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ABSTRACT

Phase one of the Ontario Literacy and Health Project established a link between lack of education and increased health problems. Phase two was undertaken for the following purposes: (1) to develop a position paper on literacy and health; (2) to foster working partnerships between literacy groups and health groups that would result in ongoing activities to address the health problems associated with literacy problems; (3) to provide short-term support for groups and individuals wishing to address the literacy and health issue; and (4) to establish a clearinghouse of literacy and health information. During phase two, the Ontario Public Health Association (OPHA) developed and adopted a position paper on literacy and health, conducted clear language workshops at seven locations throughout Ontario to give literacy and health workers an opportunity to develop easy-to-read materials, and provided support for the development of five accessible health education publications. Information and technical assistance was provided to nearly 100 groups and individuals regarding the development and implementation of programs addressing the literacy-health connection, and a clearinghouse of literacy and health information was established in Toronto. (The OPHA position paper is appended along with an 18-item bibliography.) (MN)

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

PARTNERS IN PRACTICE

THE LITERACY AND HEALTH PROJECT PHASE TWO

August 1990 - October 1992

Summary Report

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The Ontario Public Health Association would like to thank these ministries for their support and encouragement throughout the Project. Funding a community development strategy requires both financial resources and a belief that community development is a sound investment. This report is our evidence that this in fact the case.

OPHA would like to acknowledge all the partners with whom we had the privilege to work throughout the Project. Their dedication to literacy and health is the true strength behind the summary stories in this Report.

Mary J. Breen already had a long-standing and enviable reputation in the literacy and health communities before coming to OPHA as Project Coordinator. Her professionalism, dedication and enthusiasm turned difficulties into opportunities and doubters into doers. It was a privilege to have had the opportunity to work with her.

I would also like to acknowledge the initial contribution of Lidia Kemeny, Project Coordinator for the period of August 1990 to May 1991.

Use this Report. It contains project stories and important lessons for people who are active in community health and literacy. Challenge yourself with the section on the myths of literacy. Use the OPHA Literacy and Health position paper as a framework for developing a literacy policy for your workplace. Advocate for literacy as a basis for equitable access to health information.

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May 1993

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THE LITERACY AND HEALTH PROJECT PHASE TWO

August 1990 - October 1992

Summary Report

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April 1993

PARTNERS IN PRACTICE
THE LITERACY AND HEALTH PROJECT PHASE TWO
Summary Report 1993

This report is a summary of the activities carried out during Phase Two of the Literacy and Health Project. This report also examines some of the questions which have arisen in the course of this work, and makes recommendations for further work in this area.

Please note, when we speak of literacy skills, we are referring to the functional abilities to read, write, and use numbers. This is consistent with the definition used by Statistics Canada in the National Literacy Survey conducted in 1990.

The links between literacy and health

Phase One of the Literacy and Health Project examined the relationship between literacy and health through extensive conversations with literacy workers and health workers, and through a detailed literature search. One of the most important findings of that work was evidence that people with less education tend to have more health problems.[1] Although the causes of these health problems are complex and varied and by no means originate exclusively in a lack of education, there is a distinct link between poor health and poor reading skills. This link is, in part, directly attributable to restricted access - - restricted access to health information, and restricted access to safe, meaningful, well-paid employment.

Restricted access to health information

Approximately seven million adults in Canada have some literacy problems - almost two out of every five adults.[2] As a result, these seven million people have less access to essential information about health and safety issues since much of it is in print form. Like most teachers in our culture, health educators - nurses, doctors, dieticians, therapists, pharmacists, dentists, and occupational health nurses - rely heavily on print materials. These print materials are used both to convey information to their clients and to gather information from their clients. And this reliance on print material is unlikely to diminish as the fiscal crisis in our health care system escalates, and self-care regimens, which are nearly always in print form, become much more common.

The problem with this health information - whether it is immunization information or birth control instructions, hospital consent forms or prescription drug information, workplace safety instructions or instructions for self-administration of insulin - is that **it is usually written by skilled readers for skilled readers**. Little of it addresses the needs of people with lower literacy skills, and nearly all of it is hard to read because it relies on unfamiliar terms, concepts and illustrations.[3] This lack of readable information can present serious problems for people who don't read well by restricting their access to information which may be critical both to their own health and safety, and that of their families and co-workers.

Restricted access to safe, meaningful, well-paid employment

Since good reading skills are essential for nearly all jobs, people with lower literacy skills have much less access to paid work, and therefore to adequate incomes. According to a 1989 study, reading skills are needed for all but 2% of Canadian jobs, and 85% of jobs require grade nine or higher reading skills.[4] As a result, most people who lack good reading skills either work at low paid, irregular and often dangerous jobs; or they are unemployed. If they are unemployed, then they are dependent on welfare systems which fail to provide sufficient money for the essentials: adequate good food, safe housing, and warm clothing. And, without these necessities, people get sick. The negative effects of poverty on health are well documented; people who are poor die younger, are sick more often, and have fewer disability-free years.[5] People who are poor pay for their poverty with their health.

Responding to the problem

These observations about the relationship between reading skills and health lead in two directions - more opportunities for people to learn to read, and more equitable access to health information.

Literacy classes

Although learning to read will not make sick people well, the ability to read, write and use numbers can give people much more control over their lives, including over their health. Therefore, in a world so dependent on print, literacy classes need all the support and funding they require to provide accessible, safe classes for anyone who wants them.

But, of course, reading skills are not the only answer. The majority of people who do not read well are not enrolled in literacy classes, and learning to read can be a slow process for those who are. People who are unemployed may benefit from better reading skills; but they also need money, job opportunities, and healthy environments in which to live and work.

The work of literacy workers had the full support of the Literacy and Health Project, however literacy teaching was not our focus. Given the potential dangers we saw in the lack of accessible materials and programs, we did not want to simply advocate that people learn to read the existing materials. Instead, we wanted to work with groups to make health information as accessible as possible for as many people as possible, as soon as possible.

Increased access to information

Although we were aware that the barriers of class, income, gender, education, and reading skills can all stand in the way of equal access to health information, we chose as our focus the barrier of lack of reading skills.

As noted above, reading skills are a potential barrier for about 38% of Canadian adults. However, it is vital to understand that all of these people are not non-readers. According to Statistics Canada (1990), only 16% of adults are essentially non-readers.[6] Another 22% of adults (about 4 million) **can** use print material if: (a) the material is within familiar contexts, and (b) it is clearly laid out.[7] That is, these 4 million adults could benefit from print materials if they were both relevant and readable. Our goal in the Literacy and Health Project was to support projects which were working to increase access to health information.

PHASE TWO: PARTNERS IN PRACTICE

Phase Two of the Literacy and Health Project was in operation from August 1990 until October 1992. Funding was provided by the Health Promotion Branch of the Ministry of Health of Ontario, the National Literacy Secretariat of the Department of the Secretary of State for Multiculturalism and Citizenship, and the Health Promotion Directorate of Health and Welfare Canada. The original intention was for the Project to be national in scope, however funding restrictions limited our work to projects in Ontario, with one major project in each of Alberta and Quebec. Funding difficulties also necessitated our turning down many other requests for support from across the country.

The Project was staffed by a coordinator (full-time for 20 months and part-time for 7 months) and a part-time secretary. The Project was overseen by the Executive Director of O.P.H.A., and received direction from a Steering Committee made up of people from across the country with experience in both literacy and health issues.

An independent program audit was conducted at the completion of the project by Lynn Davie, Ph.D., Davie & Associates. The audit verified that the program activities conducted in the course of the project were consistent with the stated objectives, that outcomes were clearly related to project activities, and that the project objectives were achieved.

Objectives of Phase Two

Objective 1. To develop a Position Paper on Literacy and Health.

Objective 2. To foster working partnerships between literacy groups and health groups which would lead to on-going activities to address the health problems associated with literacy problems.

Objective 3. To provide short-term support for groups and individuals who wished to address the literacy and health issue.

Objective 4. To establish a clearinghouse of literacy and health information.

Outcomes

Objective 1. To develop a position paper on literacy and health.

The O.P.H.A. Position Paper on Literacy and Health (Appendix A) was developed with input from both health and literacy workers. It was adopted by the membership at the O.P.H.A. Annual General Meeting in November 1992, and copies are available from O.P.H.A. in both French and English.

Objective 2. To foster working partnerships between literacy groups and health groups which would lead to on-going activities to address the health problems associated with literacy problems.

Phase Two is called "Partners in Practice" because of our commitment to fostering working partnerships between literacy groups and health groups. We were, and remain, committed to this collaborative model for the following reasons:

• We see the "access to information" issue as a wide community issue which should be addressed **together** by health workers, literacy workers and people who live and work in the community. It was our belief that, by working together, people could best identify the community's interests, priorities, and problems with respect to literacy and health, and could then best devise their own collaborative ways to address them.

• As outsiders, we knew that we could not direct a community with respect to how they should address their particular literacy and health issues. People who live and work in a community know best what will work in their community.

• We wanted to help to establish small pockets of expertise in several communities across the province. We wanted these groups to then be available to work with others in their areas. Moreover, we wanted these groups to remain viable long after their involvement with the Literacy and Health Project.

• We see field testing as a necessity in the production of accessible, relevant materials, whether they are pamphlets, posters, or medical history forms. Working in partnership with community workers and community members can greatly facilitate this process. (For a further discussion of Field Testing, see p. 17.)

• We see the solution to the literacy and health issue as reaching far beyond the need for just more readable materials. For example, we wanted to encourage discussions regarding how to address the inaccessibility of certain community services to people with lower literacy skills. Readable materials would be only one of many solutions to a problem of this kind.

• Lastly, as we continued to work in this manner, we had the strong support and encouragement of the groups we were working with as they observed the valuable outcomes of collaborations of this kind.

Therefore, in order for us to work with a group as a major project, they had to demonstrate the following:

1. the intention to collaborate with both literacy and health groups, and, preferably, also with other social service and community groups
2. a specific health issue to address
3. a community development focus
4. a commitment to evaluating our involvement with them

As these projects evolved, we observed a variety of beneficial outcomes:

• We watched literacy workers bring to the groups their specialized knowledge about literacy and numeracy problems, and how these directly affect the health of their students.

• We watched health workers bring their specialized knowledge about health problems and about the health resources in the their communities.

• We watched community members and community workers bring their specialized knowledge of the daily life of their communities, as well as knowledge of its resources and key people to work with.

• We saw literacy workers meet health workers who were sensitive to literacy issues, and who offered to be available to help their students in a range of capacities.

• We also saw health workers meet literacy workers who could work with them to develop and field test materials.

In summary, we saw representatives of these three groups begin to make plans together - plans which were much more comprehensive and effective than if each group had been working in isolation.

Our work with each group differed according to the group's particular needs. Therefore, we spent considerable time with each helping them plan their work, and giving them support and information as needed on such issues as the activities of other groups working on literacy and health issues, how to locate materials, how to develop materials, and how to field test.

Although each project was unique, the support we provided to them fits into two general categories:

1. clear language workshops as an opportunity to bring together interested people
2. support for the development of specific materials.

1. Clear Language Workshops

The following projects opted to call together a group of health workers, literacy workers and community workers in order to (a) hold a Clear Language Workshop and to (b) provide the group the opportunity to discuss how they could, as a group, continue to work on these issues. Some of these discussions have resulted in the formation of new groups to work on this issue; others have led to much more loosely formed alliances.

The Clear Language Workshops were opportunities to discuss and practise choosing and developing easy-to-read materials based on the following principles of clear writing:

- Organization: a clearly defined purpose; functional units of information with good headings; and a logical progression of ideas
- Writing Style: conversational, informal, using familiar, ordinary words; and sensitive to the readers' cultural, economic and educational backgrounds
- Visual appeal: uncrowded, easy-to-read type size and type style; and easy-on-the-eye paper and ink colours
- Illustrations: clear, relevant and sensitive to the readers' cultural, economic and educational backgrounds.[8]

Theses Workshops also provided opportunities to discuss working with the target audience in the production of easy-to-read materials.

The following is a list of some of the activities which have followed from these workshops as of December 1992.

- **The "Literacy and Sexual Health Link Workshop". Edmonton, Alta. 1990**

The workshop was attended by literacy, health and community workers who wanted to begin the process of jointly producing readable sexuality materials. Since the workshop, the group has had additional workshops; they have developed some accessible sexuality materials; and they have continued to raise the literacy issue in their respective places of work and at conferences. An additional literacy and health group has been formed in Calgary; the Edmonton Board of Health has developed an interactive kit on clear writing of health materials; and some members are working towards provincial policy changes re plain language in public documents.

- **Huron County Health Unit. Clinton, Ont. 1990**

This workshop brought together a large group of health and education professionals to discuss the impact of illiteracy on health, how to produce health resources for lower skilled readers, and how the group might collaborate to address the issue thereafter.

Since the workshop, a Literacy Consulting Group composed of literacy workers and health workers has been established; a *Clear Language Guidelines* manual was developed; a clear language policy for the Health Unit was developed; further workshops with Health Unit staff and with community business people were held; a class of adult learners has been identified who will assist with field testing of materials produced by the Health Unit; and staff are available to other Health Unit sections to assist with writing clear materials.

- **York Region Public Health Dept. Newmarket, Ont. 1990, 1992**

The first event was a one-day workshop, attended by health workers, literacy students and workers, business people, and representatives from O.P.H.A.. The goals of the workshop were to discuss literacy and its impact on health status, to discuss community literacy resources, and to build a community action plan to promote literacy. The second event was a Clear Writing workshop for participants to build on their previous skills, and to meet again regarding this issue.

Since these events, the York Region Health Dept. has received an award from the Literacy Council for its interest in literacy; representatives of the Health Dept. have worked with literacy classes to teach health issues; literacy workers have helped to produce more readable promotional materials regarding a community program; representatives of the Literacy Council have made a presentation to the local hospital and to local physicians; other departments within the Health Dept. plan to make changes to their materials; Health Dept. policy is being developed re literacy through their Equal Access Committee; and the Health Dept. now develops materials with more involvement from members of their target audience.

- **The North Channel Literacy Council. Gore Bay, Manitoulin Island, Ont. 1992**

The workshop was organized by a Literacy Council teacher and was attended by representatives from several community groups including literacy, seniors, Agriculture Canada, a shelter for abused women, the local community college, and the YWCA. (Public health and community health nurses were unable to attend due to an emergency, but were contacted after the event to keep them informed.)

Since the workshop, the workshop organizer has conducted another workshop, has another planned, and has written two articles on clear writing for health and social service groups. She is also advising the local United Chiefs and Councils regarding the readability of a survey about local health needs. She is also working with the local shelter on an audit regarding cultural issues, including literacy; and she is helping the local Home and School to produce a readable newsletter and notices for parents. Some literacy staff are available to review draft materials, and to put producers of materials in touch with people to field test materials.

- **"Better Beginnings, Better Futures" Walpole Island First Nation. Wallaceburg, Ont. 1992**

The goals of the workshop were to discuss effective ways to reach people with average to lower reading skills, and to bring together interested people to discuss these issues. The workshop was attended by local health, literacy, and community workers.

Following the workshop, the manager of the Adult Literacy and Education Program is planning to give follow-up support re clear writing to members of the community agencies who expressed interest, and to pursue funds to assist them in

rewriting materials at a more suitable level. The workers at Better Beginnings report that they are now more effective in recruiting people to their programs because they can produce more accessible materials, and they are more able to choose appropriate materials for their programs.

- **East York Health Unit. Toronto, Ont. 1992**

East York Health Unit wanted to be better able to create easily understood print materials - pamphlets, posters, and articles for local community newsletters. The workshop was attended by both representatives of several East York community groups and by some Health Unit staff. Some of the community groups have newsletters which the Health Unit regularly contributes articles to, and all produce some written materials for their clients. The group discussed Clear Writing and the possibility of collaborating thereafter to produce readable materials.

Since the workshop, the Health Unit reports that they have richer relationships with the community agencies with whom they work allowing for easier collaborations. The Health Unit has a greater awareness and interest in developing readable materials in terms of both text and illustrations; and they have begun field testing materials with their target audience(s). The Health Unit has also done some professional development regarding literacy with the local municipal government staff.

- **Literacy Link of Eastern Ontario. Kingston, Ont. 1992**

This workshop was slightly different in that these literacy teachers wanted to be more able to do training workshops on the impact of illiteracy on health with health professionals in their local areas. The workshop was designed to increase their writing and design skills specific to health materials, to increase their understanding of the relationship between literacy and health, and to prepare them to raise these issues with health professionals.

Since the workshop, some members have begun to work on these issues with the local Health Unit; and one member has become a stronger advocate for clear materials for seniors, especially regarding drug information materials produced by pharmaceutical companies.

2. *Support for the development of accessible materials*

Each of the following projects have developed, or are in the process of developing, health materials through a collaboration between representatives of both health and literacy groups, and with the active involvement of members of their target audiences.

- **Département de santé communautaire (Department of Community Health), Maisonneuve-Rosemont Hospital. Montréal, Que. 1992**

An easy-to-read pregnancy album/journal, *Mon album de grossesse*, for poor women who have low literacy skills was produced with funding and consultation from the Literacy and Health Project. The project was developed with an advisory group made up of low-income women, health professionals, a community organization in a low-income neighbourhood and two literacy groups. The album is now being distributed. Early reports show that it has been well received, and plans are underway to consider reprinting.

- **Native Friendship Centre. Sault Ste. Marie, Ont. 1992**

The Literacy and Health Project provided support and consultation to the Native Friendship Centre regarding the development of an easy-to-read cookbook for children. This cookbook was based on recipes which were developed and field-tested with children at the Centre, with some advice from the local Public Health Unit. Progress was made on text, design and illustrations, however it has not yet been completed due to time constraints at the Centre.

- **Le Centre d'alphabétisation de Prescott. Hawkesbury, Ont. 1992**

Le Centre d'alphabétisation de Prescott, a literacy program, produces a monthly easy-to-read newsletter which now contains an expanded section, "Alpha-Santé", covering various health promotion issues. The new section is produced in collaboration with local health organizations, so it covers information about health issues and health promotion activities in the area as well as issues identified by literacy learners and teachers. Funding for initial printing was provided through the Literacy and Health Project.

- **Lawrence Heights Community Health Centre. Toronto, Ont. 1992**

The Literacy and Health Project provided funding for the reprinting of 1,200 sets of *Women's Health Fact Sheets* - easy-to-read materials which had been produced with the involvement of members of the target audience.

- **South Riverdale Community Health Centre. Toronto, Ont. 1992**

The Literacy and Health Project provided funding for the reprinting of 3,000 brochures and 5,000 cards from the *Safe Medication Program* - easy-to-read materials which had been produced with the involvement of members of the target audience.

Objective 3. To provide short-term support for groups and individuals who wished to address the literacy and health issue.

We provided information and assistance to nearly one hundred groups and individuals regarding the following:

- the relationship between literacy and health
- activities of other groups addressing literacy and health
- materials development
- policy development re literacy and health
- clear writing and design
- working with literacy groups
- field testing
- locating easy-to-read materials
- locating non-print materials
- locating health or literacy workers with whom to collaborate
- developing new networks of health, literacy and community workers

We also made several public presentations on the issue, contributed articles to several periodicals, and had representation on two advisory committees: Canadian Cancer Society, Ontario Division Literacy Task Force (Toronto), and The Community Health Information Service Advisory Committee, (Toronto).

The Literacy & Health Project had several documents available for purchase. On average, we filled six requests per week for these publications. (See Appendix C)

Objective 4. To establish a clearinghouse of literacy and health information.

In response to a wide call for materials within Canada and the U.S., we were very grateful and amazed to receive about 1000 documents on a wide range of health topics. The materials fell into two groups: the easier and the harder to read. ALPHA Ontario were given any materials which are easy-to-read, as well as those which address the production of easy-to-read materials, and those which address the relationship between literacy and health.

ALPHA Ontario is a literacy resource centre for people working in adult literacy and immigrant language training. Since the entire ALPHA Ontario collection is accessible to anyone in Ontario, both literacy and health practitioners are able to locate and borrow these easy-to-read health materials.

ALPHA Ontario
21 Park Rd.
Toronto, Ont.
M4W 2N1

(416) 397-5900	1-800-363-0007	(English)
(416) 397-5902	1-800-463-7880	(en français)
TDD: (416) 397-5901		

Those materials which are harder to read, plus any duplicate materials, were given to the Consumer Health Information Service (CHIS), which provides health information to anyone in Ontario.

Consumer Health Information Service
Metro Toronto Reference Library
789 Yonge St.
Toronto, Ont.
M4W 2G8

(416) 393-7056	1-800-667-1999

Clear language as an answer to the literacy and health problem: some issues for further discussion

Clear language, although there is no official definition, has come to mean written language which can be easily understood by the general public. Since the "general public" is such an imprecise term, and since our interest is in people with limited reading skills, we are using the term "clear language" here to refer to written language which people with no higher than about Grade six reading skills can read.

Over the last ten years, clear language has steadily gained in popularity among health care and legal practitioners who are concerned with equitable access to information. Since health workers rely so heavily on print health materials, we believe that they have a responsibility to make these materials accessible and relevant so that both the well-educated and those with limited reading skills can benefit from them. That is, not only should public documents and programs be inclusive in terms of gender, income, age, sexual orientation, disabilities, language, race, religion and culture; they should also be inclusive in terms of reading skills. Using clear language is one way to make information much more accessible.

Resistances to clear language

Although most health workers whom we worked with were committed to making health materials more accessible in terms of reading skills, many reported that they encountered considerable resistance to this goal from both their co-workers and their superiors. The following is a discussion of some of these arguments.

One initial resistance to using clear language stems from a lack of awareness of how many people do not read well, coupled with a lack of understanding of how difficult to read most health materials are. However, even after information is provided regarding the prevalence of the problem and the level of reading skills needed to read most common health materials, other objections to using clear language such as the following are frequently heard.

One commonly raised objection is that skilled readers will be offended by simply written materials; and, therefore, two levels of materials would be needed. Since this would be too expensive, they conclude that we should continue to produce only materials which skilled readers can read. Throughout this Project, we have found that skilled readers are not offended by simply written materials. Most people, both skilled and less skilled readers, prefer easy materials over difficult.[9]

Most people, even if they are capable of reading complex materials, do not choose them, **especially** when they or their family are in crisis with an injury or an illness. Therefore, health information does not need to be provided at two reading levels. Clear materials are very well received, and when skilled readers want more complex, detailed information, they usually have the skills and resources to get it.

Alternately, some people object to clear writing on the grounds that it is condescending to less skilled readers. This is also unfounded. Although clear writing has the potential to be simplistic, writers who work closely with members of their audiences produce materials which are not offensive. By relying on and incorporating feedback from their readers, many writers can and do produce relevant, useful materials which people are grateful to be able to read.

Another frequently heard objection to clear writing is that it doesn't look or sound "professional" or "scientific" - to bosses, and/or to co-workers, and/or to funders, and/or to clients. Our answer to this charge is that the purpose of health messages is not to impress skilled readers nor to teach detailed medical terminology. Instead, the purpose is to inform people - in particular those who have often been denied this information. And clear writing is one easy place to start.

An additional resistance comes from people who believe that clear materials are only needed in certain areas. As a result, some health workers, before agreeing to produce accessible materials, want to go to great lengths to try to determine how many people in their particular area are illiterate. This expenditure of time and effort is usually quite unnecessary for several reasons: grade level achievement is not an accurate determinant of reading skills; actual testing would be both highly inappropriate and very expensive; and fairly accurate predictions are possible. From the work of Statistics Canada[10] and the Southam Report[11], we already know that about two in every five adults in the general population have some reading problems. Further, if the area has a higher than average number of marginalized people, then there will be a similarly higher number of people with reading problems. For these reasons, we recommend producing accessible materials which any reader can read rather than trying to determine how many people have reading difficulties.

The apolitical nature of many clear language materials

Although clear writing is gaining in popularity, it displays one common characteristic which needs to be addressed - it tends to be devoid of political comment. Many health care workers are critical of the health care system in terms, for example, of the power imbalance between patient and doctor, the politics of women's health care, and the societal causes of ill health. However, this critical analysis is remarkably absent from the materials they produce, especially in their clear language materials.

For example, a statement such as

"Call your doctor, and he will tell you what to do."

is **much** more common in easy-to-read materials than

"Call your doctor for some advice. Find out all you can and decide what is best for you."

It is not yet clear why these issues are so seldom addressed in easy-to-read materials. Our concern with the absence of these political statements is that easy-to-read health materials, which are often very directive, may serve to increase the dependence of their readers on the medical system instead of helping them to better understand their rights and responsibilities within it. This is an important topic which requires much further discussion.

The role of collaboration in addressing the literacy and health problem.

The benefits of collaboration

Within the Literacy and Health Project we have been very committed to collaboration between literacy workers, health workers, and community members in the development of programs and materials. From our observations, collaboration can produce benefits to all concerned. The literacy workers and the health workers we worked with reported having learned new and useful things from each other. Each group brought skills and knowledge that the other lacked, and together they began to build appropriate, relevant programs. The following is a summary of some of the benefits which fall to each group involved in collaborative projects.

1. Field testing opportunities

For people who want to produce materials, collaboration gives them an enormous advantage.

Since the goal of any writer should be to make a **good match** between the reader and the material, writers need to know their readers - how they live, which issues are important to them, and which words and images are familiar to them. This process is much easier when writing for people who are familiar - people whose lives and work and problems are similar to our own. The challenge is to write for people who are different from us. When health workers are writing for people who are different from themselves in terms of language, reading skills, income, and culture, the challenge to be inclusive is much greater. Therefore, in order to accurately reflect their audience's issues, languages and imagery, writers need to develop materials **together** with people who represent the target audience.

Developing materials with members of the target audience means both **pretesting** ideas and concepts, and **field testing** materials for relevance and readability while they are being developed. Although a thorough discussion of the many ways one can work with the audience is beyond the scope of this report, it should be stressed that the process is easier than it may appear to be. Input from representatives of the target audience can be obtained relatively easily from either individuals or groups or both. For example, some health workers test materials with individuals such as clients or patients whom they see in their work. Others set up working groups of members of the target audience whom they consult when they are developing materials; and others set up "focus groups" to get feedback about their ideas and/or their materials. Others work with existing groups such as literacy classes who are willing to give their opinions of materials in progress. In addition to working with representatives of the target audience, "key informants" - other health workers, literacy teachers, community workers, and community leaders - can provide extremely valuable feedback and advice regarding programs and materials.

Within this process of working with members of the target audience, it is possible to exploit literacy students and community members by asking them to review health materials in their "spare time". Therefore, we believe that when members of the target audience act as consultants, they deserve to be paid. We strongly advocate either directly paying people who edit documents, or paying the group or organization they belong to. In this function as editors, people with lower reading skills are the experts, and hence they deserve to be paid properly for their work.

Working with the target audience is still a relatively new, undertheorized process, and we have a lot to learn. Therefore, to further discussion, we are including here a list of observations about this process which was compiled by four writers who have developed materials with the active feedback and collaboration of less skilled readers.[12]

What we as writers learned in the process of developing materials with members of the target audience:

- to trust that people can speak well for themselves
- to remember that our role, in large part, is to facilitate people's voices to be heard
- to be flexible and patient
- to work slowly and carefully
- to put our own agendas aside in favour of the group's
- to keep our sense of humour
- to be aware of our own biases
- to receive negative feedback
- to be strongly committed to working in this way
- to recognize that there is a limit to the amount of information we can provide
- to not expect unskilled readers to be skilled editors
- to develop effective ways to field test our materials with a group.

What audience members learned in the process:

- that their opinions were very important and valuable
- that we were evaluating our materials, not their reading skills
- to feel confident in giving us their reactions to the materials, i.e. in assessing written materials without fear of punishment by the group or by the leader
- some editing skills
- that they could be vital to the production of useful written materials.

Which factors greatly helped the process:

- adequate time and funding
- support - from employers and from co-workers
- the right meeting space, with space for childcare, and near public transport
- the right people for the group with respect to their reading skills, their interest in the group, and their ability to represent the target group
- the right artist/illustrator: someone familiar with the literacy issue, familiar with using design and illustrations to teach, and committed to making illustrations as clear as possible.

Despite these commonalities, the writers who compiled this list believe that a formal set of rules for field testing materials would not be useful since writers need to intimately match their methodology to the needs and abilities of each particular audience.

2. Health workers learn about literacy

Through direct contact with literacy workers and literacy students, the health workers learned many things about literacy and health. For example, they learned more about the range of health problems which people with reading problems have, as well as more about the barriers faced by people who do not read well. They became more able to understand the ways that not being able to read impact on people's lives; and, conversely in some cases, to see that learning to read was neither what everyone with lower reading skills needed nor wanted. Contact with literacy workers and learners was very useful to show health workers that one new brochure in clear language was not the total answer to a health problem nor to the difficulties people have in accessing health information. In addition, through their contact with literacy workers and learners, health workers came to examine their own ideas and misconceptions about literacy.

Misunderstandings about literacy are very common among the general public and among health workers as well. Two commonly held myths about literacy - that poor readers are in some way to blame for their reading problems, and that literacy skills are all that lower skilled readers need to make things better - are often expressed as health workers devise program plans to address the barrier of illiteracy. Since these ideas are erroneous they deserve to be addressed.

The myth that poor readers are lazy, unmotivated, stupid and/or childlike is both persistent and pernicious. In fact, there are many reasons why some people don't read well, and these reasons are seldom due to lack of drive or intelligence. Some of these reasons are personal, such as perceptual difficulties and physical health problems especially during childhood. However, much more often, the sources of reading problems are social in nature, and lie in inadequate educational opportunities both as children and as adults, unequal gender roles, abuse, poverty, and unemployment. When health workers better understand these reasons, then they can both avoid the trap of seeing people with Grade 5 reading skills as either lazy or unintelligent, (or as having the experiences, needs and aspirations of ten year olds); and focus instead on the larger social changes which are required to reduce iliteracy rates and improve access to information.

The myth that literacy skills will fix all, that literacy is a panacea is also both common and misleading. Because reading is so important to most of us, literacy has come to be seen by readers as both an essential skill and a cure-all; jobs, health and happiness are thought to follow in its wake. However, even if all Canadian adults learned to read, they would not automatically have access to information since privilege determines who can know what. Literacy is only one of **many** factors which impact on health. Political, economic, social and environmental factors all play vital roles in determining health status. Health workers are well advised to keep the need to learn to read in perspective, and focus instead on the right to equal access to information.

Although reading skills are an extremely useful set of skills, people who are not highly skilled readers are none the less complete people. In the exaggerated views presented in the popular media, lower skilled readers are presented variously as blind, crippled, wordless and ashamed people who can - and seemingly often do - have their lives radically and magically transformed with the addition of reading skills. With this view, it is not surprising that most people, including health workers, see people who don't read well as needing remedy.

While it is clear that everyone deserves the right to learn to read if they wish, and that literacy can greatly enhance a person's power, enjoyment, and self-esteem, the absence of reading skills - of and by themselves - do not make someone incomplete. In fact, many people who do not read well do not see themselves as deficient, and they are not seen as deficient by people in their own communities.[13] And further, the vast majority of people who are not highly skilled readers do not function in their lives in an unskilled, flawed fashion. By describing people in terms of what they lack, not in terms of what they have - in terms of what they cannot do, not what they can do - the media has produced a misleading picture of a very large segment of the population.[14] Most people who do not read well display memory, courage, ingenuity intellegence and dignity. They are competent workers, loving parents and good neighbours. Designing health care programs which focus on people's strengths, not their weaknesses or their deficits, is clearly the preferred approach.

Further, literacy must be seen as more than just the ability to recognize and use letters and numbers. More important than just these literacy skills are the purposes of literacy - in this instance, to access knowledge about health care. Reading is far more than just decoding, and reading skills need to be considered within the whole context of people's lives. Reading needs to be seen as a set of skills for "knowing and reading the world".[15]

3. Literacy workers learn about health care

Literacy workers, through collaborating with health workers, increased their understanding of the health care system and became more able to work with it to their students' advantage. Literacy workers are usually very aware that their students have health problems associated with their lack of reading skills. They also know that as literacy workers, in addition to their roles as teachers and advocates, are also health care workers. Although traditional health care workers may not be aware of this role, literacy workers often act as intermediaries between their students and the health care system. For example they may read and explain doctors' instructions, they may help their students to locate the medical services they need, or help their students find some vital information they need about a health problem. Their first-hand understanding of their students' difficulties with the health care system is very valuable to health care workers planning programs for people with limited reading skills.

On the other hand, literacy workers, understandably, are seldom familiar with the intricacies of an ever-more complex health care system, and may not know which facilities can best provide which services to their students. By working together on these issues, literacy workers can meet health care workers who are sensitive to the literacy issue, who will work with their students, and who can help the teachers work with the medical system, to the benefit of their students.

In addition, literacy workers also discover that, particularly among public health and community health workers, health is viewed from a much wider perspective than just traditional acute care. For example, literacy workers are very interested to learn that they can get support from health workers on a problem such as unsafe housing; or that a Community Health Centre, for example, might be interested in helping to set up a new literacy program. This broader view of health provides new opportunities for literacy workers to work together with health care and community workers to the advantage of all concerned.

4. Reliance of health care workers on print

Despite the obvious advantages of easy-to-read over hard-to-read materials, health education materials in clear language are only one way to increase access to health information. Seeing clear language as something to use to solve all the problems of people who do not have high reading skills is to misunderstand the ways reading problems and health problems are interconnected. Easy-to-read materials do make information easier to get, but only to people who can read to some degree. For

people who cannot read at all, or who cannot read in the languages we write in, easy-to-read materials are of no benefit. For people who can but seldom do read, easy-to-read materials are of very little benefit. For people who don't learn well from print materials, easy-to-read materials are of very little benefit. And, for people who are limited skilled readers, easy-to-read materials are only beneficial if the words are familiar and the information they contain is relevant to their lives.

To work towards truly equitable access to information, organizations need to examine their reliance on print and devise some alternatives. For example, some organizations, as part of their commitment to accessibility, are now producing posters, video tapes, and audio tapes to replace and/or supplement pamphlets and brochures. Others have altered their signs and their application forms to be more welcoming to people who do not read well. Some are exploring the use of pictographs and illustrations as ways to provide instructions to lower skilled readers. Others are considering one-on-one, personal instruction with no, or very little, print material. And, some organizations are developing equal access policies which include clear language as one important component.

If our goals are equal access to health information and, ultimately, equal access to healthy and safe environments, easy-to-read materials are just one, very important part of a much larger approach.

Resistances to collaboration

1. Fear of feedback

A common resistance to collaboration lies in the simple fear of receiving feedback and/or criticism regarding our writing either from our target audience or co-workers. For several reasons, including the fact that we have been judged throughout our schooling on the basis of how well we could express our ideas on paper, many people experience any feedback about their writing as painful, negative criticism. And worse, this feedback is heard as a criticism, not just of their writing, but of their very worth and integrity - rather than as some help to make their piece of writing a bit better. Therefore, instead of seeking the help of outside people as editors (which *every* writer needs), meny writers of health materials choose to write in isolation.

In addition, some health care workers expressed their reluctance to depend on the feedback of people who, these workers believe, are less qualified than they are to make decisions about health care programs. Because they are unable to see the

value of feedback from their readers, and because they don't want their work criticized, many people depend on readability formulae instead of on the feedback of the people they are writing for.

2. Misplaced reliance on readability formulae

Health care workers are relying more and more on readability formulae and grammar-and-style-checker computer programs as easy ways to create clear language materials. This reliance is misplaced and counterproductive.

Readability formulae are mathematical equations, expressed as a grade level, which attempt to predict the level of reading skills required to read a piece of writing. Because they can provide what appears to be empirical "proof" that a piece will be readable, these formulae are especially appealing to health care workers whose training predisposes them to trust mathematical test results. As a result, many people rely exclusively on the data provided by these formulae instead of on the much more useful data which could be obtained through field testing. In our opinion, this is a serious mistake.

These formulae do have some advantages. They are inexpensive, quick and easy to use; and, for hard to read pieces, they can give the writer some indication of how difficult to read the piece may be. However, their disadvantages offset their advantages. Their most limiting disadvantage is that they cannot tell the writer when and if a piece is easy to read. They cannot assess the multitude of factors which makes a piece readable, but instead only provide an assessment of two factors and sometimes a third: word length, sentence length, and sometimes word familiarity. In addition, they were not developed as writing guides; they were not validated with lower skilled adult readers; and they were not developed for health materials. The strongest reason for not depending on them is that they focus the writer in the wrong direction - on the material, not on the reader.[16] For these reasons, plus the evidence of successful outcomes when writers **develop materials with people who represent the target audience**, we recommend that these formulae not be relied on when writing for lower skilled readers.

In our view, collaboration between health, literacy and community workers is an ideal starting point in developing programs and services which will increase the capacity of everyone to access and participate in decision-making forums in all aspects of their lives.

Recommendations

In conclusion, we offer the following recommendations for continued work to address the literacy and health issue:

1. **Spread the word:** raise awareness of the prevalence of literacy problems and their effects on health. Over one third of Canadian adults has some reading difficulty. With nearly all health and safety information in hard-to-read print form, health problems are inevitable.

2. **Lobby for literacy:** work for support and funding for abundant, accessible literacy classes, and for equal access to quality education for children.

3. **Work for justice:**
   - equal access to health services and information
   - equal access to health and safety information
   - safe and full employment
   - healthy environments.

4. **Work together:** work with literacy, health, and community groups to effectively provide accessible, relevant health information for all. In particular, involve people with lower reading skills in the research, design, production, and evaluation of materials; and honour their assistance by paying them for their expertise. Lobby for funding for collaborative projects which address literacy and health issues.

5. **Lobby for accessible materials:** lobby public, private and voluntary sectors to make a commitment to producing and using accessible materials through the use of clear language and non-print media, (with the understanding that this will not eliminate all the health problems associated with illiteracy).

6. **Research:** learn more about the health implications of low literacy skills, the impact of low literacy skills on how people learn, the value of non-print materials, the factors which make materials accessible, how best to work with target audiences, how to collaborate to address these issues, and the barriers to this kind of work.

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APPENDIX A

POSITION PAPER

LITERACY AND HEALTH

THE ONTARIO PUBLIC HEALTH ASSOCIATION

1992

Equity of access is a leading concern of the Ontario Public Health Association - equal access to services and equal access to information.

The ability to read, write and use numbers well is one set of skills which is vital to this process, allowing people to make informed choices about issues from applying for a job, to voting, to understanding health and safety information.

In Canada, over one third of adults has some reading difficulties. According to Statistics Canada[1] (1990), the adult population (aged 16 to 69) can be divided into the following range of skill levels:

- 62% (11.2 million) read at a level which allows them to meet everyday reading requirements, and allows them to acquire knowledge using written material.

- 22% (4 million) read well enough to use print material in a variety of situations if the material is clearly written, clearly laid out and the tasks are within familiar contexts.

- 16% (2.9 million) cannot read well enough to deal with most of the written material they encounter in everyday life.

Nearly all public health information is in print form and is written by skilled readers for skilled readers. This information is of virtually no use to the 2.9 million who do not read well, and is of quite limited use to the 4 million who can only read well if the information is familiar and clearly written.[2] [3]

Without vital information about health and safety, many health problems result.[4] [5] For example:

1. Not having access to the information in print materials such as labels on food, medicines, infant formula, and cleaning products; safety information in the workplace; medical instructions; hospital consent forms; and environmental health information can lead to serious harm and injuries.

2. Not being able to read well frequently leads to poverty because well-paid jobs require relatively high reading skills. Poverty, in turn, is the clearest predictor of lower health status in terms of more years sick or disabled, and shorter life spans.

3. Those jobs available to lower skilled readers are often more dangerous, and result in work-related injuries and illnesses.

Illiteracy clearly has a major negative impact on health.

The mission of the Ontario Public Health Association is to strengthen the impact of community and public health workers in Ontario. Action is required in the development of **public policy** to address these issues, in the development of better **safety standards** for both homes and workplaces, in the development of more **literacy programs**, and in the provision of **accessible health information** for all who require it.

Therefore, O.P.H.A. is committed to the following:

- equal access to healthy and safe environments
- equal access to literacy and health for all
- equal access to health information

1. A COMMITMENT TO EQUAL ACCESS TO HEALTHY AND SAFE ENVIRONMENTS

A commitment to equal access to healthy and safe environments, both in the home and in the workplace means:

- eliminating poverty, because poverty unquestionably leads to health problems. A guaranteed, adequate income would allow everyone to afford the basic necessities of safe, secure housing, and adequate food and clothing.

- ensuring safe work-places and accessible safety information. Both print and non-print media must be used, and employers must ensure that safety information is understood, not just provided.

- striving for healthy communities where the health needs of the whole community are considered.

2. A COMMITMENT TO EQUAL ACCESS TO LITERACY AND HEALTH FOR ALL

With the high literacy demands of today's society, everyone deserves the opportunity to learn to read, write, and use numbers.

A commitment to equal access to literacy means:

- ensuring that all children receive an effective, useful and relevant education in which they learn literacy and numeracy skills.

- ensuring that all adults have an opportunity to learn literacy and numeracy skills.

- developing accessible literacy programs which meet the needs of anyone who needs them. These programs need to be affordable, at convenient times, and in a range of convenient safe locations, including workplaces, such as factories, offices, and hospitals. These programs must also accommodate the full range of students' learning styles, and be based on the students' needs and interests.

- removing barriers which deter women from attending classes by providing child care, relevant materials, and classes in safe, convenient locations.

- providing accessible facilities for people with disabilities.

- increasing the awareness among health, medical and social service workers of the prevalence of illiteracy, its effects on health status, and their responsibilities to consider illiteracy in their policies and programming.

A commitment to equal access to health means:

- encouraging the medical system to focus more on the prevention of illness and the promotion of health and safety.

- creating health standards which do not discriminate on the basis of income, gender, age, race, sexual orientation, geography, language, culture, religion or educational achievement.

- enhancing people's ability to manage chronic conditions, disabilities and mental health problems by providing access to skills development and community support.

- providing appropriate and culturally sensitive health services for all people, including people with lower reading skills.

- strengthening community health services.

3. A COMMITMENT TO EQUAL ACCESS TO INFORMATION

The right to equal access to information is the right to receive, understand and be able to use information related to health and safety, regardless of one's literacy skill.

A commitment to equal access to information means:

- providing everyone with accessible health and safety information which does not discriminate on the basis of income, gender, age, race, sexual orientation, geography, language, culture, religion or educational achievement.

- establishing guidelines for creating readable, practical and sensitive print information for people who have limited reading skills.

- encouraging groups who are developing materials to involve representatives of their target communities in the development, review, and design of materials to ensure that the materials are relevant and understandable.

- encouraging the use of non-print media, including diagrams, symbols, and audio and video tapes for non-readers or for those who do not habitually access information through print.

- presenting information through a wide variety of channels: television, community papers, community leaders, unions, fellow workers, peer groups, neighbours, neighbourhood organizations, as well as health professionals.

- supporting clear language policies for government, private and voluntary sectors.

- educating health professionals about the importance of clear language both for staff and health care consumers.

- encouraging health organizations, government agencies, and social organizations to collaborate with literacy groups in order to produce readable, relevant health information.

An investment in literacy is an investment in personal and economic well-being, an investment in increasing the capacity of everyone to access and participate in decision-making forums in all aspects of their lives.

Both the public and private sectors need to formulate policies which support equity of access to information, a cornerstone of social justice.

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THEREFORE BE IT RESOLVED:

THAT O.P.H.A ADOPT THE 1992 POSITION PAPER ON LITERACY AND HEALTH,

AND FURTHER BE IT RESOLVED:

THAT O.P.H.A, THROUGH ITS COMMITTEES, DIVISIONS, AND CONSTITUENT SOCIETIES, ADVOCATE FOR:

- Increased awareness of the nature of the relationship between literacy and health.
- Funding of truly accessible literacy programs.
- Use of clear language, with the understanding that it will not eliminate all the problems associated with illiteracy.
- Use of many types of communication strategies including non-print media.
- Collaboration between health organizations, literacy groups, government, and social organizations to effectively provide readable, relevant health information to people with lower reading skills.
- Involvement of people with lower reading skills in the design, production, distribution and evaluation of health education materials to better ensure readability and relevance.
- Provision by unions, management and government of accessible safety information for workers.
- Commitment by both government and public health organizations of staff and financial resources to providing equal access to health information and services.

APPENDIX B

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APPENDIX C

ORDER FORM

Name: _____

Organization: _____

Address: _____

City/Prov/Postal Code: _____

Literacy & Health Materials (6011-3)

1. PHASE ONE REPORT (French only):#_____ = n/c

2. PHASE ONE RESEARCH REPORT:#_____ @ $7.50 = $_____

3. PHASE TWO SUMMARY REPORT (Subject to availability) n/c

4. LITERACY & SEXUAL HEALTH LINK WORKSHOP REPORT
   (by Edmonton Board of Health:#_____ = n/c

Health Promotion Division Workshop Proceedings (5006-200)

1. WINDOWS OF OPPORTUNITY - STRATEGIES FOR ORGANIZATIONAL CHANGE (Dr. David Morely and Ruth Armstrong keynote speakers)
   #_____ @ $7.50 = $_____

   (Member discount 10%) = $_____

2. CHALLENGING OUR ASSUMPTION: THE ROLE OF POPULAR EDUCATION IN PROMOTING HEALTH (Edited by D'Arcy Farlow)
   #_____ @ $5.00 = $_____

   (Member discount 10%) = $_____

Report of the Public Health Coalition

HEALTH EFFECTS OF ONTARIO HYDRO'S DEMAND/SUPPLY PLAN (HEALTH EFFECTS REPORT)
(Ontario Public Health Association/International Institute of Concern for Public Health)
#_____ @ $20.00 $_____

TOTAL: $_____

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