Literacy is considered one of the most important determinants of health among Canadians (Ronson & Rootman, 2004). Engaging communities in identifying the critical connections between literacy and health is an important aspect of addressing health literacy. This article describes how participatory research, undertaken through a university-community partnership, resulted in the identification and prioritization of actions to improve practices and policies addressing health literacy needs of a largely rural population in Atlantic Canada.

The Health Literacy in Rural Nova Scotia Research Project studied links between literacy and health by exploring the experiences of people living in rural northeastern Nova Scotia. A multidisciplinary research team from St. Francis Xavier University (including faculty from the Adult Education, Human Nutrition, and Nursing Departments), partnered with five community-based literacy and health organizations in three counties, within the Guysborough Antigonish Strait Health Authority (GASHA), to a) explore factors that influence ways adults limited in literacy access and act upon health information and services; and b) identify strategies for change that build upon existing capacities for achieving health. This collaborative research project explored the lived experiences of people whose daily lives are determined by limited literacy, as well as the insights of professionals who provide education and health-related services to them. Community leaders, with awareness of the socio-economic conditions in the region, also provided their insight on how literacy and health interacted.

A Community Participatory Research Approach

Community-based research is increasingly being called for to enhance understanding of the complex issues that affect our health (Seifer & Galleson, 2004). More specifically, participatory research can engage community members who have the knowledge, experience, and expertise related to such issues. Participatory research is “a systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change” (Green et al., 1994). This approach is known to take considerable time and commitment from all who are involved. However, efforts can lead to outcomes that are relevant beyond academic boundaries with knowledge transferred to various community stakeholders, resulting in community-led actions addressing important health problems (McCauley et al., 1999).

Community partners involved in the participatory research project, described in this article, were clear from the onset that the aim of the research should be to effect change in policies and practices to build capacity for health among residents in their communities.

This participatory research project stemmed from a local community health board’s concern that low literacy could be preventing some residents’ access to health resources, services, and information. This problem was brought to the attention of university researchers, who were able to access some preliminary funding to undertake district workshops in the fall of 2000 from the Social Sciences and Humanities Research Council of Canada (National Literacy Secretariat Valuing
Literacy in Canada Strategic Grant Program). The aim of these sessions was to determine if this issue was deemed by community members and practitioners to merit further study, how the research should be undertaken, and who should help guide the process of inquiry.

Workshop participants included adult learners in literacy programs, adults with low literacy skills not in programs, as well as practitioners and managers from the fields of community health and literacy. Their input confirmed the need to explore the links between health and literacy in their communities; it also informed the design of the study. For example, they recommended that personal interviews should be conducted with individual adults who have experienced literacy difficulties, while focus groups should be used to encourage dialogue among practitioners from literacy and health practice settings. The university research team with a working group representing literacy and health organizations developed the full research proposal.

Once funding was secured, this initial group expanded into an advisory panel, who guided the implementation of the study assisted in providing access to study participants, raised community awareness of the issue and the study, provided feedback in the analysis of findings, participated in dissemination of findings, and finally, championed follow-up actions. The advisory panel was composed of community leaders from three community-based adult learning organizations from each of the three counties, the chair of the local community health board that first identified the problem, and district health managers. This partnership was unique in that it brought together, for the first time, practitioners from the fields of literacy and health. All partners were intent on ensuring that findings would be used to improve policies, programs and practices, and ultimately result in improvements in the lives of residents throughout the district—especially those who face low literacy as a barrier to their health.

**Data Collection**

By working with members of the advisory panel, as well as local service providers in literacy and health agencies, we reached 46 adults whose lives had been shaped by limited literacy and who consented to be interviewed. A research assistant, skilled in interviewing and with experience in family literacy, conducted in-depth, audio-taped interviews with 25 adults enrolled in adult learning programs and 21 adults who were recruited through the hospital diabetes out-patient clinic and community-based health agencies, such as addiction services, a community health centre, and women’s resource centre. They included 15 males and 31 females, ranging in age from 18 to over 55, who possessed an education from grade one to grade 12. Participants included four Acadians, five Mi’kmag and four African Nova Scotians. Seven group interviews were held with 64 health and literacy professionals whose practice involved working with adults limited in literacy. Twenty community leaders were also interviewed as key informants.

The interviewer used a reflective adult education process to guide all individual and group interviews.

This process encouraged participants to share their stories related to literacy and health, reflect upon the meaning of these experiences, and give any suggestions on what might need to happen to improve the situation. All individual and focus group interviews were transcribed and entered into Atlas.ti qualitative analysis software. Key themes were derived by the research team and presented to the advisory panel for discussion and feedback. In the fall of 2003, a discussion paper written in clear language that presented key findings and calls for action was developed.

**Transferring Knowledge to Action**

The publication was aptly called *Taking Off the Blindfold: Seeing How Literacy Affects Health*. The title derived from a poignant comment made by a participant, who discussed how limited literacy skills affected his opportunities for employment, adequate income, healthy food, decent housing, as well as his interactions with the health care system. As a diabetic, this man had problems communicating with health care providers, and, subsequently, managing his medication and diet. He said:

> 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.

This publication was distributed to research participants, practitioners, community leaders, and district and provincial decision makers. Two roundtables were held, where findings were presented, including a popular theatre dramatization based on stories heard through the interviews. Using a workshop format, some 80 participants identified priorities for action derived from the study’s findings. Their recommendations pointed to the need for change in improving local, provincial, and federal policies, as well as in literacy, health, and social programs and practices. Their priorities were as follows:

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

The *Taking off the Blindfold* publication was updated to reflect these priorities and more broadly disseminated to decision-makers and practitioners across the district, and province including provincial Ministers of Health, Education, and Community Services (Gillis & Quigley, 2004). The advisory panel, which had guided the three-year research project, expanded into a district health literacy network to further work on the calls for action emerging from the research.

**Follow-up Action**

Engagement in this participatory research initiative has resulted in a number of follow-up responses at various levels. One stellar example of a community-driven response to the research findings is *Bringing Health Literacy Home to Richmond County*, an initiative launched by the Richmond County Literacy Network at the beginning of 2005 with funding from the National Literacy Secretariat. With the help of health practitioners and service providers, seniors’ organizations, and community leaders and local champions, this county-wide literacy network is working towards fostering a vibrant, healthier, and more literate community. Activities have included development of public awareness presentations and workshop materials on health literacy issues, a handbook of community services and resources made available to all residents throughout the county, and an updated Web site that includes health literacy information and linkages. A particularly innovative approach is the use of volunteer “community helpers,” who provide assistance to their neighbours in relation to health and literacy issues, and promote the importance of health literacy in their respective communities. Moreover, a “community champion” has been designated as a spokesperson to advocate on behalf of health literacy issues to all levels of government.

Two action priorities emerging from the research were responded to by the GASHA. This district health authority secured funding in 2004 from the Nova Scotia Primary Health Care Transition Fund to increase awareness and support of literacy as a determinant of health and well-being, and to increase awareness of health literacy issues among service providers. First, a district-wide environmental scan of practices and policies related to literacy and health was conducted to gauge providers’ level of awareness of health literacy and what was being done to address the literacy concerns of users of the health care system. Findings were disseminated to providers, as part of a series of health literacy awareness sessions presented throughout the district. Some 185 primary health care providers at five health sites and via Telehealth participated. The sessions also included a presentation of the research and its findings, and a 20-minute popular theatre dramatization based on interviewee stories describing the direct and indirect impacts of literacy on health. These sessions were very effective and providers who participated in the sessions later reported that they had made a number of changes in their health literacy practices. Subsequently, a health literacy policy and an environmental assessment tool were developed with the aim of enabling health providers to better meet the literacy needs of population groups throughout the health district. A recommendation supporting the development of a health literacy standard for the accreditation of Canadian health service organizations was also promoted.

Using findings from the study and the follow-up work of GASHA as a model, the Primary Health Care Division of the Nova Scotia Department of Health held a provincial stakeholder workshop in December 2004, and subsequently launched a province-wide health literacy awareness initiative in April 2005. This initiative included the production of an educational video, called *Health Literacy: Making the Connections*, aimed at raising awareness of health literacy among primary health care providers across the province. Nova Scotia’s health literacy agenda continues through the efforts of a multi-sector provincial steering committee.

**Lessons Learned**

Through this participatory research process, we were able to build both the case and the commitment for improving policies, programs, and practices related to health literacy throughout the district and beyond. We were able to find and hear the stories of people, who confront low literacy as a barrier to their health. Not only did participants speak of their experiences in trying to access, understand and use health information, services and supports, but their stories also revealed the complex interactions between literacy and health, including direct and indirect impacts of literacy on health.

A clear sense of the purpose of the study, rooted in concern that came from the community, was essential to sustaining participation and transferring findings to effect change in practice and policy. A central theme emerging from the interviews was that systems themselves can be deterrents to health. Members of the advisory panel, and many of the participants, saw their involvement in this research process as one way they could be an active player in working for structural change. In this same issue, Allan Quigley gives further insight into the historic relevance of this point.

The emphasis on a participative approach to the research provided members with opportunities to identify commonalities and differences in each others'
work, and their respective institutional structures and practices—critical aspects of working together to effect change. Addressing literacy and health required open dialogue and a clear understanding of the issue as seen from multiple perspectives. Enabling individuals from diverse sectors, disciplines, backgrounds and cultures to understand each other and work together is challenging. For many literacy is not an easy issue to talk about. As noted by one health practitioner, "The words can only take you so far. It is the experience of being in health care, and coming up against that literacy issue that makes you experience and understand it . . . but I could never put it into words."

Creating opportunities for learning across disciplines, communities and sectors was a critical element in this participatory research project. One goal of such learning is to break down the institutional, cultural, and professional silos that shape the way we think and act around health and literacy issues. The need to raise community awareness of literacy and its impact on health was a theme running through the practitioners' focus groups. As one practitioner said:

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.

One of the outcomes of the participatory research process was the development of an understanding of what health literacy meant within the context of this work. Simply stated, health literacy meant finding 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

Underpinning this view of health literacy was the belief both health and literacy are critical resources for everyday living. As put by one practitioner:

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.

Our definition of health literacy emerged from a strong commitment to building bridges across many sectors and domains to enhance our understanding of the complex links that tie literacy and health. Most importantly, it valued the lived experience of people who face low literacy as a barrier to health while also acknowledging the challenge facing practitioners, as they recognize the profound influence that literacy has on health.

References


