"If you were me, how could you make it better?"

Responding to the Challenge of **Literacy** and **Health**

by **Doris E. Gillis**, **B. Allan Quigley** and **Allene MacIsaac**

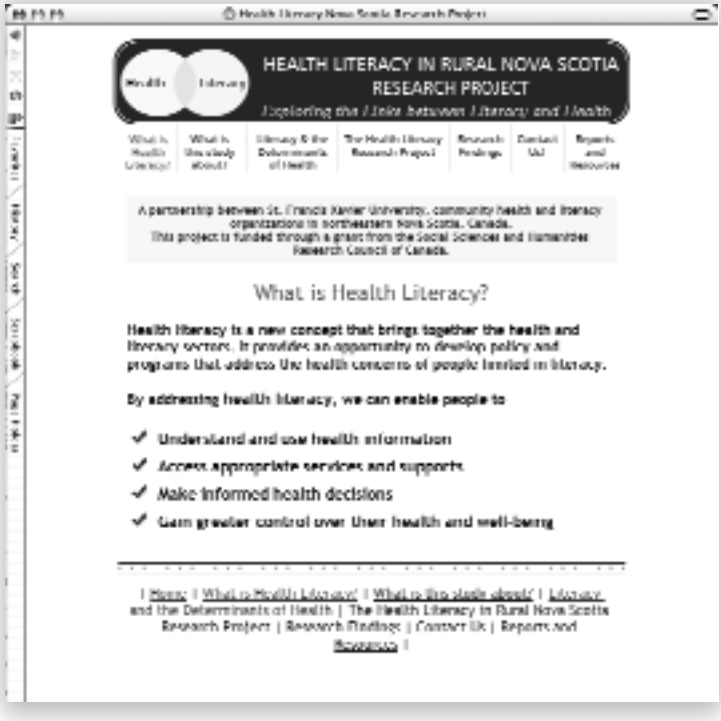
"It is not that I did not try. I tried everything that there is to try. I ran out of options...I can't go to work wherever I try....I'm a high-risk injury, they won't hire me. I got no education...I've tried to put my life together so I could support myself and my son. I can't put this together...I'm in the middle of a puzzle. There's a piece that don't fit in there, can't get it to fit.....If you were me, how could you make it better? That is my question to you."
(Unemployed fish plant worker)

"If you were me, how could you make it better?" is the overwhelming question that now challenges partners in the Health Literacy in Rural Nova Scotia Research Project who initially set out to explore how limited literacy influences the health of residents in northeastern Nova Scotia. The question posed by an unemployed fish plant worker with low literacy skills and serious health issues poignantly affirmed what the literature (Perrin; Rootman and Ronson) supports and what many practitioners in literacy and health fields confront in their everyday practice (Brown and Dryden). Low literacy not only affects health in obvious ways—such as limiting access, and limiting both understanding and the effective use of health information and services—it also exerts less direct, but often more profound, impacts on the health and life of individuals and families. Because literacy underlies most other determinants of health, the interdependent effects of literacy, income, poverty and health become the most challenging aspect of addressing the literacy and health link. This is a subject of pressing concern in Atlantic Canada, where rates of limited literacy are among the highest in the country (OECD and Statistics Canada) and rates of chronic diseases and risk factors associated with these diseases are higher than in the rest of Canada (Federal, Provincial, and Territorial Advisory Committee on Population Health; Genuine Progress Index Atlantic).

Identifying the health literacy issue

The Health Literacy in Rural Nova Scotia Research Project was a participatory action research project which explored the link between literacy and health through the lived experience of people in three primarily rural counties of Nova Scotia. A multidisciplinary research team from St Francis Xavier University, including faculty from the Departments of Adult Education, Human

Nutrition, and Nursing, partnered with five community-based literacy and health organizations within the Guysborough Antigonish Strait Health Authority. We undertook the project in response to the Antigonish Town and County Community Health Board's concern about the potential impact of literacy levels on residents' health. While evaluating the effectiveness of a health services directory that had been distributed to every household, the Board members realized that low literacy levels could be a factor affecting residents' access and use of health information and services, and their capacity for health. Significantly, Board members did not confine their health planning mandate to health services; they recognized that non-medical determinants such as income, employment, social support, education and literacy also influenced the health of their community. This initial identification of the link between literacy and health brought academics, health and literacy practitioners, and community leaders together around questions of how literacy impacts health in this rural region of Nova Scotia.



In the fall of 2000, the research team held two workshops with health and literacy practitioners, health service managers, literacy program coordinators, and adult learners participating in literacy programs. The participants not only confirmed the need for the research, they also provided valuable suggestions for the study. These workshops resulted in the formation of an advisory group that participated in developing the research proposal. This group expanded into a community-based advisory committee that guided the implementation of the study, assisted in providing access to research participants, and helped to disseminate and follow up on findings. The committee was intent on ensuring that what was learned about literacy and health from the lived experience of local people was used to improve policies, programs and practices throughout the district.

Method and participants

A skilled research assistant conducted in-depth interviews using a reflective adult education process. All participants were asked to share stories of their experience, reflect upon the meaning of these experiences, and suggest actions for 'what needs to happen now.'

Working with members of the advisory committee and local service providers, we were able to interview 46 adults whose lives had been affected by limited literacy. These included 25 adults in adult learning programs and 21 adults not in learning programs who were reached through 13 agencies such as an out-patient diabetic clinic, drug dependency services, family and women's resource centres, and a Mi'qmaq health centre. After participants consented in writing to be contacted, the research assistant contacted them to set up an interview. All participants were offered an honorarium.

Participants included 15 males and 31 females, ranging in age from 18 to over 55 years of age and from grade one to grade 12 education. There were four Acadians, five Mi'kmaq and four African Nova Scotians. Seven focus group interviews were conducted with 64 health and literacy practitioners. The research assistant also interviewed 20 community leaders considered key informants.

All individual and group interviews were audio-taped and transcribed. The research team then analyzed the transcripts, using Atlas.ti qualitative analysis software, to derive themes.

Findings and their dissemination

Our findings confirmed that limited literacy and poor health are linked in direct and indirect ways. Participants told us how low literacy affected their ability to obtain, understand and use health information, as well as their access to health and literacy services. Moreover, they talked about how their level of literacy was closely connected to other social and economic conditions that influenced their health. Many spoke of a lack of control over situations in their daily lives, which they frequently attributed to their lack of literacy skills. The words of a former forestry worker trying to manage his diabetes amply demonstrate this:

> You ought to be able to learn how to read and write in this world or you are done for....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 [health practitioners in the diabetic clinic] going to help you? You feel uncomfortable and you don't know what to ask for.

Taking Off the Blindfold: Seeing How Literacy Affects Health became the title of a discussion paper outlining the research process and preliminary findings. It focused especially on participants' suggestions for change. We used the Population Health Approach (Bhatti and Hamilton; Public Health Agency of Canada) as a framework for categorizing these actions according to determinants of health. The calls for action were directed at many levels and pointed to the need for change in improving local, provincial and federal policies; as well as in literacy, health and social programs and practices—particularly those of health care providers.

This discussion paper was distributed to participants involved in the research project, to other stakeholders, and posted on the project web site (www.nald.ca/health literacystfx). It served as the focal point for two day-long roundtable meetings held early in 2004 and attended by over 80 research participants, community partners, practitioners and policy makers. Research findings were presented by the research team and also through a vignette by a popular theatre group. Participants discussed the findings and prioritized the suggested actions. We then

updated the report to include these priorities and distributed it so people could use it as a tool to advocate for change. During the spring of 2004, we presented our findings to practitioners, policy makers and decision makers, including Nova Scotia's Ministers of Health, Education, and Community Services.

Being exposed to reports of experiences of people who face literacy as a barrier to their health has made a strong impression upon practitioners and policy makers, and has resulted in follow-up action. A health literacy network was formed to broaden collaboration and sustain efforts to address literacy and health in the region. Furthermore, the Guysborough Antigonish Strait Health Authority made a commitment to address two action priorities relevant to the health system: to increase awareness and support of literacy as a determinant of health and well-being, and increase awareness of literacy issues among service providers. They have since completed an environmental scan of their policies, programs and practices related to literacy and health, and held health literacy awareness sessions with primary health care providers throughout the district. As a result, providers are making changes to improve access to their services; their efforts include improving signage to address the ways people navigate through health facilities, and assessing print material, such as ways people are asked to complete forms. Moreover, by building on the action priorities of the research and using this health authority's work as an example, the Nova Scotia government has initiated a province-wide plan to further action on health literacy.

Conclusion and implications

The research findings and participation of community members in this research process has helped build the case for reducing barriers that people with limited literacy face when accessing the health care system. This is only a start. Much more needs to be done to fully remove the blindfold that prevents us from recognizing the many ways limited literacy acts as a barrier to health. Until we more fully see the links between literacy and health through the eyes of those whose lives are shaped by it, we will not be able to respond to the question, "If you were me, how could you make it better?" ■

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