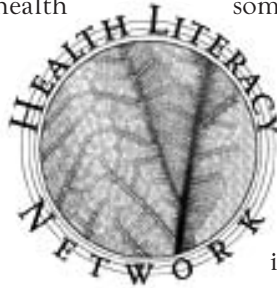


Health Literacy and People with Disabilities

by **Shelley Hourston**

People with disabilities face diverse and complex barriers to health information and services.

The British Columbia Coalition of People with Disabilities (BCCPD) has helped people access information and services for over twenty-five years. A number of different programs and projects have given the BCCPD first-hand experience of the attitudinal and systemic barriers facing people with all types of disabilities. These barriers have a direct impact on health and well-being. For people with disabilities—who must frequently interact with the health care system—health literacy becomes an issue that defines their quality of life. This article outlines what people with disabilities have told us are the most common issues and concerns about literacy and health or health literacy.



Literacy skills

People who had a disability as a child or adolescent may have a limited literacy level because of physical barriers to educational facilities or because of the direct effects of their disability. Chronic illness or disability may have prevented them from attending school. Other disabilities affect cognitive functioning and the capacity to focus or concentrate. Learning disabilities or vision- or hearing-related disabilities have an obvious impact on learning and literacy skills.

Societal barriers

Attitudinal and systemic barriers have less obvious impacts on health literacy, and are more difficult to resolve. Our society has long held a paternalistic attitude toward people with disabilities. Health care workers, family members and caregivers often believe that they know what is best for the person with a disability and become information gatekeepers, protecting their charges or loved ones from knowledge they deem unnecessary or embarrassing. They can also withhold information on the grounds that they do not want to condone a specific behaviour (safer-sex information for example). For over fifteen years, efforts

to provide HIV-prevention information to people with disabilities have met with opposition. Despite evidence that people with developmental disabilities are sexually active, some people strongly resist providing them with information about sexual health and HIV-prevention. Some caregivers object to providing the information necessary for people with disabilities to be able to protect themselves and gain credibility when reporting abuse, even though research has revealed high rates of sexual abuse in some disability communities.

Personal barriers: self-esteem

Many people with disabilities have low self-esteem and lack the confidence to insist on their right to health information and services. It is difficult for them to ask for health information in the format they need. This society created the label disability and devalues people with chronic health issues and disabilities by marginalizing them socially and economically. In this context, it takes stamina to advocate for your rights. If the clinic or health care facility is inaccessible, people with disabilities may have to choose how to spend their energy—lobbying for accessible health care or trying to find housing or enough money to eat next week.

Disability-specific barriers

In our HIV-prevention work, and in developing the Health Literacy Network, we have talked to people from many disability communities about the challenges they face accessing health information and services. A common concern across the spectrum is limited time during medical appointments. In addition, people noted that while health care workers may be experts on the clinical aspects of their disabilities, these workers are quite uninformed about or insensitive to the impact that the disability has a patient's life. This lack of understanding affects how comfortable people feel asking questions or offering information about their health. In cases where the disability requires monitoring or regular visits to a physician, the disability frequently monopolizes the

time allowed, so other health care issues and preventive-care strategies may not receive attention.

The following sections outline some challenges specific to people with different disabilities.

Deafness and hard of hearing

People with hearing or communication disabilities may need more time for medical appointments. Health care professionals are sometimes not sensitive to details that affect communication with someone who is deaf or who has low hearing. When people who are deaf or hard of hearing are asked to remove their hearing aids, it is important to remember that they can no longer hear. If the health care worker is wearing a mask, someone who is deaf or who has low hearing cannot speech read. To facilitate speech reading, the speaker must be in clear view and should avoid background glare. Background noise such as machinery or passing traffic can cause blank spots in communication. Health care workers must remember that patients who are deaf or have low hearing need time to adjust to speech rhythms and accents that are unfamiliar to them.

Brain injury

People who have brain injuries have told us that they often do not know where to go for information about their disability. When they do receive information, they are frequently confused by medical terminology. Often information is filtered down through a hierarchy—health care professionals, family members and then brain injury survivors. By the time it reaches the person with a brain injury, the information is either inaccurate or too clinical. The type and diversity of physical and cognitive impairments common in brain injury makes finding and retaining information very difficult. One person told us, "One day I can understand the words on a page...and another day I can't understand at all. It's all very up and down and unpredictable."

Developmental disabilities

People with developmental disabilities have told us that they prefer to get health information from their doctors. They are concerned about the accuracy of information they get from peers. Information from the media is typically too brief and does not contain enough detail to be helpful. Despite physicians being the preferred source of information for people with developmental disabilities, many reported that they were dissatisfied with the interactions. Some found doctors unwilling to give them complete information about their health or that their doctor spoke to a caregiver or family member in the room as if the

patient were not present. Using medical terminology and failing to take the time to explain medical information in plain language is common. Many found that doctors have stereotypical and paternalistic attitudes and people with developmental disabilities are sometimes not believed when they report health issues.

Mental illness

Mental-health consumers continue to report that stigma and low self-esteem are significant barriers to getting information and health care. Depression and anxiety disorders are frequently untreated and many people face judgmental attitudes from health care workers.

Physical disabilities

For people with physical disabilities, inaccessible facilities continue to present barriers. We have been told that another key issue is *learned dependence*, where people with disabilities do not believe they have the right to health information. People can become passive recipients of what other people think and do for them.

Barriers to health literacy

In defining health literacy, the World Health Organization notes:

Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions.

(Health Promotion Glossary 1998
available online at www.who.int)

Each element in this definition poses challenges for people with disabilities. Poverty, marginalization and stereotyping combine to erode their self-esteem and the confidence to expect and seek equal access to health information and services. In our experience, health literacy difficulties for people with disabilities have less to do with the disability and more to do with attitudes. ■

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