

visions

Vol. 8 No. 2 2013



health literacy

evaluating mental health and
substance use information

health literacy and mood disorders:
a personal reflection

visions

Published quarterly, *Visions* is a national award-winning journal that provides a forum for the voices of people experiencing a mental illness or substance use problem, their family and friends, and service providers in BC. It creates a place where many perspectives on mental health and addictions issues can be heard. *Visions* is produced by the BC Partners for Mental Health and Addictions Information and funded by BC Mental Health and Addiction Services, an agency of the Provincial Health Services Authority.

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subscriptions and advertising

Subscriptions to *Visions* are free in BC to those experiencing a mental illness or substance use problem, their families, and public or non-profit mental health or addictions service agencies. For all others, subscriptions are \$25 for four issues. **eVisions** electronic subscriptions and back issues are available for free on our website. See www.heretohelp.bc.ca/visions. Advertising rates and deadlines are also online.

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Heretohelp is a project of the BC Partners for Mental Health and Addictions Information. The BC Partners are a group of seven non-profit agencies working together to empower people to improve their quality of life by providing useful, accurate and good quality information on mental health, mental illness, substance use and addictions. We represent AnxietyBC, British Columbia Schizophrenia Society, Canadian Mental Health Association's BC Division, Centre for Addictions Research of BC, FORCE Society for Kids' Mental Health, Family Services of the North Shore's Jessie's Legacy Program and the Mood Disorders Association of BC. BC Partners work is funded by BC Mental Health and Addiction Services, an agency of the Provincial Health Services Authority. Visit us at www.heretohelp.bc.ca.

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we want your feedback!

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*pseudonym

I wrote two articles for *Visions* a few years ago. It was an exciting opportunity and I was delighted when edited versions of what I had written were published. I was not in a good place at the time and this was one of the few things that gave me any sense of optimism. Having lost my career and identity sometime before due to disability, the opportunity to have articles in *Visions* inspired me and gave me self-confidence. It was after writing for *Visions* that I decided I would begin writing in earnest, so that when someone asked, 'what do you do?', I would not have to endure that painful silence of not knowing how to respond. I can now answer that question "author" as I have written four books. It is amazing how random acts of kindness and the presentation of opportunity and hope can encourage people to change their lives in ways they never imagined. That is what happened to me and I shall not forget this life lesson. I am very grateful to the staff at *Visions* for helping me gain a meaningful life.

—Andy Sibbald, Nanaimo

We really value receiving the magazine, we read it from cover to cover and then pass it on to someone who we think might benefit from the particular issue. The choice of articles and especially the editing always stands out.

—Carol Itter, Vancouver

editor's message

Welcome to this issue on health literacy!

First, it might be useful to take a moment to clarify who I am. Regular readers will notice that I am not Sarah Hamid-Balma who skillfully introduces and weaves together each issue of *Visions* in her role as ongoing Editor. And I am not the Guest Editor for this issue. We are lucky to have Dr. Irving Rootman fulfill that role, providing a compelling analysis of BC's leadership in the area of mental health literacy. For this issue, I am more of a "visiting editor," bringing this issue to publication after we started work on it during Sarah's recent maternity leave. I am really pleased to be able to share such a strong collection of articles covering a breadth of ideas associated with health literacy. Let me take a few moments to catch you up about what we have in store for you in this issue.

When I first came across the words "health literacy" earlier in my career, the term felt both unfamiliar, and familiar, all at the same time. I remember being able to grasp the concept of literacy, but I wondered about the specifics of literacy linked to health. At first, I developed a fairly basic understanding of health literacy, thinking it meant an individual's ability to understand health information. As I have spent more time in the field of mental health, and of course during my experiences editing this issue, I have come to develop a more comprehensive understanding of what is meant by health literacy. In terms of my own relationship with health literacy, I can now see it in terms of being able to find information about health, figuring out if that information is of good quality, and communicating what I understand of that information. Of course, understanding the information I've found is still a key part. In many ways, I've increased my literacy of health literacy!

Each of the contributors in this issue do a wonderful job of bringing greater understanding to what is meant by health literacy. In keeping with the long-standing tradition in *Visions*, a number of perspectives converge in this issue, helping along a richer, thicker, and more vivid understanding of the topic. Researchers, family members, service providers, a young person, and policymakers all weigh in on the issue. I trust that you will walk away with some new learning about how health literacy supports overall health.

Jonny Morris



Jonny Morris is the Director of Public Policy and Campus Mental Health at the Canadian Mental Health Association's BC Division

footnotes reminder

If you see a superscripted number in an article, that means there is a footnote attached to that point. In most cases, this is a bibliographic reference. For complete footnotes, see the online version of each article at www.heretohelp.bc.ca/publications/visions. If you don't have access to the internet, please contact us for the footnotes by phone, fax or mail using the contact information on page 2.

Is British Columbia a World Leader in Mental Health Literacy?

Guest Editor Irving Rootman, PhD

I am delighted to be invited to be the guest editor of this issue of *Visions* on the topic of “health literacy.” The last time I was invited to submit an article to *Visions* was about ten years ago when I was asked to submit something on the topic of “health literacy and management of chronic health conditions.”¹



Irving Rootman is a Visiting Professor in the Department of Gerontology at Simon Fraser University and Chair of the BC Health Literacy Network

Since then the field of health literacy has grown considerably in Canada and throughout the world.² However, with a couple of exceptions, the focus has been mainly on general health literacy rather than mental health literacy. The exceptions appear to be Australia and Canada, which were the only two out of 34 countries in a survey about health literacy that mentioned “mental health literacy” in their responses. Moreover, the examples reported from Canada are quite recent, suggesting that it is a fairly new area of activity.

It is also interesting to note that the 2004 United States Institute of Medicine Report on Health Literacy contained no references to “mental health literacy”³ whereas the Canadian Expert Panel on Health Literacy Report⁴ issued four years later, contained several, one of which was a report on health literacy

by the Canadian Alliance on Mental Illness and Mental Health.⁵

That report defined health literacy as “the knowledge and skills that enable people to access, understand and apply information for mental health.”⁶ The report further suggested that:

... enhancing mental health literacy involves more than simply providing people with information—it involves support for skill development and empowerment so that people can understand information and make informed decisions about how to apply it to promote mental health.

This health promotion perspective on mental health literacy is reflected in the comments by Dan Reist in this issue of *Visions* who adds the notion of health literacy as a “resource or asset” and a way to enable individuals to exert more

control over health and the factors that affect it. Interestingly, most of the other papers in this issue also reflect this perspective in some way, although some of them also take a more clinical or medical approach to mental health literacy which is important as well.

The papers in this issue also recognize that individuals are not totally responsible for their own mental health literacy. Families, friends, health practitioners, health institutions, service providers, schools, voluntary organizations, the media, governments and other bodies also have a critical role to play in improving and maintaining individuals' mental health literacy and well-being.

In that regard, it is interesting to note that the recent international report on health literacy noted above mentions a number of BC initiatives related to supporting health literacy. For example, it mentions the 2003 mental health and

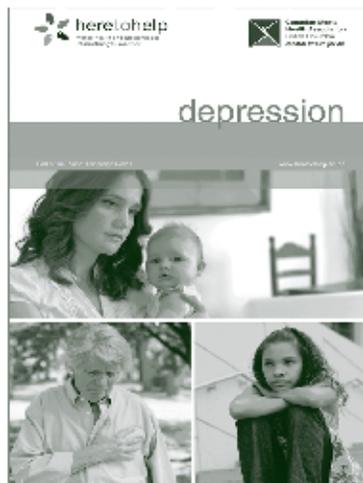
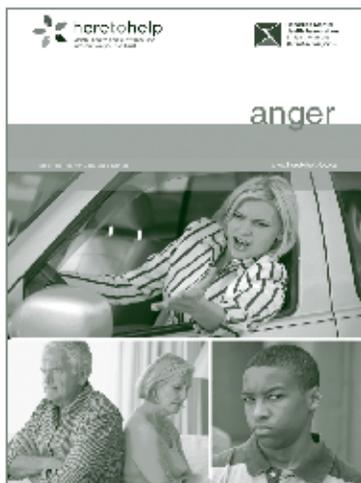
addictions information plan to improve mental health and substance use literacy among all British Columbians and the resulting establishment of the British Columbia Partners for Mental Health and Addictions coalition that includes non-profit mental health and addictions agencies and among other things, develops and disseminates mental health information to residents of this province. As part of this mandate, the BC Partners produced an outstanding article in this issue on evaluating mental health and substance use information. Being able to evaluate health information in general, and mental health information in particular, is an extremely important element of health literacy given the increasing amount of health information that is now available over the internet and from other sources.

Other mental health literacy examples from BC cited in the international report include: Kelty Mental Health

Resource Centre; Provincial Child and Youth Healthy Living Initiative; Disordered Eating and Eating Disorders Mental Health Literacy Initiative; Cross-Cultural Mental Health Literacy Initiatives; Mental Health Literacy School-Based Initiatives; and expansion and redesign of mindcheck.ca.

Thus, there is no question that British Columbia is an international leader in mental health literacy and mental health promotion and that this issue of *Visions* is one more example of the important role that this province is playing and could continue to play in this rather neglected, but nevertheless important field. I therefore recommend that you read it from beginning to end and make your own contribution to promoting the health literacy of yourself, your family, your community, your workplace, the organizations that you are part of, your province, country and the world. ▽

plainer language series



This series of booklets are easy to read resources that will help you learn about mental health and mental illness.

learn

- Tips for good mental health
- what is mental illness
- what is anxiety
- what is anger
- what is depression
- what is suicide

visit www.heretohelp.bc.ca/factsheet/plainer-language-series

What is Health Literacy?

Stephanie Wilson

“Literacy” is your ability to read, write, understand and apply the materials. “Health literacy” is an extension of literacy—the “skills to enable access, understanding, and use of information for health.”¹

An example of health literacy is following your doctor’s instructions when you receive a prescription medication. It may seem simple, but it may take quite a lot of information to achieve this task. First, you’ll need to understand your doctor’s or pharmacist’s instructions and read any patient information sheets that are included with your medication. You’ll also need to understand why you need the medication, what might happen if you don’t take the medication, and what risks may go along with the medication. All of these questions may influence your decision to take (or not take) the medication, which in turn may affect your overall health.

The general concepts described here can also be applied to “mental health literacy.” Mental health literacy simply refers to health literacy that is specific to your knowledge about mental illnesses.²

Health literacy and health promotion

Health literacy and health promotion are two different but highly related ideas. Health promotion is promotion or encouragement to take care of your health. Promotion is proactive—you take action to promote a positive goal. It might mean eating well and getting enough sleep because you feel healthier rather than to reduce the risk of catching a cold. Health literacy is a tool for health promotion. In order to make an informed decision about your health, you have to start at the beginning: you have to know what you

want to achieve. Within the context of health promotion, increasing health literacy may be reflected in activities like proactive workplace health policies. In this situation, the goal is to understand positive health and how you might protect and increase health and well-being.

Promotion versus prevention

Health promotion is proactive and encourages you to take steps that improve your health. Prevention strategies, on the other hand, encourage you to take action to prevent or reduce the risk of a health problem. A simple example is washing your hands often when someone around you is sick to reduce the risk of becoming sick. From a prevention point of view, increasing health literacy may be reflected in activities like early recognition of a problem and early treatment. It may also include identifying groups who

Stephanie is the Editorial Coordinator for Visions



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The goal is to understand mental disorders and take actions that reduce the effects of mental disorders.

experience increased risk factors and providing extra services or supports. In these situations, the goal is to understand mental disorders and take actions that reduce the effects of mental disorders.

Consequences of lower health literacy

Lower health literacy can be linked to the burden upon the health care system. When people aren't aware of how they may handle a health concern or what kinds of supports are available, they may be more likely to depend on the health care system and demand services or procedures that aren't necessary in their situation. If people believe that only a professional (like a psychologist or psychiatrist) can help, they may exclude other forms of support like self-help, social support or paraprofessionals. The demand for services often exceeds the available resources, so professionals have to allocate scarce resources most effectively.²

Critical perspectives of health literacy

Health literacy is not restricted to a particular set of beliefs or values, though the beliefs and values associated with the health care system may seem to be the dominant message for many people. Conflicting perspectives can create friction, such as the two following examples.

Top-down research versus experiences and perspectives

Health literacy generally depends on the work of experts like researchers

and doctors. These experts may rely on data collected through methods like randomized clinical trials and large sample sizes. It's a top-down system because a small number of people pass their interpretation of certain data to the rest of the population. It generally relies on the belief that people will adopt the findings because they are supported by sound research methods and evidence. However, research methods may not capture individual experiences. If someone's experiences are labelled a 'problem' and this doesn't align with their own interpretation of the problem or concern, they may be less willing to seek help or advice.²

Tensions between research and communities can also come up when the community doesn't have the resources to follow the researcher's suggested best practices. This situation can be seen around Aboriginal communities in Canada who rely on fish or wildlife that has been contaminated by pollution. While most people would likely agree that high levels of mercury can affect brain health and that avoiding fish from contaminated lakes and rivers may reduce the effects on contamination in people, it might not be a realistic solution. The people in those communities may rely on fishing because they don't have the resources to buy outside food products.³

Individual responsibility versus social determinants of health

Mental health literacy work and the mental health care system in general is often criticized for "individualizing" mental health problems—that is, they may place the responsibility of following a treatment thought to be a 'best practice' on the individual. However, the health problem may be related to factors that the individual can't control.

Mental health is influenced by many factors outside of the individual, such as income and distribution of wealth, availability of decent housing, social and community supports, and experiences of inclusion or exclusion. However, discord between individual responsibility and outside factors of health can create tensions. Here is an example: a person has a very low income and, despite their efforts, hasn't been able to find a higher-paying job. Their experiences of hopelessness lead to the label of "depression." Medication and talk therapy are considered the best practice in treatment of depression, and that person is told that they must follow this treatment plan. However, the treatments don't change income levels or job availability.⁴ ▼

Evaluating Mental Health and Substance Use Information

BC Partners for Mental Health and Addictions Information

With all of the information coming at us these days, it can be hard to filter out what is good information and what information isn't as good. This is especially true when it comes to information about mental health and substance use. If you've been looking online or in the media for information to help yourself or a loved one, you may be frustrated by some of the conflicting information you've found. With all of the information out there, how do you know what information you can trust?

Mental health and substance use information online

Many of us use the Internet to look up almost everything, and health information is no different. The problem with the Internet, though, is that anyone can post information. This means that you can read an article about depression written by someone who isn't qualified to talk about depression at all. There is also conflicting information available on the web. One website might say one thing about a substance use treatment and the next site you look at might say the opposite.

Personal experiences online

Many people living with mental disorders or substance use problems share their stories online through websites, blogs, web forums, or other social media. Our own site, HeretoHelp, provides personal stories on our home page. These stories can help inspire hope and connect you to others going through similar experiences. They are an incredibly powerful tool to help you feel less alone, see how others navigated the system, and see what their recovery journey looked like. When you read these stories, it's important to remember that it's one person's experience, not everyone's experience. For example, a blogger may write that

a particular treatment didn't work for them, but that doesn't mean the same treatment won't work for others.

Anyone can post almost anything online, so it's up to you to decide if a website, blog or post is good for you. Here are some key questions to ask:

- Do you know that you're reading someone's personal experiences from the very start?
- Does the writer claim that their opinions or views are right and everyone else is wrong?
- Does the writer claim that their own experiences are scientific facts?
- Does the writer claim to have information that no else has? For example, do they claim to have found a "miracle cure?"
- Does the writer offer detailed medical advice, even though they aren't a doctor or other health professional?
- Is the writer using the site or blog to sell or endorse their own product?

Mental health and substance use information in the media

You can find news media online as well as in print and on TV and radio. But it's important to mention a few extra points about new media.

TV shows that include substance use like drinking or news stories about

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where can I learn more about health information?

Health on the Net Foundation

Health on the Net Foundation is an organization that is dedicated to the sharing of reliable health information and the proper use of health information. Visit www.hon.ch for more.

Media Awareness

Visit the Media Awareness Network at www.media-awareness.ca for resources and tips on media literacy.

Media Doctor

Visit www.mediadoctor.ca for health-related news stories that have been rated based on their reliability.

substance use may be full of mixed messages. For instance, you often see people using substances on TV or in movies, but then a news story might tell you that any substance use is harmful and dangerous. Or you might hear about an instant “miracle cure” for substance use problems, and then hear that no treatment ever works.

The problem is that a brief news story often can't explain the full story when it comes to mental health concerns, substance use concerns or recovery options. Space or airtime in the news is limited and very expensive. Major news stories are not always balanced and might be sensational and exciting. A story may be entertaining, but it may not apply to all people in all cases. Major news stories may lead you to believe that harmful things are happening to a lot of people, when in reality they might be very rare.

News media can help you understand very complicated issues, but information that is too simple can also be misleading. For example, if new research finds a link between depression and bone loss, it's not unusual to see a headline that says, “Depression causes bone loss,”

even though that statement may not accurately describe the relationship.

What should I look for when I'm looking for mental health or substance use information?

Here are some general things to look for online and in the media:

- Where did the information come from? Is it based on research, an interview or a press release? Does the writer list their credentials?
- What website is it on? Websites that belong to governments, government-funded agencies, well-known health providers, universities, or groups of medical professionals are generally the most reliable.²
- Why are they providing the information? Are they trying to sell you something?³ Does the source have anything to gain from a media story?⁴
- Can you tell the difference between advertisements and information? A credible website will clearly define ad space. Less credible websites may not, so advertisements may look like part of the information.⁵
- Does the story seem to accurately describe the problem or the information?⁶ Does it seem logical to you?

- Does the story reflect both the possible harms and benefits? Does the story mention any alternatives?
- Does the story seem balanced? Does the story make it seem like a problem hurts (or helps) more people than it really does, or does it make something sound scarier than it really is? A balanced story generally gives real numbers.⁷
- Does the story claim to know everything, or does it mention that we don't know everything about all the issues?⁸
- How new is the information? If it's more than a couple of years old, it may be outdated.⁹
- Does the writer offer overly simple solutions for complicated problems? This is a huge warning sign.
- Does the story respect everyone?
- Does it encourage you to think, ask questions and make your own decisions?¹⁰

Where can I go from here?

If you're concerned about something you've heard, talk to your doctor or mental health care professional. If you're concerned about a medication, always talk to your doctor before you make a decision.

You can also:

- Get a second opinion from a trusted source for health information.
- Look for more stories from different media sources like newspapers or news stations.
- Read many different personal experiences from different places, online and offline in books. This is one of the best ways to benefit from what they have to offer. ▼

Mental Health Literacy

WHAT DOES IT MEAN FOR SUBSTANCE USE AND WHY DOES IT MATTER?

Dan Reist

The impact of substance use on the health and well-being of British Columbians is substantial. Substance use contributes to heart disease and cancer. It is a major factor in injuries and accidental deaths. And it adds to numerous social and relational problems for individuals, families and communities.

The growing (many would say, unsustainable) cost of maintaining our health care and social service industries is leading to increasing attention to modifiable risk factors such as food choices, physical activity and substance use. This, in turn, has led to debates about the relative roles of individual responsibility, social determinants of health, and healthy public policy. More and more, we are becoming aware that we need to ensure more people achieve and maintain a standard of health that minimizes their need for expensive health care services. It is in this context that we should consider the role of mental health literacy.

Two perspectives on health literacy

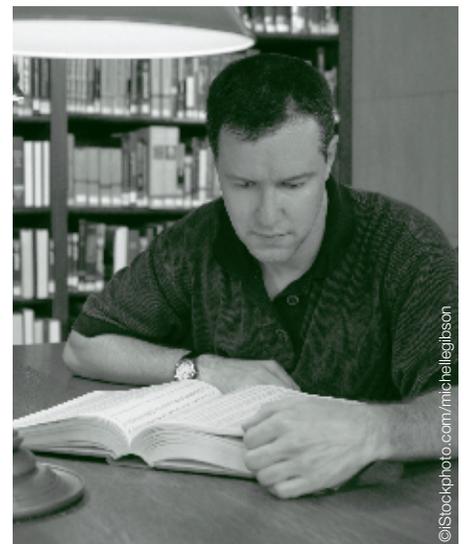
The term “health literacy” has been around for a long time and used to apply concepts about literacy to the world of health care. But the apparent simplicity of the term masks the complexity of its components: health and literacy. This complexity involves scope, setting and purpose. In a narrow definition, literacy is the ability to read and write. This ability is developed and certified in schools in order to help people communicate. Most educators, however, prefer a broader definition that includes abilities to compute and solve problems required to function in society, achieve one’s goals and develop one’s potential. The difference in scope, setting and purpose reflected in these

definitions of literacy is echoed in the discussions of health literacy.

Much of the interest in health literacy has focused on knowledge and skills related to communication within health care settings, such as a doctor’s office. This usually means the ability of patients to apply literacy skills to material such as prescriptions, medicine labels and informational brochures. The goal is increased compliance with treatment, help-seeking behaviour, or self-management of the disease or symptoms. This can be called clinical health literacy¹ or medical literacy.² Low medical literacy is directly related to low literacy (in the narrower sense) and is a risk factor associated with a range of poor health outcomes.³ Medical literacy is, therefore, important.

A different understanding of health literacy arises from a public health or health promotion perspective. Health literacy, in this case, is the “ability to access, understand, evaluate and communicate information as a way

Dan leads a team at the Centre for Addictions Research of BC, University of Victoria that is involved in developing learning resources for BC schools designed to increase mental health literacy to help young people develop the knowledge and skills they need to survive and thrive in a drug using world. See www.carbc.ca/HelpingSchools.aspx



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Low medical literacy is directly related to low literacy and is a risk factor with a range of poor health outcomes. Medical literacy is, therefore, important.

related resources

Just Health Action:
www.justhealthaction.org

to promote, maintain and improve health in a variety of settings across the life-course.”⁴ This suggests that health literacy is a resource or asset—“a means to enabling individuals to exert greater control over their health and the range of personal, social and environmental determinants of health.”³ Health literacy involves awareness of the interconnections between individual, social and environmental factors and the ways in which these connections influence the health and well-being of individuals and communities.⁵

Mental health literacy and drug education

“Mental health literacy” has almost exclusively been used in the narrow sense of medical literacy.⁶ This risk-factor understanding of health literacy has also dominated in drug education efforts. The goal has usually been to get young people to not use drugs. In other words, the goal has been to increase compliance with a pre-determined pattern of behaviour. Various approaches have been used in order to achieve this goal, but none have been very successful.

A new possibility is suggested by the asset definition of health literacy. In this model, drug education would be directed toward health capacities, which enable individuals to exert greater control over their health. This involves understanding and managing the factors that impact drug use and its consequences, among other

things. Some of these factors relate to individual behaviour choices, but many are social or environmental factors that are only minimally modifiable at the individual level. Health literacy is not, however, restricted to capacity for making individual lifestyle choices. It should, “incorporate the empowerment of individuals and communities to take action on social, economic and political determinants.”⁷ In fact, health literacy is a precondition for taking community action for health or developing healthy public policy.

Just Health Action is a Seattle-based non-profit organization that has been working to develop and teach a health literacy curriculum that encourages critical analysis and reflection. Their curriculum involves exploring knowledge about “what is health,” “health inequities” and “causes-of-the-causes.” It also focuses on building specific skills and using tools and strategies to take action on achieving health and health equity. Finally, it involves helping students find their own way of engaging in health action, including advocating for healthy public policy.⁷

The potential of mental health literacy

Building health capacities through health literacy and influencing health opportunities through other health promotion actions, such as restricting access to psychoactive substances or increasing equity through access to resources and support services, will not

guarantee individuals choose healthy actions. In fact, it may be important for society to give individuals the freedom not to choose a particular healthy action.⁸ Nonetheless, individuals and communities that understand the various factors and mechanisms that influence health and have the skills to take action on them are more likely to choose healthy personal behaviours and also more likely to advocate at the community and policy levels for actions that build healthier environments.⁹

Containing the costs and harms related to substance use will require increasing the mental health literacy of the population. This means a greater understanding of the human experience with psychoactive substances. The traditional emphasis on the health impacts of drugs is part of that story. But understanding how social inequities impact the harms related to substance use is also a critical part. Drug education should graduate students empowered to take greater control of their own health and well-being and to be active in promoting action on the social and environmental determinants of health. The success of drug education efforts might be measured as much by the types of policies citizens support as by the personal choices they make around substance use. ▼

Communities that understand the various factors and mechanisms that influence health are more likely to build healthier environments.

A Young Person Describes Health Literacy

Shelley Hine and Chloe*

This article serves as an opportunity to hear from a young person about how they make sense of “health literacy” from their own vantage point.

Q: What is your earliest recollection of being educated about your health? How old were you? What impression do you recall it made on you?

A: Basic stuff from my mom before kindergarten-age, like, “Wash your hands,” then in daycare they reinforced the basics again. The way I processed it was that I knew I couldn’t go out if I was sick, so washing my hands and staying away from germs meant I could go to the parties I was invited to and play with my friends.

Q: What is your earliest recollection of health education in school? What kinds of things were you taught and how did you respond?

A: They began educating in kindergarten, again with the basics on germ transmission. But I remember asking my mom development questions like, “Where do breasts come from, and where did I come from.” She would give me easy answers, of course, like, “You came from my tummy.” I also remember getting bored pretty quickly with the information and I just wanted to go out and play. Playing with dolls also taught me about health education, learning about anatomy, playing doctor, et cetera.

Q: What’s your earliest memory of learning something about body image? What sense did you make of it?

A: I had really long hair and I got it cut very short in Grade 3. My brother had short hair and it looked so much easier, so it felt very freeing to get



it cut. I remember getting taunted immediately by other kids telling me that I looked like a boy or asking me if I was a lesbian. I was really happy with my short hair, but the experience with the other kids had such a negative influence that I grew it long again and I haven’t changed it since.

I also developed way earlier than other girls my age and I got teased a lot about that. So, between both these things I learned at a fairly young age that being different would draw attention to me.

In Grade 6, we learned that Mary-Kate Olsen was anorexic, and I remember a popular girl in my class implying that this was cool because she was ‘famous and hot.’ I also felt like she was measuring all of us against Mary-Kate Olsen. The message was that we would be considered cool if we looked as thin as she did.

Chloe is an 18 year-old Vancouver high school student*

Shelley is a child and family therapist at Family Services of the North Shore. She also facilitates the Eating Disorder Support Group for Parents, Partners and Friends, and provides online and telephone support in the Jessie’s Legacy Eating Disorders Prevention and Support Program

*pseudonym

The Dove commercial that showed the differences between models before and after airbrushing came out around that time, and I remember not really believing what they said. We all thought that it may be true of only some models, but not all of them. And even though I know it's true, I still have trouble believing it, if that makes any sense.

Q: What were some of the earliest messages you learned about food and eating? Where did those messages come from?

A: I have really great parents, so I got good messages about food growing up. We didn't have junk food in the house, and it was always made clear that it just wasn't good for our health. The messages I got from friends and from some of their parents was that it wasn't good because it would make you fat.

The message we get at school is that you should stay healthy and fit, but



I go to a school that's huge on sports teams and very competitive, so that message has a kind of double meaning because they also really want students for the athletic teams.

Our community is more affluent and there is an 'expected look' in terms of clothing style and body shape. It is unspoken, but it's definitely there. I was probably in Grade 3 when I became aware of this, that everyone looked kind of the same. I remember seeing a kid come out of the house one day with blue hair and I remember thinking, "How did you get out of the house like that?" and trying really hard to relate to what he must be thinking to do that in such a conformist community.

Q: What about self-esteem? What were the influences that taught you to regard yourself positively? Negatively?

A: Aside from my parents, it's hard to think of what taught me to regard myself positively. I guess playing sports—I felt like I was doing something good for my body by getting exercise. I got taught about things like morals, ethics, integrity and honesty from my parents, who taught us a lot about being good people. I learned from them that it's the inside that matters. But even with all of that, I still find it hard when I feel like I'm being judged by people, and I guess that comes from some of the childhood experiences I talked about.

Q: What do you think you would have looked for more from the adult influencers in your school?

A: Really, to lessen the hype around being a cookie-cutter person: looking a certain way and excelling at everything all the time. We wouldn't be so stressed all the time if they had. I coped because I come from a good home and can talk

to my parents if something is bothering me. But there was no component in our school that taught us how to cope with stress, and there should have been. One teacher tried to do the best she could by telling me to "break things down into chunks." I guess it was her way of trying to help with the workload, make things more manageable.

Q: What did you learn and take away from your early experiences with health information?

A: Basically that health is important and not to smoke. And I believed about not smoking because the science backs it up.

Q: What about media influences?

A: I really didn't get much from media other than what clothes to wear and fashion trends to look at.

Q: Do you seek out health information on the Internet?

A: Not really. There was a girl in school with leukemia, so I looked up information on that. But not in any general sense for myself.

Q: Where do you get your information and how do you assess its validity?

A: I always go with my best judgment—websites can tell you completely different things and so can friends, so I find I have to figure it out myself sometimes. I get my information from everyone: parents, teachers, doctors, friends.

Q: Does health interest you?

A: Yeah, it does. I want to have kids, and a mom in the daycare I work in just died of cancer, so that's really made me want to take care of myself because I eventually want to have kids and stay healthy for them. ▽

Health Literacy—A Family Member’s Perspective

Patti Outram

I began to co-facilitate Strengthening Families in 2006 after I lost my brother Ted to suicide in November. Do I ever wish I’d taken the program long ago, when he was on the road to recovery!



Patti is a Strengthening Families facilitator with the BC Schizophrenia Society

My brother first experienced positive symptoms of hallucinations and paranoia when he came to live with me in Calgary at the age of 23. I just had a baby and my husband and I were struggling to get on our feet when he showed up out of the blue. I knew something was terribly wrong, and so did he—people had been talking about him on the bus from Toronto and plotting to get him, so he got off the bus in Winnipeg. Then he spent the night on a golf course, until the sprinkler system turned on and soaked him.

He was in bad shape by the time he got to Calgary and checked himself into the psychiatric ward. The hospital just released him and never even called me. I’d read about schizophrenia and showed him the article, but he didn’t think it sounded like him. I was going nuts after a few months of him living in the basement, staring into space and taking all the drinking glasses with

him. He was catatonic. My husband tried taking him out to the clubs where he worked, but Ted just stared into space. One night he came home and said he wouldn’t be bothering us anymore because he’d taken a whole pile of pills. I called 911. Later, he took off to escape the biker gangs that were after him and eventually made it back to Toronto, where my mom took him to the hospital and he was diagnosed.

The on/off cycle of taking medications and experiencing side effects began. Mom died and he went to Montreal, where my older sister stepped in big time. She went to the Alliance for the Mentally Ill Quebec (AMIQuebec) and learned all she could. Ted was devastated because his whole life was just trying to manage the disease. Gradually, he stabilized and moved into his own apartment. The meds got better (fewer side effects) and he got into exercise and diet. Then he

found a part-time cleaning job with the Montreal Institute for the Blind. He had a lot of compassion for the residents. He and I spoke on the phone every week, but I didn't have the training. I only had the memories. So when he said he wanted to live with others, I panicked. I didn't think I could cope. I needed Strengthening Families. My life was already stressful and I was suffering from my own health issues. I told him I didn't think I could invite him to live here in Vancouver—I didn't have the foggiest notion how to find housing or support.

He moved into a group home in April with two lower-functioning fellows in Montreal. He was so frustrated because he was working, playing guitar and taking care of himself, and they just seemed to drag him down. He up and moved in July 2005 to a decrepit old basement suite that cost a lot more than the apartment he'd had on his own. His bird died. He lost hope and I felt paralyzed from Vancouver. Then he was gone, and I miss him, and the opportunity I might have had if I'd taken Strengthening Families sooner.

There are success stories, more and more every year. People who learn that there is hope—the meds are getting better and alternative therapies are proving successful. Family, friends and patience are a big part of the puzzle. The only way family members can really cope is to become educated, to advocate, to support each other, and to practice dealing with their family member during an episode. It's a journey, and we all have to pull together. ▼

The image shows a screenshot of the heretohelp website. At the top, a banner reads "Check out the new & improved heretohelp website" with a logo of hands forming a flower. Below this, the website interface is visible. On the left, a large mouse cursor points towards the main content area. The website header includes navigation links in multiple languages and a "GET HELP NOW" button with the phone number 310.6789. The main navigation menu includes Home, Personal Stories, Self-Help Resources, Get Help, Discuss, and About us. The featured article is "Adjusting Our Dreams" by a mother, with a quote: "My son seemed to have everything going for him. It's hard to reconcile that image with the gaunt 18-year-old with downcast vacant eyes. This is mental illness. This is psychosis." Below the article, there are sections for "What would you like to explore?" with options like "I am not sure what's going on" and "I want to hear more about anxiety problems." There are also sections for "Individual" and "Family Member" support. On the right side, there are sections for "News" (New Visions issue on wellness, Dealing with Psychosis, Updated fact sheet on effects of childhood sexual abuse), "Events" (Healthy Minds Healthy Campus Learning Activities, Family Events Calendar, Beyond the Blues), and "eNewsletters" (Subscribe to our newsletters to get useful information delivered right to your inbox). At the bottom left, there is a Twitter link: "Follow us on twitter @heretohelpBC". At the bottom right, there is a "Follow us" button with a Twitter icon.

Health Literacy and Mood Disorders

A PERSONAL PERSPECTIVE

Kathy*

“You have depression and anxiety,” the psychiatrist told me.

In some ways I wasn't too surprised because I had been living with symptoms for weeks. If I only knew how challenging life would become.



Kathy is very passionate about helping people get the proper medical and social care they need

*pseudonym

I immediately went out and bought books and went to the library. I personally found that the downtown Vancouver library has the best selection to borrow books. I had the urge to find out as much information as I could on the topics of depression and anxiety. In some ways, it soothed me because the books described a lot of what I was feeling. I began to attend group therapy at a local hospital, taking a series of groups that I found quite helpful. Again, there was reading material, which was beneficial. The other group members and I shared our experiences in a safe place with excellent facilitation by the group leaders. I continued to read and discuss my situation with others who understood.

I joined the local Mood Disorders Association support group, which I still attend today.

When I was having difficulties, my first psychiatrist was unavailable, cancelled appointments at the last minute and saw patients for a five to 10 minute appointment. I have been told that this has been the experience of others as well.

A few months into my journey, my world came crashing down when I was given the diagnosis of bipolar disorder. This rocked me a bit harder because I could feel the stigma entering my body more intensely. It's interesting, because while I was reading about depression,

I came across the term *cyclothymic*.¹ Cyclothymic is a mild bipolar disorder characterized by instability of mood and a tendency to swing from euphoria to depression. Although I had an episode of depression at 16, it was not as difficult as the current one. I went on to complete a diploma, advanced certificate and a BA. I worked in my field of practice for many years, starting out as a volunteer in the community and making my way to becoming a supervisor in a health care-related career. I always found ways to learn new skills through literacy and would encourage others to do so as well. When I looked back to my 20s, I could see the cyclothymic symptoms in me.

Then, as my habit became, I found a workbook on the topic and read as much as I could. When I asked my first psychiatrist about it, she gave me lithium—and no real diagnosis—with an appointment in a few months' time that was eventually cancelled. That is when I began looking for a new psychiatrist with the help of my GP. I also began attending a psycho-educational group at UBC, which was extremely beneficial, especially since it solely focused on bipolar disorder.

I believe that the Mood Disorders Questionnaire, a screening tool that looks for the possibility of bipolar disorder, should be given to any person

presenting to a medical professional with symptoms of depression. It may help “catch” those with bipolar disorder, especially bipolar disorder II or other “soft” forms on the spectrum. It could decrease the amount of suffering for people if they can get the proper treatment early on.

My diagnosis of bipolar disorder was made by a different (my newer) psychiatrist, one who specializes in mood disorders. He remained my psychiatrist for four years, until his schedule and commitments made him change the scope of his practice to consultation/short term follow up only. However, he has remained my “hospital psychiatrist” when needed, as I have had multiple hospitalizations. I have also had a consultation with one of the top psychiatrists in Canada who specializes in mood disorders. Due to the fact that I need regular monitoring, I am now in the capable hands of my current psychiatrist, who is accessible and who has sound clinical skills and a witty sense of humour—which helps! My bipolar disorder has become challenging in many ways. It is now classified as bipolar disorder I (no psychosis), rapid cycling, treatment resistant. I am given the appropriate amount of appointment time and frequency on a regular basis, and more if I have a flare up. As I write this article I am in a fairly positive, stable phase, which is something that I am thankful for given my history. One must live one day at a time, literally.

Another group of professionals I have found extremely helpful are the pharmacy team I deal with on a very regular basis. They know me by name and are up-to-date on what medications I take and others when needed. They never make me feel rushed when I have



I believe that the Mood Disorders Questionnaire, a screening tool that looks for the possibility of bipolar disorder, should be given to any person with symptoms of depression. It could decrease the amount of suffering for people if they can get the proper treatment early on.

questions. The literature provided on the medication information sheet is helpful, too.

I tried using skill-based books for my learning, but ended up preferring what they wrote versus doing the tasks.

I appreciated reading research articles and some personal stories, especially those that related to bipolar disorder. I found the internet to be a good use of information. However, I chose sites that had a good reputation and are medically sound.

Another area of “literacy” that can be considered is a person reviewing their hospital records or any other reports. A person must be in a stable mood state, for the most part, to look at these documents. These documents can include entire record(s) of hospital stays, community agencies or a portion of what the person wants. It can be interesting and sometimes stressful to read what is written. There are times when the truth is not portrayed. However, a person may be able to make notations in their chart and/or provide extra information that is correct. More information about this topic can be found through the Privacy Act of BC, and the Patient Care Quality Offices in each health region.

I believe that it is important for health care professionals who do not know a patient, especially those who support individuals in the ER, to obtain information from the patient’s community doctor(s). This will allow for an accurate picture of the person when they are well and unwell. It could also limit and hopefully prevent a misdiagnosis which could negatively affect a patient’s care on a long term basis. I have encountered a variety of health care professionals, some that are

There needs to be a continued effort to tackle stigma, improve health literacy and provide balanced media coverage of all psychiatric disorders in Canada.

very compassionate, understanding, effective, and go “that extra mile,” others who are average clinicians, and unfortunately some who appear to be judgmental of patients and their illness and do not make one feel understood or comfortable. It is important for professionals to have an anti-stigma approach in the care of their patients. Information can also be shared with the hospital professionals in writing by the patient and primary helping professional for times when acute care is needed. I must say that my GP has been my biggest advocate throughout this entire process. She has always been at my side, giving me strength, a light in the darkness and doing whatever she can to get me what is needed. She is a very caring person who wants the best for her patients. She has always encouraged me to find out as much information as I could on bipolar disorder and share it with her and others when needed. My psychiatrist is also interested in my writing related to mood disorders and has also proven very effective to intervene in my treatment whenever necessary.

I am currently on long-term disability (LTD). It was a huge adjustment in the beginning as I loved my work. I did not inform my workplace of my diagnosis because I feared the truth would go against me due to the stigma. I also knew that some people spoke freely of others’ personal information which made me even more leery of

disclosure. I began to research literature on workplace/human rights, which gave me a lot of insight into the subject.

Now that I am on LTD I find other ways to occupy my time, such as writing, photography, attending church, visiting friends and family, and walking.

There needs to be a continued effort to tackle stigma, improve health literacy, and provide balanced media coverage of all psychiatric disorders in Canada. This can be done by the government, agencies and the media outlets. It could make life a whole lot easier for people living with mental health conditions their families and friends. ▼

Understanding Health Literacy in Immigrants

Sangeeta Bhonsale

When you arrive in Canada as an immigrant, everything is new—from where to stay to where to buy groceries. Of course, understanding how the health care system works is extremely important because it's about your health. When you come, you carry an idea of how the system works in your country, but you have no idea how to get a doctor here.



Sangeeta is a program coordinator for Family Life Education at Burnaby Family Life, a non-profit organization that provides community support services. She also coordinates Safe Harbour, a diversity workshop, and Moving Ahead, a program that supports vulnerable immigrant and refugee community members in the Lower Mainland

I will give you my personal example. I come from India, where there is no government health care. There is only private health care. I just have to look for a doctor, any doctor, and I can enter his clinic. That's how I will access services, and I don't need to be in the government system for that. Here, you need a CareCard to access service, or, if you are a visitor, you need to have health insurance. I knew about this system, but it was a system that I was not used to.

Health literacy starts right from there—understanding how the system works in Canada. It's the ability and knowledge to get a CareCard, and then find a family doctor that has space for you. That was new for me. I thought I could just approach any doctor in the community and they should take me

on, but I realized that was not the case. They have to have space for you.

If you don't have a family doctor, you have to go to a walk-in clinic. That can be quite hard for a lot of immigrants who have come from developing countries or countries where there is no government health care. When you have your own doctor and you have a relationship with that doctor, going to a walk-in clinic can be very hard. You're talking about something which is very personal, very private. Even if it's the common cold, you still have to explain everything—if you have certain allergies, for example. It's something that you may not be used to.

Understanding immigration

In order to understand the factors that affect health literacy in immigrants, it is important to understand that immigrants are a diverse group coming from different countries, religions, cultures, and ethnic backgrounds. There are also categories in how a person comes as an immigrant to Canada. You can come as a skilled immigrant, under family reunification, or as a common-law partner. If you have come here as a skilled immigrant, you have already come with a set of skills and a certain level of education. But if you have come as a grandparent under the family reunification plan, your health literacy will be quite different than that of a skilled

immigrant who is coming in at the age of thirty.

There is so much information that you have to learn when you come to Canada as an immigrant. When I interviewed a settlement worker, she put it very well, saying that health literacy comes in a bit later. You do your initial part in getting a CareCard, but the basic things—finding a job, getting your children into school, finding a safe place to stay—come first. Of course you never know what might happen in the future, but the immigrants who come here are generally healthy, both physically and mentally.

However, immigration does affect your mental health. You may have high anxiety when you come here, especially if English is not your first language. You may come in as a very hopeful person, but not having the language can isolate you so much that it can have an effect on your mental health. This doesn't mean that you'll experience depression or any sort of anxiety disorder, but it's important to recognize that it does take time to settle.

When I came to Canada as an immigrant, I could speak English, but there was still a certain level of anxiety. For example, you might get lost driving down the road. You don't know the road. Getting lost in a place and not knowing where to stop or where to turn and who to ask for help—all of these little things cause a lot of anxiety. You may be a capable person, but it does take a toll on you.

Coming here as an immigrant and settling down is a process. It takes time. We do get an information package from the Canadian government when

we come in, so it's also that person's responsibility to try and do something. In that sense, health literacy is actually related to time.

Suppose you need to go to the doctor in the first month of your arrival in Canada. That experience could be completely different from going to the doctor two years later. One recommendation would be to include this sort of information in the settlement process. For example, someone could write a fact sheet that explains what you could feel, such as feelings of being lost or having anxiety or not knowing the system. It would give people permission to understand that it is a process and you will feel lost at times.

Change starts with sensitivity

One change I would like to see at the point of service is sensitivity. This is sensitivity towards any person who walks through the door, not just cultural sensitivity. If the doctor or mental health clinician is not a first-generation immigrant, they may not understand what the person could be going through, why the person is not answering their questions, or why the person doesn't understand something. It's not that the person doesn't understand the questions. The person may have their own anxiety, or they may have a certain image of a doctor or expectations of a doctor. But it's a two-way process. Yes, the clinician needs to be sensitive, but the immigrant or newcomer to the country also needs to learn the process.

The human aspects of health literacy

I interviewed a mom as part of my research for this article. She had a baby born with a heart defect. English was not her first language,

and she experienced distress and trauma because she was not able to understand directly what her child was going through. If someone could have explained it to her in her own language, she would have understood. Instead, she had to wait for her husband to translate this information. Very often, people assume that you don't understand anything if you don't understand English. It's important that clinicians, doctors and nurses understand that people come with very good education. When people don't look at you and make eye contact with you because you don't speak English, your dignity is hurt in the process. This mom definitely wanted to know what was happening with her child, but she could not follow what the doctors were saying. That doesn't mean she didn't have the intellectual capacity or ability to understand.

I also interviewed a mom who had the opposite experience, where both parents were fluent in English and could understand what the doctors were saying. This mom had meetings with the doctors. Different people explained what was happening with the child and what the process of treatment would look like and handed her fact sheets. I can imagine how relieved this mother felt at every step and every level, knowing what was happening with her child because she knows the language. On the other side, you see the child that had a heart defect and had surgery at two months old. The mom had to wait for every piece of information to be translated for her. This is the human aspect of health literacy.

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Mental Health Literacy Improves Service Delivery

Alex Berland

For non-experts like me, staying current with new thinking in mental health and addictions is challenging. Although my nursing education included an overview of mental illness, this was very basic. Moreover, mental health is not my only subject, so other topics compete. I am not always sure what is important or just trendy. As a discipline, mental health seems vulnerable to unstable theories. I always seem to have another article or website to read.



Alex is a senior manager and planner with experience in government and all sectors of the health care industry. Presently, Alex lives in the West Kootenays and runs a private consulting firm specializing in improving strategy and delivery of health care and social services. Prior to this he was a senior official in England's Department of Health, and from 1992-97 he was responsible for all clinical programs at one of Canada's largest teaching hospitals. From 1998-2000, Alex was CEO of Riverview Hospital while at the same time Provincial Director of Adult Mental Health Services with the Ministry of Health

Back in the last century, when I was appointed to lead Riverview Hospital (RVH) after many years in general hospitals, I found myself in a foreign environment. The first thing I did was to visit every ward, meeting staff and patients. I spoke with everyone, including a very active family group. I also read every government report and every relevant article in the literature—many sent by people advocating competing viewpoints. Then I went out into the community, meeting the acute and community mental health teams, touring Vancouver's Downtown Eastside services, and meeting with patient groups and officials in health authorities and local government around the province.

From these direct contacts I learned much, but a profound experience

came from an on-site disaster. Leaving RVH late one winter evening, I was phoned about a fire in a building that housed many adults with serious and persistent mental illness. As we shepherded them to safety, I saw that most were severely limited in their functioning, with deficiencies in orientation, judgment and mobility.

After this experience, I began referring to the effect of mental illness as “disabling.” Journalists, mayors and community members get this. They understand and empathize with disability as a condition. This description helped me to describe the functional level of our patients in a way that evoked compassion rather than uncertainty or even fear. I described their needs in terms of activities of daily living and accessibility, the help they needed to feed and house themselves, to get and keep a job. Mental health literacy is critical for interpreting to the general public the knowledge of experts (be they patients, family or service staff).

I found that mental health literacy was also invaluable in conveying the information needed by other officials in terms they understood. Many policy-makers do not have the benefit of a clinical service background. This can make it hard for them to understand clinical problems such

as the unpredictability of how young adults respond to their first course of anti-psychotic medication, and the implications for services such as length of hospitalization and type of follow-up needed. As with any audience, officials benefit from a balance of data and anecdotes. Data help explain the scale of a problem and why it is important; personal stories convey the impact, urgency and scope.

Sometimes the issues are administrative rather than clinical. For instance, speaking with senior health authority executives during my RVH days, I explained how brain disorders affected their bottom line: people with mental illness, stroke, brain injury and dementia spend a long time in hospital. Community treatment may cost as much for clinical staff, but avoids the very high fixed costs of institutional settings.

For service providers, the purpose of advancing mental health literacy is

“doing what we know works best.” During my RVH work, acting on the advice of Dr. Rick Hudson, I allocated Mental Health Plan funding to adapt a World Health Organization publication, *Management of Mental Disorders* by Professor Gavin Andrews. This summarizes the wisdom and expertise of clinical management gathered over many years. We gave a copy to every psychiatrist and community mental health team in BC. With the benefit of hindsight, I wish we had given it to every GP (general practitioner) as well. Nowadays, the internet provides such information, maybe too much. One of the most important tasks of experts is translating their knowledge about “better practice.” Translation works best if it can be applied by various levels of users, accessible in a form they can use, exactly when they need it. (Hurrah for www.heretohelp.bc.ca.)

In principle, good policy analysts can apply their skills to any topic. In reality, officials may become dependent on

external experts contracted for specific tasks. However, there are risks. Firstly, mental health promotion and mental illness/addiction prevention and treatment cut across many different health and social service areas. In-house expertise helps to ensure these concerns are reflected in various forums. Secondly, when senior decision-makers (elected and staff) do not know much about a topic, they are vulnerable to persuasion by vested interest groups.

I have discussed this topic from my own perspective of course: mental health literacy involves much more than service delivery for mental illness. But because service delivery affects many lives, it is important we get this right. By the way, my most lasting reference from the RVH years was *Impossible Jobs in Public Management* by Hargrove and Glidewell—still a good read. ▽

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We have problems and we have solutions. That’s what the medical system is used to. But these solutions—sensitivity and dignity—are not that straight-forward. The doctor can’t just say one thing or do one thing and solve the problem. It’s absolutely about bringing human aspects into services. You have to listen to people’s emotions and look at the bigger picture.

Moving forward: Equity, not equality

In my diversity workshop, Safe Harbour, we talk about equitable treatment. Equitable treatment is fair treatment. The medical system has to think about treating people with

equity, not equality. Whether you are an immigrant or non-immigrant, that equity piece is more important than anything else.

Dignity and dignifying processes are also important. I think the Canadian government does a lot. For example, there are a lot of services available in different languages, and settlement agencies provide people who can go along with you if you don’t speak the language.

Health literacy is a process. It’s not related to any individual, intelligence level, or anything else. Once people

are settled—and that may take several years—things get easier. In spite of all the challenges, many immigrants improve their skills in navigating the system as they gain confidence and familiarity. It is this resiliency of the thousands of immigrants and new Canadians that needs to be recognized and valued so that their health and their positive contributions to Canadian society are sustained. ▽

resources

New and Improved HeretoHelp Website

www.heretohelp.bc.ca

HeretoHelp.bc.ca is a dynamic website designed to communicate high-quality, trusted, and accessible mental health and substance use literacy materials on behalf of the BC Partners. Recently re-launched with a new look and feel, coupled with enhanced search and navigation, HeretoHelp.bc.ca hosts personal journeys of recovery, publications, and other resources including a message board, self-tests, multilingual resources, and interactive toolkits.

New Plainer Language Series

www.heretohelp.bc.ca/factsheet/plainer-language-series

You will find a new series of booklets that discuss mental health in plain, clear language at HeretoHelp. The six booklets are: Tips for Good Mental Health, What is Anger, What is Anxiety, What is Mental Illness, What is Depression, and What is Suicide. Each booklet offers background information, practical tips, and strategies to try at home, and key resources in BC communities. All of the booklets are recorded for readers who prefer to follow along while they read.

WithinSight

withinsight@heretohelp.bc.ca

This free, email delivered newsletter, features BC resources about mental health, well-being, alcohol use, and other substance use that are designed for multicultural and multilingual communities. The goal of WithinSight is to bring these useful resources “within sight” of service providers and communities. To learn more or subscribe, email withinsight@heretohelp.bc.ca.

 This list is not comprehensive and does not imply endorsement of resources.

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