About the Authors

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Who Are People With Disabilities?

INTRODUCTION

Who are people with disabilities? Since people with disabilities are the major focus of this book, we need to be clear about what we mean by the use of the phrase, "people with disabilities." People with disabilities are often our neighbors, our family members, our teachers, and our friends. People with disabilities are not *them*. They are *us*! As Shapiro (1993, p. 5) so accurately stated nearly 25 years ago:

> There are hundreds of different disabilities. Some are congenital; most come later in life. Some are progressive. . . . Others are episodic and progressive. Some conditions are static. . . . Still others . . . can even go away. . . . Each disability comes in differing degrees of severity.

Regardless of the specifics of a particular disabling condition, first and foremost, when we talk about disability, we are talking about people who happen to have a disability or disabilities. Beyond that, it becomes somewhat more difficult, because we are talking about a wide range of people

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who have a wide range of conditions that may cause functional limitations with varying degrees of severity and impact many different areas of life. We are talking about people who cannot hear or who have significant hearing loss, people who cannot see or have debilitating loss of vision, and people who cannot think, understand, problem solve and reason as well as most people. We are talking about people who have psychological or emotional difficulties. We are talking about people who have major or minor physical limitations. All of these people are considered to have or are diagnosed with a disability. But it is not that easy. Just because a person has a diagnosed disability, he may or may not consider himself to have a handicap or a limitation. What one person might describe as a limitation, another person might describe as merely an inconvenience. To establish some common ground, we will provide definitions of key concepts. In Section II of this text, we will give considerably more detail about several major disabling conditions.

DEFINITION OF DISABILITY

Disability is a complex and differentially defined concept. It is used routinely as if it were universally understood. And even though there is some basic universal understanding of the term, there are a multitude of meanings and intentions depending on the intent of the user of the term. There is often confusion over such terms as *disability, handicap*, and *impairment*. They are used interchangeably; yet they can imply very different things. To ensure that you have a clear understanding of disability as you start your class, we use the WHO (2016) definition that says that a disability is:

> …any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).

The World Health Organization (WHO) publishes a disability classification system that is widely used. The most current classification system was developed following extensive discussions among WHO collaborating centers, advocacy groups, representatives of disabilities organizations, governmental health programs, consultants, researchers, and WHO staff. The International Classification of Functioning, Ability, and Health (ICF) that was adopted unanimously in 2001, recognized the importance of including people with disabilities in community life and a redefined health to move beyond the absence of illness to focus on quality of life. The International Classification of Functioning, Disability and Health includes three dimensions: Body Functions and Structure (formerly referred to as Impairments), Activity Limitations, and Participation Restrictions (Imrie, 2004). Figure 1.1 provides a graphic representation of the relationship among these ICF dimensions.

According to this definition, *disablement* is an umbrella term, covering impairments, activity limitations, and participation restrictions (WHO, 2016). It is clear that the current definition is much more focused than previous iterations of the WHO classification, on the abilities of the person, as compared to the disabilities, which is certainly in keeping with the person-centered philosophy of this book. Figure 1.1 also suggests
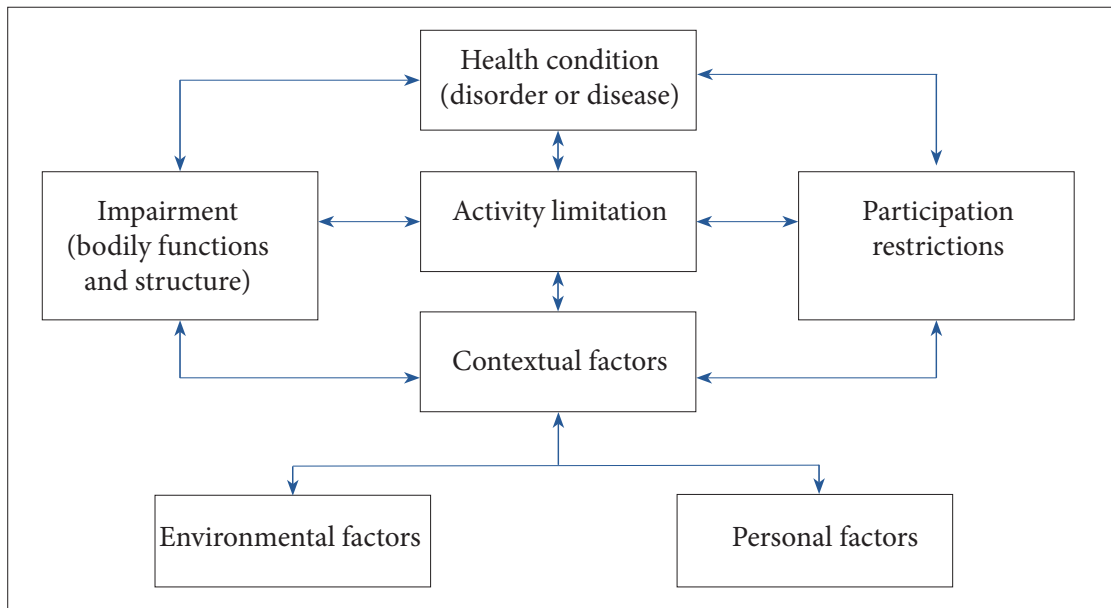
Figure 1.1. Model of disability that is the basis of International Classification of Functioning, Disability, and Health (ICF).

that disablement is a complex relationship that includes the interaction between the disorder or disease and personal and environmental contextual factors. Personal factors are intrinsic to the individual and include such things as gender, age, other health conditions, fitness, lifestyle, and individual psychological assets. Extrinsic to the individual are environmental factors such as attitudes of society, architectural structures, and legal systems.

Imrie (2004) attempts to help us move toward a greater understanding of the ICF through a discussion of its theoretical underpinnings, which leads him to suggest "that three parts of the ICF require further conceptual clarification and development: (a) (re)defining the nature of impairment, (b) specifying the content of biopsychological theory, and (c) clarifying the meaning and implications of universalization as a principle for guiding the development of disability policies" (p. 287). Masala and Petretto (2008) provide an overview of the conceptual foundations of "disablement" from the twentieth century that have contributed to the development of our current concepts of disablement and suggest "further considerations on how to create virtuous processes of enablement" (p. 1233).

To help you to understand each of these ICF dimensions, we have restated each dimension and then provided an example of each.

"Impairment (bodily functions and structure) is a loss or abnormality of body structure or of a physiological or psychological function." Rather than the underlying pathology, impairment is the manifestation of the pathology, which can be permanent or temporary.

Activity limitations are the level of functioning of the person, which can be limited in the nature, duration, and quality. This dimension refers to the individual's capacity to perform things that we consider typical in our lives, such as walking, talking, driving a car, writing a letter, eating a meal, or ice skating.

Participation restrictions are, in a sense, the operationalization of the disablement process, in that it refers to the person's engagement in the activities of life, as a function of his impairment(s), health conditions, and contextual factors.

As an example to understand these ICF dimensions, we will use a young girl who has an intellectual disability whose parents do everything for her. She has:

A deficit in intellectual functioning **which is her impairment (bodily functions and structure);**

Slowness in learning developmental skills, for example, talking at the usual developmental time, walking at the usual developmental time, etc., which are her **activity limitations;**

Parents who speak for her, parents who carry her around even when she begins to be able to walk, and she does not play with other children her age. These are her **participation restrictions.**

In the example above, slowness in learning developmental tasks is caused by the intellectual impairment. Plus, there were external circumstances (parents) that prohibited her from speaking for herself, walking on her own, and playing with other children her own age. It is not her impairment/bodily function and structure (deficit in intellectual functioning), nor activity limitations (slowness in learning developmental skills) that keep her from speaking for herself, walking on her own, or playing with other children her own age. What restricts her from participation are external forces (overprotective parents).

It can be argued that the little girl might not be able to speak well for herself because of her intellectual deficit (impairment) or that she is at a different developmental level (activity limitations), and therefore not a good playmate for other children her own age. Both of these contentions might be true, but her participation restrictions in life are caused by social forces (parents). Throughout this text, we will attempt to identify a number of strategies aimed at eliminating the existence of participation barriers.

What should be clear from this new definition of disability (ICF), is that the process of disablement is complex. It is a function of multiple factors that are both intrinsic and extrinsic to the individual. This book will discuss many of the factors that can contribute either positively or negatively to the disablement process. A disability is a construction of many factors, some of which we can influence. Our goal in this book is to provide you with information and ideas on how you can have a positive influence on or work to limit the process of disablement for the people with whom you work.

Regardless of the classification, it is most appropriate to refer to an individual's ability rather than a "medical condition" or "*dis*-ability." In this text, we nearly always use the word disability since is so prevalent in common usage. In the final analysis, however, it is most important if you (and others around you by your example) refer to people with

disabilities not as categories or even as an amalgam of traits and characteristics, but as *people*! One of the best ways to do that is to be careful about the language you use.

PEOPLE-FIRST AND RESPECTFUL LANGUAGE

There has been considerable discussion around people-first and respectful language. Person-first language was a strategic battleground for transforming the ways of thinking about disability (Withers, 2012). According to Von Peers et al., (2014), it is worth acknowledging that debates around disability terminology have not escaped criticism. Most notably, Shakespeare (2013), a prominent disability scholar, argued that "quibbling over 'disabled people' versus 'people with disabilities' is a diversion from making common cause to promote the inclusion and rights of disabled people."

Hutchinson and McGill (1992) suggest that language tends to shape beliefs about a person's potential needs and desires. Language is very often the manner in which the subjective norm is communicated. A Parliamentary Committee on the Status of Disabled Persons in Canada concluded that

> (Vocabulary can orient an entire perception in the public mind; pejorative or negative words not only bias a person's understanding, but trivialize genuine community support for people with disabilities. (Department of the Secretary of State of Canada, as quoted by Hutchinson and McGill, 1992, p. 4)

Much debate has taken place regarding the appropriate language to use in relation to individuals with disabilities. Historically, the terms *disabled, handicapped*, or more specific descriptors such as *blind* were most commonly preceded by the article "the." Such labels as "the disabled" or "the blind" categorize and imply that all people with disabilities are similar. Instead of making reference to "the mentally retarded" or "the intellectually disabled," we should use the more acceptable and appropriate term, "people with intellectual disabilities." Referring to people with disabilities as "the disabled" or "the mentally retarded" creates an image of a group of people, all of whom have many of the same characteristics. In fact, such labels as "the blind" and "the mentally ill" often do not even include the additional word "people."

A person who works in an institution for people who are mentally ill can often be heard describing her job with the phrase, "I work at Dorothea Dix State Hospital with the mentally ill." Although unintentional, such usage is dehumanizing and places more emphasis on disability than on personhood. Once such phrases become commonplace in our language, they can lead to our conscious or unconscious stereotypical attitudes that all people with disabilities are the same. Nothing could be further from the truth!

The aim of this text is to foster an individual, not a categorical, approach to understanding and working with people with disabilities. The language that we use must contribute to, rather than detract from, this goal. "*People-first*" language promotes a positive attitude toward people with disabilities and contributes to our focusing on each individual.

People first means exactly what it denotes. That is, when we talk about people with disabilities, we first say "people" followed by "who are ..." or "who have ..." or "with ...".

That emphasizes personhood before acknowledging the disability. We should be careful and deliberate about the words we use and the way we refer to people with disabilities. What may seem tedious initially as we use people-first language will become second nature over time. People with disabilities are individuals just like any other members of society and should be referred to using people-first language. It should be noted, though, that a group within the ranks of those persons with a hearing impairment prefer to be referred to as the "deaf community" and have a "deaf culture."

The cartoon in Figure 1.2 makes the point clearly about language and people with disabilities. It suggests that when considering the language we use, we not forget the person, whether it be Joan, Jim, or Samantha. During the past few decades, great concern has often been expressed by professionals and advocacy groups regarding the terminology we use to describe people with different types of disabilities. Nearly every professional and advocacy group in the United States and Canada has provided strong leadership in the promotion of positive and respectful language in the disability movement. According to von Peers et al. (2014), the American Psychological Association adopted language standards that specifically reflect a rights-based approach to disability:

> …the guiding principle for handicapping language is to maintain the integrity
> of individuals as whole human beings by avoiding language that implies that a

person as a whole is disabled (e.g., disabled person); equates a person with his or her condition (e.g., epileptic); has superfluous, negative overtones (e.g., stroke victim); is regarded as a slur (e.g., cripple) (von Peers, Spencer-Cavaliere, & Eales, 2014).
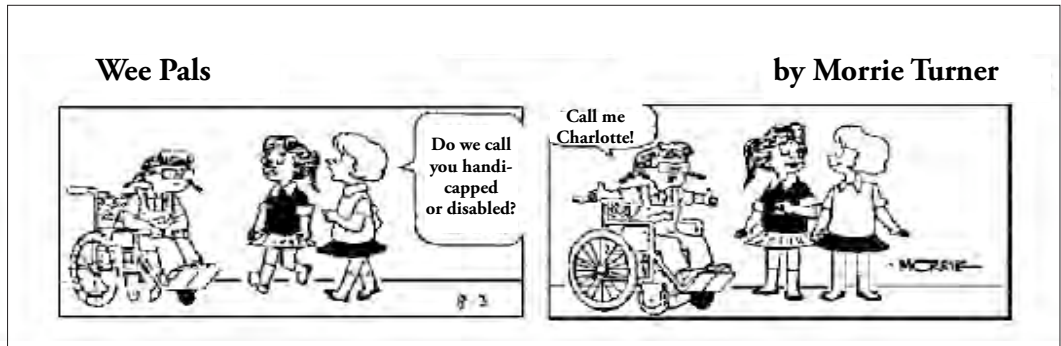

Wee Pals   **by Morrie Turner**

Figure 1.2

CREATE POSITIVE IMAGES

In addition to using "people-first" language, we should be careful not to use negative or pejorative words. Certain terms can be dehumanizing and can perpetuate negative stereotypes about people with disabilities. The way a society refers to persons with disabilities shapes its beliefs about and responses to them. Positive communication is a powerful way to bring about the full acceptance of people with disabilities into all aspects of our daily lives. Using language that affirms the dignity of people with disabilities fosters positive attitudes and paves the way for more inclusive communities.

Terminology that emphasizes the person rather than the disability is preferred. There is a need for a shared vocabulary that both grants dignity to people with disabilities and promotes an understanding of disability as an ordinary part of life. A list of phrases in Table 1.1 gives examples of both positive, appropriate terminology as well as negative, inappropriate terminology. Many of the negative, inappropriate phrases are ones that we have heard or used throughout our lives. Many people do not even think of the negative image they present when they call a person a "cripple." Nearly everyone has joked about psychos or dummies, thinking nothing about it. What is important, however, is to think about it, to "catch ourselves" as we unintentionally use negative or pejorative words. Others will notice our deliberateness and hopefully will model our language. Still others will not notice, and we will have to explain to them why we do not say, "confined to a wheelchair." We will have to explain that we use positive, ability-oriented language rather than negative, inability-oriented language. Our persistence will be a good role model for others.

Table 1.1

Examples of Appropriate/Inappropriate Terminology

Appropriate	Inappropriate
Person with a disability	Disabled person, the disabled, the handicapped, handicapped people
Individual with mental retardation/mental disability	MRs, dummy, feebleminded, mentally retarded person, the mentally retarded
Person with a physical impairment	Disabled people, cripple, invalid
Person with Down syndrome	Down, Mongoloid
Person who is blind	Afflicted with blindness
Person with mental illness	Lunatic, psycho, crazy, schizo
Person who is unable to hear or speak	Deaf and dumb, deaf mute
Person who uses a wheelchair	Wheelchair bound, confined to a wheelchair

The terminology used to refer to persons with disabilities may both reflect and influence attitudes toward them. Negative references may perpetuate negative attitudes and stereotypes (Auslander & Gold, 1999, p. 1395). The movie, *Tropic Thunder* (2008), was soundly criticized for the extensive and very inappropriate use of the negative term "retard." Some even refer to this use of the term as "hate speech" and have created a website asking people to pledge to not use the "r-word" (www.r-word.org). The preferred terms focus attention on the uniqueness and the worth of an individual rather than emphasizing the individual's disabling condition. The connotation of disability is very important to avoid. It is not uncommon to hear someone use words that are outdated or that are dehumanizing and create a negative image of the individual. Such terms contribute to negative stereotypes and should be avoided. They include such words and phrases as crazy, defective, deformed, retard, deaf and dumb, lame, cripple, spastic, unfortunate, he's an amputee, etc. By choosing words carefully, you can convey positive images about people with disabilities. As a recreation specialist, you will be expected to model good behaviors in your communication with and about people with disabilities.

"People-first" language focuses on the sequence in which a term such as disability and words like "person" or "individual" appear in a written or spoken sentence. The sequence of the word individual before disability focuses the sender or receiver of the

message. Reversal of this sequence, such as saying disabled people or blind people, tends to focus both the sender and receiver on the diagnostic label. It is often argued that the use of "people-first" language in either written or verbal communication is awkward. As long ago as 1992, Hutchinson and McGill (1992, p. xvi) suggested that "Whenever we use language, we are making choices about how we want to define the situation or the person." As more people with disabilities become active participants in community life, our shared vocabulary will continue to change. The disability is no longer the primary, defining characteristic of an individual but merely one aspect of the whole person.

Following are some recommendations that will put both you and the person with the disability more at ease:

- Talk directly to the person with the disability, maintaining eye contact, even if he/she is using an interpreter or personal assistant.
- Encourage the person with the disability to express his/her own opinions, even when parents or friends feel they can speak for the individual.
- Ask if assistance is needed rather than assuming it is. If the person says, "No, thanks," don't pressure him/her to accept help anyway.
- Use a normal tone of voice. If the person cannot hear or understand you, he/she will let you know.
- When talking with a person with a cognitive disability, speak in simple, clear sentences. Remember that simple language does not mean childish language. When appropriate, ask the person to put in his or her own words what has been said to confirm understanding.
- If appropriate, sign or gesture to make yourself understood. If you do not understand what the person with the disability is saying, you should say so. Ask the person to repeat if necessary.
- When interacting with a person with a speech or language disability, be patient. Give the person ample time to respond to your question. Do not try to finish a statement for him/her.
- Be careful not to assume that a person with one disability also has other disabilities. A person with a physical disability does not necessarily have a cognitive disability; nor is a person who is blind particularly likely to have a hearing loss.
- When talking with an adult who uses a wheelchair, sit across from the person at eye level. If no chair is available, stand. Kneeling may convey a demeaning attitude toward the individual.
- Use the same terms with persons who have disabilities as you would with anyone else. For example, don't avoid using "look" or "see" with a person who has a vision loss. Likewise, do not hesitate to say, "Let's walk over …" to a person using a wheelchair.
- In casual conversation with someone with a disability, talk about the same things as you do with others; the weather, the garden you want to plant, the latest baseball game. While people with disabilities may be willing to answer questions about their disability, making such questions the focus of an interaction can inhibit friendly conversation.
- In social settings, treat people with disabilities just as you would anyone else. Avoiding contact or being overly attentive calls attention to the disability at the person's expense.

- Be aware that an assistance animal, for example, a guide dog helping an individual who is blind, is on duty. Petting or otherwise distracting the animal is discouraged unless first approved by the owner. Also, keep in mind that there are other types of working dogs and other working animals used to assist an individual in being more self-sufficient.

- Encourage children and adults to learn about people with disabilities. Open, informed communication helps overcome fear and misleading attitudes. People with disabilities are their own best spokespersons. Disability is not "abnormal," it is normal. It may affect any of us at some point in our lives.

When in doubt about the correct word/phrase to use, or way to say/do something, simply ask the person what she prefers, or ask her family or friends. Remember that it is best to focus on getting to know a person, not on his/her disability. We stress the importance of making the decision to use "people-first" and positive, respectful language as one method of fostering a person-centered approach to recreation and therapeutic recreation services.