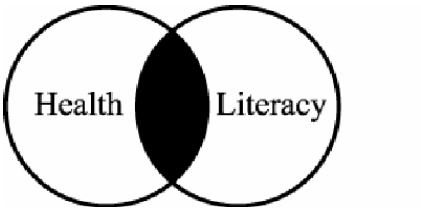
Taking Off the Blindfold:

Seeing How Literacy Affects Health



A Report of the

Health Literacy in Rural Nova Scotia Research Project

June 2004

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Seeing How Literacy Affects Health

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Health Literacy in Rural Nova Scotia Research Project

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Website: http://www.nald.ca/healthliteracystfx

Doris Gillis, Associate Professor
Department of Human Nutrition

dgillis@stfx.ca

Tel: (902) 867-5401
Fax: (902) 867-2389

Allan Quigley, Professor
Department of Adult Education

aquigley@stfx.ca

Tel: (902) 867-3952
Fax: (902) 867-3765

St. Francis Xavier University
Box 5000, Antigonish,
Nova Scotia, Canada, B2G 2W5

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Acknowledgments

St. Francis Xavier University Research Team

Doris Gillis, Department of Human Nutrition – Principal Investigator
Allan Quigley, Department of Adult Education – Co-Investigator
Allene MacIsaac, Department of Nursing – Collaborator
Janet Shively – Research Assistant
Donna Gallant and Sharon Dublin – Former Collaborators, Nursing Department

Additional Assistance:

Andrea Anderson, Jennifer McLaren, Melanie Parker, Christine Carpenter – Students
Erin Casey – Plain Language Consultant
Susan Eaton – Facilitator and Editor

Community Advisory Panel

Judy Cairns, Antigonish County Adult Learning Association (ACALA)
Madonna MacDonald, Guysborough Antigonish Strait Health Authority (GASHA)
Cheryl Chisholm, Public Health Services, (GASHA)
Millie Hatt, Richmond County Literacy Network
Evelyn Lindsey, Antigonish Town and County Community Health Board (ATCCHB)
Grail Sangster, Guysborough Adult Learning Association (GALA)

Community agencies who helped recruit participants

Addiction Services, Antigonish
Antigonish County Adult Learning Association (ACALA)
Antigonish Women's Resource Centre
Diabetes Clinic, St. Martha's Regional Hospital, Antigonish
Family Place Resource Centre, Port Hawkesbury
Guysborough-Antigonish Black Development Association
Guysborough County Adult Learning Association (GALA)
Kids First Family Resource Centre, Antigonish
Naomi Society, Antigonish
Paq'tnkek Health Centre
Pictou County Continuous Learning Association (PiCCoLA) – (pilot phase)
Richmond County Literacy Network
Richmond Villa Home for Special Care

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Summary

It is well known that people who have trouble reading and writing often have poor health. The *Health Literacy in Rural Nova Scotia Research Project* brought together people from Antigonish, Guysborough, and Richmond counties to learn more about how literacy affects health. Most importantly, we wanted to find out what can be done to break down the barriers to health that low literacy creates.

We talked to 46 people who had struggled with getting an education. Some were in adult learning programs. Others had difficulty reading but were not in classes. These people told us stories about their lives and how literacy affected their health and their family's health. We also held seven meetings with health and literacy workers, and we talked to 20 community leaders. All of these people lived in the counties of Antigonish, Guysborough and Richmond. All were asked to share their views on how literacy and health were linked and to tell us what needs to be done to make it easier for people in this region of Nova Scotia to have better health.

The report called **Taking Off the Blindfold: Seeing How Literacy Affects Health** highlights what participants told us. For example, people had different ideas about what literacy meant. For some, it meant being able to read and write, or not. For others, it was more than just reading and writing. Literacy was important to many parts of their life such as getting a good job and feeling good about themselves. People also had different ideas about health. Some people thought health meant just not being sick. Others felt being healthy meant being able to do what they wanted to do in their life. Both literacy and health were seen as important to getting along well in life.

Many people told us that it was sometimes hard living in the rural areas. For example, lots of people talked about not being able to find a job or to get to a learning program. Some talked about not being able to get into town to get food or medicine. Prices were often higher at small local stores. Going to a gym or skating rink was hard. Many talked about feeling lonely. However, people also spoke of the good things about living in a rural area. For example, people take care of each other in small communities.

People had many ideas about what could be done to make it easier for people who don't read and write well to have healthier lives. They suggested ways that information about health could be made clearer and within reach. They talked about how services and programs could be improved to better meet their needs. Their suggestions are listed in this report.

Those who took part in the study and others interested in health and literacy met in January and February 2004 to talk about the results and suggested actions for change. They said that it was most important that we address the following actions:

- ✓ Increase awareness and support of literacy as a determinant of health and well-being.
- ✓ Increase awareness of literacy issues among service providers.
- ✓ Find ways to reduce barriers to enrolling and attending literacy programs.

- ✓ Increase networking among service providers to reach those who may "slip through the cracks."
- ✓ Make health information more accessible to everyone and write it in plain language.
- ✓ Take health information and services to the people, for example, drop-in health centres and health mobiles.
- ✓ Support the use of client advocates to help people move through the health care system and to interpret when English is not the first language.
- ✓ Support community-based organizations and services in fostering health and literacy.
- ✓ Develop health and literacy promotion strategies that address needs in rural areas, including the lack of public transportation.

These actions for change show that participants see important links between literacy and health. The findings can help build the case for improving policies, programs, and practices that support the health of people who experience limited literacy.

By continuing to work together, we hope to find ways that all people, no matter how well they read and write, can:

- Find, understand, and use the information that they need to stay healthy
- Get the services and supports that they need
- Make choices in their own lives that help keep them healthy
- Speak up about their own health needs
- Have more control over the things that make and keep them healthy.

Participants in this research have shown us how literacy affects their lives and their health. By sharing their stories they have helped us take off our blindfolds so we can see the importance of health literacy. Now that we have seen through their eyes the impact of literacy on health, we must take action.

Introduction

> "See, we are kind of like blindfolded…yeah, just like you are in the dark. A lot of people, you know, can't read…You don't know what you want…so how are they going to help you? You feel uncomfortable and you don't know what to ask for." (NP-7)*

About 43% of adults across Canada have problems using the written word (International Adult Literacy Survey, 2000). In Atlantic Canada, literacy is an even bigger challenge. About 53% of adults here have limited literacy skills (International Adult Literacy Survey, 1994). Atlantic Canadians also have the highest rates of sickness and death from chronic disease in Canada (Genuine Progress Index Atlantic, 2002).

Simply said, people with limited literacy are more likely to have poorer health. Health Canada calls literacy a major factor linked to health: "However health is defined or measured, people with limited literacy skills are worse off than others with higher literacy skills." (Perrin, 1998). Literacy affects all aspects of our lives, including health, social status and opportunities for employment and education. It is time we all become aware of the impact that limited literacy has on the health of people in our communities, and work together towards change.

The purpose of this report

This paper highlights findings of the *Health Literacy in Rural Nova Scotia Research Project*, a project that began in 2001 to explore the links between limited literacy and capacity for health in northeastern Nova Scotia. The study looked at the experiences of people whose lives are shaped by limited literacy, as well as the experiences of practitioners working in literacy and health fields in the region. The focus of this report is on the voices of participants who shared insights into how their own levels of literacy influence their health.

A preliminary Discussion Paper was presented at the **Roundtable on Health Literacy** in January 2004 in Antigonish, and again at a Roundtable meeting in Port Hawkesbury in February 2004. These Roundtable meetings, attended by a total of 81 people, provided an opportunity for research participants, community partners and practitioners to react to the project findings, in particular to the actions for change identified by participants in the research. Those attending the Roundtables suggested how policies, programs and practices can be improved based on the research findings, and established a list of priority actions. Their recommendations are included in this Report and it is hoped that they will serve as a tool for change.

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* To ensure confidentiality, interviews are identified throughout this report by the following key (see page 4, "The participants"):

KI = key informant	FG = focus group
P = program participant	NP = non-program participant

One practitioner's perspective
on speaking out

"Empower those people who are living it to get a voice and to speak what it is that they are living. I think that is so much more powerful than another document. If a tape recorder could be set in the House of Commons about women living in poverty…I think that would have more of an impact on those people sitting there and hearing it than a study on paper would have. If we can empower the people who are living it to somehow have a voice…" (FG 1)

Part 1: Taking Off the Blindfold

Health and literacy as a priority for research and action

When the Antigonish Town and County Community Health Board (ATCCHB) was setting health planning priorities, it identified literacy as a key issue requiring research and action. Members discussed their concerns with researchers from the Departments of Human Nutrition, Adult Education and Nursing at St. Francis Xavier University (St. FX) in the fall of 2000.

As a first step, workshops were held with health and literacy practitioners, adult learners and community leaders in Richmond and Antigonish counties to explore their views on literacy and health. Participants confirmed the need for the research, decided its focus, and identified community partners from the fields of health and literacy to give advice. These community partners formed an Advisory Panel to work with the St FX research team. Together, they developed a research proposal to explore the links between health and literacy in this region of Nova Scotia. The ***Health Literacy in Rural Nova Scotia Research Project*** was funded by the Social Sciences and Humanities Research Council (SSHRC) and the National Literacy Secretariat (NLS) Valuing Literacy in Canada Strategic Grant Program and began in April 2001. Community partners from Guysborough County joined the project early in 2002.

Partners for health literacy

"Health literacy" is a new concept that brings people from the health and literacy fields together. Health literacy builds on the idea that both health and literacy are critical resources for everyday living. Our level of literacy determines our ability not only to act on health information but also to take more control of our health as individuals, families and communities.

Since 2001, the St. FX research team has been working with partners from health and literacy agencies to increase awareness of health literacy as an important public issue. This research is meant to provide a base for improving policies and programs in order to enhance the health of adults with limited literacy skills who are living in rural northeastern Nova Scotia.

The Partnership

- St. Francis Xavier University (St FX)
- Antigonish County Adult Learning Association (ACALA)
- Antigonish Town and County Community Health Board (ATCCHB)
- Guysborough County Adult Learning Association (GALA)
- Guysborough Antigonish Strait Health Authority (GASHA)

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

The purpose and method of the study

In this study, we explored the links between literacy and health by looking at the personal experiences of people living in Antigonish, Richmond, and Guysborough counties. We wanted to:

- learn more about how adults with limited literacy skills get and use health information and services, and
- find strategies for change that build on the services and supports that we already have in our communities.

The participants

With their informed consent, we interviewed 25 adults enrolled in adult learning programs (P) and 21 adults with limited literacy not enrolled in adult learning programs (NP). We recruited the non-program participants through community-based agencies.

Of the 46 participants, 20 were from Antigonish County, 16 from Richmond County, and 10 from Guysborough County; 15 were male and 31 were female; four were of Acadian descent and spoke French as their first language, five were Mi'kmaq, and four were African Nova Scotian. Their ages ranged from 18 to over 55, and they had grade levels ranging from grade one to grade 12. All of the participants had struggled with "getting an education" and spoke from the experience of limited literacy.

> "I really appreciate having someone…to give me the time to talk about all of this stuff. It makes me feel good." (P-5)

We also held seven focus groups (FG) involving 64 health and literacy professionals from a wide range of organizations and agencies that work with clients limited in literacy. Four focus groups were held in Antigonish County (including one at Paq'tnkek First Nations), two in Richmond County, and one in Guysborough County.

As well, we interviewed 20 community leaders as key informants (KI). The key informants represented a variety of community and departmental organizations and although their jurisdiction often included more than one county, they were interviewed in their home counties as follows: eight in Antigonish, nine in Richmond, and three in Guysborough. Key informants included one Mi'kmaq and four African Nova Scotians. Two males and 18 females were interviewed.

All interviews were audio taped and later transcribed. The findings of this project reflect the voices of the 130 people who generously shared their stories and offered their insights.

The interview process:

The interview style was relaxed and informal. We wanted participants to feel comfortable enough to share their experiences and their reflections on those experiences, so we used a guided conversation approach. Personal stories and opinions flowed freely in most cases, and several participants said they appreciated the opportunity to discuss these important issues.

To start the discussion, we asked participants to talk about what the terms "literacy" and "health" meant to them, and to assess their own levels of literacy and health. Next, we talked about the factors that make and keep us healthy. With this broad definition of health in mind, we asked participants to think about a time when they had to deal with a health issue, either for themselves or someone else. When they shared their experiences, we prompted them to reflect on the situation: what was difficult about the situation, what supported them, and their level of satisfaction with the information or services they received. We then asked participants about how they usually got information and support, what they found useful, and what could make obtaining information and services easier for people with limited literacy. Finally, we asked them how they thought they could have more control over their own health and the health of their families.

What does "literacy" mean?

The research team looked at literacy as more than the ability to read and write. Some definitions of literacy focus on the basic reading and writing skills that help us function in everyday situations, such as following a recipe or reading the instructions for an appliance. Other definitions of literacy include the skills we need to participate effectively in daily life, such as communication, critical thinking, and social skills. Literacy also means having greater control over life events and situations.

During the interviews, we asked people about their own literacy and what it meant. We discovered that almost one-third of the 46 participants with limited literacy had no understanding of the term. Some people confused the term "literacy" with "illiteracy." Among those who had some understanding of the term, most thought of it as reading, writing, and upgrading. Others had a broader view.

> "Literacy means the understanding of what's wrote in front of you…to understand the meaning of something in your mind and to be able to write it out if you have to also and understand what you are writing out." (P-19)

One practitioner's perspective *on literacy*

"There is one woman that I worked with for four years and she had three children…I went one day to her house to make bran muffins. When we were finished making them, I said, "Here, I am going to leave the recipe with you so that when you want to make them again, you can make them." She looked at me and she said, "And what good is that going to do me?" I said, "Well, you probably can't remember what goes in them." "Oh, I can remember. I can't read." That is the first time I knew in four years that she couldn't read. I said, "Oh my gosh, I didn't know." I mean she hid it very well from me, she really did. Then I mentioned learning to read. Well, she resisted it so strongly that she was almost crying. She said, "Please don't make me do it." She was scared, I think…If literacy is enhanced, all of these other determinants of health are going to be impacted on, too, because things are possible now. The self-esteem of that individual is going to go, probably, through the roof because they are going to then know that they can take control and take charge of their life. It is that sense of personal power that when you don't have it, the world is a very scary place." (KI-5)

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

What does "health" mean?

The research team viewed health as more than not being sick. We accepted the broad definition of health as a state of physical, mental and social well-being. To be healthy, one must be able to identify and achieve goals, satisfy needs, and cope with change. Health is a resource to draw on for everyday living.

Many factors work together to make and keep individuals and communities healthy. Health Canada calls these the *determinants of health*:

Income and social status	**Social support networks**
Literacy and education	**Healthy child development**
Social environments	**Physical environments**
Personal health practices and coping skills	**Employment and working conditions**
Biology and genetic endowment	**Health information and services**
Gender	**Culture**

All of these factors are key today to understanding health and to improving it. Health promotion means helping people increase control over and improve their health.

We asked participants what they thought health meant. Although many people saw health as being "without illness" and "no aches and pains," others talked about things like healthy eating and getting enough exercise. Many saw health as having many parts. Concerns about mental health came up often.

We asked participants to assess their own health at the beginning of the interview, and again after we briefly discussed the factors that work together to keep us healthy. Some participants' responses shifted. At the beginning, they saw their health as adequate (meaning no serious illness). After the discussion, they had a more critical view of the lack of conditions and supports needed for health.

Several participants felt that in spite of a "few problems they had to deal with" they were generally satisfied with their health and their lives, as long as everything was "under control." Control over health, however, is often fragile in the face of limited literacy, under-education, unemployment, and poverty.

"Healthy means to have confidence in oneself; being able to deal with issues in today's society; keeping your family motivated to be able to deal with issues; being able to enjoy life -–having time to enjoy life after all the daily drudgery is taken care of." (P-23)

"I couldn't cope with what was happening around me that I had no control over, but that affected every inch and every moment of my life." (NP-8)

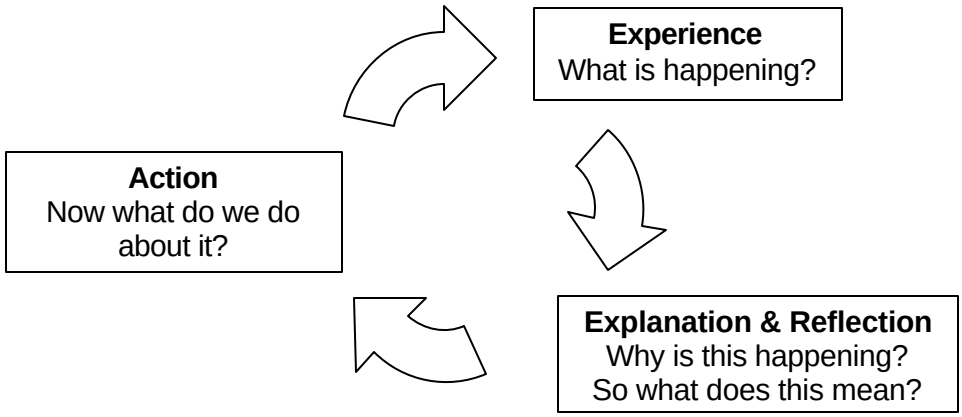
One practitioner's perspective *on health*

"What is the difference between a focus on just lack of disease versus real health? … Trying to explain to a person who has lived in very deprived circumstances and who hasn't been thriving and living a really healthy and happy and fulfilling life what [real health] is like… to do that is like trying to explain to a person who has never been able to see what the colour orange is like. Or a person who has never been able to hear what Mozart sounds like. It is not politically correct to talk about it. It needs to be talked about. It's a real key thing." (KI-7)

Reflecting on experience

By using an adult education approach in our interviews and focus groups, we invited participants to share their stories **and** think about the meaning of their experiences as they related to literacy and health. Their stories gave us valuable insights into the complex links between literacy and health. Two examples are found on the next pages.

Adult Learning Cycle



Experience: Participants explored past experiences by "telling their stories." (What is happening?)

Explanation and Reflection: Participants thought about their experiences by looking at underlying causes (Why is this happening?) and how the experiences fit into a larger picture. (So what does this mean?)

Action: Identifying what needs to be done on a personal, community, or policy level to make their situation better. (Now what do we do about it?)

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

In Plain Words:
A story about information and support from service providers

Explanation and reflection

"Well, I was stupid, like to stuff like that. OK, you would take a book and you would try to read about emphysema and cancer and all of that. Sometimes there are words there and if you broke it down in your own way – but it may not mean that at all…I went to the library, and little pamphlets that you get at the doctor's office about it – I found out on my own…Now you don't like to ask, what do you think they are saying? That happens and then they know that you don't have enough schooling to understand whatever they are saying…You don't like to say, well I haven't got that much schooling; what does this mean? …They don't use plain words.

People they don't realize when a person is sick, they change their moods. Such as my husband; he could be happy right now and in two minutes he could be just the opposite. There was never nobody to come in and say, "Well now, you take an hour off."…I had nobody. My kids, but there was nobody to come in and talk to me or make me a cup of tea, you know what I mean? When I used to come here to those ladies [women's centre], when I used to go home I would feel great because they laughed and they told little jokes. They took my mind off of him, you know…Nobody knows until they have to go through it, and I hope if I could help somebody I would."

Action

"You know there should have been somebody come out and sit me down, like us [the interview], and say, "This is what it is," and explain more to me than they did…So you have got to come down here to them [women's centre]…and they will get you the contact with people, you know what I mean? Social service, they are good for people, yeah, if you go up there to ask for money. You don't go up there just for a friendly visit, you know what I mean? It is kind of well, this and well, that, the budget is cut back so much…But you come down here and they will tell you to go to the food bank or go see a parish priest or a minister, whatever. They will get you in contact with other people…I know when we started [name of community – based program]…that was a beautiful program…That was like people on fixed income. We would come here once a week and we would talk like how you would try to help each other…It was for us women that were all like in the same bracket...I think there should be more support groups because you can talk about a lot, and people may have more trouble than I would. We could settle it out with each other…

If they had something like, say people with lung trouble or cancer; if they had a group of people like come in and sit down and a nurse or a doctor, or someone like that, they come in and sit down and say, OK this is cancer, this is emphysema, or this is whatever, and have a little board and write it down onto the board and explain at two or three meetings. By then you should have a kind of picture of what it is…But there is not enough of it. They seem to hide everything, you know. Cutbacks, you know, so much cutbacks. But that is not helping the people that has to go through this. (NP-4)

Breaking the Cycle: A story about the role of literacy programs in supporting the health of families

Experience

"As I was growing up my mom moved from place to place. We never stayed in one place long enough to have a home. We have always moved here and there. My mother was a very heavy alcoholic and lots of times we never went to school. Actually we did not know what school was for a while. When I went back and was in grade 8, I was being sexually harassed by a male student and each time I tried to report it to the office, they never did anything. So I left and never went back. I could not deal with that kind of stuff in school…I started drinking and I got mixed up with the wrong crowd, and I was drinking every night and going and getting into trouble."

Explanation and reflection

"Then finally one day I realized that this ain't me. I hate being dirty and smelling like this. I am making myself sick on this brew. So finally one day I said, 'That is it, I can't do this anymore.' It is going on 6 years I have not drank."

"I told myself everyday that I don't want to be like my mother; I want my health to be different…Her liver is gone, her kidneys are failing, she has a heart pacer, she is a high diabetic. She has so many problems in her now. My mother's alcoholism destroyed my life, me and my sisters' lives, but she will not admit it. I am not going to deny it. I don't care what anyone says." "I was following her footsteps until one day I realized…I affected my kids. I left them all the time; I'd come home loaded. I always said to myself I would never let my children see me, and I always did come home when they were asleep. And then one time I came home and they were awake. That was it…I can't take it..."

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

"A lot of time when my kids were doing homework and they would ask me I would say, "I'm sorry, I can't help you."…It makes you feel bad because I am the mother and I am supposed to be able to help them. I tell my children every day, it hurts me so bad that I never finished school, and I wish I had because I could help them a lot. But I tell them what happened to me in the past and I don't want them to take the same path that I did. I want them to go to school and do something with their life, do something that I never had a chance to do."

Action

"It's a little late right now, but I'm trying. I am trying so hard to put these kids on the right track and keep them there...I was determined to come back to school. When my son got into trouble, that is what gave me the idea…My son and daughter have gotten into some trouble at school with drugs, which upsets me. My son had to leave school. So I made a deal that if he comes back to school here, I would come with him. I am making a change for myself going back to school...We are together all the time, we joke a lot, we have a good time…When I have problems that I don't understand, he will help me. And then, where I am a little ahead of him in math, when he needs something he will ask me…I enjoy this. I never thought I would, but I really enjoy being here. My kids think it's cool."

"That is my biggest dream. That's what I told my children, 'I want to die knowing that you all have your education and a good job to hold you down. You guys can get all the things that you want that I never got. That is my dream, for you children to make something of yourself. Don't follow in the same footsteps that I did.' And I almost followed my mother's until I woke up and realized what I was doing." (P-8)

Part 2: Seeing How Literacy Affects Health

Literacy affects health directly and indirectly

Literacy influences health both directly and indirectly. The direct effects are the most obvious. They can include difficulty understanding and using health information and finding our way through a complicated health system.

Less obvious but often more profound are the indirect effects, including the personal and socioeconomic challenges that often go with limited literacy: self-confidence, employment, income, housing, healthy eating, and the stress that comes from constant worry about meeting these basic human needs for ourselves and our families.

> "I didn't even know about community services until the daycare teacher told me. I could have gotten help a lot sooner if somebody had told me it was there." (P-22)

> "If a person can't read very well they get put down a lot. Like my neighbour, who was always being put down because she couldn't read…[That] makes you sad. And you can't get a good job." (P-22)

> "That is one thing I find stressful. When you try to read a prescription and you can't read it…I don't know how to read labels…if I could get to read the label…" (P-24)

Looking at the realities of rural life

The ***Health Literacy in Rural Nova Scotia Research Project*** explored the links between literacy and health through the eyes of people living in three rural counties. Several major themes came out of the interviews: social isolation; lack of transportation; and limited opportunities and/or decreased access to employment, recreation, health care, education, and social support services. Participants also said that small communities are often close and supportive, which can lessen the negative impact of limited literacy on health. As one person said, "There's people that can help you." (NP-16)

Despite the support in many small communities, people did name a number of problems:

- **Social isolation:** "I don't even think he sees it because it has been happening so long that he is not noticing. His behaviour is a learned behaviour. Like he grew up in that area and it is all the same. I hate that area. To me it was like Alcatraz. I lived in Alcatraz for nine years and would people ask me, even back then…well, I live in Alcatraz and I can't get out. I mean you can't get any more desolate than that [area]." (NP-17)

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

- **Limited employment opportunities/social support services/transportation:** "[His] brother worked at the fish plant…He was in school here; he could not travel, he did not have the money to travel back and forth to come to school. He needs school to help him because he doesn't have the education. Right now, what is he going to do if they don't have that plant open? Two years ago, they got money from the plant and he had enough money…It would be good if they had somebody here to counsel these people…They had it in Port Hawkesbury. We would have to travel. We don't have the money, ways to get there." (P-24)

- **Accessibility of affordable health care resources:** "I buy my insulin at the drug store. You go to the drug store in Guysborough and get your pills for insulin…I can get one kind of pills in Antigonish for half the price that I can get it down here. A bottle of insulin down here is $26. I can get two bottles in Antigonish for $36.00. I can get groceries in Antigonish a lot cheaper than I can here." (NP-26)

- **Lack of social support services:** "But how would you set up a thing like that around here [women's shelter]?…I always think that she could have gotten more help. She went to social assistance and they gave her money, but money isn't everything. It's all right to help you along, but you're stressed out in a lot of ways…not just money wise, right." (NP-9)

In the middle of a puzzle..

"It is not that I did not try. I tried everything that there is to try. I ran out of options. I don't know what else to try. I got nothing else to try. I can't go to work wherever I try. They won't hire me. I'm a high-risk injury, they won't hire me. I got no education…I've tried to put my life together so I could support myself and my son. I can't put this together...I'm in the middle of a puzzle. There's a piece that don't fit in there, can't get it to fit. That's how I feel…For me to explain to you, how can I make my life better? Well, I just told you everything I know. If you were me, how could you make it better? That is my question to you. How you could make your life better if you were me?" (P-5)

Part 3: A Call for Action

The ***Health Literacy in Rural Nova Scotia Research Project*** is an action research project. This means that what we find out is to be used to make a difference in the lives of people. Participants had many suggestions about what needs to happen. All of the identified actions for change have come directly from the interviews. They incorporate the voices of participants who experience limited literacy as well as key informants and practitioners working in communities in this region of Nova Scotia.

Their suggestions for action called for change at the level of policy (local, provincial, and/or federal); programs (literacy, health, and social programs, as well as departmental and community-based programs); and practices (how service providers work with the people they serve). Because their proposed actions addressed the many direct and indirect links between health and literacy, they are organized according to determinants of health.

The suggested actions for change were discussed at Roundtable meetings and priorities set. Although all actions were considered necessary, those listed first were considered important to work on first.

Actions

1. Literacy and Education

- **Literacy**

> "Go to school and get your reading so you can help yourself…you ought to be able to learn how to read and write in this world or you are done for, if you don't know how to read and write." (NP-7)

1.1 Increase awareness and support of literacy as a determinant of health and well-being.

- Provide sustained funding to literacy programs.
- Provide adult learning programs at all levels to allow uninterrupted progress from one level to the next.

1.2 Find ways to reduce barriers to attending literacy programs.

- Ensure that literacy programs are accessible in rural areas.
- Provide more flexible literacy programming to meet the life and learning needs of more people.
- Provide both small group and one-on-one instruction to accommodate different learning styles.
- Increase opportunities for home-visits from literacy tutors.

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

- Use personal contact in recruitment; involve familiar community members in encouraging potential learners to enrol.

♦ **The School System**

> "The reason I became a Student Program Assistant is because I want to help those kids in school that are falling through the cracks. Not the ones that are labelled, because if they are labelled that they have a learning disability they get help…But how many children are in school that haven't got a learning disability, that are just naturally slow or haven't got the home support that gives them the little extra help? If it means just spending ten minutes with the child and a little bit of attention to brighten their day and to help them out so that they are going to do better, it is worth it. The smiles and the hugs I get from the kids is worth all the money they can pay me." (NP-18)

1.3 Identify and deal with learning difficulties early.

- Place more trained professionals in schools to recognize and address learning and behaviour problems early.
- Follow-up assessment with appropriate and sustained treatment.

1.4 Recognize and address the impacts of physical and emotional health on learning.

- Make sure that no child goes to school hungry.
- Promote family awareness of health through children in schools.

1.5 Turn kids on to reading good quality books for the health of it; support children's literature in school and community.

2. Health Information and Services

♦ **Health Information**

> "Written information is not enough. There has to be personal contact. It has to be explained, and people's questions have to be answered." (P-23)

2.1 Increase awareness of literacy issues among service providers.

2.2 Make health care information more accessible to everyone.

- Simplify explanations and instructions; learn and use principles of plain language.
- Put clear information about health and services where it will be seen and heard.

2.3 Provide alternatives to written information that meet the needs of a variety of literacy levels and learning styles.

- Provide time and funding for professionals to develop appropriate resources to use with those limited in literacy.
- Make better use of visuals.
- Put health information on audio and video cassettes, and make them available in a variety of health care and community locations.

2.4 Take information and services to people rather than waiting for them to come to services.

- Create health drop-in centres where individuals can access information and find someone to talk to about health issues.
- Provide "health mobiles," similar to mobile libraries, that go out to rural areas with information and someone to talk to.

2.5 Recognize and make use of the key role of pharmacists in providing health information.

- Provide a private area in pharmacies where people can ask questions and get instructions for using medication.

♦ Health Services

> "Take a little time. I know you are busy but there are some people that need it…Help them, don't leave them wondering." (P-1)

2.6 Give more time to each patient/client to listen and explain

- Encourage questions and listen carefully to all information provided. Be patient; recognize that change requires both courage and time.
- Follow up with clients and make certain that they understand important information and instructions.
- Provide a sense of caring, dignity, and respect in all provider-client relationships.

2.7 Support the use of client advocates.

- Provide facilitators or advocates to help people navigate through the health care system.
- Encourage the use of family members or friends as advocates.
- Make interpreters available where the first language is not English.
- Support public health professionals in taking an advocacy role.

2.8 Provide more resources in rural areas

- Increase the number of doctors and/or nurse practitioners.

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

- Increase the number of medical facilities and services.
- Improve transportation to make services accessible.

2.9 Increase efforts of all program and service providers to reach those who might "slip through the cracks."

- Increase networking among service providers.
- Integrate services for maximum effectiveness.

3. Income and Social Status

"To go out and get a job – that is healthy. When you earn your own money, you got a purpose then…Being on the system is not my cup of tea…All winter long I am isolated, I don't go anywhere. My big outing is to get my cheque and pay my bills. Don't dare spend a dollar for a coffee while you are out. That kind of living is just existing. It is not living life to the fullest, as they say…You have to have gas, money to buy the food. Money is the main thing today. I used to think love was. You loved your children, you loved each other, that is all that mattered. That doesn't go very far if you have no income." (P-15)

3.1 Involve the community in taking action to reduce poverty.

- Provide safe affordable housing for all.
- Ensure that healthy and affordable food is available to everyone.

3.2 Work towards policies that support the health care needs of those with limited income.

- Recognize that prescribed medications are often not affordable by those who need them.
- Address the issue of ambulance costs.
- Provide funding for regular dental and eye care.

4. Employment and Working Conditions

"The last 26 years I have always had money coming in…Before, there was lots of work; you could get work anywhere. But now…the woods is gone, the fishing is gone, the jobs are gone and you need education for everything…I could get a job cutting wood or something like that, but the way my hip is, I just can't make enough to get by on. I have a limit to what I can do…The last time I worked, I drove a machine in the woods. That is what happened to my hip. It was too hard on my hip – pretty long hours and worked hard. I have to try and get some education…I have two kids I am trying to keep in school." (P-26)

4.1 Respect people's innate abilities and life experiences when determining their "employability."

4.2 Create more job readiness programs that focus on developing personal and life skills as well as employment skills.

4.3 Reduce hazardous working conditions that often accompany low literacy.

4.4 Provide accessible compensation and support services.

5. Healthy Child Development

> "I'm surviving, but sometimes there's a lot of things I don't have and sometimes there's a lot of things I can't give my son…It makes you feel like a failure when you can't provide what you want for your kids. The way I look at it, my mother and father had a hard time bringing us up. There were seven in the family and it takes a lot of money to keep seven kids going, so they were working all the time to put food on the table. Even if they were doing that, they weren't providing me help with my school books. So a person can't provide everything; I understand that. But still, that's most of the reasons why people end up having literacy problems when growing up, as far as I'm concerned. If there were a little more support in the community, people volunteering and helping other people…" (P-5)

5.1 Ensure that every child has healthy, secure, and supportive physical and social environments in which to develop.

5.2 Increase funding for early prevention programs in health and education.

5.3 Provide more family literacy programs to support parents in their role as first teachers and caretakers of family health and well-being.

5.4 Provide more youth programs and youth groups within the schools and at community youth centres to promote positive health practices and social development.

6. Personal Health Habits and Coping Skills

> "I do everything that I can to control my health right now. I quit smoking. I eat healthy. I exercise every day, and I stay away from stress…A lot of it, I think has to do with my attitude. It took a long time, because I had to learn to believe in myself first." (NP-18)

6.1 Support the efforts of people to improve their own self-care practices.

- Make physical and recreation facilities accessible for all.
- Close down the gambling machines.

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

6.2 Hold local information workshops and support groups on a variety of health care issues.

- Provide hands-on experience in planning and preparing healthy meals, in the home or in community workshops.

7. Social Support Networks

> "I have lots of stress. My husband has asthma and prostate problems, and one of my sons has mental illness. Sometimes it's been so bad that if I didn't have support from my classmates at [community-based literacy program], I don't know how I would have coped." (P-23)

7.1 Value and support the important role of community-based organizations and services in fostering health and literacy.

7.2 Refer individuals to appropriate community-based services for support.

8. Social Environments

> "You would go somewheres and see kids all dressed up with nice short sets on. We would see them playing with bicycles and swings, and you are left out…You would go to their homes and it would be so nice and they would have everything up to date…and it hurt…We were left out. We were one of the poorer groups. When I started having a family I tried to get them anything they wanted, because I didn't have it." (NP-4)

8.1 Address social exclusion and isolation as significant factors when planning programs and services.

8.2 Ensure that all programs and services support the development of self-esteem and a positive attitude to life

9. Physical Environments

> "One of our barriers is our isolated community…With isolation comes lack of transportation, and lack of transportation becomes lack of knowledge." (KI-17)

9.1 Develop health and literacy promotion strategies that address the impact of a rural environment on health and literacy.

9.2 Create more opportunities for public transportation in rural areas to increase access to education and health services.

10. Biology and Genetic Endowment

> "If I would've known how to read it would've been easier to pick it up then. I couldn't make no sense out of it at first. Dad's mother, she had it [diabetes] for a long time. I didn't know nothing about it, see, and one of dad's sisters – she had it too, and she died from it. She was only 38. I knew she died, but I really didn't know what she died from at first. I didn't know nothing about it." (NP-5)

10.1 Educate people on the genetic links of many physical and mental conditions.

- Encourage people to become aware of their family medical history.

10.2 Provide genetic information to adoptive and foster families.

11. Gender

> "What we found resoundingly is that when women come out of that program it was the life skills that have moved them forward…Overwhelmingly what they talk about are the components that we do on self-esteem, on assertiveness, on learning to like yourself…That kind of personal growth they do…which is essentially about validating them as being worthy people in the world…is a huge motivator. After that, almost anything seems possible." (KI-13)

11.1 Be sensitive to gender issues and provide appropriate programs, services, and supports.

11.2 Recognize and support the important role of women as caretakers of family health.

11.3 Reduce barriers to programs and services for women: provide transportation, childcare, flexibility.

12. Culture

> "I think of when the community was loved, and that old African proverb where it takes a village to raise a child. Well, when I was a kid everybody raised you…When someone was called in for a slice of bread, everybody was called in for it, even if that meant you were drinking water or weak tea out of a Miracle Whip bottle…Everybody was on equal grounds. We were all poor…Then came destruction, because the white man started coming in and he was going to save us all. Not only the white man, but then you got these black organizations and people were coming from the Halifax area and they were going to save us. Everybody came in and they were going to save us, and they started bringing in all their bad habits along with them." (KI-17)

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

12.1 Recognize that racism exists in our communities and work to undo it.

12.2 Educate practitioners and policy makers about cultural differences and the importance of social inclusion to health and well-being.

12.3 Involve participants in designing, delivering, and evaluating their programs and services.

12.4 Provide early language programs so that all children thrive in their first language.

Priorities for Action

The following is a summary of the priorities that Roundtable participants considered important to act on first. Under some priorities are also suggestions for more specific action.

- **Increase awareness and support of literacy as a determinant of health and well-being.**
  - Provide sustained funding to literacy programs
- **Find ways to reduce barriers to attending literacy programs.**
  - Ensure that literacy programs are **accessible** in rural areas.
  - Provide more flexible literacy programming to meet the life and learning needs of more people.
- **Increase awareness of literacy issues among service providers.**
- **Make health care information more accessible to everyone.**
  - Simplify explanations and instructions; learn and use principles of plain language.
- **Take information and services to people rather than waiting for them to come to services.**
  - Create health drop-in centres where individuals can access information and find someone to talk to about health issues.
  - Provide "health mobiles," similar to mobile libraries, that go out to rural areas with information and someone to talk to.
- **Support the use of client advocates.**
  - Provide facilitators or advocates to help people navigate through the health care system.
  - Make interpreters available where the first language is not English.
- **Increase efforts of all program and service providers to reach those who might "slip through the cracks."**
  - Increase networking among service providers.
  - Integrate services for maximum effectiveness.
- **Value and support the important role of community-based organizations and services in fostering health and literacy.**
- **Develop health and literacy promotion strategies that address the impact of a rural environment on health and literacy.**
- **Create more opportunities for public transportation in rural areas to increase access to education and health services.**

Participants also suggested two priorities beyond those identified from the research.

- **Redirect funding to place greater emphasis priority on disease prevention and health promotion.**
- **Use the report, *Taking off the Blindfold: Seeing How Literacy Affects Health*, to raise awareness and influence decision making.**

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

One key informant's perspective
on taking action

"I think the barrier around literacy is people want to put specific issues away where they don't have to look at them." (KI-3)

Part 4: Taking the Next Steps

The Roundtables on Health Literacy provided an opportunity to begin thinking about how to work together to implement some of the actions that resulted from the research. Participants' feedback was very positive. All participants reported that the Roundtable had increased their understanding of the links between health and literacy. All left feeling that there were specific steps they could and would take to address literacy and health issues. As one project participant who attended a Roundtable session said, "It's very comforting to know that people like myself might have a chance to improve our way of living the way it should be."

Taking Action

Participants identified and prioritized actions for change that recognize literacy as an important determinant of health. Their input helps build the case for improving policies, programs, and practices that support the health of people who experience limited literacy.

Since the Roundtable, meetings have taken place among representatives from a number of health, literacy, and community-based organizations to determine how we can work together to address health literacy. Representatives of organizations and concerned individuals have formed a health literacy network to further the work.

The **Guysborough Antigonish Strait Health Literacy Network** includes individuals and organizations who are working together to:

- Identify what should be done in this region to make it easier for people with limited literacy to have better health
- Increase public awareness of health literacy as an important social and economic issue
- Influence policy and programs to enhance the capacity for health of those who experience limited literacy
- Advocate to remove literacy barriers in finding and using health information, services and supports
- Share information and resources to increase action on literacy and health.

(Draft May 3/2004).

Building on the collaboration and findings of the *Health Literacy in Rural Nova Scotia Research Project*, the Guysborough Antigonish Strait Health Authority is looking at how their primary health care (PHC) policies, programs and practices can better meet the needs of adults limited in literacy. Supported through the Nova Scotia Department of Health Primary Health Care Transition Fund, the **"Building Capacity among Primary Health Care Providers to Address Literacy and Health Project"** is addressing the following two priorities for action which emerged from the research.

- Increase awareness and support of literacy as a determinant of health and well-being
- Increase awareness of literacy issues among service providers

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

Other initiatives are being developed, such as that of the Richmond County Literacy Network which has submitted a proposal to address the impact of low literacy on health of seniors in their rural communities.

Putting the pieces together

This report provides a glimpse into what participants told us about health and literacy based on their experiences. From the stories they shared, we can see the far-reaching impact that limited literacy has on their lives and their health. Their voices challenge the assumption that almost everyone can read well enough to use health information and access the services they need to support their health.

> "Those all link together. Depending on what kind of job you get, education, where you live – it all links up. If you don't have no education, you won't get a good job. Odds are you are going to be a transient, not be stable, not be in good shape. Not good mental health, not making the money that you should be…depressed, worried about paying their bills – those are the people I see." (P-4)

The experiences and insights shared by participants in this study show that health and literacy are connected in many ways. Participants told us how low literacy reduced their use of medical advice and health information, and limited their access to the services they needed. They also talked about how their lack of literacy was closely connected to other social and economic conditions that influenced their health. Links among education, employment, economic and social status, and health were emphasized repeatedly.

Many spoke of the lack of control they had over the conditions that shape their daily lives. Their stories have provided ample evidence that limited literacy is influencing the physical, mental, and social well-being of people living in Antigonish, Guysborough and Richmond counties.

Working together for better health literacy

Health literacy is a term we have used to talk about how our level of literacy affects our ability to find and act on health information and services and, ultimately, take control of our health. Both health and literacy are essential resources for our well-being and for making our lives better.

Health literacy is an opportunity for practitioners and policy makers from the fields of health, literacy, and other sectors to work together to address the health concerns of people limited in literacy, and the literacy concerns of people experiencing poor health. Many things must and can be done to reduce the barriers that limited literacy imposes on the health and well-being of people in this region and beyond.

Addressing health literacy means breaking down the barriers to health that low literacy creates and finding ways to enable all people to:

- access the services and supports they need
- understand and use information to promote health and prevent disease
- make informed decisions about self-care and treatment of illness
- advocate for their own health, as well as family and community health
- have more control over the factors that determine their health and well-being

> "Now that I'm back in school everything is cleaned up. Like I don't drink, I don't do nothing like that. The thing is, if you're going to go to school everyday it's the same thing as being healthy, really. You have got to be there every day and you are going to feel good every day. Somehow you know you gotta try to do it." (P-16)

To improve practices, programs and policies, we need to build new partnerships and strengthen existing ones between the health and literacy sectors and between policy makers and practitioners. Working together to address health literacy will promote both literacy and health as resources for everyday living for participants of this study and the many others facing similar challenges.

Through this research, participants have shown us how literacy affects their lives and their health. They have helped us take off our blindfolds to recognize the importance of health literacy. Now that we have seen through their eyes the impact of literacy on health, we must take action to address it.

KI = key informant; FG = focus group; P = program participant; NP = non-program participant

One practitioner's perspective
on raising awareness about health literacy

"The community's awareness of the issue is probably the key factor that will affect somebody's health if they are not literate…The more aware people are, not only in the health care system, but just in the community, it's going to affect health." (FG-3)

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For more information on health literacy, see:

Gillis, D.E. *Beyond Words: The Health-Literacy Connection* at www.canadian-health-network.ca (type "beyond words" in search window to reach link).