Introduction to Recreation Services for People With Disabilities
A Person-Centered Approach
4th Edition

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Michael J. Mahon
Kay Holjes was an untiring advocate for the rights of people with disabilities. She so believed in the values of person-centeredness, self-determination, and inclusion, that her spirit permeates our book. We dedicate another edition (fourth) to the memory of Kay Holjes (1947-2002). We hope that through this book at least one student will “catch Kay’s spirit” and become a strong advocate for people with disabilities.
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As with previous editions, the fourth edition of this text represents years of reading, teaching, thinking, and talking with students, friends, colleagues, and the Internet. We think you will be really pleased with the updated material. We certainly are!

Sandy Negley, a well-respected educator and practitioner from the Department of Occupational and Recreational Therapies, University of Utah, who rewrote Chapter 14 for the third edition, did an even stronger rewrite for the fourth edition. She retitled the Chapter “Therapeutic Recreation: The Profession of Therapeutic Recreation, the Practice of Recreational Therapy” to address the awkwardness and inaccurate usage of the words therapeutic recreation and recreation therapy. In her chapter, she provides the latest statement of meaning and guiding principles of the field. We are honored to have her as a contributing author and friend.

This fourth edition introduces a new contributing author. Dr. Nancy Spencer-Cavaliere, associate professor, Faculty of Physical and Recreation, University of Alberta, worked with Mike to coauthor the significantly revised Chapter 16, “Sport and People with Disabilities.” The sport chapter now has significantly updated research and literature. Her insights in this chapter really strengthened the chapter.

There is no way to thank everyone who has been a part of this book. For those unnamed, however, know that your contributions were significant and appreciated in the development of this book.

We want to thank our students at the University of North Carolina, University of Nevada, University of Manitoba, University of Alberta, San Jose State University, and the University of Lethbridge, who have helped us in ways that we never imagined. You are graduate and undergraduate students who span countless years collectively. We appreciate your insights and challenges. We appreciate your willingness to listen and learn from us and for our opportunity to listen and learn from you. Your patience and your insights have truly enriched this book.

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For this fourth edition, we particularly thank BJ Grosvenor, faculty in the Department of Health Science and Recreation at San Jose State University. Throughout the revision, BJ was always there encouraging and offering suggestions to strengthen the fourth edition. Cassie Landicho, a student at San Jose State University, worked with Charlie extensively. Cassie helped to identify current resources and figures and read the text from a student perspective that helped us to make the text more user friendly for students. Thanks, Cassie, for your work on the fourth edition. Unlike the first three editions, this edition has pictures. Four students in Charlie’s class at San Jose State University who use this text helped us to choose pictures that relate to the content of each chapter. Thanks so much to James Wooley, Allison Darouze, Jenna Healy, and Keifer O’Hara. Your help has found pictures that relate to the content and tone of each chapter from a perspective of students which we don’t have. In addition, Allison Darouze and James Wooley proofread the entire book just before publication. Thank you to my great SJSU students! And there is no way that this third edition would have been completed without the tireless work of Susan Davis, our editor at Sagamore. Your nudges and your amazingly fast turnarounds really kept our work moving forward. Your editorial assistance was superb. Thank you for being part of our team and for always keeping a smile and a positive, can-do attitude.

We would also like to thank our wives, without whose love and support this revision would not have been completed. To Lyndy and Maureen, we thank you for helping us to achieve our goal.

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This fourth edition of *Introduction to Recreation Services for People with Disabilities* represents a major revision. This book continues to reflect a broad-based explanation of the role of practitioners in the interrelated fields of therapeutic recreation, inclusive recreation, and special recreation. We have worked hard to ensure that our book reflects the most current research and thinking about the interdisciplinary fields of recreation and disability studies. In earlier editions, we included “related websites” at the end of each chapter. In the fourth edition, “related websites” have been deleted from the end of chapters since websites can change frequently and most students and faculty are used to “Googling” to find additional information. This was suggested by many students who used the text.

It is important to us that we are on the same wavelength with you, the reader, and we have written this text to share with you our perspective. This book is about recreation and therapeutic recreation services for people with disabilities. There are similarities, but there are also major differences in recreation and therapeutic recreation/recreation therapy. For example, recreation services are purely for enjoyment, while therapeutic recreation/recreation therapy services are enjoyable but are intentionally more goal directed and treatment oriented. In this book, we will describe the full range of recreation services for persons with disabilities.

Another important part of our perspective is that recreation services must be centered around the person who is being served. That is, whether treatment-oriented recreation therapy, goal-oriented special recreation, or activity-oriented inclusive recreation, it is the person and not the professional or even the activity that must be at the center of service delivery. This is not a new concept; however, it is one that must be emphasized within the recreation and therapeutic recreation literature. If there is one central theme in this book, it is that people with disabilities are people who have the same needs and wants as everyone else and deserve the right to be at the center of recreation and therapeutic recreation services that are, after all, “for” them.

**About the Book**

This book represents our personal learnings and beliefs, supported by research, that have come from many sources, particularly from people with disabilities with whom we have worked, our students through many years of collective teaching and research experience, and our colleagues. We have extensive experience working with people with disabilities. As we have worked with people with disabilities, we have learned about them and learned from them. Probably the most important lesson we’ve learned from them, however, is that each person with a disability is a person first, not a disability.

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For example, as a recreation leader in a special recreation program, Mike once worked with John and Sarah, who were blind. He worked with them and got to know them over a period of several months. Mike had not spent much time around people who were blind, so he did not know much about blindness. Mike assumed that by working with John and Sarah, he had learned about blindness and about people with blindness. In fact, however, Mike had learned more about John and Sarah than he had about blindness. Mike realized that even though they both were blind, they had very different needs and wants, let alone skills and capabilities. Mike had learned a lot about two people and a little about blindness!

There are countless stories that reiterate the importance of centering the services within the person. Some of these stories are from treatment settings, some from special settings, and others are from inclusive recreation settings. The examples span the full range of recreation services, yet the message is always the same: “Treat me as a person first. Let me be involved in decisions that involve me. Do not stereotype me because of my disability.” We heard them then and we have tried to write this book from that perspective.

Manifestations of disabling conditions differ from person to person. There are indeed some generalities about blindness or intellectual disability or mental illness, but people with disabilities expect to be treated as people and not be prejudged because of their disabilities. Throughout this book, as we give examples and explanations, we will always discuss the importance of centering recreation services around the person.

In addition to the insights we have gained from people with disabilities, as we have taught students in recreation and therapeutic recreation curricula, we have learned from them as well. As professors and administrators, we always try to challenge our students and ask that we be challenged as well. We want our students to think critically and to go beyond mere memorization of information. We ask the same of you, our readers. We want you to read for concepts and to think critically about these concepts. That is why there are suggested “Learning Activities” at the end of each chapter. You will see that the learning activities are practical and pragmatic and require you to go beyond the text as you think critically about what you have read.

Through the years, our students have taught us that they are more interested and more motivated to learn when they are involved in their learning in a meaningful way. We have attempted to write this text to facilitate interest and motivation. We have always told our students that we expect to learn from them. They often patronizingly nod affirmatively, never really believing that they have anything to “teach” us. Nothing could be further from the truth. We have learned lessons from our students. Our students have challenged long-held beliefs and concepts and have insisted that we rethink and sometimes modify our positions.

Students assume that their professors have read all of the relevant literature. Professors have not and cannot read all of the relevant literature. In fact, there is often “relevant” literature in places professors may not routinely look. However, our students’ work has often uncovered new literature in journals that we had yet to discover. Their papers have often sparked alternative thinking that has allowed us to go beyond think-
ing about issues in the same way. In this book, we have used the collective wisdom of many of our students. This book is sounder because of the contributions to our learning from our students. We hope that you students will participate in this learning and that you will teach your instructors at the same time.

Not only have we learned from people with disabilities and from our students, we have also learned from our colleagues. We are indebted to the many whose work we have read. In many cases, we have had the privilege of discussing and sometimes arguing issues and topics with other authors and researchers. We count as our colleagues not only those educators, researchers, and practitioners in recreation and therapeutic recreation, but also those in special education, rehabilitation, social work, psychology, and other related and sometimes seemingly unrelated fields. This book is strengthened by the diversity of thought from so many of our colleagues.

This book is intended to be an introductory text for all students in parks and recreation/leisure studies departments. Every student, whether she or he intends to work in a provincial park or a state hospital, a community recreation center or a community mental health center, a public school or a cruise ship, needs a basic level of knowledge about people with disabilities. As a result of current legislation and a societal sensitivity to diversity, people with disabilities are increasingly present in all types of recreation service systems. Therefore, all recreation professionals, not just therapeutic recreators, must know something about people with disabilities. You will not learn enough to become a therapeutic recreation specialist, but you will learn enough to understand therapeutic recreation. If you are interested in pursuing a therapeutic recreation specialization, you will have a strong base from which to continue your more detailed study in that area. If, on the other hand, you are interested in tourism, recreation management, or some other specialization, you will know enough to feel comfortable including people with disabilities into your ongoing activities and programs.

Following this Introduction, the book is divided into three sections. Section I, “Introduction to Disability Issues,” contains six chapters that establish the philosophical, conceptual, historical, and political underpinnings of recreation and persons with disabilities. Section II, “Disabling Conditions,” includes six chapters that provide both general and specific information about people with disabilities. Section III, “Delivery of Services,” discusses the recreation service delivery system and issues and trends related to service delivery. The concluding chapter in this text revisits the central themes of this book in an effort to address issues and trends and to challenge all students to promote person-centered and responsive services and programs.

Since the central theme of this book is that people with disabilities are people who have the same needs and wants as anyone else and deserve the right to be at the center of their services, attention is given in Chapter 1 to a person-centered understanding of disability, using both seminal concepts augmented by the most current literature. Chapter 1 presents a major revision of the definition and conceptual understanding of disability put forth by the World Health Organization. This basic knowledge is referred to throughout the text. Next is an introduction to “people-first” and respectful language that will familiarize you with preferred terms that focus attention on the uniqueness
and worth of an individual rather than emphasizing the individual’s disabling condi-
tions or perpetuating stereotyping based on negative labels and images.

To further understand the issues presented in the text, a history of the treatment of
people with disabilities is presented in Chapter 2. The harsh and seemingly inhumane
treatment will be eye-opening to most readers. Very little of the history we present even
resembles our person-centered theme. Yet, it is important to understand “where we
have been.” An understanding of the past makes it clear why there is a need for ever-in-
creasing person-centered and responsive services. Since history does not change, much
of the information is the same as in the third edition with some new pictures added.

Chapter 3 provides a philosophical and conceptual basis for much of the information
about people with disabilities presented in Chapter 1 and throughout the book. The
major concepts covered in detail are normalization/social role valorization, self-deter-
mination, independence/interdependence, and inclusion. These concepts are consistent
with a person-centered approach to recreation services and will be referred to both im-
plicitly and explicitly throughout the text. We have expanded and significantly updated
our analysis of these concepts. This is an important chapter, since it is these concepts
that will ensure that people with disabilities, whether in a recreation or a therapeutic
recreation environment, will be encouraged and supported to achieve their full poten-
tial. These concepts, if learned and practiced, will place the person and not the profes-
sional at the center of service delivery.

Chapter 4 recognizes the importance of legislation in understanding past and cur-
rent services to people with disabilities. Chapter 4 presents a major revision to make
the chapter less dense and to give an updated and clear understanding of the federal
laws relating to disability. The fourth edition presents the most up-to-date legislation in
both the United States and Canada. Throughout this section, Canadian legislation that
roughly corresponds to the U.S. core laws is presented.

Chapter 5 covers how people with disabilities are treated today. We look theoreti-
cally at attitude formation and attitude change as we suggest that as aspiring profession-
als in recreation, you must become advocates for the rights of all people. This chapter
covers accessibility and the removal of barriers to ensure equal access to all people.
The information presented in Chapters 4 and 5 is quite detailed, yet it is information
that is important for all potential recreation and therapeutic recreation professionals to
understand. In fact, the basic premise (person-centeredness) of this text is supported
and reinforced by legislation and practice, which has grown out of several pieces of core
disability rights legislation.

The final chapter in Section I (Chapter 6) begins our discussion of recreation and
therapeutic recreation services. We first describe recreation and leisure as important
parts of the lives of all people. We juxtapose work and leisure, as is so often, although
unknowingly, done. We then begin a basic overview of special recreation, therapeutic
recreation, and inclusive recreation. We describe all terms as recreation-based, but we
try to make clear distinctions among the various services. We particularly explain the
differences in services and settings because our extant literature is filled with inaccura-
cies in this area. The concept of mandate for service is presented as a way of organizing
and understanding various services. Throughout this chapter, attempts have been made to relate recreation and therapeutic recreation to the information presented in this section.

Each chapter in Section I (and in each subsequent section) includes thought-provoking questions as independent and/or interactive learning activities as well as traditional and online references to assist you in more detailed study of a particular topic.

Section II includes chapters that familiarize you with basic information about various disabling conditions. All chapters on Disabling Conditions (Chapters 7–12) have been revised to reflect the most current knowledge and advances in the field of disability consistent with the new DSM-V and recent literature. This section begins with Chapter 7, which is a detailed discussion of a number of issues that cut across all disabilities. Issues and topics that are covered include the individual versus categorical approach to understanding and working with people with disabilities, life-span issues such as the various transitions throughout life, cultural diversity, poverty, and employment. In this chapter, we acknowledge the importance of focusing on the individual rather than on the disability, but at the same time recognize the need for readers to have some general information about specific disabling conditions. Many people do not neatly fall into one disability category, but in fact have more than one disabling condition. As such, we consider the issue of multiple disabilities within this chapter.

Following this introductory, cross-cutting information in Chapter 7, information about disabling conditions is presented. This information is basic, but we feel it is essential that all future recreation professionals be informed about different disabling conditions. It includes information about broad categories of disabling conditions, such as people who have mental intellectual and developmental disability (Chapter 8), people who have physical disabilities (Chapter 9), people who have visual impairments (Chapter 10), people who have hearing impairments (Chapter 11), and people who have mental illness (Chapter 12). We believe that this level of information is sufficient for any recreation professional to be able to provide responsive, person-centered recreation services to all people. Of course, the more specialized the service, the more in-depth knowledge about disabilities is needed. Since this is mainly a textbook for all students in recreation curricula, it is not intended to provide the level of detail needed for a person to become a therapeutic recreation/recreation therapy specialist. Rather, it is intended to provide basic information that is needed by anyone who comes in contact with people with disabilities. The person wishing to pursue a career in therapeutic recreation will no doubt need to learn more specific information about implications of disabling conditions, as well as medical/psychosocial terminology that is pertinent to clinical practice. This, hopefully, will come from future courses, as well as from practicum and internship experiences. Whatever your career aspirations, the information presented in Section II will provide a strong and needed base.

Section III, “Delivery of Services,” moves beyond the disability-specific information to discuss the service delivery system that includes inclusive recreation, therapeutic recreation and sport.
Chapter 13 explains special and inclusive recreation services that are available to people with disabilities. The bulk of recreation services for people with disabilities are found within public recreation programs. This is true both in Canada and in the United States. However, in both the United States and Canada, these recreation services and programs within the public sphere have mostly been segregated—that is, programs that were only available to people with disabilities. With current laws, it is clear that there will continue to be more and more emphasis on integrated or inclusive recreation programs. In this chapter, we explain the differences between integrated and segregated/specialized programs. We describe the special recreation service delivery model and give examples of exemplary special recreation throughout the United States and Canada. We then describe the LIFE (Leisure is for Everyone) philosophy, which is a philosophy of integrated/inclusive recreation services from an individual and an organizational perspective. Following an overview of the LIFE philosophy, exemplars of integrated/inclusive recreation services throughout the United States and Canada are presented.

Chapter 14 describes the profession of therapeutic recreation and the practice of Recreation Therapy. In this chapter, there is a presentation of the most current definitions and models as well as a discussion of the various settings in which recreation Therapists work. The chapter includes the most current statement of meaning, guiding principles and scope of practice of recreation therapy. There is detailed presentation of the therapeutic recreation process, including assessment, goal setting, treatment/discharge planning, intervention, documentation, and evaluation. Many of the examples used previously have been modified to reflect current practice in therapeutic recreation/recreation therapy. After reading this chapter, students should have a clear picture of what a therapeutic recreation specialist does and a solid base to build the clinical skills necessary to work as a therapeutic recreation specialist. Students not interested in pursuing therapeutic recreation specialization will understand and better appreciate therapeutic recreation and the potential interfaces with other recreation settings.

Chapter 15 focuses on leisure education as a key process that can be utilized in both recreation and therapeutic recreation settings. On the one hand, it can be education for leisure, while on the other it can be used as an individually conceptualized intervention. In this section, we describe in detail the definition and process of leisure education. We give examples from therapeutic recreation and recreation to make the concept clear both in Canada and in the United States.

Sport and people with disabilities is explored in Chapter 16. As in public recreation, there are also issues about how participation should and can occur within sport. Within this chapter, we provide an overview of the history of sport for people with disabilities. In addition, we describe the benefits of sport for people with disabilities. We then describe the delivery system for sport, using wheelchair athletics and Special Olympics as examples of different types of sport systems for people with disabilities. The changes to practice since the second edition are included to ensure that students have the most comprehensive understanding of sport and people with disabilities. The final part of this chapter discusses some of the controversies/issues within sport that exist today, using current examples.
The concluding chapter of this book, Chapter 17, deals with issues and trends in the area of recreation and disability. It includes a detailed explanation of Healthy People 2020 as well as a section on the development of professional education and training. As we continue to stress the importance of person centeredness, issues covered in this chapter are issues that are crucial to the lives of people with disabilities and are consistent with a community membership paradigm.

Summary

It is our hope that you will begin to see people with disabilities as people as you learn about recreation and therapeutic recreation services. If you emerge from this book (or your class) with this person-centered knowledge, then you will have learned a lot about how to provide recreation services to people with disabilities. Whether or not you happen to be a person with a disability, our more earnest hope is that you will emerge with a commitment to ensure that people with disabilities are treated as people who are at the center of their programs and services. This means that you will become an advocate, maybe even a zealot, on behalf of people with disabilities. You will encourage friends and colleagues to use “people-first” and respectful language. You will refrain from jokes that perpetuate stereotypes. You will be part of a new breed of recreation and therapeutic recreation professionals who celebrate differences and strive to provide person-centered and responsive services.
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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
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
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).

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.
Introduction to Recreation Services for People With Disabilities

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

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**Examples of Appropriate/Inappropriate Terminology**

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

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.

**HOW MANY PEOPLE HAVE DISABILITIES?**¹

In 2011, WHO and the World Bank published the first ever World Report on Disability, estimating that 15% of the world’s population—over 1 billion people—experience some type of disability; with 80% of these people living in low-income countries (WHO, 2011). There is a serious need for more and better data about people with disabilities. We need better information about the nature of disabling conditions and their social and economic consequences, both to guide policy and programmatic decisions as well as to enrich our understanding of disability. We need to know more about demographic trends, the impact of impairments on employment, recreation, the range of life functions, the ways in which people with disabilities participate (or not) in public and private programs, and the values and attitudes of people with and without disabilities (Scotch, 1990).

The definition of disability is a critical issue. Even though we have the suggested guidelines as outlined by the World Health Organization, disability has been used to mean everything from a minor impairment that has little or no impact on activity to a condition that requires one to rely on others for assistance in one’s most basic functions. When it comes to surveying for the purpose of disability statistics, no one accepted definition exists. National surveys or programs serving people with disabilities use specific stated definitions, but each program or survey uses definitions addressing its specific purposes (Scotch, 1990). Simply put, the number of people who have a disability depends on which surveyor is asking the questions!

There are no simple, straightforward answers. Some people with disabilities do not admit that they have a disability, while others do not even consider themselves to have a disability. Americans with disabilities are evenly divided between those who do and those who do not consider themselves disabled (activity limited/participation restricted). About 47% of people with disabilities said they consider themselves disabled (activity limited/participation restricted), while 52% said they do not. However, there are
dramatic differences in self-perceptions between people with slight or moderate disabilities and those who have severely disabilities. People most likely to consider themselves disabled (activity limited/participation restricted) are those over 45 years old, those disabled later in life, those most limited in their activities, and those who describe their disability as severe. In fact, nearly a quarter of people who identify themselves as very seriously disabled do not consider themselves activity limited/participation restricted. Many factors clearly influence self-perceptions about disability (U.S. Census Bureau, 2016).

To be clearer about the numbers, most national surveys cover only the noninstitutionalized population. In the United States, and proportionately in Canada, an additional 1.5 to 2 million individuals are unaccounted for, most of whom have disabilities and reside in institutions such as nursing homes, psychiatric hospitals, residential facilities, and facilities for people with intellectual disabilities (U.S. Census Bureau, 2016). Whatever the estimates developed as a result of survey efforts, a significant observation is that large numbers of people in North America have functional limitations, activity limitations, and participation restrictions.

In the United States, there are four frequently cited surveys that measure the extent of disability. They include the Census Bureau’s Current Population Survey (CPS), the American Community Survey (ACS), and the National Center for Health Statistics’ National Health Interview Survey (NHIS), the Census Bureau’s Survey of Income and Program Participation (SIPP). In Canada, the main sources of disability data come from the Canadian Survey on Disability (CSD) and the Participation and Activity Limitation Survey (PALS).

United States

The Current Population Survey (CPS) is a survey conducted by the United States Census Bureau to collect estimates of employment, unemployment, earnings, hours of work, and other indicators. The CPS defines people with a disability as people who have a “health problem or disability which prevents them from working or which limits the kind or amount of work they can do.” Supplemental questions to produce estimates on a variety of topics including school enrollment, income, previous work experience, health, employee benefits, and work schedules are also often added to the regular CPS questionnaire. In 2014, an estimated 8.4% of civilian noninstitutionalized men and women, aged 18–64 in the United States reported a work limitation (von Schrader & Lee, 2015). Although this is helpful, it does not include two large segments of the population, people 0–18 and people over 64.

The American Community Survey (ACS) is an annually conducted survey. The objective of ACS is to give communities the current information they need to plan investments and services. Information from the survey generates data that help determine how more than $400 billion in federal and state funds are distributed each year. The ACS definition of disability is based on six questions. A person is coded as having a disability if he or she or a proxy respondent answers affirmatively for one or more of these six categories.
Hearing disability (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?

Visual disability (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

Cognitive disability (asked of persons ages 5+): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?

Ambulatory disability (asked of persons ages 5+): Does this person have serious difficulty walking or climbing stairs?

Self-care disability (asked of persons ages 5+): Does this person have difficulty dressing or bathing?

Independent living disability (asked of persons ages 15+): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as grocery shopping or visiting the doctor?

According to the 2013 ACS, an estimated 12.6% of noninstitutionalized males or females, all ages, all races, regardless of ethnicity, with all education levels in the United States reported a disability (U.S. Census Bureau, 2016). This too, is helpful, but there is a fairly large institutionalized population of people who have disabilities that are not included in the ACS number.

The National Health Interview Survey (NHIS) covers similar topics in the same way, (i.e., self-reported). This annual nationally representative survey asks people about long-term limitations or short-term restrictions in activities due to acute or chronic conditions. Major activities for those aged 5 to 69 include going to school, working, and keeping house; nonmajor activities include participation in civic, recreational, and other activities. The ability to engage in normal play is the benchmark major activity for preschool
children; the ability to live independently signifies the same for those aged 70 and older. The NHIS allows people to indicate any kind of physical or mental condition that limits their activity in any way. Researchers in turn can define disability as they see fit, based on various combinations of responses. Because of the variability of information collected, the NHIS gives numbers of people with disabilities in a number of different demographics. As such, when looking for specific population information, the NHIS is very good, however, not good for an overall population figure.

As you can see, it is difficult to say exactly how many people have disabilities in the United States or in Canada. The only agency that estimates a composite number of people with disabilities in the United States is the United States Census Bureau’s Survey of Income and Program Participation (Brault, 2012), who estimated that there are 56.7 million people in the United States who have at least one disability. The estimate of Canadians with at least one disability is proportionally the same. In point of fact, however, estimating the number of people with disabilities in any country is not easy.

Canada

The 2006 PALS reported that 4.4 million Canadians living in households reported having an activity limitation yielding a disability rate of 14.3% (Statistics Canada, 2013). Participation and Activity Limitation Survey (PALS) provides information every 5 years on the number of persons with some type of disability that makes daily living activities difficult. The survey provides valuable insight into the type and severity of a disability as well as employment statistics, income levels, and social involvement.

The 2012 The Canadian Survey on Disability (CSD) reported that an estimated 3.8 million adult Canadians reported being limited in their daily activities due to a disability in 2012. This represents 13.7% of the adult population. CSD gathers information about Canadians aged 15 and over whose daily activities are limited due to a long-term condition or health-related problem. This information is updated every 5 years and uses the ICF framework of disability (Statistics Canada, 2013). The concepts and methods used to measure disability in the 2012 CSD represent a significant change from those used in the 2006 PALS. The most important change is that the two surveys used a different definition of disability. In the CSD, the definition was applied by using the new set of disability screening questions (DSQ). These screening questions reflect a fuller implementation of the social model of disability, greater consistency in disability identification by type, and improved coverage of the full range of disability types, especially mental/psychological and cognitive (learning and memory) disabilities.

SUMMARY

Although the ways of determining how many people have disabilities vary by the private or government agency definitions of disability, according to the U.S. Census, about 56.7 million people—19% of the population—had a disability in 2010, according to a broad definition of disability, with more than half of them reporting the disability was severe, according to a comprehensive report on this population released by the U.S. Census Bureau. The report, Americans with Disabilities: 2010 (2012) presents estimates of disability status and type and is the first such report with analysis since the Cen-
sus Bureau published statistics in a similar report about the 2005 population of people with disabilities. According to the report, the total number of people with a disability increased by 2.2 million over the period, but the percentage remained statistically unchanged. Both the number and percentage with a severe disability rose, however. Likewise, the number and percentage needing assistance also both increased. Although measured a little differently, the best number of people with disabilities in Canada is 14.3% of the population. Almost certainly if the parameters for collecting data were the same, the percentages in each country would be much closer. But for now, we have approximate numbers of people with disabilities as well as definitions that will help you better understand the content of this book. In the next chapter, we will look at how people with disabilities have been treated through history.

**LEARNING ACTIVITIES**

1. List as many words or phrases that you have heard (or said) that you would consider negative language toward people with disabilities. What makes them negative?

2. Using the ICF classification for a person who has become blind in her late teenage years from a degenerative eye disease, describe what might be her
   • bodily functions and structure/impairment,
   • activity limitation, and
   • participation restriction.

3. Now that you understand the distinction among terms such as *impairment*, *activity*, and *participation*, when you read the newspaper or when you hear people talk, pay attention to how the writers or speakers use the terms *impairment* and *disability*. How does the way the writer/speaker uses the term(s) change the meaning from your understanding of the term(s)? What term do you think should have been used and why?

4. For the next seven days, pay particular attention to the number of times that you hear or see language that is not “people first.” As you listen to your friends and/or family, listen to radio and television shows, read newspapers, magazines, or books, note the “offenses.” Keep a log of the number of offenses and where they occurred. Don’t forget to listen to yourself!

5. Refer to Table 1.1 and add as many additional examples of negative language as you can. After each one, write a more positive and respectful alternative. Reflect on how easy it was to complete the negative list.
REFERENCES


Footnote

1 Statistical data sources on disability

This discussion is meant to help users who are beginning to use disability statistics or who want a clearer understanding of data sources.

The most often-used sources of disability statistics in the U.S. are those based on large-scale surveys conducted by the federal government. These surveys are intended to help guide policy decisions of various federal agencies. They also offer researchers,
advocates, local policy-makers, and others valuable data they can use to identify needs, create programs to meet those needs, and shape proposals for improving policies.

One advantage of these large-scale federal surveys is their reliability, because they are nationally representative and involve relatively large samples of households or individuals. Another advantage is the availability of the data they yield. All the major surveys done by the federal government maintain their own websites, providing information for a wide range of users. Typically, this includes data summaries, descriptions of the survey design and content, explanation of the sampling and weighting strategies used, the survey instruments themselves, publications, and availability of micro-level data.

**Micro-level data and aggregate data**

Nearly all federally sponsored surveys that deal with disability-relevant data allow users to download data sets directly from the surveys’ websites. Surveys usually also make these data sets available on CD-ROM as well.

Some websites, such as the U.S. Census and the Behavioral Risk Factor Surveillance System, provide aggregate data in the form of prepared charts and summary tables. They also allow users to specify the geographic, demographic, and other variables of interest.

Depending on the user’s information needs and skill in doing statistical analysis, either aggregate data or analysis of micro-level data may be more appropriate.

*Micro-level data sets* include data on each individual or household surveyed, with codes (usually numbers) representing the response for each question the person is asked. The set of all responses for an individual is called a record. Some records represent answers that a person gives about himself or herself; others represent answers that the person gives about other members of the household. Each of these records has an identifier that allows a researcher to retrieve a particular record or set of records. Micro-level data sets may contain tens of thousands of records.

Users familiar with statistical software such as SPSS, Stata, or SAS can conduct a variety of statistical analyses on specified variables for all records or a subset of records in the data set. The advantage of using micro-level data is that users can develop customized analyses using specified variables of interest.

**Aggregate data**

Aggregate data are summary-level data, the result of applying statistical analyses to micro-level data sets. Analysis may entail summing the number of each type of response for a given variable, then applying additional calculations such as weighting and estimation of sampling error. These procedures are meant to provide reliable inferences about an entire population based on data collected from the sample, or set of samples, surveyed.

Aggregate data provide estimates of selected characteristics of the entire population surveyed (for example, how many people in the U.S. have a disability) or a specific sub-set of the population (for example, the proportion of working-age women with disabilities who have college degrees). Aggregate data are frequently used to describe
trends over specific time periods (for example, how the employment rate for people with disabilities has changed from year to year).

As noted earlier, the websites of many federally sponsored surveys provide aggregate data on their websites in the form of tables, graphs, or maps. One limitation of these prepared aggregate data is that they might not use all the variables of interest to the user.

**Major statistical data sources on disability**

**U.S. disability data**
- Decennial Census and Supplementary Surveys
- American Community Survey
- Survey of Income and Program Participation (SIPP)
- Current Population Survey (CPS)
- National Health Interview Survey (NHIS)
- National Health Interview Survey on Disability (NHIS-D)
- Behavioral Risk Factor Surveillance System (BRFSS)
- Medical Expenditure Panel Survey (MEPS)
- N.O.D./Harris Survey of Americans with Disabilities

**International disability data**

*United Nations Statistics Division—Disability Statistics.* This site provides a statistical reference and guide to national sources of disability, basic disability prevalence rates, and questions used in each national survey to identify persons with disabilities. The data available on this site are in the United Nations Disability Statistics Database, version 2 (DISTAT-2). http://unstats.un.org/unsd/demographic/sconcerns/disability/

*World Health Organization—International Classification of Functioning, Disability, and Health.* This site does not include disability data, but provides extensive information on WHO’s current system for classifying disability. The system is noteworthy for its recognition of disability as an interactional process between the person and his or her environment. http://www3.who.int/icf/icftemplate.cfm

(Acquired from the Disability Statistics Center, University of California, San Francisco. http://www.dsc.ucsf.edu)
History of Treatment of People With Disabilities

INTRODUCTION

This chapter covers more than what is generally known of the relationship of recreation and disability/illness throughout history. Whether you work in recreation therapy/therapeutic recreation or community recreation programs, in order to be an effective professional, you will need to have a comprehensive historical perspective of the treatment and services of people with disabilities.

It is hard to imagine that some of the history presented here could have happened; however, readers are cautioned to remember that what happened occurred in an historical and cultural context. As horrific as some of it might sound, in large measure, the people of the time believed that they were providing the best possible alternatives for people with disabilities in their societies. By today’s standards, we regard most of the ways that people were treated as inadequate, if not inhumane. At the same time, some of the history—when considered in context—seems entirely adequate, if not progressive.

Throughout human civilization, people with disabilities have been discarded and disrespected, treated like freaks, and often assumed to be a punishment from God to the parents. Many years were characterized by
inhumane and animalistic treatment. People with disabilities were too often seen as “deviant” and were abandoned, abused, used for sport and entertainment, involuntarily sterilized, and systematically ostracized from the social mainstream.

Fortunately, in recent decades, an ideological shift has occurred within our collective conscious that has redefined our perception of people with disabilities. Slowly but surely, humanity has replaced inhumanity, inclusion has replaced exclusion, justice has replaced injustice, education has replaced misinformation, and consideration has replaced ignorance. But these shifts have been a long time coming. In this chapter, we will look more closely at the history of treatment of people with disabilities.

**EARLY HISTORY**

Disability has existed since the beginning of time. In ancient civilizations, there was public awareness of a variety of illnesses and disabilities and an organized system to treat illness. In ancient Mesopotamia, care and treatment was provided by priests because it was believed that illness and dysfunction were attributable to demons, evil spirits, and transgressions against the gods. No specific records from ancient times exist to absolutely confirm what is understood from archaeology; however, there is ample evidence to support our assertions (Avedon, 1974). There are even indications that activities were used both in ancient Mesopotamia and in ancient Greece to appease the gods and, thereby, to alleviate the illness and dysfunction that was attributable to demons, evil spirits, and transgressions against the gods.

The oldest written records of ancient Greece and Rome contain evidence that people with mental illnesses and a variety of sensory and physical disabilities existed at that time. Examples of disability occur in the Bible, evidenced in the stories of people who were “crippled,” blind, had leprosy or other illnesses and diseases, and were brought for healing. There are examples during the medieval period of people with disabilities being used as court jesters to entertain or amuse other people.

Historically, determination of disability was more dependent on social factors than on a diagnosis of an illness. Whether or not a person was considered mentally ill, intellectually disabled, or physically disabled depended both to the degree to which the person’s behavior was different and the attitudes of members of his social group toward such deviant behavior (Rosin, 1968). “People-first” language, of course, was not even considered at the time. In fact, words such as *disability* and *the handicapped* have become used only in modern times. During earlier periods, people whom today we would call people with disabilities were referred to as dysfunctional, mad, crazy, deformed, or defective. Many of the words and phrases that we characterized as negative in Chapter 1 have existed for many, many years. However, the definition and understanding of people as “defective” and “shameful” were overriding notions that guided the treatment and services of people with disabilities.

As mentioned, from the earliest times, and even through parts of the twentieth century, common wisdom among the general public was that “madness” or “defectiveness” came from demons or evil spirits and was seen as a punishment from an angry God. You might be familiar with the expression: “I’m going to beat the devil out of him.” Such
a colloquial comment is rooted in early treatment of people with disabilities. That is, one of the ways that people with disabilities were treated was to actually beat them in hopes of beating out the demons or evil spirits that were the reason for “defectiveness.”

From Roman law, we see that typical members of the community were legally protected from harm from people with mental illnesses. As “defectives,” people with mental illnesses (and indeed other disabilities) were thought to be dangerous and unpredictable. People were afraid of the members of their community who had mental illnesses, and they demanded protection. As a result, specific laws were written to protect the general public. Roman law even protected the property rights of the family if the head of the household had a mental disorder. An example is the story about Sophocles, who worked well into his extreme old age and often became so absorbed in his work that he neglected his business affairs. His sons believed that he was incompetent in the dealings of family property, so they took him to court to gain control of their father’s property. They were successful and did in fact gain control. Roman law did not protect those with mental illness, but instead protected the right of the family and the general public from people with mental illnesses.

Two basic views in the ancient world existed regarding the etiology of disability. One attributed illness to supernatural or divine intervention, and the other view was that illness and disability were due to natural causes (Rosin, 1968). As stated above, it was not uncommon for the community to think that a “defective” child had been sent as punishment for the sins of the parents, even if those “sins” were not common knowledge to others in the community. In other cases, supernatural or divine intervention was somewhat more positive. If a person’s disability was believed to be the result of or possession by a supernatural power, she was thought to have extraordinary abilities and thus considered to be “above” normal man, even sacred. In “primitive” cultures such as some North American First Peoples tribes, there was a belief that when a person killed an enemy in battle, the spirit of the person killed, including many traits and characteristics, was absorbed by the victor. As a result, if an enemy was known, or even thought to be possessed, he/she would not be harmed for fear of absorbing that person’s condition. Sometimes, people with mental illnesses were looked at as if they were closer to the gods than regular people.

On the other hand, if a person was thought to be ill or dysfunctional as a result of natural causes, the illness or dysfunction was thought to be curable. Wide varieties of herbs, animals, and minerals were used to treat illness and dysfunction. Activity was also used. According to Avedon (1974), “…the first Greek physician, Melampus, treated the daughters of Proteus by having them play a game that involved running. This is reported to have cured them of the delusion that they were cows.”

Also in the early Roman and Greek eras, music, drama, reading, and sport were used to ease dysfunction and discomfort of the mind. A number of temples were even built as curative centers. One example of such a curative center in ancient Greece that was built and continually upgraded throughout the first millennium was one that included a library, a stadium, and a theatre. Also sometimes used for treatment of mental disorders in ancient Greece was music played in conjunction with gymnastics and dancing (Avedon, 1974). In ancient Rome, as early as A.D. 124, people who were mentally ill
were taken from their dark cells, brought into the sunshine, and provided music, games, poetry, and gentle exercise.

Although there are some examples of humane treatment, what is not recorded is the maltreatment of many people with serious illnesses and dysfunctions. People with illnesses and dysfunctions were put in dark cells with little or no attention or were the responsibilities of families. No measures were ever taken to help most people with disabilities unless they were among the wealthy class or if they were a threat to others.

Instances of people with disabilities being “useful” exist as well. The primary mode of production throughout human existence has been foraging, and it was most likely a source of employment or even occupation for some people with less serious disabilities. As long as people were capable of “keeping up” with group movement and contributing to the gathering of necessary resources, such individuals probably survived relatively well in foraging communities (Scheerenberger, 1983).

However, people with serious disabilities most likely shared the fate of people who were injured or aging: they were either euthanized or left behind so as not to interfere with the survival of the group. As early societies moved from hunting and gathering to cultivating and harvesting, it is still likely that many people with disabilities fared well. For example, “in less complex, less intellectually centered societies, the mentally retarded would have no trouble obtaining and retaining a quality of realizable ambitions... They could make successful peasants, hunters, fishermen, and travel dancers.” (Scheerenberger, 1983). In other earlier societies, infants believed to be defective were abandoned and left to die from exposure (Macklin & Gaylin, 1981).

Some people with disabilities who survived infancy were used to entertain. Throughout early history around the world, there are countless examples of the use of slaves for entertainment. Welsford (1935) relates the earliest mention of the dwarf-fool with the Egyptian pharaohs who chose members of the Danga pygmy tribe as mainly a curiosity, but also for amusement. In the fourth century B.C., wealthy families kept people with disabilities to amuse their guests; in the 2nd century, the viewing of people with physical or developmental disabilities became a source of public entertainment (Evans, 1983; Scheerenberger, 1983). It was customary for wealthy men in the Roman Empire to keep half-witted and deformed slaves in their houses for purposes of entertainment; further, females were known to keep physically stunted and mentally deficient slaves as substitutes for “lap dogs and teddy bears” (Welsford, pp. 58–59). Further examples include spectators being amused by deformed figures around A.D. 500 in the court of Attila (Wells, 1961, pp. 411–412). Bedini also mentions the forum morionium, where people with disabilities were bought and sold as slaves (1991, p. 63). Such “slaves” were frequently traded or given as payments or gifts. According to Welsford (p. 107), even in death there was no peace, as people were known to break into laughter when merely looking at a “fool’s” grave. Such abuses of people with disabilities being used for amusement robbed them of any shred of dignity and forced them into a state of dependence.

Another era of early recorded history about which we know a considerable amount is the era in the Middle East during the early Jewish tradition. Disability was believed to be inflicted on those being punished by God. As early as the seventh century B.C., Moses told his people in the Book of Deuteronomy (28:15, 28) that “if you do not obey
the Lord your God and do not carefully follow all his commands and decrees ... the Lord will afflict you with madness, blindness, and confusion of the mind.”

As in Rome and Greece, the use of music in the Middle East was also prevalent. In biblical literature, David often played the harp in the court of Saul, King of Israel, to soothe the King’s mind when the “spirit of God came upon him.” From the context and everything else we know of King Saul, that phrase was a euphemism meaning when he became emotionally unstable. For example, in Samuel (16:23) is the statement: “Whenever the spirit of God came upon Saul, David would take his harp and play. Then relief would come to Saul; he will feel better and the evil spirit will leave him.”

**MIDDLE AGES**

During the Middle Ages, people with disabilities or people who looked and acted differently than normative society were considered outcasts. They were sent away to prisons, abandoned in the wilds, or even worse, they were killed. They were expelled from their communities where there was no one to care for them. In medieval times, outcasts or people whose behavior did not fit within the norms of that particular society were often labeled as witches and were summarily persecuted.

There was also further evidence of people with disabilities being used for amusement in the middle ages. Billington (1984) found evidence of both English and French mobility keeping “simpletons” as fools throughout that time. From the 14th through the 17th centuries in France and England, people who were mentally deficient were also considered to possess supernatural powers and strengths and, as such, were an added source of “entertainment” (Welsford, 1935, pp. 78, 94). Irish court jesters were termed “miclach,” “mer,” and “faindelach,” all denoting not only idiocy but also men who “were regarded as “disreputables” and in a state of semi-outlawry” (Welsford, 1935, p. 110).

During the Middle Ages, a “ship of fools” sailed from port to port displaying its cargo to the curious (Foucalt, 1965). Jesters or fools were commonly attached to courts and wealthy households. In one 17th century Spanish monarchy, Philip IV was reported to have “kept” a sizable collection of people with disabilities (Evans, 1983). Although people with severe and obvious disabilities were treated as “non-people” during the Middle Ages, most people with less severe disabilities were reasonably integrated into a highly stratified agrarian society. Marie
Crissey (1975, p. 800) writes that “In an almost wholly illiterate population, functioning at the simplest vocational level, a group we now label educable retarded no doubt was indistinguishable.” In other words, people with less severe involvement and the less obvious differences seemed to blend more easily into the rest of the population.

The French Renaissance introduced the rise of humanism and the intervention of the church. By the end of the 14th century, the church had excommunicated all those who earned a living by mimicking the witless man (Billington, 1984, p. 20). In contrast to this protection by the church, any man brought before a jury in 16th century England and declared a purus idiota (simple idiot) became the property of the crown, losing all personal property (Billington, 1984). There was a wide range in the treatment of people with disabilities!

Around the 12th or 13th centuries, some advances in the treatment of people who were different occurred. “Defectives” as they were often called, who had no family or nowhere to go, were put into sections of hospitals not necessarily for treatment purposes but to get them off the streets, out of the community, and out of sight. Even though we might not consider this humane treatment by today’s standards, by the standards of that day, this was considered extremely humane. In essence, society was taking care of those people who they thought were completely unable to take care of themselves. They were placing “defectives” into “safe” settings where they would not be ridiculed, mistreated, or ignored. Although today we might call it segregation and keeping people from interaction with “typical” society, at the time it would have been proudly said that they were being segregated for their physical and emotional protection. And for the time, they were probably right!

Researchers might argue that the goal was to “cast the mad out of the community and separate them from their society” (Perrucci, 1974). However, the proponents of early institutionalization felt that they were providing what was needed for the ones defective among them. By the 16th century, an increasing tendency arose to place people with mental illnesses and other disabilities into special institutions. This was particularly influenced by policies of the religious reformers in Europe. The belief that illness and disability was caused naturally rather than supernaturally was becoming more popular, and medical treatment was beginning to be prescribed accordingly. Still, in cases where the illness seemed to be too bizarre or beyond medical explanation, supernatural explanations were given (Rosin, 1968).

Even though some people with disabilities contributed to the economy during this time, with the rise of urbanization in the 17th and 18th centuries, there was a need to get people “out of circulation.” The removal of people with disabilities from urban areas and their incarceration along with devalued people created new opportunities for exhibition and profit making. This occurred in one of the first lunatic asylums in Europe (England), the Bethlehem Royal Hospital—popularly known as Bedlam. Evans (1983, p. 37) notes that:

In Bethlehem (Bedlam), idiots and lunatics were exhibited for a price of about a penny every Sunday. The annual revenue for these shows at Bethlehem in 1815 was 400 pounds, indicated an audience of approximately 96,000 people that
year. The visitors’ curiosity was evoked, in part, by certain attendants who were particularly adept at getting the inmates to “perform dances and acrobatics with a few flicks of the whip.”

The Enlightenment brought about some improvement in the treatment of people with disabilities, and its new ideas contributed to notable clinical attempts to enhance the lives of such individuals. Itard’s efforts to socialize the “wild boy of Aveyron” and Johann Jacob Guggenbuhl’s attempts to “cure” people with disabilities through environmental stimulation were among the first efforts to prepare people with disabilities for integration into the developing society. There were other notable exceptions. Philippe Pinel, an 18th century French physician, consciously used recreative experiences for treatment purposes. He taught that ill persons, particularly mentally ill persons, would respond and often improve (with the use of recreative activity such as games, dance, music and the like for treatment purposes) (Albee, 1959).

Additional evidence of the use of recreative experiences as part of the curative process is provided in an early example of self-determination and self-advocacy. An inmate of the Glasgow Royal Asylum for Lunatics tells it this way:

For the last two years, I have attended the concerts and balls given during the dark months of the year to the inmates of Gartnavel Royal Lunatic Asylum; and from what I have seen, and also what I have heard from the inmates themselves, I know that these meetings have soothed the excited, cheered the desponding, and turned the mind aside for the time from the corroding task of contemplating its own sorrows, and consequently ministered to the great purpose for which asylums are instituted—the cure of insanity. ...There are people here listening to the song and joining in the dance—enjoying the clear light, the beauty and fragrance of the fresh evergreens which festoon the hall—who under the old system would be lying in bonds and darkness, their only music the clanking of the iron bolt and the rattling (sic) of the prison keys (Anonymous, 1860).

MODERN HISTORY: EARLY INSTITUTIONS IN NORTH AMERICA

Little tolerance existed for people who were “defective” in Colonial North America. A family member who was “insane” or “defective” was taken care of at home. If the family member was violent or troublesome and the family could not care for the person or was ashamed of the person, he was often locked up or chained up by his family in the cellar, a strong house, an out building, or other flimsy building with few or no amenities (Deutsch, 1967). In such cases, these “defectives” were given very little food and often beaten. People who were considered defective were hidden away from society and often considered a “family disgrace.” During this period of preinstitutionalization, people who were “different” lived very isolated lives, if they were allowed to live at all.

In the 18th century in North America, many institutions were built. They were originally intended to house criminals, but often people with mental disorders (mental illness and intellectual disabilities) were incarcerated and treated as if they, too, had committed some criminal act (Deutsch, 1967). Connecticut’s first house of correction, which
was opened in 1727, was mandated to include persons who “aren’t fit to go at large and whose family and friends do not take care of their safe confinement” (Deutsch, 1948). Although extreme and even cruel by our standards, much of the treatment of people who were defective was more humane during this period than had been in the medieval or earlier periods when people with disabilities were ridiculed at best and at worst, imprisoned, tortured, hanged, or otherwise persecuted.

In 1752, a Pennsylvania hospital was the first hospital in the country to admit mental patients for curative treatment. This was the beginning of what has been called moral treatment. Treatment changed from being cruel to being kind. This was the beginning of a revolution to understand illness and disability and to treat it accordingly. Even though this was the beginning of more humane treatment for people with disabilities, treatment was still a largely custodial situation in which it was clear that the ultimate objective was to cast these people out of the community and to separate them from the rest of society. These institutions were located in the country and housed up to 250 to 300 “patients.” The asylums, as they were later called, were surrounded by a substantial wall intended to keep the patients in and away from the rest of society.

In the United States, attempts to “cure” people with disabilities through environmental stimulation began in 1848 with the opening of an experimental school in Boston. That preliminary effort was followed by state funding for the Massachusetts School for Idiotic and Feebleminded Youth, which between 1848 and 1869 was reported to have prepared 365 “feebleminded youths” to become self-supporting members of the community (Evans, 1983). By 1889, there were 24 state-supported institutions in the United States (Crissey & Rosen, 1986). However, support for public funding of these facilities began to erode in the late nineteenth century, and with decreased funding, state institutions became much more custodial (Evans).

Although there had been advances in institutional care during the 17th

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**Figure 2.2.** “Cincinnati’s Problem.” Cover of The Feeble-Minded, a pamphlet distributed by the Juvenile Protective Association of Cincinnati. (James W. Trent, Jr. (1915). http://www.disabilityhistory.org/dd_camp2.html)
and 18th centuries in England, many of those would not last in the new world. As in-
stitutions became more custodial, forms of recreation diminished. Patient or resident
populations within institutions such as these increased during the 19th century. As
more and more people were placed in institutions, they quickly became overcrowd-
ed. Throughout the 19th century, asylums popped up in every state. Surprisingly, even
as early as this period, the after-care movement began (Deutsch, 1967), during which
there was the first successful attempt at assisting patients with being discharged from
mental hospitals.

Prior to the late 19th century, institutions and programs for “dysfunctional” people
were not organized by type of disability. Rather, any person with any illness or disability
was placed into an institution. Programs and services for people who were mentally ill
were indistinguishable from programs for people who were intellectually disabled, for
people who had cerebral palsy, or for that matter, for people with any other disability.
In the late 19th century and early 20th century, separate institutions began to be de-
veloped. There were institutions for people who were mentally handicapped as well as
special schools for people who were blind and for people who were deaf.

During the early 20th century, many scientists and professionals scapegoated “defec-
tives” as the cause for increasing disorganization and crime. In 1912, Walter E. Farnald
shared the following view with the Massachusetts Medical Society (Evans, 1983, p. 43):

The social and economic burdens of uncomplicated feeblemindedness are only
too well known. The feebleminded are a parasitic, predatory class, never capable
of self-support or of managing their own affairs. … They cause unutterable sor-
row at home and are a menace and danger to the community.

We have only begun to understand the importance of feeblemindedness as a
factor in the causation of pauperism, crime, and other social problems … every
feebleminded person, especially the high-grade imbecile, is a potential criminal,
needing only the proper environment and opportunity for the development of
his criminal tendencies.

Fearing that “mental defectives” were reproducing themselves in substantial num-
bers, many began to call for their sterilization. In 1918, Popenoe and Johnson, as cited
by Evans (1983, p. 46), supported sterilization while arguing against the “release” of
unsterilized persons. They suggested profitable use be made of the people they called
“waste humanity”:

Feebleminded men are capable of much rough labor. Most of the cost of seg-
regating the mentally defective can be met by properly organizing their labor,
so as to make them as nearly self-supporting as possible. It has been found that
they perform excellently such work as clearing forest land, or reforesting cleared
land, and great gangs of them might profitably be put at such work, in most
states. … (Thus) these unskilled fellows find happy and useful occupation, waste
humanity taking waste land and thus not only contributing to their own support
but also making over land that would otherwise be useless. … Nor need this be
confined to the males alone. The girls-women raise poultry, small fruits, and

vegetables very successfully. … No manufacturer of today has let the product of his plant go to waste as society has wasted the energies of this by-product of humanity.

Many states did develop dual policies of segregation and sterilization. By 1926, 23 states had mandatory sterilization laws; in 1927, the Supreme Court upheld the constitutionality of such legislation. Justice Holmes (in *Buck v. Bell*, 1927, p. 207) wrote the following:

> It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. …Three generations of imbeciles are enough.

Researchers have estimated that over 50,000 people with disabilities, or those who were labeled as “defective,” were sterilized in the United States between 1925 and 1955 (Evans, 1983). Countless others were confined to state institutions and endured the oppressive, if not torturous, conditions documented in a variety of works (Blatt, 1970; Blatt & Kaplan, 1966; Deutsch, 1948; United States Senate, 1985; Vail, 1966).

**Treatment of People with Disabilities in Nazi Germany**

The oppression in the United States and Canada was bad, but it was nothing compared to what was occurring at the same time in Germany. Anyone who had a physical or mental disability was not thought suitable to live. The killings of people with disabilities were the Nazis’ first organized mass murders and were the proving ground in which they developed their killing techniques. The murder of children with disabilities began in October of 1939. A decree ordered midwives and physicians to report all infants born with specified medical conditions such as “Down syndrome, blindness, deafness, abnormally small head size, severe or progressive hydrocephalus, any deformities, and paralysis” (Friedlander, 1997, p. 48).

The most common method of killing was an overdose of medication so that death was not immediately obvious as murder. Toward the end of the war, however, starvation was used often. The killings were seen as important to the advancement of science. Children with disabilities were studied before their murders and autopsies were performed on them after their deaths. Their organs, especially their brains, were regularly removed for scientific studies.

Many of these institutionalized children in Germany, like many of the institutionalized children in North America, were institutionalized for less severe disabilities and sometimes because they were slow learners and/or had behavior problems. The project to kill children with disabilities was overshadowed by the killing of adults with disabilities (Friedlander, 1997). The most influential criteria for deciding whether institutionalized adults were killed was ability to perform productive work. Sometimes, however, the killings were far more indiscriminate. For example, at a psychiatric hospital in Poland, members of the German security police shot 420 patients on January 12, 1940. (Friedlander, 1997). The atrocities go on and on; people with disabilities at this time in Germany were seen as nonhumans.
During the summer of 2004, a group of Canadian and U.S. disability studies scholars attended a month-long summer institute in Potsdam, Germany, to investigate the psychiatric institution murders of German citizens with disabilities. They visited commemoration sites and archives specific to this history. The group of scholars also studied the impact of these events on the lives of contemporary German citizens with disabilities. The result was a difficult, yet rich, community effort to engage each other in the legacies of T4 (the National Socialist name for systematic “euthanasia”). To learn more about the Nazi atrocities and to learn more about the summer institute in Postdam in 2004, go to http://www.uic.edu/depts/idhd/DSGermany/.

Although people with disabilities were not systematically killed in North America, the humanity of their treatment in North America as described in the previous section is suspect. And, even though not to the extent as in Nazi Germany, institutions in North America were on a downward spiral.

The Height of Dehumanization in Institutions

Initially, institutions were intended to serve as medical settings for people with disabilities. However, as time went on, they increasingly became places where a person was sent if he or she were considered unmanageable. Very few doctors, nurses, or psychologists worked at such institutions because they were largely custodial. Institutions were so overcrowded that eating was often done by pureeing food, and then people were given straws or forced to drink their food. In fact, as recently as the 1950s, in a study that was conducted at an institution in New Jersey, the average feeding time at the state school for people who were mentally retarded was around three minutes (Butera, Patton, & Columbus, 1981).

During the height of institutionalization, institutions were so crowded that baths were seldom given. When they were, people were herded into shower stalls and hosed down to save time. Because of overcrowding and understaffing, it was not uncommon in institutions for people to walk around with soiled clothes for days at a time. To deal with this problem, inmates (as they were called even though they had committed no crimes) in institutions often remained unclothed. This is not surprising since leaving people unclothed was much easier than constantly cleaning clothes that had been soiled. In addition, while residents were being hosed down, floors that caught feces and urine could be hosed and disinfected as well. Needless to say, sanitation was not a high priority, and disease was common in institutions (Korbin, 1987). The workers were not intentionally trying to be inhumane, but as mentioned, many of the staff were poorly educated and often took institutional jobs as second jobs to earn money. Workers were caught in a cycle where they were overworked and underpaid in badly overcrowded institutions. Workers might have

(Source: NIH, n.d.)
done their best with what they had during this period, but people in institutions lived in filthy surroundings.

**Humanization of Institutions**

Throughout the 20th century, there were a variety of attempts at improving the care and treatment of people with various disabilities. In the case of people who were mentally ill, treatment was being tested on mental disorders. An array of treatments was used, including insulin shock therapy, where a coma would be induced. By 1938, electric convulsive shock therapy was introduced and soon became a standard procedure for treating people with mental disorders.

Also around this time, lobotomies were performed to treat patients (Martindale & Martindale, 1985). A lobotomy is a surgical procedure that would actually disconnect the frontal lobe of the brain, which was thought to be the area of the brain that caused mental dysfunction. In Ken Kesey's classic book, *One Flew Over the Cuckoo's Nest*, the Chief is a graphic example of the effects of a lobotomized patient who walked around zombie-like as a result of having a frontal lobotomy. In the early 1950s, drug therapy as a treatment for a variety of disorders increased; this type of psychopharmacology continues extensively today.

The overcrowded and unsanitary conditions were moderated somewhat beginning in the 1950s, for several reasons. First, many citizens were repulsed by the eugenic solution practiced in Nazi Germany, where people with intellectual and developmental disabilities were systematically killed along with others labeled “undesirable.” Second, parents of children with disabilities began to advocate for their needs, and the time was right for their pleas to be heard. Third, the 1950s began a period of relative prosperity, and public resources again became available for services. Finally, in the early 1960s, President Kennedy—whose sister had a developmental disability—legitimized the
movement by creating a Presidential Commission to recommend a national strategy to assist people with developmental disabilities. Still, despite these efforts, people with disabilities continued to suffer from stereotypes, stigma, near total economic dependency, physical and social isolation, and physical and sexual abuse. Their continued oppression is thoroughly entrenched in 20th century popular culture.

Prior to the 1950s, trained staff was uncommon. People who staffed institutions were often the least educated and least paid members of society. People who lived in institutions were barely treated like humans. In fact, descriptions of these populations often sound like descriptions of livestock animals. People were “let out of their rooms” or let out of their buildings only once or twice a day and only then to walk. Inmates (as they were still called even in the 1950s and 1960s), were often left unclothed and often fed and bathed in large groups.

During the 1950s and 1960s, a movement occurred to further humanize institutions and to reverse the wide-scale abuses in the treatment of people at these institutions. The move was toward more intervention and more habitation—where people in institutions were taught functional living skills to be able to live in society. In some states and provinces, more institutions were built to ease overcrowding. Institutions began to hire professional staff: physicians, nurses, psychologists, vocational workers, and in some cases, recreational workers. Institutions also hired additional residential staff, most of whom were still lower educated and untrained, but were professionally functional when staff training became a priority during this period. Once staff received training on how to work with people with disabilities, they could then provide the best possible services (Bichenbach, 1981).

Also during the 1950s, populations began to be segregated by type of disability. This specialization is revolutionary because prior to this time, institutions often corralled all persons with various degrees of disabilities together. For example, a person with severe cerebral palsy—yet who had relatively good cognitive functioning—might be placed together with a person with a severe and profound intellectual disability or with a person with a serious mental illness. During this period of humanization in institutions, people were separated so that the best possible services could be provided to people according to their needs. With the addition of the professional staff, assessments and evaluations were conducted on a wide scale to determine skill level and to determine who should be institutionalized and what type of services were needed to assist people to have an improved quality of life.

This movement to humanize institutions also included ensuring that people wore clothes—clothes that fit them rather than the old practice of no clothes or baggy or unattractive clothes. Residents were assisted in taking their own showers rather than being hosed down. Beds were provided for everyone as opposed to having beds for some and none for others. Residents of institutions began to have foot lockers that included their own personal things. Prior to this, residents had been stripped of everything that ever belonged to them, and everything they had was communal. For example, at the time when residents did wear clothes, after the wash was done, clothes were simply passed out with no attention to ownership. Progressively, more attention was paid to choice of clothing and to personal belongings.
In addition to improvements such as these, there were also changes to the physical environment. In most cases, residents in institutions were not “dangerous,” so the fencing and walls were less necessary than they had been thought to be previously. As a result, many fences and walls came down, and many doors were left unlocked. Lobotomies were performed less frequently, and sterilization became a choice rather than a mandate.

There was a move toward more individuality and choices for people who resided in these institutions. Recreators were now hired; previously, if there was any recreation at all, it was conducted by staff after their daily tasks were done. Unfortunately, when they were hired, seldom were they people who were trained in recreation or recreation therapy. Nonetheless, there was a growing awareness of the importance of quality of life, which included recreation participation.

In spite of all of the positive changes in institutions, many things were still dehumanizing about them. Institutions were started as a humane response to inhumane treatment of people with disabilities. In fact, most institutions were started to keep people out of jails or other inappropriate places where they were even more grossly ill-treated. Yet, institutions soon became “people warehouses.” These institutions, so debased from their supposed humanitarian origins, often subjected their “inmates” to inhumane, cruel conditions more like those of a concentration camp than of a hospital. One example of such abuse was Fairview in Pennsylvania, which was referred to as “the place of no return, hell, the animal farm, Auschwitz, the last stop” (Rawls, 1980, p. 18).

Deinstitutionalization

In the late 1960s and 1970s, there was a push toward deinstitutionalization. “Deinstitutionalization referred to the move away from large-scale, institution-based care to small-scale, community-based facilities” (Dear & Wolch, 1987, p. 16). People with mental or physical disabilities began moving into community facilities instead of state facilities. “Community-based care was a possible means of solving the continuing rise in mental health costs and the heavy financial burden mental illnesses posed on the states” (Halpern, Sackett, Binner, & Mohr, 1980, p. 2). Even though many people with disabilities were getting out of institutions and away from inhumane treatment, funding in communities was insufficient. When 75% of the residents left the institutions to join the community, only 25% of their funding followed (Halpern et al., 1980).

The decrease in total institutional population brought about a smaller but even more severely disabled population. As a result, the cost of care dramatically increased between 1950 and 1994. In 1950, the average per-person annual cost of care was about $745.60 (or about $2.04 per day). By 1994, at the end of the deinstitutionalization period, the average annual cost had risen to $75,051.30 per person (or $205.62 per day). In dollars adjusted for changes in the Consumer Price Index over this period, cost of care in 1994 was 18 times as great as in 1950.

Today, there are still moves in many states to further deinstitutionalize and, in fact, close state institutions for people who are mentally retarded or mentally ill. While the move to downsize or close large institutions is continuing and has provided the former residents opportunity for more home-like living conditions, they still exist in many U.S. states and Canadian Provinces. In fact in the U.S. and Canada, there are a few states and
provinces that have not closed institutions or have only minimally reduced institutional populations. This is occurring differently in different states and different provinces. However, in some states, new institutions are being proposed and/or built.

**BEYOND INSTITUTIONS**

With the onset of deinstitutionalization, we began to see group homes, halfway houses, and other community living arrangements. The philosophy at the time was to prepare people to move from institutions into the community. We had come full circle. People with disabilities were living at home again. The difference is, this time, people would live in homes and communities with pride rather than being hidden away. As such, prior to discharge or deinstitutionalization, people were increasingly taught to work and play. They were taught social skills so they would be able to “get along in the real world.” It seemed logical and was widely believed that if a person who was institutionalized could be made “ready” in the institution, the institutional resident could transfer the learning and be “ready to live in the community.”

This may have been logical thinking, but there were problems. Preparing people, or getting them “ready,” might be a good idea, but there needs to be community support for these efforts to be continued and expanded. The problem is simple. Initially, very little money was appropriated at state, local, or national levels to ensure effective deinstitutionalization. Essentially, no money was appropriated to follow along with people who left institutions. In most states during this period of deinstitutionalization, roughly 75% of the institutional population was discharged from institutions. However, only 25% of the money followed previously institutionalized people into the community. That left 75% of the money to the institution that housed only 25% of the former institutional residents. The fact could be argued that the residents who were left behind were more severely disabled and, in fact, that is accurate. However, the disproportionate amount of money that followed individuals from the institutions into the community made it hard for them to have appropriate habitation and treatment options available to them in the community. This was not the best way to deinstitutionalize!

Deinstitutionalization, for all of its hopes to rehumanize the treatment of people with disabilities, caused some additional problems. Previously institutionalized individuals were not always welcomed into communities, especially in the 1970s and 1980s. The idea of deinstitutionalization was to “release” people from institutions and allow them the opportunity to live in the community. However, it became clear that many people without disabilities who reside in the community did not want groups of people with disabilities living in their neighborhoods. A number of people even protested adamantly against that occurring. As strange as it sounds, comments such as, “I don’t want them living next door to me. I want my family to be safe” were heard. People who were being deinstitutionalized were thought to be dangerous, or at least scary. Other comments were also heard, such as “My property value will go down.” Whatever the reason, people who were once locked away in institutions were now being shunned and unwelcomed in the communities to which they were being returned. In a sense, devaluing did not end, but was renewed in new settings.
It is fair to say that even though advocates and, in most cases, previously institutionalized persons themselves were ready for deinstitutionalization, communities were not. Not only were people being discharged from institutions, but also very few people were being admitted. In other words, all of the people who had been in institutions, plus the ones who heretofore would have been sent to institutions, were now in communities throughout North America.

In retrospect, deinstitutionalization happened too quickly and with too little preparation within communities. Many people with disabilities, who were no longer in institutions but were instead in local communities, had nothing to do. Few jobs, few educational or recreational opportunities, and few services were available, and there was little accessibility to business and services. Inadequate transportation was the norm, as were inadequate policies and procedures. The reality was that communities and their citizens were not ready for the mass of people with disabilities that were turned out among them.

The biggest concern for advocates of people with disabilities who were now back in the community was that there was nothing for them to do. There were special education classes in some schools, but most of the people being deinstitutionalized were beyond school age. With so few jobs available for recently deinstitutionalized people with disabilities, a need for vocational options arose. During the period when institutions became more humanized and began preparing residents for discharge, one of the main institutional programs was vocational rehabilitation. Residents were learning work skills in institutional workshops, yet they were not taught skills preparing them for competitive employment. Because few options were available, one of the first services for previously institutionalized people with disabilities was increased vocational services, especially in the development of sheltered workshops.

Sheltered workshops were an environment where individuals with disabilities went for work-like opportunities. Sheltered workshops were proposed as one of the first steps to a smooth deinstitutionalization. For the most part, sheltered workshop “jobs” were very low-skilled jobs in sheltered environments (not real job sites) that provided inadequate preparation to move into competitive employment with people without disabilities. Finally, some advocates have questioned the legitimacy of sheltered workshops and have moved toward supported employment where people with disabilities are provided choices in types of work and are trained and supported in regular competitive jobs rather than the institution-like sheltered environment.

Also, no public recreation programs for people with disabilities existed. As a result of deinstitutionalization and the needs of people with disabilities for recreational services, a number of special populations’ programs were started in public parks and recreation departments, YM/YWCAs and other nonprofit agencies, especially in larger cities. Like sheltered workshops, these programs were intended only for people with disabilities. There was no differentiation by disability. That is, whether a person had an intellectual disability, mental illness, cerebral palsy, blindness/visual impairment, or any other disability, he would be included within the same program or activity.

Over time, and as public recreators gained more training and began to provide increased specialized services, people were divided by disability groupings, which was thought to be a more appropriate way to provide recreation for people with disabilities.
Like sheltered workshops, special recreation programming continued and expanded over time and filled a needed gap in the provision of services. And now we have moved beyond only specialized recreation programs to more inclusive recreation programs as we discuss in later chapters.

CONCLUSION

Although there have been periods of humanistic treatment throughout time, the bulk of history seems less respectful when viewed through 2016 glasses. Since ancient times, people with disabilities have been devalued and often kept apart from the rest of society. In more modern times, institutions moved from the ethic of moral treatment to a norm of custodial care as institutional populations steadily increased. Overcrowding and understaffing led to deplorable and squalid conditions.

People with disabilities have definitely come a long way from the treatment they received only 50 or so years ago. But while the horror of institutionalization was over, the fight to provide dignity and respect for all people was not. As Blatt and Kaplan (1966, p. 1) assert, “Indeed, it appears that disabled people [sic] are some of the last people to be engaged in this historical sweep of the struggle for human rights.” Even after the inhumane treatment stopped in institutions, it did not stop in the everyday world.

In the mid-1960s, in the height of the humanization of institutions, the systematic depopulation of state institutions began. Unfortunately, communities were not properly prepared to accept people who had heretofore been set apart from the mainstream of society. People with disabilities were discriminated against everywhere they went in the community because the outside world was not prepared with the facilities, let alone the attitudes needed for them.

Even now that there are fewer institutions and fewer people with disabilities who are institutionalized, there are still disturbing things that happen. In Chapter 3, we will discuss concepts that if used in the development and implementation of recreation services will ensure respect and dignity of people with disabilities.

LEARNING ACTIVITIES

1. Pick a period in history at least 50 years ago. Do some research into that era and try to understand the widely held attitudes and values of the time. Then from the perspective of a reformer of that era, write a newspaper article about the treatment of people with disabilities. Remember not to impose your later 20th century view.

2. Contact your state/province mental health administration on intellectual and developmental disabilities (AIDD). Find out as much as you can about state/province institutions in your state/province. How many are there now? Is the
trend in your state/province to close state/provincial institutions, maintain existing institutions, or to build new ones? What are the timelines for closures or for opening new institutions?

3. Interview your parents about deinstitutionalization. Find out how much they know about the history of institutions and the current trends in your state. See how close their understanding is to what you find out from the state/provincial Mental Health/AIDD.

4. Ask your parents how they would feel if a small group of people with mental illness bought a house and moved into your neighborhood? How would you feel?

REFERENCES


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**ADDITIONAL RESOURCES**


INTRODUCTION

In Chapter 1, we discussed the importance of focusing on the individual with a disability as a person with unique talents and needs. In Chapter 2, we showed how the majority of past treatments and services for people with disabilities were not person-centered, and in fact, were often not even respectful of personhood. Early moves toward institutionalization made initial attempts to recognize the need for more respectful treatment. Similarly, the later move toward deinstitutionalization was driven by advocates who demanded better treatment of people with disabilities. Today, there are federal as well as state and provincial laws that ensure humane, respectful treatment. In Chapter 4, we will highlight key federal legislation. In this chapter, we will describe theories and concepts that we believe are the cornerstones of person-centered recreation service delivery.

The people-first concept of service delivery is crucial for ensuring that recreation services are responsive to individuals with disabilities. In other words, the person-centered approach is all about enhancing quality of life for persons with disabilities. Findings in the Survey of Income and Program Participation: Americans with Disabilities (2010) continue to provide critical evidence of the need to consider quality of life within the
field of disability (N.O.D./Harris, 2004). As with the 2004 Harris Poll, over one-third of Americans with disabilities say that they are satisfied with their life, compared to nearly 80% of nondisabled Americans. For these reasons, quality of life is a concept that has increasingly received attention by people with disabilities, families, and service providers. According to Schalock (1996, p. vii), however, quality of life is a concept that has been around for many years; however, it has gained prominence as we have come to recognize the disparities regarding the quality of life of people with and without disabilities:

. . . and what makes the concept of quality of life so important to our field is our attempt to use this concept as a process and an overriding principle to improve the lives of persons with mental retardation and closely related disabilities.

Quality of life is foundational to the person-centered approach. In many ways, our recognition of the importance of quality of life helps us to understand the essence of the person-centered approach. This is because quality of life is rooted in the person. Schalock (1996) outlines some of the core principles of quality of life for people with disabilities. Those that are most germane to our discussions appear in Table 3.1. The core principles outlined in Table 3.1 provide a useful frame of reference for later chapters in this book that address service delivery issues.

In this chapter, we will discuss several other concepts that are embedded within the dimensions of quality of life discussed by Schalock (1996). The overarching framework of quality of life as well as the concepts of normalization, social role valorization, self-determination, interdependence, and social inclusion provide the conceptual cornerstones for the recreation service delivery system. For the purposes of this text,

*Principles of Quality of Life Central to the Person-Centered Approach*

- **Quality of life** for persons with disabilities is composed of those same factors and relationships that are important to all persons.
- **Quality of life** is experienced when a person’s basic needs are met and when he or she has the same opportunities as anyone else to pursue and achieve goals in the major life settings of home, community, school, and work.
- **Quality of life** is a multidimensional concept that can be consensually validated by a wide range of persons representing a variety of viewpoints of consumers and their families, advocates, professionals, and providers.
- **Quality of life** is enhanced by empowering persons to participate in decisions that affect their lives.
- **Quality of life** is enhanced by the acceptance and full integration of persons in their local communities.
- **Quality of life** is an organizing concept that can be used for a number of purposes, including evaluating those core dimensions associated with a life of quality, providing direction and reference in approaching customer services, and assessing persons’ feelings of satisfaction and well-being. (Adapted from Schalock, 1996)
we will consider the conceptual basis to be defined as the ideals that contribute to the facilitation of recreation opportunities for people with disabilities. The ideals provide something against which to measure our services. In some ways, they can be utilized to ensure service quality. If these ideals are not understood and used as the basis upon which to develop and deliver recreation services, then we contend that the services rendered are not conceptually sound, and thus they do not provide a proper level of consistent, respectful, person-centered services. These ideals are the standard; they are infused both implicitly and explicitly throughout the remainder of this text, so make sure you understand these concepts! The remainder of the chapter will describe the ideals that we feel contribute to the satisfactory provision of recreation services for people with disabilities.

NORMALIZATION

The principle of normalization was first defined by Nirje in a series of papers that he presented during the late 1960s and early 1970s while lecturing across Sweden, the United States, and Canada. This principle has become an internationally influential paradigm that has served as the cornerstone of service delivery for people with disabilities (Howe-Murphy & Charboneau, 1987). In a collection titled The Normalization Principle Papers, Nirje (1992) wrote the following contemporary version of his original definition:

The normalization principle means that you act right when making available to persons with intellectual and other impairments or disabilities patterns of life and conditions of everyday living which are as close as possible to or indeed the same as the regular circumstances and ways of life of their communities. (p. 16)

The attractiveness of Nirje's current definition is that it is written in very basic language. His definition clearly underscores that normalization is a value that should be adopted by all, and all who do not, are not “acting right.” In one of his very early works, Nirje (1969) described in great detail what he meant by patterns of life and conditions of everyday living. In this seminal article, he described normal patterns. However, in a later article, Nirje (1985) indicated that the use of the word normal was misinterpreted over time and should be dropped. Table 3.2 provides a summary of his description of the patterns and conditions of life that are in keeping with the principle of normalization.

Patterns and Life and Conditions of Living

1. Patterns of the day
2. Patterns of the week
3. Patterns of the year
4. Developmental experiences of the life cycle
5. Patterns of economic development
6. Patterns of environmental conditions
7. Sexual patterns of one’s culture
8. Respect for the integrity of the individual
When you think about your daily life, you can identify some basic areas that create a pattern: getting out of bed, going to work, eating in a family situation, and going to bed when you feel tired. Though we do not always value any one of these experiences, we do value the ability to make choices relating to our daily patterns of sleeping, eating, and working. In addition, the opportunity to experience leisure during one's day is extremely important. For example, we may develop a pattern over time where we jog at noon or watch the news before we go to bed. On the other hand, we also value that we can change our patterns of the day when we want to. We may make a decision to go to a movie, which interrupts our usual pattern, yet that provides us with a different type of leisure experience.

It is this type of lifestyle that Nirje suggested should exist for people with disabilities. Unfortunately, all too often these sorts of patterns are not present in the lives of people with disabilities. We have seen many instances where the daily patterns of individuals with disabilities are controlled by service providers rather than the individuals themselves. For example, consider a teenage boy who has an intellectual disability, who lives in a group home, and who wants to go fishing on Saturday afternoon. There is nothing out of the ordinary about a boy going fishing on a Saturday afternoon. But such an option might not be available to this teenager. State or provincial regulations might require a staff member to accompany him on the fishing trip. If the majority of other members of the group home want to go to the mall, then the staff might not be able to accommodate the fishing request. Therefore, the teenage boy might be stuck with only one option and not one that he has chosen. This is the sort of situation that goes against the ideals of normalization.

Patterns of the week and year are similar to our daily patterns. We value having set patterns, while at the same time we also value breaking such patterns. The changing nature of our world has resulted in much less “traditional” daily and weekly patterns for many people. People work at various times during the day and week. Thus, for people with disabilities, having a pattern that is “typical” is hard to achieve. However, as was mentioned earlier, one aspect that has remained over time is the opportunity to control, at least to some extent, what our daily and weekly pattern looks like. The other patterns noted have a similar logic.
Shortly after Nirje presented his original version of the normalization principle, Wolfensberger (1972) provided what he described as a reformulation of the principle. The principle of normalization was defined by Wolfensberger (1972, p. 28) as the “Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible.”

Wolfensberger’s definition has tended to receive greater attention in North America than Nirje’s definition for a variety of reasons, including that he developed an evaluation system based on his definition of normalization called the Program Analysis of Service System (PASS). PASS has been used extensively throughout such countries as the United States, Canada, and Australia. However, Perrin and Nirje (1985) argue that Wolfensberger’s (1972) principle is dramatically different than Nirje’s, and is in fact based on a fundamentally different value base. They present the following as their argument for the differentiation:

Normalization as originally defined is based upon a humanistic, egalitarian value base, emphasizing freedom of choice and the right to self-determination. It emphasizes clearly respect for the individual and his or her right to be different. Wolfensberger (1972, 1980), on the contrary, interprets normalization as specifying various standards of behavior to which a mentally handicapped person must conform. He speaks openly of ‘normalizing’ people through ‘eliciting, shaping, and maintaining normative skills and habits’ (Wolfensberger, 1972, p. 32, 1980, p. 17) or even through the use of force: ‘Normalization measures can be offered in some circumstances and imposed in others.’ (Wolfensberger, 1982, p. 28)

It is important to understand the distinction between these two definitions, because each has quite different implications when applied to recreation service delivery. If one bases service delivery on Nirje’s definition, then the rights of the individual with a disability to freely choose such things as where to participate, with whom, when, how, or whether to participate at all become central concerns.

In contrast, Wolfensberger’s definition clearly suggests that services must be designed in such a way that they facilitate behaviors in individuals with disabilities that are considered normative, and also that the services themselves be normative. Choosing one or the other as a basis for service delivery is less important than ensuring that one understands the implications for each. Though Nirje’s definition is in many ways more attractive, we must understand that society as a whole, and more specifically persons participating in recreation programs, often have expectations about the types of behaviors that are acceptable and/or appropriate.

For example, when one attends an aerobics class, participants expect that others will do such things as follow the leader and not create unnecessary disturbances. These are culturally normative behaviors. Choosing to do otherwise is most often considered taboo. As a result, it is appropriate to consider both definitions when designing and implementing recreation services.

Beyond the fact that there has not been complete agreement on the definition of normalization, some confusion over this term has also arisen; many professionals have
focused on the word “normal” in attempting to understand its application to the recreation service delivery system. It is important to understand that the intent of normalization is not to transform people with disabilities into “normal individuals.” For one thing, defining what a normal individual looks or acts like is impossible. Rather, the principle should be interpreted as a process for facilitating the creation of recreation environments and experiences for people with disabilities that are typical of all people. An additional common misconception related to the normalization principle is that special services are inconsistent with the term. According to Perrin and Nirje (1985), however,

The normalization principle, on the contrary, supports, indeed insists on the provision of whatever services, training, and support are required to permit living conditions and routines similar to that of others in the community. (p. 90)

**SOCIAL ROLE VALORIZATION**

As a result of the misrepresentation/interpretation of the normalization principle, Wolfensberger (1983) reconceptualized the principle into that of the theory of *social role valorization*. In this reconceptualization, he cited the 1977 work of Briggs's dynamic and multifaceted model of self-concept where one's perceptions of self come from interactions with significant others. Conclusions drawn from those interactions, self-attributions, and previous life experiences are influential in his reconceptualization. With this new awareness of self-concept, Wolfensberger (1983) said of people with disabilities:

… the most explicit and highest goal of normalization must be the creation, support, and defense of valued social roles (emphasis added) for people who are at risk of social devaluation. (p. 234)

Social role valorization theory advocates for each individual's right and responsibility to assume a valued social role in society and society's obligation to allow individuals to pursue that role without constraint. The overarching goal of social role valorization is, according to Wolfensberger (1983), achieved by way of the following two sub-goals: 1) enhancement of their social image, and 2) enhancement of their competencies.

Social image is influenced by such things as the following:

- Physical setting
- Relationships and groups
- Activities, programs, and other uses of time
- Language and other symbols and images

Similarly, personal competencies can be enhanced in relation to the following:

- Physical setting
- Relationships and groups
- Activities, programs, and other uses of time

Wolfensberger indicates that image and competency enhancement are generally reciprocally reinforcing. Individuals with high competency generally have a positive image, while those with low competency often are associated with negative images. The
same can be said for images influencing competencies. Most importantly, those with positive images are generally afforded more opportunities and experiences to enhance their competencies.

Rancourt (1990) posed the dilemma and the challenge that social role valorization theory presents to the field of therapeutic recreation. Neither the identification with disability nor leisure are generally socially valued roles. Yet, often people with disabilities have large amounts of time free from normative constraints such as work, which is therefore available for leisure. Rancourt urged therapeutic recreation specialists to “… demonstrate the worth of that which is presently culturally deemed as worthless” (p. 52). By this she means that we must work to facilitate positive images of people with disabilities experiencing leisure. Such images will serve to create positive social roles for people with disabilities.

**SELF-DETERMINATION**

Self-determination is essentially the ability of a person to be autonomous regarding meaningful life choices, and it encompasses activities such as problem solving, decision making, goal setting, self-observation and evaluation, self-management and reinforcement, acquiring an internal locus of control, experiencing positive attributions of efficacy and outcome expectancy, developing a realistic and positive self-image, and self-awareness. Self-determination and decision making have been described as important considerations related to the facilitation of community-based recreation and leisure opportunities for people with disabilities (Brown, 1988; Dattilo & St. Peter, 1991). This is based to some extent on the contemporary definition of leisure, which suggests that choice is a critical regulator for what we do or do not define as leisure (Iso-Ahola, 1980; Neulinger, 1980). Self-determination also grew out of Nirje’s (1972) construction of normalization. He suggested that normalization meant having (among other things he described): “Opportunities to have choices, wishes, and desires taken into consideration and respected” (Nirje, 1976, p. 364).

Self-determination has become a well-recognized priority for people with disabilities. So much so, that in 1988, the U.S. Office of Special Education and Rehabilitative Services (OSERS) began a self-determination initiative to focus on system-wide activities that would promote greater decision making for people with disabilities. During these past decades, a number of definitions and conceptualizations have been proposed for self-determination. Wehmeyer (1994) suggests that there have been two primary conceptualizations of self-determination, as a motivational construct, and an empowerment issue. Those that promote self-determination as an empowerment issue portray self-determination as both a means toward empowerment and an illustration of the existence of empowerment (Kennedy, 1996; Ward, 1996). Making decisions and speaking out for oneself are examples of self-determining behaviors that lead to a greater sense of empowerment but are at the same time illustrations of empowerment. Self-determination has also appeared in the motivation literature as an internal need that contributes to a person’s performance of intrinsically motivated behaviors. In addition to these two conceptualizations, Wehmeyer argues for the appropriateness of viewing self-determi-
nation as an educational outcome, which is defined according to the characteristics of actions or events (Marks, 2008; Wehmeyer, Palmer, Soukup, & Garner, 2008).

The American Institute for Research (1993) identified the process necessary for being self-determined. The process is illustrated in Table 3.3. As you can see from this table, the process of being self-determined includes the opportunity not only to make decisions about the course of one’s life but also to take actions based on those decisions. Also, the opportunity to evaluate the results of actions and adjust future decisions accordingly is given as well. The last two steps in the process are particularly important. All too often, we help people with disabilities to make decisions and even to carry them out. However, we will often do one of two things that disallow them from experiencing these last two steps. The first thing is not allowing people with disabilities to make bad decisions. This is due to the strong need we often feel to protect people with disabilities from experiencing failure. However, by not allowing a person to make a bad decision, we negate his opportunity to evaluate the outcome of the decision, decide whether he felt the decision was bad, and therefore possibly alter future decisions. Secondly, if we have allowed a person to make a bad decision, we are often too quick to jump in and tell her why we thought the decision was bad in the first place and how she should change it in the future so as not to experience such an outcome again. Both of these work against a person becoming truly self-determining.

Process of Being Self-Determined

1. Identify and express one’s own needs, interests, and abilities.
2. Set expectations and goals to meet one’s needs and interests.
3. Make choices and plans to meet goals and expectations.
4. Take action to complete plans.
5. Evaluate results of actions.
6. Adjust plans and actions, if necessary, to meet goals more effectively.

When we present this concept in class, our students often challenge us on this point, suggesting a need for guided democracy. When this happens, Mike often tells a story about a situation he experienced in a study he conducted a few years ago. Consider Case Example 3.1.

This short case example illustrates the need to let the self-determination process follow its own course, so that the individual is able to make decisions for him/herself. If the TRS had pushed Liz to abandon her desire to show jump, Liz might not have been satisfied and would never have felt truly self-determined. Many people have argued that self-determination and decision making should be incorporated into as many developmental experiences as possible for people with disabilities because they have historically had little opportunity to exercise choice within their lives, and as a result of a lack of practice, have a difficult time making decisions related to the use of their leisure time (Dattilo & St. Peter, 1991).

Dattilo (1986) has demonstrated that people with severe intellectual disabilities are capable of making choices regarding leisure activities, and that such choices can
The leisure education study was conceptually grounded in self-determination. Liz, who was a participant in a leisure education study, expressed a desire to take up horseback riding. Liz happened to have a severe multiple disability, used an electric wheelchair, and had little motor control. When Liz first expressed this goal, the therapeutic recreation specialist (TRS) talked to her about a riding program—which was specifically for people with disabilities—that was available in her community and that could well meet her needs. Liz refused to participate in this program, saying that she wanted to be a part of “show jumping.” The TRS was at a loss as to how to help Liz facilitate her goal. The TRS felt certain that Liz’s level of disability would prevent her from show jumping. She did not want to disallow Liz’s decision, but at the same time, she didn’t want Liz to fail. The TRS decided to take Liz to a local horse club and show her the facility and then see what happened. Once Liz arrived at the facility and had watched the riders for a while, she informed the TRS that she had never been to such a facility before, and that now that she was there and had seen the riders in action, she did not want to try show jumping. Eventually, a schedule was worked out that allowed Liz to visit the horse club once a week to watch and to help groom the horses, and later she began a highly structured and supervised riding program.

be assessed in a consistent fashion. Research by Mahon (1994) and Mahon and Bullock (1992), which used the Decision Making in Leisure (DML) Model (Mahon, 1990), showed that by using self-control techniques, decision making could be taught to people with intellectual disabilities. That seminal work laid the groundwork for many of the moves toward inclusion of people with disabilities that we see today.

Self-determined behavior is reflected not only in making decisions but also in carrying out such decisions. Independent planning and initiation are important skills related to self-determination. Few studies have been conducted within the field of recreation
and leisure related to independent leisure initiation by people with intellectual disabilities. In one of the few studies, Mahon (1994) found that planning and initiation skills could be facilitated through the use of self-monitoring. Table 3.4 provides a list of keys for enhancing self-determination for people with disabilities within the context of leisure.

**Keys for Enhancing Self-Determination**

1. Teach decision-making skills that include setting goals, weighing options, identifying resources and supports, identifying consequences, and solving problems.
2. Provide opportunities for choice making across environments—schools, homes, community.
3. Identify and establish with the individual the necessary and appropriate supports.
4. Provide opportunities for challenge and success.
5. Project belief in a person's ability to succeed as well as in the person's ability to survive failure.
6. Allow individuals the opportunity to take risks.
7. Allow individuals the opportunity to make mistakes and/or fail and to learn from those mistakes.
8. Provide specific, positive feedback to facilitate self-awareness, confidence, and self-efficacy.
9. Allow the individual to accept and take responsibility for his decisions and actions.
10. Provide environments that are accessible and promote individuals’ utilization of strengths and abilities.
11. Offer reinforcement and acknowledgment of efforts and process of achieving goals.

**INTERDEPENDENCE**

As we have suggested, self-determination is an important concept relative to facilitating the leisure needs of people with disabilities. In a discussion of the relationship between autonomy and disability, Christopher Robertson (2001) encourages us to re-examine the too-readily accepted idea that autonomy should be the goal of life. Importantly, he reminds us that we are all more dependent on others, and on interdependence, than we are willing to acknowledge. Condeluci (1995) says similarly that a state of interdependence between people with and without disabilities is most conducive to facilitating social inclusion and quality of life. Interdependence focuses on relationships that lead to a mutual acceptance and respect between people with and without disabilities. Interdependence is only achieved by those who are independent. Covey (1989) describes interdependence in this way:

Interdependence is a choice only independent people can make. Dependent people cannot choose to become interdependent. They don’t have the character to
do it; they don't own enough of themselves. … As you become truly interdepen-
dent, you have the foundation for effective interdependence. (p. 3)

Thus, according to Covey, self-determination is a precursor to interdependence. If 
an individual is self-determined and independent, he is capable of being interdepen-
dent.

Why do we want people with disabilities to be interdependent? Most of what has 
been written in the field of disability during the past decade has emphasized the need to 
facilitate self-determination and independence in people with disabilities. Most have ar-
gued that people without disabilities (often parents, institutional staff, etc.) have had far 
too much control over people with disabilities, and we must work to sever such control. 
Schoeller (1993, 1994) suggests that our brain, our spirit, our emotions, our psyche, and 
our sexuality all function better in social interaction than in isolation. Positive interac-
tion, facilitated through an interdependent relationship, can in fact allow people to ex-
perience more choices and opportunities, leading to a determined spirit. Nevertheless, 
we must ensure that the individual with a disability, who represents one person in an 
interdependent relationship, is a valued and contributing member of the relationship.

Condeluci (p. 93) identifies actions of the interdependent paradigm that “are de-
signed to promote and empower the people to take more charge of their life.” These 
actions are depicted in Table 3.5. The first action identified by Condeluci is similar to 
the first component of the self-determination process (i.e., identify and express one's 
own needs, interests, and abilities). Condeluci suggests that most often the first action 
is facilitated by people with disabilities being listened to. If we think about Liz in Case 
Example 3.1, we notice that Liz and the TRS started to move toward an interdependent 
paradigm once the TRS decided to respect Liz’s decision about show jumping.

*Actions of the Interdependent Paradigm*

1. Allow the consumer to define the problem
2. Focus on capacities
3. Establish the importance of relationships
4. Develop supports
5. Recognize system change

Relationships are a cornerstone of interdependence. Relationships need to be based 
on the norm of reciprocity. Also important is that relationships are based on the in-
terest of each person in each other. In the field of recreation, much interest has arisen 
in the facilitation of friendships between people with and without disabilities (Heyne, 
Schleien, & McAvoy, 1993). This interest has grown from the fact that often people with 
disabilities have few friends and very small social support networks. It is crucial that any 
focus on friendship development be framed within the interdependence paradigm and 
the norm of reciprocity. Condeluci (1995) supports the following:

To achieve interdependence mandates that we understand the reasons why friendships break up after injury, or for the person with a congenital defect, rarely form in the first place. Then we need to turn our attention to the ways whereby people can have the opportunity to forge new acquaintances that can mature over time. (p. 98)

Closely connected to the issue of relationships is that of natural supports. There is a strong need to identify situations where it makes sense to create supports in the environment that enable people with disabilities to reach given goals. Though at first glance this may seem to be in opposition to the concept of self-determination, it is not. People with disabilities must be given the opportunity to decide when and if they would like to be supported.

In relation to the issue of supports, we need to recognize that very often natural supports (versus paid) can be developed within the community to help individuals achieve goals. A colleague recently told us about a beautiful example of natural supports within recreation. In a retirement planning meeting with John, an older adult who has a developmental disability, John and the facilitator were exploring John’s options for retirement. John lives in a rural setting and indicated that he “just wanted to go fishing.” The two were having some difficulty figuring out how John could fish regularly because John could not drive and the river was two miles out of town. One evening, the facilitator was talking to a friend who told him that his dad (Larry) had retired recently and had taken up fishing with a vengeance, something he had always wanted to do. The light came on for the facilitator. Today, John and Larry go fishing three or four times a week, enjoy each other’s company, and are catching lots of fish. This is natural support at its best!

The final action of the interdependent paradigm is system change. This action recognizes that systems such as the traditional medical model and others within the expert paradigm have created many constraints for people with disabilities. They have led to the creation of delivery systems that are more responsive to the needs of professionals than people with disabilities. As Condeluci (1995) points out, the most dramatic example of systems change is the Americans with Disabilities Act. Within the field of recreation, we must begin to recognize that our systems of service delivery often do not facilitate interdependence. We have worked within an expert system where the professional decides what is best for individuals with disabilities and also whether and when an individual is able to or capable of controlling her leisure experiences.

We have begun to recognize the need to allow individuals to become more self-determining in leisure. However, in order that we function more within an interdependent paradigm and move away from an expert paradigm and move away from an expert paradigm, we must begin to listen to people with disabilities and restructure our systems so that they are indeed designed to foster the actions inherent in the interdependent paradigm and, therefore, are person-centered.

**INCLUSION**

Integration, mainstreaming, and inclusion have been some of the different concepts used to help people with disabilities gain access to recreation, education, work, and life opportunities. Integrating people with disabilities into community life is important for...
people with disabilities, their families, community support personnel, and policy makers. Mainstreaming and integration are older terms and have been defined by a number of authors (Bullock, 1979; Hutchinson & McGill, 1992; Nirje, 1985; Wolfensberger, 1972). The two terms are relatively synonymous, as they are most commonly used, even though they are not commonly used in the disability field today. Both mainstreaming and integration are commonly accepted as a process that consists of both the physical presence of people with disabilities in settings where people without disabilities are typically present and participation in social interactions and relationships between people with and without disabilities in typical settings (Wolfensberger & Thomas, 1983).

Today, we seldom use the words *mainstreaming* and *integration*. We use *inclusion* instead. The operationalization of inclusion goes beyond the common conceptions of mainstreaming and integration. Inclusion provides opportunities for a participant to choose to be with her peers in the regular setting and also provides the supports and accommodations needed to ensure personally satisfying and valued participation. Pearpoint and Forest (2008) state that “*Inclusion* is a wonderful word. It is about embracing humanity and figuring out how we are going to live WITH one another in the challenging years to come” (p. 1). They continue:

Inclusion means inclusion! It means affiliation, combination, comprisal, enclosure, involvement, surrounding. It means WITH. … Inclusion means BEING WITH one another and caring for one another. It means inviting parents, students, and community members to be a part of a new culture, a new reality. Inclusion means joining with new and exciting educational concepts (cooperative education, adult education, whole language, computer technology, critical thinking). Inclusion means inviting those who have been left out (in any way) to come in, and asking them to help design new systems that encourage every person to participate to the fullness of their capacity—as partners and as members. (p. 1)
Many years ago, Mike was involved with three adults with mental disabilities who liked to bowl. They were a part of a local Special Olympics bowling program, were all excellent bowlers, and expressed an interest in trying out other bowling programs. Mike helped them to connect with a local bowling program that had never included people with disabilities. Mike was extremely excited about this new initiative and considered it to be quite “cutting edge.” A few months later, the three bowlers came back to see Mike and told him that they were quitting the new program. Aghast, Mike asked why. They told him that they were not having any fun; they were never asked to join any of the other bowlers for a beer, and no one spoke to them much. They wanted to rejoin their friends and the Special Olympics program. Mike saw his “model program” crumbling before his eyes. He tried to convince the three bowlers to keep at it and indicated that he would help them to become more connected, but sadly, it was too late. Many years later, when we reflect on this story, we recognize that Mike had assumed that by physically integrating the bowlers into a program, that they would be welcomed by and included into the program by those already in that setting. He learned the hard way that this is just not the case. They had been “integrated” but not included!

From the above example, it is clear that inclusion means not only physical co-presence, but also social co-involvement, sometimes in the literature called social integration. Lord and Pedlar (1991, p. 217) suggested, “in the community does not mean of the community.” The social aspect of inclusion, the extent to which people are included in social networks, is arguably the more significant aspect of inclusion. Integral to social integration is the belief that “being of the community” positively influences the life quality of individuals with a disability. In fact, social integration is recognized as one of the core dimensions that contribute to quality of life (Schalock, 1996; Wehmeyer & Schwartz, 1998).

Many have argued that people with disabilities continue to struggle to be part of the social fabric of their communities; to be socially included (Ralph & Usher, 1995). Implicit in this argument is a definition and understanding of social inclusion that is rooted in the knowledge and opinions of researchers, service professionals, and other individuals who work in support of people with a disability. Consequently, a number of researchers have criticized this body of knowledge because of its failure to include the perspectives of individuals with a disability. For example, Biklen and Moseley (1988) argued that researchers are “outsiders” who “cannot take for granted the views or positions of insiders (people with a mental disability) ... but must formulate enhanced understanding by directly studying the perspectives of “insiders” (p. 155).

Forest and Pearpoint (2008) believe that people with disabilities and service providers or advocates face at least three barriers to effective inclusion. They state that the effectiveness of inclusion is impacted by what they call “the three monsters”: fear, control, and change. It is a fear of failure on our part rather than the fear of the people to be included. It is accepting “that ‘I’ don’t have all the answers—that ‘I’ am not in total control” and being able to ask others, including those being served, to share control. It is realizing that “Inclusion is the beginning of change” (p. 2).

As we discussed earlier, many agencies have been very successful in physically integrating individuals with disabilities, but much less successful at social inclusion. This
has led many to search for a means of achieving social inclusion in more meaningful ways. The introduction of the term *inclusion* served notice that there is dissatisfaction with the extent to which people with disabilities have become a part of their communities. Inclusion gives people equal opportunity to grow and develop to their fullest potential. The fundamental principle of inclusion is the valuing of diversity within the human community. When inclusion is fully embraced, we abandon the idea that children or adults have to become “normal” in order to contribute to the world. Inclusion is about programs that embrace differences, where all people have their needs met, where people learn to live with one another, and where basic values are important to each child, not just to some of the children (Strully, 1990, p. 26).

As we discussed in Chapter 1, language has tremendous impact on action. Our feeling is that the movement toward the term *inclusion* gives more attention to some key areas not yet dealt with successfully; those areas include the cultivation of friendships, the development of natural supports in the community, and related things that are necessary for a person to be reciprocally and mutually accepted in, and connected to, his community.

**CONCLUSION**

We have discussed what we believe to be the key cornerstones to service delivery within the fields of recreation and therapeutic recreation. We believe that the concepts of normalization, social role valorization, self-determination, interdependence, and inclusion provide important ideals for recreation-based programs. Throughout this chapter, we have given some examples of how these concepts specifically relate to recreation.

This chapter will serve as a basis for other chapters within the book. Throughout, you will read numerous examples of how adherence to these ideals serves to create programs and services responsive to the needs of people with disabilities. As we have just discussed in relation to the concepts of inclusion, we should never be satisfied with our present ideals. We should always strive to create new ideals or retool existing ones so as to continue to improve the lives of people with disabilities. Chapter 4 will discuss legislation that has been introduced over the years to create self-determined, inclusive opportunities for people with disabilities.

**LEARNING ACTIVITIES**

1. Think of as many words as you can that reflect the concepts of normalization, inclusion, self-determination, and interdependence.

2. James lives in a group home with five other adults. In his spare time, he participates in Special Olympics; he also enjoys going to movies and to a local pub from time to time. Discuss what aspects of this scenario are consistent/inconsistent with the social psychological concepts presented in this chapter. For those that are inconsistent, how might they be altered to become more consistent?
3. Do a time log for a few days. Record everything that you do from when you wake up until you go to bed. How much of your day is spent in activities that are dependent (you dependent upon another person), independent, or interdependent?

4. How would your life change if you were not allowed to make choices for yourself?

REFERENCES


INTRODUCTION

Relatively few federal laws related to the treatment or well-being of people with disabilities were passed prior to World War II. Those that did exist were intended to address the needs of war veterans with service-connected disabilities. This meant that for most of North America’s history, schools, businesses, recreation and parks agencies, and other public entities were allowed to, and often did, exclude children and adults with disabilities.

The first federal laws in the United States designed to assist individuals with disabilities date back to 1798, when the Fifth Congress of the United States passed the first federal law concerned with the care of people with disabilities (Braddock, 1987). This first law authorized a Marine Hospital service (which became known as the United States Public Health Service in 1912) to provide medical services to sick and disabled seamen. There was actually very little legislation passed between that time and the 1960s. Since the 1960s, however, a lot of federal legislation has been passed in the United States and in Canada that relates directly to individuals with disabilities. As a result, today people with disabilities have accomplished
more than was ever dreamed possible—due to more and better programs, better trained professionals, continuous research, information dissemination, and technical assistance—much of which is the direct result of federal and state/provincial legislation.

To provide the best possible services to all people, we must understand not only what has happened to people with disabilities historically but also what has happened and is happening recently and currently. Many recreation professionals have little knowledge about these laws, even though knowledge of disability law will help recreation professionals understand the entire service delivery system, can ensure the protection of civil rights, and can improve collaboration with other agencies and families. In this chapter, we will give a general overview of major disability laws, giving specific attention to how they relate to recreation facilities and programs.

**CURRENT U.S. LAWS AFFECTING PEOPLE WITH DISABILITIES**

Although there have been many state and federal laws that have included disability-related issues, the rights of individuals with disabilities in the United States have been most significantly strengthened by the passage of six federal laws and their subsequent periodic amendments and reauthorizations. By far, the most important disability law in the United States is the Americans with Disabilities Act (ADA). In a sense, the ADA is a tightened version of all of the laws that preceded it. That is not to say that the earlier laws have been subsumed under the ADA. Rather, the earlier laws pointed to a need for a “master law” that includes many of the pieces of earlier laws. Conversely, the earlier laws have changed their language and foci to be consistent and compliant with the ADA. Let’s first review the ADA and then we’ll look at five of the earlier laws that paved the way for the ADA. These U.S. laws we will review are:

1. PL 101-336, the Americans with Disabilities Act of 1990
2. PL 90-480, the Architectural Barriers Act of 1968
3. PL 93-112, the Rehabilitation Act of 1973
4. PL 94-142, the Education of All Handicapped Children Act of 1975
5. PL 100-146, the Developmental Disabilities and Bill of Rights Act Amendment of 1987
6. PL 100-407, the Technology-Related Assistance for Individuals for Disabilities Act of 1988

These six laws, and their subsequent reauthorizations, form the core of protection against discrimination and guarantees of equal opportunity that individuals with disabilities have in the United States. Because these laws are so important to ensuring the rights of those with disabilities, you should become familiar with both the laws and their regulations. Each law is described in some detail in the following sections.
PL 101-336, the Americans with Disabilities Act of 1990

The Americans with Disabilities Act (ADA) was signed into law by President George Bush on July 26, 1990. The ADA has been referred to as the 20th century emancipation proclamation for individuals with disabilities. The central purpose of this act is to extend to individuals with disabilities civil rights protections similar to those provided to individuals on the basis of race, sex, national origin, and religion. Based on the concepts of the Rehabilitation Act of 1973 and other laws discussed later in this chapter, the ADA guarantees equal opportunity for individuals with disabilities in employment, public accommodation, transportation, state and local government services, and telecommunications. The Americans with Disabilities Act (ADA) is a comprehensive civil rights law intended to eliminate discrimination against people with disabilities in all aspects of American life. It is the most significant federal law in the U.S. assuring the full civil rights of all individuals with disabilities. The following overview will include each of the key sections and a brief description of enforcement methods.

**Title I: Employment.** Any employer of 25 or more people is prohibited from discriminating on the basis of disability against a “qualified individual with a disability” in any aspect of employment—advertising, recruiting, hiring, training, promoting, and discharge. Employers should develop a job analysis to determine the essential functions of each job. When an individual with a disability meets legitimate educational, skill, and experience qualifications for a position, and can perform the essential functions of a job, the employer must make a reasonable accommodation. Reasonable accommodations include, but are not limited to, reassignment of nonessential tasks, providing auxiliary aids or services, removing architectural barriers in the workplace, changing the individuals’ work schedule, permitting supplemental unpaid leave, or reassignment of an employee to a vacant position. This, of course, includes employment in recreation and therapeutic recreation settings. Title I employment complaints are enforced by the Equal Employment Opportunity Commission.

**Title IIA: Government Services.** Any unit of state or local government, or any extension or instrument thereof, is prohibited from discriminating on the basis of disability in the provision of state or local government services against an individual who, with or without a reasonable accommodation, meets essential eligibility requirements for receipt of that service. State and local government services are broadly interpreted to include every program, service, and activity of such an entity. A reasonable accommodation shall include, but is not limited to, the changing of rules, policies, and practices; the removal of architectural, transportation, and communication barriers; and the provision of auxiliary aids and services. Units of local government must conduct an ongoing self-analysis to identify discriminatory practices and barriers and shall remove all barriers as soon as possible after detection. Title IIA is particularly important to recreation professionals who work in state, county, or municipal parks and recreation departments. Title IIA complaints against units of local government can take three routes. First, complaints may be filed with the municipality or state for internal resolution.
Second, complaints may be filed with the U.S. Department of Justice or a designated federal agency, such as the Department of Interior. Or third, a lawsuit may be filed in federal court.

**Title IIB: Public Transit.** State and local governments that operate public transit systems may not discriminate on the basis of disability in the provision of these services. Public transit includes fixed route systems, demand responsive systems, para-transit systems, and rapid rail systems. Certain requirements are phased in over a period of time because of the anticipated difficulty in funding massive structural changes. The most significant requirement that is still being completed is the requirement that key rail stations must be accessible not later than July 26, 2020. Title IIB complaints must be filed with the U.S. Department of Transportation. Or, a lawsuit may be filed in federal court.

**Title III: Public Accommodations.** A place of public accommodations is a private establishment (for profit or not for profit) that provides goods, services, or facilities; examples include hotels, restaurants, theaters, banks, stores, and health clubs. Public accommodations may not discriminate against qualified individuals with disabilities from participating in, or benefiting from, full and equal enjoyment of the services, goods, facilities, and advantages provided by that entity. Reasonable accommodations include, but are not limited to, changing rules or practices; the removal of architectural or communication barriers; and the provision of auxiliary aids or services. Where the removal of a barrier will require structural change, removal must be readily achievable. If not, alternative methods of accommodation must be considered. New construction must be readily accessible to, and, usable by, individuals with disabilities. Title III complaints may be filed with the Department of Justice, or complainants may file a lawsuit in federal court.

**Title IV: Telecommunications.** Telephone companies must provide telecommunications relay services for people with hearing impairments and people with speech impairments all day, every day, with no restrictions on the number and length of calls made. Title IV complaints may be filed with the Federal Communications Commission. The implementation of the ADA through these new federal rules has produced a fundamental and dramatic shift in the way in which America perceives and values people with disabilities.
There have been no recent significant changes to the ADA, although it has a profound influence on opportunities for people with disabilities. For additional information and answers to questions regarding the ADA, contact the U.S. Department of Justice, Civil Rights Division, Coordination and Review Section, P.O. Box 6618, Washington, D.C. 20035-6189. Telephone: (Voice) (202) 514-0301 and (TDD) (202) 514-0381-83, 11 a.m. to 4 p.m. Eastern time. Every state has an ADA coordinator. Additional information can be obtained from your state's ADA coordinator, usually housed in the state's capital.

**PL 90-480, the Architectural Barriers Act of 1968**

The Architectural Barriers Act (ABA) of 1968, enacted August 12, 1968, by President Lyndon Johnson, was one of the first efforts to ensure that federally funded buildings and facilities are designed and constructed to be accessible to people with disabilities. The law requires that facilities are designed, built, altered, or leased with funds supplied by the United States Federal Government be accessible to people with disabilities. Facilities that predate the law generally are not covered, but alterations or leases undertaken after the law took effect can trigger coverage under the ABA.

The General Services Administration is the federal agency that establishes and enforces standards for design, construction, and alteration of particular types of buildings and facilities which primarily affect public recreation facilities. Recreation professionals will refer to the GSA's Uniform Federal Accessibility Standards (UFAS) when assessing building design. Indoor facility standards can be found in sections 4.1.1–4.3.4 of the UFAS guideline. They dictate a multitude of building codes, such as curb ramp inclines, access routes, space allowance and reach in doorways, and even bathroom sink heights.

The ABA paved the way for ADA to exist. Today, accessibility for people with disabilities has transformed into a concept even more far-reaching—universal accessibility, meaning that features that benefit people with disabilities also benefit all people regardless of ability. Curb cuts into sidewalks were created with the intention to make it possible for people in wheelchairs to get onto the sidewalks and streets safely. But curb cuts are seen as an example of universal accessibility because they also benefit bicycle riders, skateboarders, par-
ентs pushing baby strollers, people who can walk but have trouble with steps, and a lot of other people without disabilities.

The ABA guidelines originally only related to buildings and spaces that are federal or funded by federal grants or money. Achieving accessibility in outdoor environments has long been a source of inquiry due to challenges and constraints posed by terrain, the degree of development, construction practices and materials, and other factors. In May 2014, the Access Board (the federal board that is tasked with ensuring ongoing accessibility compliance), in coordination with the National Park Service and the National Forest Service, issued requirements that are now part of the Architectural Barriers Act (ABA) Accessibility Standards and apply to national parks and other outdoor areas developed by the federal government. They do not apply to outdoor areas developed with federal grants or loans, nor do they apply to nonfederal lands and spaces. The new provisions address access to trails, picnic and camping areas, viewing areas, beach access routes, and other components of outdoor developed areas on federal sites when newly built or altered. Exceptions are situations where terrain and other factors make compliance impractical. These requirements are located in sections F201.4, F216.3, F244 to F248, and 1011 to 1019 of the ABA Standards. The Access Board is in the process of developing guidelines for nonfederal outdoor sites covered by the Americans with Disabilities Act (ADA) and areas developed with federal grants and loans covered by the ABA.


The most significant federal law in the U.S. prior to the ADA was the Rehabilitation Act of 1973, usually called the “Rehab Act.” There are a number of sections of the Rehab Act. This law grew out of and strengthened earlier acts, including PL 90-480, the Architectural Barriers Act of 1968, and the Vocational Rehabilitation Act of 1962. Among other things, the Rehab Act provides funds for vocational rehabilitation and independent living services. However, the most noteworthy part of the Rehab Act is that it addresses discrimination against people with disabilities. As such, it is the first major piece of civil rights legislation in the U.S. that relates specifically to people with disabilities. The law has different sections that refer to different areas of discrimination. They include the following:

- Section 501: Employment
- Section 502: Architectural and Transportation Barriers Compliance Board
- Section 503: Employment under federal contract
- Section 504: Nondiscrimination under federally funded programs

The most important section was and continues to be Section 504, often called the nondiscrimination section. Even today, Section 504 provides individuals with disabilities with basic civil rights protection against discrimination in federal programs. The law states that:

no otherwise qualified handicapped individual in the United States shall, solely by reason of his (her) handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.
To be eligible for the protection under Section 504 (and under the ADA), an individual must meet the definition of a handicapped person. This definition includes any person who

1. has a physical or mental impairment that substantially limits one or more of such person’s major life activities,
2. has a record of such impairment, or
3. is regarded as having such an impairment.

Major life activities include self-care, performing manual tasks, seeing, hearing, speaking, breathing, learning, and walking. Section 504 covers only those people with disabilities who would otherwise be qualified to participate and benefit from the programs or other activities receiving federal financial assistance.

Section 504 assures equal opportunities for people with disabilities in programs receiving federal funds—municipal and county recreation departments, YM/YWCAs, state institutions, colleges and universities, hospitals and clinics, and public and private groups of all kinds that receive any federal financial assistance. Agencies that discriminate face the loss of federal funds.

Recreation remains specifically mentioned in the most recent reauthorization as an important part of the rehabilitation process. Practitioners in recreation and therapeutic recreation are empowered to ensure that recreation is utilized to the fullest extent to enhance the quality of life and rehabilitation of all people. The most notable addition in reauthorizations of the Rehab Act was the change to the use of people-first language in place of demeaning language that had been used previously within the wording of the Rehab Act.

To learn more about the precise nature of this act, including the sections not described here, how to file a discrimination complaint, or to obtain a copy of the Rehab Act’s regulations, go to the U.S. Department of Education, Office of Civil Rights, Operations Support Service and Technical Assistance Branch, 330 C St., S.W., Room 5431, Washington, D.C. 20202.

**PL 94-142, the Education for All Handicapped Children Act of 1975**

Although there existed some early special education legislation, nothing before compared to the Education for All Handicapped Children Act of 1975 (EHA). This law was passed in 1975 and went into effect in October of 1977 when the regulations were finalized. Ballard, Ramirez, and Zantal-Weiner (1987) summarize the major purposes of PL 94-142:

To guarantee that a free appropriate education, including special education and related service programming, is available to children and youth with disabilities who require it.

To assure that the rights of children and youth with disabilities and their parents or guardians are protected (e.g., fairness, appropriateness, and due process in decision making about providing special education and related services to children and youth with disabilities).
To assess and assure the effectiveness of special education at all levels of government.

To financially assist the efforts of state and local governments in providing full education opportunities to all children and youth with disabilities through the use of federal funds.

Of particular importance to recreation and therapeutic recreation is the related service provision that legitimizes recreation as an important augmentation to special education services. Related services are defined in the law as:

developmental, corrective, and other supportive services may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children.

Bullock and Johnson (1998) list the related services specifically identified in the law:

- audiology
- psychological services
- counseling services
- recreation
- medical services for diagnostic or evaluation purposes
- rehabilitation counseling
- occupational therapy
- school work services in schools
- parent counseling and training
- speech pathology
- physical therapy
- transportation
Recreation as a related service for students with disabilities must be administered in a manner consistent with other related educational services. As a related service, recreation assists, augments, and enhances the educational process. Recreation and leisure are essential parts of a total education (Bullock, Morris, Mahon, & Jones, 1992). Recreation is further defined in the regulations of the law as having four components:

- Assessment of recreation and leisure functioning
- Leisure education
- Therapeutic recreation
- Recreation in school and community agencies

Any child with a disability is entitled to a free and appropriate public education. In addition to special education, the child may receive any of the additional related services, including recreation, as long as the services assist a child with a disability to benefit from special education. It also must be specifically identified and written into the child’s Individual Education Program (IEP). Although parents and teachers work together on writing the child’s IEP, often recreation is not included because it is not readily recognized as a related service. Efforts in many states, with New Mexico as the clear leader, are increasingly including recreation as a related service to assist students to benefit from their education.

As a result of this inclusion of recreation as a related service, recreation has been statutorily validated as an important part of the education process. Funds authorized by this law have been used to train graduate and undergraduate students to work as related service personnel, to conduct research into the efficacy of this related services, and to conduct special projects.

In October 1990, President Bush signed into law the Education for all Handicapped Children Act Amendments of 1990, PL 101-476. The new law has resulted in some significant changes. For example, the name of the law, the Education for all Handicapped Children Act (EHA), was changed to Individuals with Disabilities Education Act (IDEA), to be consistent with people-first and respectful language. Many of the discretionary programs authorized under the law were expanded. Some new discretionary programs, including special programs on transition, a new program to improve services for children and youth with serious emotional disturbance, and a research and information dissemination program on attention deficit disorder were created. These additions represent a significant opportunity for therapeutic recreation to become more involved in a variety of discretionary programs. Services and rights were expanded to more fully include children with autism and traumatic brain injury. In addition, the law now includes both transition and assistive technology services as new elements of special education services that must be included in a student’s IEP. In other authorizations of IDEA, children with disabilities must have access to the regular curriculum, and the Individualized Education Program (IEP) must relate more clearly to the general curriculum that children in regular classrooms receive. The IDEA states:

The IEP now must include the following:

- A statement of measurable annual goals, including benchmarks or short-term objectives related to meeting the child’s needs that result from the child’s disability to enable the child to be involved in and progress in the general curriculum; and

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- An explanation of the extent, if any, to which the child will not participate with nondisabled children in the regular class.

In developing an IEP, the bill requires that the IEP team consider the strengths of the child and the concerns of the parents for enhancing the education of the child. In cases where the child is receiving related services, the related services personnel should be included on the IEP team to ensure the most efficient implementation of the plan. The bill also requires that the IEP team consider the need for assistive technology devices and services when developing the IEP. Now IDEA provides higher expectations and significantly improved student achievement for children with disabilities.

PL 100-146, the Developmental Disabilities and Bill of Rights Act Amendment of 1987

The original law, the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, PL 88-164, which includes a Bill of Rights section for people with developmental disabilities, was amended in 1987. People covered under this law now include not only those with intellectual disabilities but also those with autism, cerebral palsy, epilepsy, and other disabling conditions as defined in the act. The term developmental disability, as defined in the act, means the following:

… a severe, chronic disability of a person that

1. is attributable to a mental or physical impairment or combination of mental or physical impairments;
2. is manifested before the person attains age twenty-two;
3. is likely to continue indefinitely;
4. results in substantial functional limitations in three or more of the following areas of major life activity: a) self-care, b) receptive and expressive language, c) learning, d) mobility, e) self-direction, f) capacity for independent living, or g) economic sufficiency; and
5. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated.

Each state or province may have a more inclusive definition of developmental disabilities, yet a definition should be at least as inclusive as the federal law. The act mandates the establishment and operation of a federal interagency committee to plan for and coordinate activities related to people with developmental disabilities. This federal agency is the Administration on Developmental Disabilities and is often referred to as ADD.

All services provided under this law must be aimed at providing opportunities and assistance for people with developmental disabilities to enable them to “achieve their maximum potential through increased independence, productivity, and integration into the community.”

The purpose of the Developmental Disabilities Act is to assure that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports, and other assistance and opportunities that promote independence, productivity, and inclusion into the community. The inclusion
of “self-determination,” in a recent reauthorization of the DD Act as one of the priority areas is significant since it is one of the conceptual cornerstones of person-centered services discussed in the previous chapter. This concept is now infused throughout the entire law. It is extremely important that recreation and therapeutic recreation professionals be aware of the DD Act because of the importance of recreation in enhancing the quality of life of people with developmental disabilities.


**PL 100-407, the Technology-Related Assistance for Individuals with Disabilities Act of 1988**

Commonly referred to as the Tech Act and signed into law by President Reagan in August 1988, this was the first federal legislation with the sole purpose of expanding the availability of assistive technology services and devices to individuals with disabilities. The law is a systems change initiative enacted to increase access to assistive technology for individuals with disabilities, including the promotion of access to financing. Its three purposes are as follows:

1. To provide financial assistance to the states to help each state develop and implement a consumer-responsive statewide program of technology-related assistance for individuals of all ages with disabilities.
2. To identify federal policies that facilitate payment for assistive technology and those that impede such payment and to eliminate inappropriate barriers to such payment.
3. To enhance the ability of the federal government to provide the states with technical assistance, information, training, public awareness programs, and funding for model demonstration and innovation projects.

The legislation was enacted in recognition that for:

… individuals with disabilities, assistive technology is a necessity that enables them to engage in or perform many tasks (and) to have greater control over their own lives; participate in and contribute more fully to activities in their home, school, and work environments, and in their communities; interact to a greater extent with nondisabled individuals; and otherwise benefit from opportunities that are taken for granted by individuals who do not have disabilities.

The act also references underserved groups, defined as any group of individuals with disabilities who, because of disability, place of residence, geographic location, age, race, sex, or socioeconomic status, have not historically sought, been eligible for, or received technology-related assistance.

A comprehensive definition of assistive technology is used to include services that help individuals select, acquire, and use assistive technology devices as well as the devices themselves. Assistive technology device is defined by the act as:

any item, piece of equipment, or product system—whether acquired off the shelf, modified, or customized—that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.
The broad definition of devices included under the law gives states great flexibility in the programs to be developed.

The ATA reaffirms the federal role of promoting access to assistive technology devices and services for individuals with disabilities. The bill allows states flexibility in responding to the assistive technology needs of their citizens with disabilities, and does not disrupt the accomplishment of states over the last decade through the state assistive technology programs funded under the Tech Act (Council for Exceptional Children, 2005).

Assistive technology is the key that provides access to employment, education, transportation, and other activities of daily living such as recreation, for many people with disabilities. As technology continues to be more prevalent in our culture, there is increasingly a need for a national program with state-level flexibility to ensure that employment, education, recreation, and independent living become more accessible.


**LEGISLATION IN CANADA**

Laws in Canada are passed at three levels: federal, provincial, and local. Laws from all three levels influence the rights of people with disabilities. Federal authority is derived from the constitution provisions laid out in the 1867 British North America (BNA) Act, and in the Canadian Constitution Act of 1982.

The history of legislation in Canada related to people with disabilities is similar to that of the United States in that very little happened until the 1960s. In 1962, Parliament passed the Vocational Rehabilitation for Disabled Persons Act (VRDP). Unfor-
Fortunately, the act was passed without consultation with people with disabilities. The act defined disability in the following way: “Disabled person means a person, who, because of physical or mental impairment, is incapable of pursuing regularly any substantially gainful occupation” (Enns, 1981). The act provides for equal cost sharing of vocational rehabilitation services between provinces and the federal government. It continues to be criticized because of its narrow definition of disability and rehabilitation. The VRDP was lauded in its day for providing rehabilitative supports for people with disabilities, although it only covered vocational issues and not other issues of civil rights and access for people with disabilities in Canada.

The VRDP framework and agreements with each province were revised in the early 1990s. For example, a new Canada-Manitoba agreement was signed in 1993. These agreements give more responsibility to the provinces while still containing provisions for a continuing role for the federal government. The VRDP agreement allows for a comprehensive program of vocational rehabilitation for people with disabilities to be co-funded by each Province and the Federal Government including ongoing support for provincially based independent living resource sectors. The program consists of the following six provisions:

1. Assessment and counseling
2. Follow-up goods and services for people with disabilities
3. Services and processes of restoration, training, and employment placement designed to enable a person with a disability to dispense with the necessity for institutional care or the necessity for the regular home service of an attendant
4. Provisions for utilizing the services of voluntary organizations that are carrying out activities in the Province in the field of vocational rehabilitation of people with disabilities
5. The training of persons as counselors or administrators to carry out programs for the vocational rehabilitation of people with disabilities, the coordination of all activities in the Province relating to vocational rehabilitation of people with disabilities
6. Such other services and processes of restoration, training, employment placement, and follow-up goods and services in respect of people with disabilities as may, by agreement between the Minister and Province, be made part of the agreement

Both the third and sixth provisions (bolded above) have been used to introduce therapeutic recreation as a rehabilitative service.

The International Year of the Disabled Person (1981) and International Decade of the Disabled Person (1982–1993) occurred during the period of time between the initial passing and revisions to the VRDP. This was a very significant period of time for the entrenchment of disability rights in Canada. During the International Year of Disabled Persons, the Canadian Federal Government appointed an all-party Special Committee on the Disabled and Handicapped. This committee, which conducted hearings across Canada, undertook a comprehensive review of federal legislation that related to people with disabilities. The report, Obstacles, presented 130 recommendations on all aspects of public policy, including human rights, income security, assistive devices, transpor-
tation, recreation, and communication. One of the most significant accomplishments of the Committee was the inclusion of people with physical and mental disabilities in the equality rights section of the Charter of Rights and Freedoms. At least half a dozen reports have been published since Obstacles was released that have analyzed the success of the implementation of the 130 recommendations.

In April of 1982, the Canadian Charter of Rights and Freedoms (hereafter referred as the Charter) came into being. Section 15 of the Charter, which focuses on equality rights, came into full force in April of 1985. Within it, Section 15(2) provides the foundation for the assertion of rights for persons with disabilities. It states that all individuals are “equal before and under the law,” and have the “right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on . . . mental and physical disability.” Lepofsky (1997, p. 1) suggests that this section “triggered unprecedented optimism among people with disabilities.”

Lepofsky (1997) conducted a thorough analysis of the impact of Section 15(2), in an article in the National Journal of Constitutional Law, titled “A Report Card on the Charter’s Guarantee of Equality to Persons with Disabilities After Ten Years: What Progress? What Prospects?” Lepofsky considered the following areas in conducting his analysis: Access to education, community living, equality in the criminal justice system, civil justice, health care, licenses, and freedom from civil detention, discrimination due to disability-based income support, and coerced sterilization. This detailed, case-by-case analysis, highlights the successes and failures of Section 15(2). In his conclusion, Lepofsky (p. 430) suggests that Canada’s justice system deserves a “C minus on its implementation of the equality guarantees. Lepofsky asserted that Canada must go much further … to secure the rights of people with disabilities in Canada. (p. 431).

Another province initiated legislation as well. In Ontario, the Government’s Bill 125, “An Act to improve the identification, removal, and prevention of barriers faced by persons with disabilities and to make related amendments to other Acts,” also known as The Ontarians with Disabilities Act, received Royal Assent on December 14, 2001, and came into force on February 7, 2002. The bill’s original purpose was to achieve a barrier-free Ontario for persons with disabilities—a right of full participation. It was to require the timely removal of existing new barriers, within reasonable time lines and in accordance with reasonable cost parameters. It was meant to apply to employment, public transit, education, provincial and municipal government services and facilities, and other goods, services, and facilities offered to the public.

Those who supported the idea of an ODA hoped that it would require government bodies and others bound by law to identify the barriers that they now have which impede persons with disabilities from full participation, and to design reasonable plans consistent with their resources to remove these barriers and to prevent new ones from being created, all within reasonable time lines. They wanted it to allow for the enactment of regulations with input from disability groups, business interests and others, to set out measures to be implemented to achieve the ODA’s goals, and reasonable time lines for their achievement. It was meant to incorporate an effective, fair, and timely process for enforcement.
Unfortunately, Bill 125 only suggested voluntary action without enforcement, penalties, or deadlines. Critics of the bill (e.g., the Ontarians with Disabilities Act Committee) petitioned the government to revisit the Act and pass a stronger, more effective Act, which they did in 2005, with the enactment of the Accessibility for Ontarians with Disabilities Act, 2005 (AODA). The AODA remains in force and has been used as a model in other provinces and within the federal government.

Following the AODA, the Accessibility for Manitobans Act was created by the Manitoba Government and has been in effect since December 5, 2013. The purpose of this legislation is similar to the AODA. It is to prevent and remove barriers that affect persons with disabilities. It is being implemented through the introduction of five standards:

1. customer service
2. information and communication
3. transportation
4. employment
5. the built environment

The Accessibility Standard for Customer Service came into effect November 1, 2015. Other standards are nearing completion.

Since the introduction of Section 15(2) of the Charter, and Lepofsky’s subsequent analysis of its impact, in addition to the strong provincial laws mentioned above, two significant federal initiatives took place. In 1997, the federal government initiated a Federal Task Force on Disability Issues, chaired by Member of Parliament Andy Scott. The Scott Task Force traveled across Canada and conducted 16 public consultations. The report put forth a far-reaching set of recommendations, including the creation of a Canadians with Disabilities Act, much like the Americans with Disabilities Act and the Disability Discrimination Act, the corresponding UK legislation, a legislative review of all laws that have the potential to impact people with disabilities, the incorporation of a disability lens in the development of all laws, policies, and programs, changes to the labor market program, improved tax assistance, and income programs.

The final and most recent initiative of the Governments in Canada was the release of the report *In Unison: A Canadian Approach to Disability Issues*. The report, which was a joint effort of the Federal, Provincial, and Territorial Ministers of Social Services, sets out a blueprint for promoting the integration of people with disabilities in Canada. The key values and principles necessary to achieve the vision of full citizenship for Canadians with disabilities are very much in keeping with the philosophy of person-centered recreation.

In contrast to the United States, education and many other services for people with disabilities are driven by provincial rather than federal legislation. For example, provincial authority in education relies on the statutes enacted by the legislatures that provide the legal framework by which each system of education is governed. In addition, provincial schools acts provide a variety of rules and regulations set out by various departments of education. The fact that education is a provincial responsibility in Canada has resulted in different types of legislation dealing with people with disabilities. The major-
ity of provinces mandate special education services for persons with disabilities; however, four provinces have only permissive legislation, meaning that services are permitted but not mandated. The same can be said for other services for persons with disabilities.

Canada does not at this time have legislation that is as far-reaching as the Americans with Disabilities Act. For the time being, Canadians with disabilities must rely on Section 15(2) of the Canadian Charter of Rights and Freedoms and/or their Provincial legislation to provide the basis for litigation and other means of asserting rights.

CONCLUSION

It is imperative that professionals have knowledge about disability laws. Such knowledge of the law can help recreation professionals understand their entire service delivery system, can ensure the protection of civil rights, and can improve collaboration with other agencies and families. If you know the standards you must address and why you must address them, you can go above these standards and create an even greater experience for your participants/clients, thus setting your agency apart from others who meet the bare minimum standards and requirements.

These laws ensure physical and programmatic access to resources and services, thus giving people with disabilities an opportunity to lead a richer, fuller life. With time and careful planning, perhaps we will reach a point in the U.S. and Canada where providing access to people with disabilities becomes second nature, rather than a response to law or an afterthought.

LEARNING ACTIVITIES

1. Identify the most current state or provincial legislation that is similar to federal legislation discussed in this chapter.

2. Study the state or provincial legislation that you discover. How is it different from federal legislation? If state or provincial legislation needs to be more person-centered and/or consumer responsive, brainstorm ways that you can advocate for changes in your state/provincial legislation.

3. Identify your state’s ADA coordinator. If you live in Canada, who is a similar governmental official in your province?

4. Consider each of the pieces of core legislation. How are they consistent with the concepts of self-determination, normalization, social role valorization, interdependence, and inclusion?
5. Find out when the next scheduled reauthorization of each of the pieces of core legislation is scheduled. Volunteer to assist an advocacy organization or your professional organization in the reauthorization process.

**REFERENCES**


*PL 90-480, the Architectural Barriers Act of 1968.*


*PL 94-142, the Education of All Handicapped Children Act of 1975.*

*PL 100-146, the Developmental Disabilities and Bill of Rights Act Amendment of 1987.*

*PL 100-407, the Technology-Related Assistance for Individuals for Disabilities Act of 1988.*

*PL 101-336, the Americans with Disabilities Act of 1990.*

As discussed in the previous chapter, the Americans with Disabilities Act (ADA) is, and continues to be for those living in the United States, the most important piece of civil rights legislation ever written. However, even with the passage of updated versions, referred to as “reauthorizations,” there are still issues and challenges that people with disabilities, and those who are their advocates, face. The ADA was written to address the pervasive discrimination that had existed for so many years against the millions of Americans who have physical or mental disabilities. It was enacted for the following reasons:

1. Society tends to isolate or segregate people with disabilities.
2. People with disabilities experience intentional as well as unintentional (and well-meaning) discrimination.
3. Discrimination is pervasive, occurring in all levels of society.
4. Discrimination occurs in critical areas of life, including employment, housing, access to government services, transportation, communication, and recreation.
5. There is often no satisfactory legal recourse for people with disabilities who have experienced discrimination.
6. People with disabilities generally occupy inferior social positions.
7. People with disabilities, as a group of individuals, have been powerless to address these social inequities (McGovern, 1992).
As important as the ADA is, it cannot put an end to discrimination. Discrimination has arisen over centuries, and it will take time for lasting change to occur. Isolation and segregation have become the norm for people with and without disabilities. Isolation has even become preferable to many people with disabilities who over time have lived in an oppressive and discriminating society. Many people with disabilities have been forced into an attitude of complacency. They have felt discrimination for so long, whether intentional or unintentional, that they have chosen to isolate and segregate themselves. Some people who have disabilities might sit at home and not become involved in things they enjoy because of the potential embarrassment of subnormal performance or of performing at a level that will alienate people without disabilities. People with disabilities may choose isolation to avoid the stares of others. As a result, people without disabilities come to assume that people with disabilities want “to keep to themselves.” It all becomes a cyclical and pervasive situation that is hard to change. Discrimination leads to isolation and segregation, which creates powerless and socially inferior people who feel devalued and discriminated against. As powerless people, they find advocating for changes to be hard, because the majority of the population do not even realize changes are needed.

People with disabilities did not just emerge as a segment of the population. As we saw in Chapter 2, people with disabilities have always been part of society. However, to say they “have been a part of” would be inaccurate. Such a phrase implies that they have been involved and included in society, but this does not accurately reflect history. Had this been the case, there would have been little reason for federal legislation such as the core civil rights laws presented in the previous chapter.

There are many reasons why people with disabilities have been less included and less involved in society. These reasons are barriers that are faced regularly by people with disabilities and are both intrinsic and extrinsic in nature. Intrinsic barriers result from a person’s own physical, psychological, or cognitive limitations. These are real barriers that are usually permanent, but they may sometimes be temporary. Regardless of the duration, intrinsic barriers reduce a person’s ability to be involved in a normative society. What compounds the intrinsic barriers are the countless extrinsic barriers faced by people with disabilities. Extrinsic barriers (sometimes called environmental barriers) are things external to people with disabilities that impose limitations upon them.

Except in the case of temporary disability, intrinsic barriers do not just go away. For example, a cognitive deficit, a consequence of intellectual disability, and the inability to walk as a result of a spinal cord injury are permanent conditions. Of course, through education and rehabilitation, people with various disabilities often improve physical, psychological, or cognitive functioning and therefore reduce the effects of intrinsic barriers. For people with disabilities, intrinsic barriers will likely always exist. The onus is on the person to do whatever is possible to reduce the inconvenience caused by these barriers.

On the other hand, extrinsic barriers, while real, are changeable. They include inconveniences that are imposed on people with disabilities, such as inaccessible architecture, rules and regulations that inhibit or discourage access, and negative attitudes. Many such extrinsic barriers make it difficult for people with disabilities to be included
and involved in normative society. The two extrinsic barriers that have the greatest negative impact are attitudinal barriers and physical barriers.

Now, we will take a closer look at attitudinal and physical barriers and discuss ways to eliminate them. We will also address programmatic accessibility, the lack of which is perhaps the most subtle and least understood type of discrimination.

**ATTITUDES AND DISABILITY**

One of the easiest extrinsic barriers to detect is a negative attitude, but it is also a difficult one to change. There are often predetermined perceptions of people with disabilities, and when these are negative attitudes, they become extrinsic barriers. Negative attitudes create major obstacles to the free movement of individuals within society. Often, attitudes toward people with disabilities are a convenient excuse to avoid contact with them. Unfortunately, this avoidance is often motivated by fear, discomfort, and an inability to see people with disabilities as people first. Negative attitudes impose limitations on people with disabilities and are a form of discrimination.

Negative attitudes are not always extrinsic barriers, however. In fact, negative attitudes can be intrinsic barriers as well. A person with a disability might have a negative attitude about himself or his disability or may have a “chip on his shoulder,” which can create a bad attitude from people without disabilities. In these cases, the person has created an intrinsic barrier for himself. While it might be hard, these intrinsic attitudinal barriers are changeable.

Though an understanding of the attitudes of individuals and the subjective norms that might influence them provide us with some indication of the behaviors and actions they might initiate with individuals with disabilities, a number of other factors can have an impact on behavior as well. Kennedy, Smith, and Austin (1991) point out that we must know an individual’s specific attitude to understand what that person’s specific behavior may be. For example, an individual might have a different attitude toward a person with an intellectual disability than his general attitude toward people with disabilities. This differential-specific attitude is based on the amount of exposure to the person with an intellectual disability (attitude object), the person’s personality traits, and/or the perceived consequences of the person’s behavior. What this suggests is that we cannot assume that a generally positive predisposition to individuals with disabilities will necessarily result in the specific behaviors we would describe as positive and nondiscriminatory. Specific strategies must be identified to facilitate behavioral change—through changes in attitudes and subjective norms.

Prejudice and discrimination against people with disabilities remains very much a part of contemporary culture. For example, prejudice against people with disabilities can be reflected in the form of insults. One of the most denigrating ways of insulting someone is to suggest that he or she is somehow slow. The lexicon of such terms is vast: stupid, dumb, nitwit, half-wit, dimwit, blockhead, bonehead, numbskull, lame brain, pea brain, fool, dopey, retard, and so forth. For the entertainment of viewers, characters in popular television programs are frequently called idiots, morons, and imbeciles—formerly scientific and legal classifications for levels of retardation. And it’s not just re-
served for television or movies. Most likely, every person reading this book can recall a
time in the past few months if not past few weeks/days, that he “jokingly” called a friend
an idiot, or stupid, and maybe a retard. When you have done this, it is not because you
have a negative attitude toward people who are slow, yet it does communicate that you,
like most of our society, have little patience with people who don’t think as quickly
as the typical person. Unintentionally you are equating disability with undesirability,
which stigmatizes people with disabilities. The negative value we assign to people with
different levels of abilities becomes all-encompassing; it becomes their master status.
People may not even realize or be willing to admit that they have negative attitudes.
Nonetheless, negative attitudes get in the way of responsive, person-centered services.

Poor attitudes concerning people with disabilities are all too common among all
kinds of people in all kinds of situations. Stereotyping is generally the rule and not the
exception, and stereotypes typically are not positive. Stereotypes of people with disabil-
ties as dangerous and dysfunctional have saturated the culture. For example, one of
America’s foremost writers, John Steinbeck, wrote a popular novel that reflected these
stereotypes and has helped to perpetuate them even today. Of Mice and Men describes
Lenny, a large and powerful man with a disability who unintentionally kills a young
woman. Lenny’s character and the bare outline of the plot have been copied innumer-
able times in television programs, movies, and even cartoons, and the novel itself has
been made into a movie several times (Korbin, 1987). The most recent version, released
in 1992, emphasized Lenny’s dangerousness by opening with an image of a terror-strick-
en woman in torn clothing, running from an encounter with Lenny, even though the
novel does not begin this way. The screenwriter, who is otherwise quite faithful to the
original work, apparently liked the dramatic effect of such an image, demonstrating
that the cultural prejudice against people with disabilities that allows and accepts these
stereotypes is still strong.

Frequently, villains and monsters in stories and films are characterized by some
form of physical and mental disability (Korbin, 1987). Repeated exposures to such neg-
ative images cannot help but generate fear and distrust of people with disabilities.

While our society frightens itself at the expense of people with disabilities, it con-
tinues to amuse itself as well. The Three Stooges, Laurel and Hardy, Step ’n Fetchit, Jerry
Lewis, and numerous other comedians have made careers out of portraying characters
who have apparent intellectual deficiencies. Similarly, physical abuse of someone who
does something “dumb” is seen as a normal response. Audiences laugh as Oliver Hardy
hits a dim-witted Stan Laurel for doing something “stupid,” as Moe hits Curly, and as
Bud Abbott hits Lou Costello; on Cheers, Woody Boyd is called an idiot and is some-
times struck by Sam Malone; in Disney’s Beauty and the Beast, the character Gaston
repeatedly punches his dim-witted sidekick, and on and on. This form of entertainment
can be seen as a contemporary version of the ancient practice of “displaying” people
with disabilities. Authors, screenwriters, directors, and producers typically do not in-
tend to create and expand attitudinal barriers, but without a doubt, negative attitudes
are the result.
Not only have people with disabilities felt the negative attitudes toward them, but in many cases, they have come to internalize and believe them. As a result, we could say that people with disabilities are often scripted into preconceived roles. This scripting, labeling, or stereotyping has not been malicious; however, it has had negative effects. The process works like this:

We see someone who is different and we do not understand. We call on our past experiences with television shows and advertisements or comments from parents, neighbors, and friends. We use anything that we recall to help us to understand this “difference.” Unfortunately, much of what we recall is negative, although almost always unintentionally so.

Wolfensberger (1972) describes various deviance roles that are often attributed to people with disabilities. He suggests that people with disabilities are often seen as menaces, objects of pity, sick, burdens of charity, objects of ridicule, eternal children, and holy innocents. These learned preconceptions create and sustain negative attitudes:

1. **Menaces.** In this situation, people with disabilities are seen as annoyances at least, and even as a threat to themselves or to the community. In the early days of institutionalization and even to some extent today, strong resistance continues against group homes being placed in established residential developments. Although the objection has often been out of ignorance and lack of information, typical residents often make comments such as “I don't want to subject my children to that kind of potential danger.” Another example of the annoyance or menace of people with disabilities is a comment that is often heard from parents when discussing inclusion of kids with disabilities into regular programs: “I want them to have all the opportunities they can, just not at the expense of my kids.”

2. **Objects of pity.** It is very common that people with disabilities are pitied. As we strive to elevate people with disabilities into areas of dignity and respect, the presence of pity is counterproductive. In fact, pity and respect are at opposite ends of the same perspective. A person who is pitied can never really be respected. The most obvious example of pity is telethons. For many years, telethons have been used by charitable organizations to raise funds. They are promoted as educational opportunities to help the community understand ramifications of disability by using stories or interviews
about their sad lives and ways in which they have overcome great difficulty. Stories like these undoubtedly pull at heart strings of givers and as such, the pity angle raises enormous amounts of money. The entire scene is very emotional and one that is intended to imply “Aren’t we fortunate that that’s not us?” Pity raises funds but discourages self-determined action.¹

3. **Sickness.** Sickness or illness is often synonymous with disability. People are often labeled as patients and less seldom as people. Although people with disabilities may indeed have some illnesses, they are far from perpetual patients, and this association continues to devalue differences.

4. **Burdens of charity.** People with disabilities are often seen as not able to take care of themselves and, therefore, must be taken care of by society. In other words, charity is the only option for people with disabilities. Charity is also associated with worthlessness. People with disabilities are perceived to not have much contribution to make; others must step in to help them. People with disabilities are a burden and need society’s collective handouts.

5. **Objects of ridicule.** Often, people with disabilities are made fun of and ridiculed. This has been a carryover from much earlier times. You will remember in the discussion of history that people with disabilities were often used in the courts of kings as jesters and fools. Although not quite so ruthless today, numerous examples of people with disabilities being the brunt of jokes still exist, as discussed previously in this chapter.

6. **Eternal children.** Regardless of age, people with disabilities are often referred to as kids. People with disabilities find themselves in the role of eternal or permanent child. This is deep-seated and insulting. Regardless of ability level or type of disability, people with disabilities are often talked down to and attempts are made to simplify things for them. Particularly degrading and insulting is this situation for a person who has severe physical disabilities, for example, severe cerebral palsy. Although unable to speak or to move fluidity, he is often cognitively very capable. To be relegated to this eternal child status is degrading.

7. **Holy Innocents.** Even today, some people view the birth of a person with a disability, the sudden onset of a debilitating disease, or an accident causing a disability to be a punishment or sometimes a gift from God. People believe that as parents or as individuals, they are being tested or punished for some religious reasons. The belief is deep-seated, and as we saw in Chapter 2, imposition of disability has for centuries been associated with deity. People who have a child born with a disability often try to understand why this “bad thing” has happened to them. They often think that they have done something “wrong” and that God is punishing them.

Although the social roles help us to understand many of the attitudes about and of people with disabilities, we need to understand the ways these roles can be adjusted to enable people who have been disenfranchised to have full access to community life.

¹ In the January 1996 United Cerebral Palsy telethon, and all telethons subsequently, fewer instances of pity and more instances of individuals as valued, self-determined people were used throughout the fund-raising campaign.
Attitude Change

Changing negative attitudes to positive ones or even to neutral ones is a complex task that no one seems to know for sure how to accomplish. The generally accepted approach is to refute information that was acquired in the development of the negative stereotype while at the same time providing positive information and experience that supports the development of a positive stereotype, or at least a resistance to ongoing stereotyping. There are at least three ways to enhance the possibility of changing attitudes toward people with disabilities:

1. **Personal contact and interaction** with people who have disabilities seems to be the most effective way to change attitudes. To be in the presence of and to interact with anyone is the best way to get to know and understand him. Yet there must be more than just contact or exposure to change attitudes. There must be positive interaction that is mutual and reciprocal. As Donaldson (1980) suggests, negative attitudes can result if people without disabilities experience tension or anxiety or perceive information that reinforces existing stereotypes. Therefore, there needs to be a positive experience during personal contact with people with disabilities. Positive personal contact cannot be engineered; it must occur naturally in situations.

2. **Persuasive communication** is another way to change attitudes about people with disabilities. To hear someone talking about people with disabilities, trying to convince you—to persuade you that you should have positive attitudes is effective. Persuasive communication might include such phrases as “People with disabilities have the same wants and desire as anyone else” or “People with disabilities are people just like anyone else. …” This book, especially certain chapters, could be called persuasive communication. Hopefully, it is effective, but is not nearly as effective as it would be for you to spend time interacting with real people with real disabilities.

3. **Assumption of disability** involves giving students a taste of the experience of disability. Role playing and assuming a disability for a few minutes, an hour, or a day have all been tried. Assumption of disabilities includes such things as using a wheelchair around campus for an hour, guiding a person who has been blindfolded around so she can “feel” what it is like to be blind, putting cotton in a person’s ears to simulate hearing impairment, and other such role-playing exercises. All of these efforts are well intentioned, and there is research that supports assumption of disability as an appropriate method of attitude change. However, it must be remembered that this is not the best way to change attitudes and should be a last resort. There is no way a person who does not have a disability can “assume” one, because at the end of the “exercise,” he no longer has the disability. Such exercises give the inaccurate perception that he now knows what it is like to be blind or to use a wheelchair. Nothing could be further from the truth. After such an exercise, he knows what it is like to “not see” for a time, but there is no way that he can understand what it is like to be blind. Although one way of changing attitudes, assumption of disability should be used carefully, and an extensive discussion of the experience should follow the experience.
As we said earlier in this chapter, the ADA was enacted to combat pervasive discrimination and to eliminate barriers. It is naive to think, however, that by merely enacting a law we would eliminate discrimination. It is not naive to think that the very existence of a law such as the ADA could both reduce discrimination and provide recourse to people with disabilities who have been discriminated against.

In this section, we have described the pervasive and often unintentional negative attitudes. We ended the section with three suggestions of ways to be agents of attitude change. Using any of these three ways represents a proactive way to change attitudes. Sometimes, however, negative attitudes cause barriers that deny people with disabilities the very rights that the ADA is suppose to protect. Sometimes it is necessary to be reactive in an effort to “right a wrong” and to use the force of the law to remove barriers caused by negative attitudes.

**PHYSICAL BARRIERS AND BARRIER REMOVAL**

Barriers that are attitudinal are hard to deal with, because they are not always easily observable, they are not always clear and obvious, and they are ever changing. Physical barriers, on the other hand, are much easier to understand. There is nothing unclear about a door that is not wide enough to allow a person who uses a wheelchair to enter. There is nothing unclear about an audible warning device that cannot be “heard” because a person cannot hear. Physical barriers are more obvious and, therefore, are easier to change.

A physical barrier is a condition of the physical environment that restricts or complicates access, movement, or participation by individuals attempting to use recreation facilities or areas. Physical barriers include more than just architectural barriers, like stairs, or curbs, or narrow hallways, or doors that are hard to open. Natural, physical barriers also abound, such as steep hills, thick tree growth, and other frustrating obstacles for many people who have mobility or visual impairments.

Here is where the ADA can help and can help quickly. As you learned in Chapter 4, public entities are required by the ADA to remove architectural barriers—those elements of a facility that impede access by people with disabilities—to ensure access for customers, clients, or patrons where it is possible to do so in a readily achievable manner. Examples of barriers are curbs and steps, narrow exterior and interior doorways and aisles, restroom doorways and stalls that are too narrow for use by a person who uses a wheelchair, inaccessible drinking fountains and telephones, and many other obstacles/barriers that inhibit access.

Because of the ADA, many public and private agencies are required to ensure that they provide accessibility for all people. To do this, especially in the case of existing buildings and areas, a lot of money will be spent. The ADA recognized this and specifically provided language in the statute to prevent bankrupting businesses and government agencies. This recognition did not “let them off the hook,” it simply provided a structure within which changes might be reasonably made.

Title III of the ADA requires that physical alterations to public accommodations undertaken after January 26, 1992 be readily accessible to and usable by people with
disabilities to the maximum extent feasible. The term *alterations* refers to changes a business is undertaking for its own purposes, such as renovation, and does not refer to steps a business takes to comply with the ADA’s requirements for barrier removal. Alterations do not include normal maintenance. Alterations that affect or could affect usability are required to be accessible.

When alterations are made to *primary function areas*—work areas and areas used by the public—alterations must also be made to provide an accessible path of travel to the altered areas. *Path of travel* means access to restrooms, telephones, and drinking fountains serving the area. The cost of providing an accessible path of travel need not exceed 20% of the total cost of the original alteration.

While the cost of alterations to existing buildings and areas can be quite expensive, the additional cost to make a building physically accessible from the outset usually costs less than 3% more than it otherwise would. Therefore, “building in” accessibility from the beginning is much more economical than changing an existing structure to make it accessible. All newly constructed facilities must be readily accessible to and usable by people with disabilities if an application for a building permit or permit extension was filed after January 25, 1992, and the facility was occupied after January 26, 1993. The technical standards for accessible new construction and for elimination of existing architectural barriers are set out in the Americans with Disabilities Act Accessibility Guidelines (ADAAG). A checklist based on the most current ADAAG standards is included in Appendix A.

**ACCESSIBILITY GUIDELINES AND BARRIER REMOVAL**

The Americans with Disabilities Act Accessibility Guidelines (ADAAG) issued by the Architectural and Transportation Barriers Compliance Board can serve as a guide for the following:

1. identifying various kinds of barriers that exist, and
2. identifying measures that can be taken to remove barriers and how best to remove them.

A copy of a survey called the Americans with Disabilities Act Checklist for Readily Achievable Barrier Removal, developed by Adaptive Environments Center, Inc. and Barrier Free Environments, Inc. that use the ADAAG standards, can be found in Appendix A.

If steps lead to the front entrance and the front door is very narrow, businesses must provide a ramp and widen the door according to ADAAG standards if it is readily achievable to do so. If it is not readily achievable to follow the ADAAG standards for ramps and doorways, public accommodations must take other safe alternatives that are readily achievable measures, such as installation of a slightly narrower door or a slightly steeper ramp than that permitted by the ADAAG. Although these barrier removal measures would not meet the ADAAG standards for alterations, they would nevertheless afford significant access for many customers or clients. In other words, they would be functionally usable even though not legally accessible. They would comply with the spirit of the law even if not the letter of the law.
Where some elements of a facility come very close to meeting the ADAAG standards and others fall far short, public entities are advised to put first priority on removing the barriers that most deviate from ADAAG standards. For example, if the front entrance already has a ramp that is just slightly steeper than that permitted by the ADAAG and the front door is just slightly narrower than that permitted by the ADAAG, but elements in the interior areas that serve clients or customers are wholly inaccessible, then public barriers that should draw first attention are those areas that offer the biggest impediments for consumers. Establishment owners should remove those that can be removed in a readily achievable manner before turning their attention to elements that deviate only slightly from the ADAAG standards.

The Department of Justice (DOJ) has recommended an order of priorities for barrier removal that it urges business to follow:

1. Provide access from parking areas, sidewalks, and entrances to the public accommodation so a person with a disability can “get through the door.”
2. Provide access to those areas where goods and services are provided.
3. Provide access to rest room facilities when they are open to the public.
4. Take other measures to provide access to the goods, services, or facilities.

A good idea is to become familiar with the full array of access concerns that the ADAAG addresses. One of the must learning activities at the end of this chapter is to use the Americans with Disabilities Act Checklist for Readily Achievable Barrier Removal (Appendix A) to conduct an accessibility survey to identify existing architectural barriers and to suggest solutions for barrier removal. An excellent quick reference checklist for accessibility and ADA compliance is contained in Figure 5.1.

Great progress has been made toward providing entry into and use of buildings and facilities for people with disabilities. And recently, standards that relate to outdoor areas that are typical in public and private recreation have become available (United States Forest Service, 2012). Many people with disabilities have seldom, if ever, sat directly on the grass or the beach to en-
joy the sun, enjoyed flowers up close in a garden, played in the sand with a child, or experienced an extended hike on a wilderness trail. Even though outdoor standards are the most difficult to address, the Architectural and Transportation Barriers Compliance Board (ATBCB) has recently developed and piloted standards for accessibility in outdoor areas such as campsites, swimming pools, lakes, trails, beaches, game and sports areas, and others. The Access Board has issued requirements that are now part

How well does your organization comply with the ADA? To find out, answer “yes” or “no” to any of the questions, and take the appropriate steps to comply with the ADA.

Yes No

1. All positions (not just entry level) are open to qualified applicants with disabilities.
2. Interview areas are readily accessible to people with physical disabilities (e.g., wheelchair users).
3. Testing does not discriminate against employment applicants with speech, vision, and/or hearing disabilities.
4. Selection criteria are related to the job description and the needs of the business.
5. Applicants are not asked if they have a disability or the nature or extent of any disability. (Applicants may be asked about their ability to perform specific essential job functions).
6. Medical examinations are not required unless they are required of all employees in similar positions.
7. Reasonable accommodations—including adaptive aids and assistive technology—are made for employees with disabilities unless they impose an “undue business hardship.”
8. Existing facilities used by all employees are accessible to people with disabilities.
9. Jobs are redesigned to accommodate a person’s disability. If necessary, tasks are reassigned to other employees with disabilities.
10. Part-time and modified work schedules are considered to accommodate employees with disabilities.
11. Qualified people with disabilities are considered for promotions.
12. Employees are notified of an employer’s obligations under the Americans with Disabilities Act.
13. Customers are not denied service based on their association or relationship with a person with a disability.
14. Criteria for service does not limit the participation of a person with a disability unless it applies to everyone.
15. Readily achievable, architectural barriers (narrow doorways, stairs without wheelchair ramps, heavy doors) are removed.

(Information provided by DATA, Inc., 1990) For a free copy of the ADAAG contact Architectural and Transportation Barriers Compliance Board, 1331 F Street, NW Suite 1000, Washington, D.C. 20004-1111, (Voice/TDD) (800) USA-ABLE.

Figure 5.1. ADA Compliance Quiz
of the Architectural Barriers Act (ABA) Accessibility Standards and apply to national parks and other outdoor areas developed by the federal government. They do not apply to outdoor areas developed with federal grants or loans. A guide that explains these requirements also is available. The new provisions address access to trails, picnic and camping areas, viewing areas, beach access routes, and other components of outdoor developed areas on federal sites when newly built or altered. They also provide exceptions for situations where terrain and other factors make compliance impracticable. The new requirements are located in sections F201.4, F216.3, F244 to F248, and 1011 to 1019 of the ABA Standards (United States Access Board, 2013). Another good resource for outdoor accessibility is the U.S. Forest Service 2012 publication, Accessibility Guidebook for Outdoor Recreation and Trails.

Online Accessibility

With great strides in access to built and natural environments, not surprisingly, the Access Board turned to online access for guidelines. The first set of new online standards covers accessible routes, animations on wheelchair maneuvering, entrances and doors, toilet and bathing facilities, and protruding objects. On June 15, 2016, new standards for online access to design guidelines were released. The new standards feature animation and technical bulletins on accessible parking and passenger loading zones. It also includes a technical bulletin on stairways. This guidance for online accessibility clarifies and illustrates provisions in the standards, answers frequently asked questions, and offers best practice recommendations (United States Access Board, 2016).

Programmatic Accessibility

Basic needs such as accessible parking, ramps, and restrooms often have been addressed through improved planning and design. However, people with disabilities often find that although they might be able to enter a facility or even an outdoor area, they find themselves excluded from many basic activities that people without disabilities take for granted. Things as basic as orientation are often difficult for those with visual impairments or limited language skills due to inadequate or inappropriate signs. Title II of the ADA prohibits public entities from denying people with disabilities equal opportunity to participate in programs and activities because they are inaccessible. This does not mean that all buildings must be made fully architecturally accessible. The requirement is that a public entity operate each program so that, when viewed in its entirety, the program is readily accessible to and usable by people with disabilities. This is known as program accessibility and is one of the most important concepts in the ADA.

What does it mean to view a program in its entirety? The legal and ethical ideal is that all recreation programs should be equally accessible to all people, because to the extent that an opportunity is not accessible, it is not really an opportunity. As we have discussed, the most commonly understood kind of accessibility is physical accessibility, which generally refers to the physical environment within which an activity or program is offered. Stairs, bathroom facilities, and elevators can all be physical barriers that can complicate or preclude the participation of people with certain disabilities. Program access includes physical access, but it can also include administrative policies and pro-
Discrimination, Barriers, and Accessibility

Procedures that can also be barriers to the participation of a person with a disability. The existence of such barriers is one major problem in fulfilling the mandate that people with disabilities receive equal opportunities for participation. The elimination of such barriers is essential if equal opportunity is to be achieved. Further, programmatic accessibility relates to designing programs and activities in ways that enable people with a variety of disabilities to participate fully and have fulfilling experiences. It means that any criteria for participation are applied to all potential participants equally, based on skill levels or realistic safety considerations and not on characteristics such as “race, sex, religion, national origin, or handicap.”

In other words, a public entity is not allowed to apply eligibility criteria for its goods and services that tend to, or actually do, screen out people with disabilities except when the criteria are necessary to provide the goods or services that are being offered. A health spa cannot require a driver’s license as a sole acceptable document for identification when paying membership fees by check. This policy would discriminate against people with disabilities such as blindness who are ineligible to obtain a driver’s license. An exception to the policy must be made to permit these customers to present another form of identification.

The ADA requires that any criteria used be applied fairly and equally to all members of the public. It prohibits public entities from basing their eligibility criteria on assumptions that would unnecessarily exclude individuals with disabilities who, in fact, are eligible to participate in an activity. Sooner or later, the public is going to run into some people, things, or conditions that have the potential to diminish their enjoyment of certain activities. These situations are not restricted to people with disabilities, but they probably occur more often to them. We refer to these situations as potential barriers to participation. Think of them as challenges to be overcome or with which to be coped. In Chapter 13 we will deal extensively with programmatic accessibility as we look at the accommodations needed to ensure equal opportunity and participation in recreation programs and services. Access to information technology is increasingly important in today’s world. To be afforded full citizenship, people with disabilities must have access to information technology. A list of accessible information technology is listed at the end of this chapter.

Achieving Program Accessibility

As we have suggested, Title I (Employment), Title II (Local Government), and Title III (Business) of the ADA are the provisions of the act that will have the greatest impact on public and the most insight into achieving program accessibility. As McGovern (1992) states:

The key to the Title II requirements is the determination of whether an individual with a disability could meet essential eligibility requirements for use or enjoyment of, or participation in, parks and recreation agency programs. (p. 9)

Essential eligibility means that a person either meets all of the typical requirements to be eligible for involvement in a particular activity or could meet the requirements with the provision of reasonable accommodations. In other words, when accommo-
dations are made, people with disabilities become like other participants in terms of essential eligibility required for that particular activity. Such eligibility requirements must be applied consistently and cannot be used to screen out participants, especially participants with disabilities.

The next logical question is “What is a reasonable accommodation?” Although the word reasonable is intentionally nonspecific, the law and its regulations name five types of reasonable accommodations. McGovern (1992, pp. 12–14) lists five ways that a parks and recreation department can help people with disabilities to meet essential eligibility requirements by having them to do the following reasonable accommodations:

1. **Change policies, practices, or procedures.** This could include, but is not limited to, changing rules for the use of facilities (e.g., rules that prohibit animals from being in a recreation center could result in exclusion of an individual who is blind and uses a guide animal), changing registration policies (e.g., permitting an individual with a physical disability to set an appointment during a first-come, first-served registration process), or changing the playing rules in a particular sport (e.g., tennis players who play from a wheelchair are allowed two bounces before returning a ball hit into their court).

2. **Remove transportation barriers.** This could include providing door-to-door transportation for people with disabilities who cannot come to a park district service or facility because of the disability, or making home visits (if appropriate to the activity) to take a program to the person who cannot come to the parks and recreation department facility.

3. **Provide auxiliary aids or services.** This could include, but is not limited to, providing a sign language interpreter, a sound amplification system, an assistive system, or a text telephone for people with hearing impairments or deafness, raised lettering on signs, large print brochures, Brailled communications, or a qualified reader for people with sight impairments or blindness.

4. **Remove architectural barriers.** This could include creating a path in a park between playground areas and picnic areas, beveling an uneven surface at the entrance to a doorway, or installing a lift in the deck of a swimming pool.

5. **Remove communication barriers that are structural in nature.** This could include the installation of visual alarms in a recreation center to allow individuals in a room away from other people to “get the message” transmitted by an aural fire alarm.

Many other acceptable ways exist to make reasonable accommodations; we will discuss some of them in Chapter 13.

As stated earlier in this chapter, the ADA intends to assist in protecting the rights of people with disabilities, yet it does not intend to impose an undue burden on an agency or business. As such, the ADA encourages changes that are readily achievable. The ADA defines readily achievable as “easily accomplishable and able to be carried out without much difficulty or expense.” Examples of barrier removal possibilities include providing

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2Not all people with disabilities will need accommodations or assistance. Therefore, accommodation should not be provided just because a person may be blind but because a specific individual needs a specific accommodation to render him essentially eligible. When assistance is needed because of a disability, the ADA requires an agency to make reasonable accommodations for people with disabilities.
a ramp for one or even several steps, widening doorways, reconfiguring display shelves to increase aisle width, widening bathroom doorways, moving toilet stall partitions, and installing grab bars.

The readily achievable standard does not require barrier removal that involves extensive restructuring or burdensome expense. Required barrier removal for a particular public accommodation will depend on its financial and other resources. The readily achievable standard is intended to be a flexible one that is applied on a case-by-case basis. Readily achievable barrier removal is a continuing obligation. Barrier removal that was not readily achievable initially might later be required because the public accommodation has more resources available. Therefore, a public accommodation must continually monitor its accessibility as well as its financial and other resources and engage in barrier removal as new measures become readily achievable (Johnson, 1992).

Achieving effective communication for people with disabilities is also a continuing obligation. Auxiliary aids that were not required initially because they posed an undue burden might be required later in light of changing resources or changing technologies. Public entities may not add any surcharges on individuals with disabilities for auxiliary aids and services, barrier removal, or alternative measures taken in lieu of barrier removal.

Public entities are required to communicate effectively with customers or clients who are deaf or hard of hearing or who have speech or vision impairments by whatever means are appropriate. In the ADA, the term *auxiliary aids and services* refers to the means for achieving effective communication. This term includes sign language interpreters; written materials; assistive listening devices; Telecommunication Devices for the Deaf (TDDs); taped, Brailled, or large-print materials; readers; and other communication tools (Evan Terry Associates, LLC, 2011).

The auxiliary aid requirements are flexible. The goal is to find an effective means of communication that is appropriate for the particular circumstance. For example, jotting down a fitness center’s membership rates on a note pad for a customer who is deaf may
suffice, but this means of communication will not be appropriate in a martial arts training class where complex concepts must be communicated clearly.

A business is not required to provide any particular auxiliary aid or service that it can demonstrate would fundamentally alter the nature of the goods or services being provided or would result in an undue burden on the business. It must, however, provide those needed auxiliary aids and services that would not result in an undue burden. Undue burden is defined as significant difficulty or expense when considered in light of a variety of factors, including the nature and cost of the auxiliary aid or service and the overall financial and other resources of the business. The undue burden standard is intended to be applied on a case-by-case basis.

If providing access by removing barriers is not readily achievable, the law requires public accommodations to provide readily achievable alternatives to barrier removal. For example, if barriers in a fitness center cannot be eliminated, the facility could move exercise classes or equipment to another accessible location. This is called post burden alternative thinking. It means that if an identified accommodation is too difficult or costly (i.e., if it causes a substantial economic or administrative burden or would result in a fundamental alteration of the nature of the service), the agency does not have to incur this burden, but they must find an alternative method of accommodation that is not an undue burden, and that allows participation by the person with a disability.

WHERE TO BEGIN

It should be clear by now that accessibility is more than just ramps. Buildings and grounds accessibility is what most people think about when they think about accessibility, but there is so much more. You know that the definition of accessibility is more inclusive and that accessibility means not only getting in the door but also being able to participate once inside. Most people really want their facilities and their programs to be accessible but just do not know how to proceed. They may feel that they need an expert before they can do anything. They do not need an expert if they have you! After reading the information in this text, completing many of the learning activities, and being aware of the additional resources available, you will be able to provide invaluable assistance. It is true that ensuring accessibility is a complicated process, but you can help your agency to remove extrinsic barriers and to achieve accessibility. Usually barrier removal is relatively simple, although sometimes it is a complicated process. Nonetheless, when you get a job in a recreation agency, you can help your agency to remove extrinsic barriers and to achieve accessibility. Here are a few simple steps that the Department of Justice recommends for getting started, as cited by Gostic and Beyer (1993):

1. **Contact organizations of or for people with disabilities** in your community to help identify physical barriers to your facility or your goods or services and to familiarize you with various kinds of auxiliary aids and services that can help you communicate effectively with your customers or clients.
2. **Make a list** of architectural, policy, and communication barriers.
3. In consultation with organizations of or for people with disabilities, **set priorities for removing architectural barriers**, changing any discriminatory policies, and providing effective communication.
4. **Develop an implementation plan** designed to achieve compliance with the ADA. Such a plan, if appropriately designed and diligently executed, could serve as evidence of a good faith effort to comply.

5. **Avoid making judgments** based on myths, fears, or stereotypes.

**CONCLUSION**

All people have the right to choose what they would like to do for recreation and with whom and where they would like to do it. This is both a moral and a legal right for all people. Yet, people with disabilities often are denied access to the full range of recreation opportunities that constitute this right. Your responsibility as a recreation leader is to be sure that all your recreation programs are accessible to all people—whether they do or do not have a disability. Most recreators really want their programs to be accessible. The problem is that a lot of recreation professionals do not feel comfortable accommodating people with disabilities into their regular programs. They believe that they must have a lot of training or even a degree in therapeutic recreation to provide recreation programs for people with disabilities. That is just not true.

What is true is that you need to feel comfortable when working with people with disabilities, just as you would with anything that you do. In many ways, working with people with disabilities is no different than working with anyone else. People with disabilities have the same array of needs, wants, desire, expectations, and abilities as other people. However, making programs accessible to people with disabilities might require some kind of adaptation, either by the specific participant to compensate for a skill or capability deficit or to the activity itself in a way that does not significantly affect the enjoyment and satisfaction of other participants. However, the primary reason for making programs accessible is the basic right of all people to be judged according to their capabilities, not their disabilities; their right to be included in all aspects of public life; and their right to have fun like everybody else.

People with disabilities are entitled to the full benefits of citizenship, including all of its rights, privileges, opportunities, and responsibilities. As such, the general public should support people with disabilities in the following areas:

1. Encourage and support them to achieve their full potential.
2. Grant them dignity of risk.
3. Help them to live, learn, work, play, and retire in environments of their choice.
4. Encourage them to be primary participants in all aspects of the planning, implementation, monitoring, and evaluation of services and supports.

We believe that it is important to know about discrimination and barriers and their removal as you begin to understand more about recreation and therapeutic recreation.
LEARNING ACTIVITIES

1. List as many extrinsic barriers to recreation participation as you can. Which barriers on your list are easiest and which are hardest to change? Why?

2. Think of popular books, television shows, or movies that include people with disabilities. How are people with disabilities portrayed? How does the portrayal affect attitude formation and/or change?

3. What is one specific action that you can do to change someone’s negative attitude toward people with disabilities? Do it!

4. Conduct an accessibility survey using the ADAAG in Appendix A. What did you find? What was most surprising? What was most pleasing?

5. Plan an attitude change exercise that could be used in your class. Provide rationales to explain why you have planned the exercise in the particular way that you did.

6. As you walk around campus, try to find subtle examples of physical barriers that are often overlooked but are nonetheless problematic. Share your examples with fellow classmates and/or roommates.

REFERENCES


**ADDITIONAL RESOURCES**


**OTHER SOURCES OF INFORMATION ON ACCESSIBILITY**

**Americans with Disabilities Act Resources**

**ADA Information Line**, Department of Justice (DOJ), Civil Rights Division, Public Access Section, P.O. Box 66738, Washington, D.C. 20035-9998, (Voice) (202) 5140301, (TDD) (202) 514-0383.

Responsible for developing and enforcing the ADA state and local government (Title II) and public accommodation (Title III) regulations; it also coordinates technical assistance programs for federal agencies.

An automated information system offers the following information 24 hours per day, seven days per week:

1. Overview of the act and effective dates
2. List of federal government agencies that provide assistance and information
3. Agencies that operate information lines to assist in compliance with the act and grants from the Department of Justice
4. Title II—Overview of major requirements
5. Title III—Overview of major requirements
6. How to file a complaint under Title II or III

7. Order information—free of charge, including a) the ADA information packet and accessibility guidelines, b) Technical Assistance Manual—Title II and III, and c) ADA Handbook that includes regulations, public law, and other resource information
8. Staffed operator lines. Questions can be asked from 1:00 p.m.–5 p.m. EST. Monday through Friday.

Disability and Business Technical Assistance Centers

The National Institute on Disability and Rehabilitation Research (NIDRR) operates a network of 10 regional Disability and Business Technical Assistance Centers (DBTACs). These centers provide information, training, and technical assistance to businesses and agencies covered by the Americans with Disabilities Act and to people with disabilities who have rights under the ADA. You can contact the center in your region by calling (Voice/TDD) 1-800-9494ADA.

Disability Rights Education and Defense Fund, 2212 Sixth St., Berkeley, CA 94710, (Voice/TDD) (510) 644-2555.
Specializes in training and technical assistance for people with disabilities and their representatives, state and local government units, businesses and trade associations; it also provides public policy advocacy and litigation.

Easter Seal Society, 70 East Lake St., Chicago, IL 60601, (Voice) (312) 726-6200, (TDD) (312) 726-4258.
Offers a catalog of books, brochures, and video cassettes that can help state and local governmental agencies and businesses to implement the Americans with Disabilities Act.

National Center on Accessibility, 5040 State Rd. 67 North, Martinsville, IN 46151.
Operates a toll free number (1-800-424-1877) to offer assistance in making programs and facilities accessible to all people.

National Recreation and Park Association (NRPA), 2775 South Quincy St., Suite 300, Arlington, VA 22206, (703) 820-4940.

Over 1,300 state and local chapters represent 140,000 individuals with intellectual disabilities and their families; it also offers technical assistance and a fact sheet on the ADA.

The following is a list of sources of information and assistance available to help state and local governments understand and respond to Title II of the ADA. Many of the listed organizations and agencies produce or distribute publications relating to the ADA.
Barrier-Free Environments, P.O. Box 30634, Raleigh, NC 27622, (Voice/TDD) (919) 782-7823.

Founded in 1975 by Ron Mace, AIA. It provides consulting and design services, produces accessibility guidelines, and presents educational seminars. A publications list is available.

President’s Committee on Employment of People with Disabilities, 1331 F St., NW, 3rd floor, (Voice) (202) 376-6200, (TDD) (202) 376-6205.

Organization of 600 volunteer members nationwide works to build and maintain a climate of acceptance of people with disabilities in the workforce. It produces technical assistance materials, including videotapes, public service announcements, and fact sheets. Information on job accommodation, assistive technology, tax incentives, and other topics (call for list of publications) is also provided.


Provides information and professional consultation related to assistive technology services for states that have assistive technology grants from NIDRR. Contact RESNA to learn whether your state has a technology project.