Connecting literacy, wellness and mental health

by Kelly Robinson

Sometimes in life we come across an interesting idea, meet an inspiring person or perhaps have a chance conversation. This happened to me while I was taking a break from my job in community mental health and working toward my master's degree in Adult Education and Community Development at OISE/University of Toronto. One summer evening I was floating down the Otonabee River during a fundraising boat cruise and struck up a conversation with Jeanine. Jeanine is a woman who has used both mental-health and literacy services, and is currently a mental-health worker and a literacy practitioner herself. When I told her that I was interested in exploring alternatives to a functional approach to literacy and medical approaches to health and mental health, she said, "Well, you should really look at the links between literacy and mental health. I bet there's not a lot of literature out there." She was right. As I searched for research, I found a considerable amount of work in the area of "health literacy." It highlighted a connection between the ability to read and write and one's personal health and illness. Still, there was much less research on mental health and literacy. What did exist tended to focus on the way that mental-health issues and the medicines prescribed for it can affect memory and concentration and therefore make it difficult for a person to read and write well.

At about the same time, I had the fortune to meet with a group of Toronto-based literacy practitioners and health-care workers who have an interest in alternative approaches to their fields. Their discussion about the relationships between literacy, learning and wellness suggested that there was something worth exploring. I became convinced that there was more to this story of literacy and mental health and continued to delve into the issue. One of the results is this article. It provides a brief overview of some of the findings of my recent research that flowed from my serendipitous conversation with Jeanine.

The requirements of my degree were such that I had to shape my thinking and interest into a research question that was clear and well-defined. Therefore, the question I asked was: "What are the experiences, successes and challenges for some clients of community mental-heath centres in gaining access to and benefiting from literacy services?" I worded the question this way because I recognized that there

are a variety of experiences and many successes as well as challenges. I wanted to provide an opportunity for people to acknowledge and celebrate their accomplishments as well as explore what they perceived as barriers. The purpose of the work was not to evaluate the quality of literacy services in the community; rather I was interested in gaining a better understanding of the relationships between literacy and mental health, and on a broader level, between learning and wellness.

I thought it was important for the research question to come from my own community and not simply my curiosity. I was strongly influenced by Patricia Maguire's (1987) writing about the importance of the question or issue originating in the community and her call to "dig where you stand." I recalled my conversation with Jeanine and sought input from my community members as well as through published research. I found that indeed there were some literacy practitioners and mental-health workers who identified that barriers exist for many people seeking literacy services, including those with mental-health issues.

I started with the assumption that people have deep and valuable knowledge about themselves and their own experiences. One of the key messages I took from my work in the mental-health field is that people are the experts in their own lives. Therefore, I decided to use discussion groups and open-ended questions so that participants had opportunities to talk about what is important to them in their own words. I had hoped that the group process would help people express and clarify their views in a way that might not happen in a one-to-one interview. I then followed up with individual conversations because I wanted participants to have space to talk about issues that weren't addressed in the group or that they did not want to discuss with others. I thought that the individual conversations could also be used to explore ideas that bubbled up after the discussion groups. The discussion groups and individual conversations were not occasions to simply gather facts seen as objective and external to me, but rather for me to explore meaning and interpretation, both mine and others', related to literacy through loosely structured conversations guided by my research question. These methods provided opportunities for people to tell their own stories in their own words. This helped create a richer, deeper and broader picture of what literacy, health,

www.literacyjournal.ca LITERACIES #9 fall 2008 13

wellness and mental health means to them.

I hosted three discussion groups in Peterborough, Ontario between February and March 2007. The first was for mental-health workers; the second for literacy practitioners; and the third was for clients of community mental-health centres who had used or attempted to use literacy services in the past. It took me a considerable amount of time to determine how to identify and define the third group, which I am calling "learners." There is considerable controversy about issues related to mental health and mental illness. I decided that I did not need to know participants' diagnoses and it was not up to me to determine who did or did not have a mental-health issue, or even how to define mental-health issues. As a result, I chose to define this group as "clients of community mental-health centres." By nature of using these community-based, government-funded services, people would have been diagnosed with a mentalhealth issue of some sort at some point in time. Participants didn't feel obligated to tell me the details and I didn't feel obligated to ask or know. Since they were also recipients of literacy services, I have chosen to call this group "learners" throughout the study. Although participants may have been diagnosed with a mental-health issue, it is their existence as learners and their experience with literacy that is important for the purpose of this study. I also see them as autonomous individuals participating in a project, rather than "clients" who "belong" to a particular mental-health or literacy agency.

I began each group discussion by asking the question, "What does the word literacy mean to you?" and asking people to identify some barriers to literacy. The responses surprised and excited me. I thought that many would talk about waiting lists, difficulties with transportation and childcare, cognitive challenges such as concentration and memory, and medication side effects. What actually surfaced was the idea that literacy is fundamental to the ability to participate in the world as a regular citizen. This was a key issue that arose almost immediately in all of the group discussions and individual conversations. It came through in conversations about barriers such as depression, anxiety, stigma, lack of self-esteem and the importance of personal connections. Participants' deep understanding of the complexity and interconnectedness of issues was exemplified in the stories they told about their own experiences with literacy and mental health.

I think it's important to hear what people said in

their own words and have incorporated a number of their comments in order to illustrate the themes that arose in this research.

Participating in the world

In our culture, the use of language is a necessary tool to navigate through the world. If you are not able to be literate, to comprehend or utilize language, there are a lot of things you can't take part in. You avoid them and so you exclude yourself. Lack of literacy and exclusion go together. Doug, mental-health worker

Discussions and conversations with all three participant groups suggested that stigma, self-esteem and identity are three issues that arise and are related to participating in the world. People talked about the way in which stigma can be internalized, which can affect self-esteem and sense of identity. Acknowledging reading and writing difficulties can be a huge first step for learners because they feel embarrassed:

Like any other program, you have to admit it. You have to say that you are illiterate and many people don't want to do that. It comes down to something called P-R-I-D-E, pride. People don't want to admit that they have a problem.

Brendan, learner

One of the literacy practitioners, Christine, identified being labelled "illiterate" and the resulting stigma as a significant challenge: "I wondered what it would be like if you have to stop someone and ask them to read something for you. I've done it a few times in the grocery store to see what it's like. I've said, "I can't read this, can you read it for me?" You see this look of horror in people's faces. I think of how my clients have to face that, it's terrible."

She noted that government attitude and policy toward people living in poverty is a major problem:

Poverty further stigmatizes people, undermines their efforts and can make mental-health issues worse. I would guess that about 25 per cent of the centre's learners come for help with computers, but once they begin it is often apparent that they need help with reading and writing as well. I think it's because it's more socially acceptable for people to tell themselves and others that they are getting 'help with computers' rather than with reading and writing.

Some learners talked about the stigma related to being labeled "mentally ill" and said that they were reluctant to add the label of "illiterate" by seeking literacy services. It is therefore not surprising that most of the participants identified low self-esteem as a common barrier to seeking and/or benefiting from literacy services.

When participants talked about depression and anxiety it is clear that this can get in the way of literacy, but problems with literacy can also lead to anxiety and depression. This in turn is related to self-esteem and the effects of isolation due to health issues or poverty. For some learners, abusive or violent living conditions were related to lower self-esteem and an increased sense of isolation. They revealed how difficult experiences in the early school years can hinder progress and confidence in adult life. When people talked about comprehension, they suggested that literacy is not all or nothing. Taking a simplistic view can lead us to overlook people's strengths and, as a result, can add to the factors that decrease confidence.

Most of the literacy practitioners and mentalhealth workers talked about the way that addictions, mental-health issues, lack of opportunities, trauma, poverty, hunger, lack of childcare, lack of transportation and unpleasant past experiences are all linked and related to each other and to learning. Many people also noted that sometimes learners are facing so many challenges that improving literacy is not at the top of the list of priorities:

Literacy is not a simple issue. All of these things, mental health, poverty, addictions and trauma, are linked and are working together. Sometimes literacy is the last thing on a person's mind.

Krista, literacy practitioner

Since self-esteem, substance abuse and poverty are such pressing issues, focusing on literacy is like putting the cart before the horse.

Catherine, mental-health worker

As these comments suggest, the issues related to literacy combine, overlap and are connected. In discussion and conversations, people rarely separated mental health from health in general. All of the factors identified by participants clearly have an impact on a person's mental health and literacy. On a broader scale, they are tied directly to a person's overall health, wellness, and ability to learn and participate in the world.

www.literacyjournal.ca LITERACIES #9 fall 2008 15

Why is this important?

I think these findings and the themes are significant for literacy practitioners, mental-health workers, learners, funders, governments and institutions for a number of reasons. They suggest that there is a complex combination of social, economic, cultural, personal and political factors related to health and learning. As the key theme of participation emerged, it became evident to me that people were not just talking about literacy or mental health, they were talking about how we all live as people in today's world. I would suggest that participation means more than the ability to work for wages, pay taxes, vote and purchase consumer goods. It includes an awareness of the world, of the structures and systems, of differences and similarities among people and cultures, of giving and accepting care, of our relationships as humans to other living things and the natural world.

Throughout the study, I noted the eagerness of participants to share their experiences and talk about some of the issues. They each have a wealth of experience and knowledge but too few opportunities to discuss such issues amongst themselves or across sectors. Conversations between people in different communities are important because literacy, health, mental health and wellness are socially constructed and contested terms whose definitions and approaches depend on who is talking about them and for what reason.

Participants said that the discussions brought up some new ideas that they hadn't previously considered and they looked forward to talking more about them during the individual conversations and with other people. Their comments about ideas "bubbling up" from discussion groups reveals the value in increasing opportunities for more in-depth discussion about literacy and health. In the literacy field this can be accomplished by building sharing, reflection and discussion into orientation sessions and ongoing training programs for literacy practitioners, thereby incorporating a more holistic perspective into the culture of literacy provision. Literacy practitioners and mental-health workers would also benefit from regular forums that could help them explore some of the themes that have arisen in this and other research and discuss what it might mean for their practice.

Participants' comment and conversations suggest that we can't talk about literacy or mental health without talking about learning or wellness. They reinforced the idea that we lose something when we separate literacy from the context of broader learning, or remove mental health from the context of overall health in a person's life. Unfortunately, many current approaches to learning and to health make little space for integrating the mind, body, spirit and heart. Therefore, I think it's not surprising that we hear so much about a "health epidemic" or that there is a "literacy crisis." Expanding and integrating our approaches and breaking down barriers is necessary for people to fully participate in life.

By continuing to seek a richer understanding of these factors, we might learn more about the way in which they can affect participation in the world for people who use both literacy and mental-health services. They also suggest some directions for future research that might increase participation of those who are actively involved in literacy and health.

KELLY ROBINSON has worked in the mental health field for over ten years. She is currently Family Worker with the Toronto Branch of the Canadian Mental Health Association and a PhD student in Adult Education and Community Development at OISE at the University of Toronto. She is interested in participatory and community-based research that explores the social determinants of health.

SOURCES:

- Antone, E., P. Gamelin & L. Provost-Turchetti, L. (2003). Literacy and Learning: Acknowledging aboriginal holistic approaches to learning in relation to "best practices" literacy training programs. Prepared for the Ministry of Training, Colleges and Universities and the National Literacy Secretariat.
- Breen, M.J. (1998). Promoting literacy, improving health. Canada health action: Building on the legacy. V2 adults and seniors. Ottawa: National Forum on Health.
- Casey, J. E. (2005). Factors affecting success in community based literacy programs: Phase 2 summary report. Windsor: University of Windsor.
- Davis, T.C., H. Meldrum, P.K.P. Tippy, B. Weiss, & M. Williams (1996). How poor literacy leads to poor health care. *Patient Care*, 30 (16), 94-124.
- Freebody, P., & Freiberg, J. (1997). Adult Literacy and Health: Reading and writing as keeping well practices. Melbourne: National Languages and Literacy Institute.
- George, P. (Nigwakwe) The Rainbow/Holistic approach to aboriginal literacy.Keynote Address at *Mamawenig–Sharing and Celebrating Our Knowledge*. May 14, 2002. Fort Qu'Appelle, Saskatchewan.
- Gillis, D. E., & A. Quigley (2004). Taking off the blindfold: Seeing how literacy affects health. Antigonish: Literacy in Rural Nova Scotia Research Project.
- Greenberg, D. (2001). A critical look at health literacy. *Adult Basic Education*, 11 (2), 67-79.
- Health Canada (2003). How does literacy affect the health of Canadians? Retrieved on November 15, 2006 from www.hc-sc.gc.ca/hppb/literacy/literacy.html.
- Ontario Prevention Clearinghouse, Ontario Chronic Disease Prevention Alliance and the Canadian Cancer Society – Ontario Division, *Primer to action: Social determinants of health*, Toronto, 2007.
- Rootman, I., & R. Ronson (2003). Literacy and health research in Canada: Where have We been and where should we go? Ottawa: Canadian Institute for Health Research.
- Rootman, I., D. Gordon-El-Bihbety, J. Frankish, H. Hemming, M. Kaszap, L. Langille, D. Quantz, & B. Ronson (2003). National literacy and health research program, needs assessment and environmental scan.