictures, symbols, and audio-visual aids in communicating health information and medical directions
- use of one-on-one interventions and demonstrations, as well as small groups sessions
- use of creative strategies such as drawing a picture of a clock showing when to take medication or making use of a volunteer to assist a patient with a coronary who could not read in following medical directions
- television and radio, although it was noted that persons with limited literacy skills tend to watch entertainment rather than informational programs, thus potentially limiting the usefulness of this approach.

simplify language

Many people indicated the need to simplify the language used in brochures and other written health information. Related suggestions included:

- **pretesting**
- testing for readability
- pretesting for comprehension
- **adaptations**
- use of large print
- “friendly” formats with increased use of pictures and white space
- more translations and adaptations into other languages

Awareness has already increased within the health field of the need to simplify the language of written information, and there have been greater efforts at producing “readable” health information.

readability not a cure-all

Increasing the readability of written materials is undoubtedly a good idea. For many people, this will make a wider range of information about health accessible. However, many people will still be unable to read, not matter how simplified the language. Others who in theory could read will not: the printed word is not a preferred or trusted means of obtaining information for many people. Although it is a useful approach, enhancing the readability of written materials should not be viewed as a cure-all to the problems of illiteracy.

The following strategy was suggested at the provincial consultation. As an incentive for agencies to communicate their information more creatively, an awards system could be developed. Annually, community members would reward agencies, professional organizations and individuals who created a variety of media to communicate their information and services, and who ensured these messages were received and understood.

4. *Co-ordinated Action*

The information gathered and analysis developed from the research and consultation process strongly calls for concerted action by governments, organizations and individuals.

open communication channels

share plans of action, information and ideas

To accomplish a coordinated approach, it was suggested that the channels of communication must be opened between local and regional agencies, public and private organizations and government. A commitment must be made to share plans of action, information and ideas. Until this occurs, there will be gaps and overlaps in services and information, which are detrimental to the health and safety of the community members.

ENDNOTES

1. C. Slater and B. Carlton, "Behaviour, Lifestyle, and Socioeconomic Variables as Determinants of Health Status: Implications for Health Policy Development," in *American Journal of Preventative Medicine* (1985, 1,5).
2. See *Achieving Health for All: A Framework for Health Promotion* (Health and Welfare Canada, 1986).
3. Locations and affiliations could include libraries, church groups, neighbourhood organizations, special interest groups, health care providers, general community literacy programs, workplace programs, school board and community-based programs.
4. See R.A. Spasoff, *Health for All Ontario: Report of the Panel on Health Goals for Ontario* (Toronto: Ontario Ministry of Health, 1987); S. Podborski, *Health Promotion Matters in Ontario: A Report of the Minister's Advisory Group on Health Promotion* (Toronto: Ontario Ministry of Health, 1987); and J.R. Evans, *Toward a Shared Direction for Health in Ontario: Report of the Ontario Health Review Panel* (Toronto Health Review Board, June 1987).

VI. RECOMMENDATIONS

The issue has been stated – we need to make the world healthier and safer for people who can't read. The impact of illiteracy on health is becoming better understood, but there are many areas for improvement and action. Commitment, action and responsibility are required in three broad areas:

- to achieve literacy and health for all
- to make environments healthy and safe
- to ensure equitable access to vital information

Various strategies to create change in these three areas have emerged consistently throughout the research, the regional workshops and the provincial consultation. We now need to examine the types of recommendations that have evolved from the consultation process.

- The need for Provincial and Federal Government policy.
- The need for a range of activities and commitments related to equitable access to information by organization
- The need for a coordination capability to stimulate and coordinate policy and actions.

These recommendations involve the partnership of

- government
- organizations
- a coordinating body.

Most of the recommendations deal with issues of equitable access to health-related information. Participants throughout the consultation process saw this as the major area for action. At the same time, they saw action related to achieving literacy and health for all and creating healthy and safe environments as important related areas.

GOVERNMENT POLICY AND ACTION

To achieve literacy and health for all Canadians, we must:

- Improve the education system for young people, which ensures they will develop the skills necessary for meeting the literacy demands of today's society.

- Develop an adult education and training system, which will allow individuals to move in and out of education and training opportunities which respond to their changing learning needs.
- Create policy and funding commitments to ensure that adults have access to a variety of literacy and learning opportunities in their home communities in order to accommodate individual needs and preferred learning styles.
- Support public participation within the health care system. This would mean encouraging people to take more control over factors which affect their health and to enable and equip people to act in ways that maintain and improve their health.
- Strengthen community health services. To do so, would require realigning the present health care system in such a way as to assign more responsibility to community-based services, which in turn would require allocating a greater share of resources to such services.
- Coordinate a healthy public policy. Policies that eliminate or reduce health inequities involve the following areas, among others, income security, employment, education, housing, business opportunities, agriculture, transportation, justice, quality of environment and technology.¹

To create social and physical environments which promote and allow for health and safety, we must:

- Develop policy, funding and action to ensure that Canadians have access to decent housing, an acceptable level of income, safe work places and a clean environment.²

To promote equitable access to health-related information, we must:

- Establish specific content and evaluation criteria to ensure literacy has been considered in every grant and/or contribution application.
- Ensure that information and materials provided by the government are written in plain language.
- Provide incentives, especially financial incentives, to organizations which attempt to make information more accessible to Canadians who have low literacy skills.

- Encourage and fund research and pilot or demonstration projects aimed at increasing the accessibility of information.
- Encourage and fund joint undertakings involving literacy, health, medical and business organizations.
- Ensure when developing policy and regulations related to safe and healthy practices (such as Workplace Hazardous Materials Information System) that requirements and incentives are included to ensure that people with low literacy skills have access to and understand vital information.
- Ensure attention be paid to literacy when health promotion and education strategies are developed.
- Encourage and fund training and human resource development opportunities concerned with equitable access within literacy, health, medical, social services and business organizations.

ORGANIZATIONAL ACTIVITIES

Organizations, both public and private,³ involved in health and health-related matters must individually and jointly:

- Analyze on an on-going basis the effectiveness of the way information is distributed within and outside the organization. This would allow organizations to determine the extent to which information has been received, understood and used by people with low literacy skills.
- Review and develop organizational policies and practices which ensure greater access to health-related information by people with low literacy skills. In-house training plans also need to be developed to ensure these policies and practices are implemented.
- Involve the users of the information (consumers) in the process of reviewing and developing information content, as well as the design, production, distribution and evaluation procedures.
- Ensure that any translation of information is *adapted* to the cultural background of the people for whom the information is intended.
- Inform the broader community (within a geographic area, and within interest or discipline areas) of the nature of the relationship between

literacy and health, what is being done and what individuals can do.

- Encourage and promote governmental and organizational commitment and policy development for achieving literacy and health for all, equitable access to information and creating environments which promote health and safety.

COORDINATING BODY

An organization must be given the mandate to stimulate and coordinate policy and action related to equitable access to health services and health-related information for people with low literacy skills. Such a coordinating body would:

- Disseminate and promote the work done in Phase One of this project in Ontario and other provinces.
- Stimulate commitment by governments, organizations and individuals in working for change.
- Develop and deliver training, including the development of training manuals.
- Consult and advise community groups and service providers on literacy-related issue identification, policy writing and project/program development, implementation and evaluation.
- Develop awareness-raising activities directed at both the public and professional organizations
- Make the necessary linkages with related organizations and activities and encourage on-going communication.
- Stimulate and encourage research and pilot/demonstration projects by supporting communities with appropriate resources and expertise.
- Encourage and facilitate the formation of task forces, committees and so forth for joint action on specific issues (such as drug labelling) at the federal, provincial and local levels and among organizations from different disciplines and interest areas.
- Assist in development of and access to organizations and individuals able to help others in the development of policies and practices aimed

at ensuring equitable access to information and services

Implementing these recommendations and refining the strategies suggested to us throughout Phase One of the Literacy and Health Project represents a major challenge.

At this point in the project, we are confident in the capacity of the Ontario community to respond to the challenge. Together, we have:

- documented the nature of the direct and indirect relationships between literacy and health
- developed a complex set of ideas and strategies which can begin to address the issues
- identified and involved a constituency or concerned people who are interested in taking action in their organizations and communities.

Responding to the challenge involves commitments to achieve literacy and health for all; to ensure healthy and safe environments; and to ensure equitable access to vital information. Throughout this report, we have built on previous studies already conducted in this province recommending strategies to ensure literacy and health for all, and healthy and safe environments. And, we have begun to develop an agenda which will ensure equitable access to vital information.

Many of the issues raised during Phase One are not new – quality education, the impact of poverty on people’s lives, the consequences of having limited access to opportunities and so on. To these ideas, we have added another – the need to ensure that our fellow citizens receive, understand and are able to use information vital to their health and safety.

Clearly, the ongoing development of healthy communities will require us all – professionals and consumers, individuals and organizations, policy makers and service deliverers – to assume our respective responsibilities. It will require us all to respect the diversity of our communities by communicating with each element and individual, and ensuring that what is said and written is understood.

We believe these are all challenges worth meeting, responsibilities worth assuming.

ENDNOTES

1. For more information concerning this point and the two points that precede it, *see Achieving Health for All: A Framework for Health Promotion* (Health and Welfare Canada, 1986).
2. The Premier's Council on Health Strategy was established in Ontario in 1988, recognizing that good health is dependent on a safe, nonviolent environment, adequate income, housing, food and education as well as a person's valued role in family, work and the community.
3. Including health service providers, social service workers, manufacturers and retailers, professional organizations and workplaces.

VII. RESOURCES

Throughout the research and consultation process, documents have been prepared for the use of the participants. They include:

- summary research findings report
- regional workshop notes, both in summary and in full
- provincial consultation notes
- final research report, which includes a copy of the questionnaire, the verbatim responses of questionnaire, an analysis of questionnaire responses, the case study summary and the bibliography
- final public report (this document)

For further information concerning the availability of this material, please contact:

- Literacy and Health Project
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Attn: Resources

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