Introduction to Recreation Services for People with Disabilities

A Person-Centered Approach

Third Edition

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The first and second editions of our book were dedicated with love to our wives and best friends, Kay Holjes and Maureen Mahon, who supported and encouraged us throughout our writing.

Since the publication of the second edition, Charlie's wife passed away. Kay 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 miss her dearly. Mike, Maureen, and I, along with our new co-author, Chuck Killingsworth and our new contributing author, Sandy Negley, dedicate the third edition 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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Acknowledgments

This revision is long overdue. We sincerely appreciate our colleagues who have used earlier editions and who have encouraged this update. As with other editions, this book also represents years of reading, teaching, thinking, and talking with students, friends, colleagues, and libraries. We think you will be really pleased with the updated material. We certainly are!

This third edition introduces a third author, Dr. Charles Killingsworth. Chuck has had teaching and practice experience in both Canada and the U.S. His experience and commitment to the concepts in this book make him an excellent author for this edition. In addition to Chuck's work on nearly every chapter, two chapters have been completely rewritten by another well-respected practitioner educator, Sandy Negley. Sandy's solo work on Chapter 14 and her work with Steve Bell on Chapter 17 really strengthen this new edition. 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, and Pittsburg State University, 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.

We also acknowledge and thank our colleagues and staff from the Universities listed above. You were colleagues who helped us grow and helped us continue to learn and contributed in so many ways to the realization of this book. Your constant support and queries helped us to continue to move forward even at times when progress seemed stalled. The original concepts and assistance of Carrie McCann, Karen Luken, Frank Brasile, Jennifer Mactavish, Laurie Selz, and Charlsena Stone were invaluable and remain part of the core of this book.

For this third edition, we particularly thank Christine McClure, who was a student assistant to Charlie at San Jose State University. You were untiring. Your hard work and attention to detail in finding references and graphs, typing, and editing are greatly appreciated. Also, thanks go to Ms. Cynthia Pfannenstiel, Professor Emeritus, Axe Library, Pittsburg State University, Pittsburg, KS, for all of your help in locating and obtaining numerous articles and other materials for use in the revisions. 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, Maureen, and Lynda, we thank you for helping us to achieve our goal.

Finally, the writing of this book would not have been possible were it not for the insights of the countless people with disabilities and advocates with whom we have spent time during the past few decades. Hopefully, you can hear your voices, thoughts, admonitions, and encouragement throughout this book. Together we have completed a revision that we hope will be useful to students in a variety of fields.

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Introduction

This third edition of *Introduction to Recreation Services for People with Disabilities* represents a significant revision. Much has changed, and we have worked hard to ensure that our book reflects the most current research and thinking about the interdisciplinary fields of disability studies.

The field of parks, recreation, and leisure studies has also made significant advances and these are included in this revised text. As the information available on the Internet has greatly expanded and is constantly updating since the last revision, we have included new electronic resources. We challenge each student and each professor who uses this text to continually monitor those electronic resources. We have made every effort to provide current and timely updates to this edition.

It is important to us that we are on the same wavelength with you, the reader, and we have written this introduction to share with you our perspective. To us, recreation is very important. 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. For example, recreation services are purely for enjoyment, while therapeutic recreation 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 has not been adequately 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 ostensibly "for" them.

About the Book

This book represents our personal learnings and beliefs 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.

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 from all of us that reiterate the importance of centering the services within the person. Some of these stories are from treatment 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 mental retardation 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, 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 informa-

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tion. 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 your response.

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 any-thing 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 thinking 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 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 the 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 curricula. Every student, whether he or she 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 disabili-

ties. 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 and a Conclusion. Section I contains six chapters that establish the philosophical, conceptual, historical, and political underpinnings of recreation and persons with disabilities. Section II includes six chapters that provide both general and specific information about people with disabilities. Section III 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. Initially in Chapter 1, there is a discussion of the definition of disability put forth by the World Health Organization to establish a continuity of terms that will be used throughout the text. Next is an introduction to "people-first" and positive 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 conditions or perpetuating stereotyping based on negative labels and images. In Chapter 1, we also present data on the number of people who are considered to have a disability.

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-increasing person-centered and responsive services.

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-determination, independence/interdependence, and inclusion. These concepts are consistent with a person-centered approach to recreation services and will be referred to both implicitly 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 potential. These concepts, if learned and practiced, will place the person and not the professional at the center of service delivery.

Chapter 4 recognizes the importance of legislation in understanding past and current services to people with disabilities. The chapter begins with the earliest legislation of modern times and moves toward more current legislation. The third edition presents the most up-to-date legislation in both the United States and Canada. To make this section more meaningful, a brief overview of how laws and their regulations are determined is presented. Following that, five U.S. laws and their subsequent amendments that form the core of protection against discrimination for people with disabilities are presented. Throughout this section, Canadian legislation that roughly corresponds to these five core laws also is presented. The final law that is presented is the Americans with Disabilities Act (ADA), which is the most persuasive piece of civil rights legislation that has ever been passed in North America. In many ways, the ADA is the culmination of the other core laws. The ADA has such an impact on all areas of life that it is covered in even more detail than the other laws.

Since all of these core laws deal with protection against discrimination, Chapter 5 covers how people with disabilities are treated today. We will look theoretically at attitude formation and attitude change as we suggest that as aspiring professionals 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 very detailed, yet it is information that is important for all potential recreation and therapeutic recreation professionals to un-

derstand. 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 therapeutic recreation, special 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 inaccuracies 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 questions as independent and/or interactive learning activities as well as traditional and on-line 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. 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. Other topics include information about life-span issues such as the various transitions throughout life, cultural diversity, and 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 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 will consider the issue of multiple disabilities within this chapter. Because the field of disability studies is changing rapidly, we have revised this section quite extensively to capture the most recent thinking on all of these topics.

Following this introductory 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 retardation/intellectual 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, as well as the knowledge of where to find more detailed 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 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/psycho-social 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 moves beyond the disability-specific information to discuss the service delivery system that includes recreation, therapeutic recreation and sport.

Chapter 13 explains 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.

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Chapter 14 describes the nature of therapeutic recreation. 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 therapeutic recreation specialists work. We have added current professional practice information. The first edition included three models. An additional model was added in the second edition, and a new therapeutic recreation service delivery model is in this third edition. This edition also has updated the old therapeutic recreation service models that have been revised over the past 10 years. 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.

Sport and people with disabilities is explored in Chapter 15. 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.

Chapter 16 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.

The concluding chapter of this book, Chapter 17, is totally different from the second edition. Although it still deals with issues and trends in the

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area of recreation and disability, the chapter begins with an introduction of the National Council on Disabilities report, "The Current State of Health Care for People with Disabilities," 2009 and explores its relationship to recreation and therapeutic recreation treatment/services. It also includes a detailed explanation of Healthy People 2010 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. We have used the latest literature to explain advocacy, self-advocacy, friendships/community connections, natural supports, and futures planning. In this edition, we have further developed the relationship between self-determination and self-advocacy. All of these issues involve recreation in some way. Therefore, rather than to talk narrowly about recreation and only secondarily about the larger issues, we have chosen to first look at the current issues and trends and then determine how recreation can or should be involved. This is entirely consistent with centering recreation in the person and will ensure that recreation and therapeutic services are provided on the basis of needs and strengths rather than only on professional judgment.

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" 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.

Learning Activities

1. How can you teach your fellow students and your instructor? Think about your previous life experiences, including but certainly not limited to how you like to be treated, a memory of a critically ill or institutionalized relative, a movie, a television show, a conversation you have had, or something you have observed but may not have even thought about. All of these experiences, combined with many others, make you who you are. This is your stock of knowledge and gives you much to share with others. Discuss with a classmate or a friend the extent to which you believe that you have or ever will have anything to teach to others. Discuss your level of confidence about sharing/teaching. What makes you reluctant to take on this role of student as teacher? Next, write down two things that you can teach others. (They do not have to be original, just things from your stock of knowledge that you can teach others.)

2. What do you notice about the way the authors refer to people with disabili- ties? What specific phrases and concepts do the authors use? Choose a person in your class who has read the same introductory material that you have read and discuss these two questions.

Section I

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Chapter 1

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) suggests:

> 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/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 in 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 different disabling conditions.

Definition of Disability

There is often confusion over such terms as disability, handicap, and impairment. They are used interchangeably; yet they can imply very different things. In 1980, the World Health Organization (WHO) published a definition of disability titled the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). Helander et al. (1989) described the 1980 classification system as a linear process that starts with an impairment that leads to a disability that may in turn lead to a handicap. The three terms are defined as follows:

Impairment: any loss or abnormality of psychological, physiological, or anatomical structure or function, which might result from a disease, accident, genetic or other environmental agents;

Disability: any restriction or lack of ability to perform an activity in the manner or the range considered normal for a human being; and

Handicap: a disadvantage for a given individual that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

An example we can consider as a means of understanding this definition is a child who has an intellectual disability whose parents do everything for her:

Impairment: deficit in intellectual functioning;

Disability: slowness in learning developmental skills, for example, talking at the usual time, walking at the usual time;

Handicap: parents speak for her, parents carry her around even when she begins to be able to walk, does not play with other children her age.

Impairment is a rather static term. Impairment refers to loss or abnormality and is a descriptive term. To know about a person's impairment only gives you very general information and really tells you very little about

that person. There is no doubt that by knowing what a person's impairment is, you can probably guess what some of the person's restrictions are. You can probably also guess what inconveniences or disadvantages a person might face. But your guesses are just that—guesses! Knowing about a person's impairment really doesn't tell you much about that person's disability or handicap. There is no doubt that your guesses might be accurate a lot of the time, but what you are doing is stereotyping. You are inferring specific information from general knowledge. You have ascribed certain characteristics to a person who is blind because you associate certain characteristics with blindness. That is unfair to the person who is blind and also to you. Both of you deserve the right to know more about a person than simply his "category."

For that reason, it is important to know about a person's disability and handicap. Unfortunately, the two terms are often used interchangeably, and that can cause confusion. To ensure that the distinction is clear, here is a simpler way to understand the differences among impairment, disability, and handicap. Think about disability as a functional challenge that is caused by an impairment, whereas a handicap is a function of the relationship between the individual and her physical and social environment.

In the example above, the disability of slowness in learning developmental tasks is caused by the intellectual impairment. Typically, a handicap is a social phenomenon facilitated by external circumstances (Lord, 1981) that causes people with disabilities to be at a disadvantage in relation to peers and the rest of society. A handicap might be caused by an environmental barrier, by lack of opportunities for recreation, or by societal attitudes. As compared to most disabilities, many handicaps can be eliminated or minimized. Unlike an impairment or even a disability, a handicap is not a taken-for-granted reality.

In the case of the little girl described above, 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 (deficit in intellectual functioning), nor her disability (slowness in learning developmental skills) that keeps her from speaking for herself, walking on her own, or playing with other children her own age. What keeps her from doing these things, (i.e., what handicaps her), are external forces.

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 (disability), and therefore not a good playmate for other children her own age. Both of these contentions might be true, but the belief that handicaps are social constructions suggests that social change

can in many cases lessen the existence of handicaps. Throughout this text, we will attempt to identify a number of strategies aimed at eliminating the existence of handicaps.

Most people with whom you come in contact will think in terms of the WHO 1980 definitions of impairment, disability, and handicap. However, the 1980 definition has been criticized as being too narrow. The 1980 definition was a cause-and-effect model that indicated that disease/injury leads to functional and organic impairment, which leads to disability in a person's behavior and activities, that results in some level of handicap. According to ICIDH and Environmental Factors International Network (1998), the model was criticized because of its linear nature—suggesting that the disablement process does not necessarily occur in a linear fashion. The 1980 classification also was criticized for not meeting the modern standards of cross-cultural applicability necessary for an international classification.

In 1993, the World Health Organization agreed to begin a process to revise the ICIDH. In 1998, following an exhaustive international collaboration, the draft of the International Classification of Impairments, Activities, and Participation (ICIDH2) was presented. A field-based empirical test of a revised version of the ICIDH was conducted in 17 centers in 15 nations (Trotter et al., 2001, p. 15). After the field test and following extensive discussions among WHO collaborating centers, advocacy groups, representatives of disabilities organizations, governmental health programs, consultants, researchers, and WHO staff, one final modification process produced a new classification that was adopted by the World Health Assembly in 1999.

At its meeting in 2001, the Assembly unanimously approved the adaption of the International Classification of Functioning, Ability, and Health (ICF). In 2006, the publishing company Idyll Arbor, Inc. published "the first commercially available book about the ICF and with ICF in its title." The book, written by Heather Porter and joan burlingame, is titled *Recreation Therapy Handbook of Practice: ICF-based Diagnosis and Treatment*. Prior to this new book, in October of 2005, the board of directors of the American Therapeutic Recreation Association strongly endorsed the ICF classification concept.
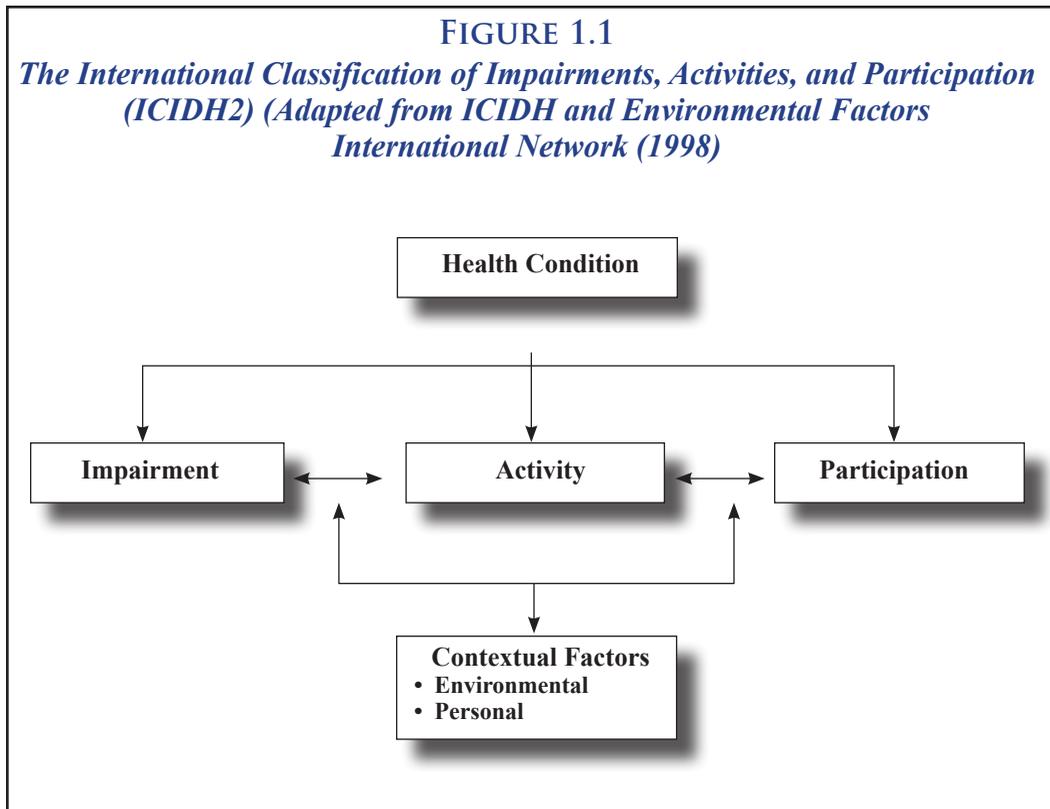
The revisions to the definition of disability occurred within the context of a society that has developed an enhanced awareness of the functional limitations faced by many of its citizens. Such things as increased recognition of the importance of including people with disabilities in community life and a redefinition of health to move beyond the absence of illness to focus on quality of life have served as a backdrop for this new definition. The ICIDH2 classification has three dimensions: Impairment, Activity, and Participation, that roughly relate to the previous categories (impairment,

disability, and handicap). Figure 1.1 provides a graphic representation of the relationship among these dimensions.

According to this new definition, disablement is an umbrella term that includes three key dimensions: body structures or functions, personal activities, and participation in society. The personal activities dimension is formerly the category disability, and participation is formerly handicap. It is clear, even at this level, that the redefinition is much more focused on the abilities of the person, as compared to the disabilities, which is certainly in keeping with the 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.

According to ICIDH and Environmental Factors International Network (1998, p. 27), "*Impairment* is a loss or abnormality of body structure or

FIGURE 1.1
The International Classification of Impairments, Activities, and Participation (ICIDH2) (Adapted from ICIDH and Environmental Factors International Network (1998)

of a physiological or psychological function." Rather than the underlying pathology, impairment is the manifestation of the pathology, which can be permanent or temporary.

The second dimension, *Activity*, is 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.

The final dimension is *Participation*. Participation is, 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.

What should be clear from this new definition of disability, 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 come into contact.

Imrie (2004) attempts to help us move toward a greater understanding of the ICIDH 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 universalisation 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).

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, for convenience and to establish a common terminology throughout, we nearly always use the word disability. 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 Language

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:

> (V)ocabulary 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, 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. There is growing consensus that the use of "*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 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.

FIGURE 1.2

Wee Pals   **by Morrie Turner**
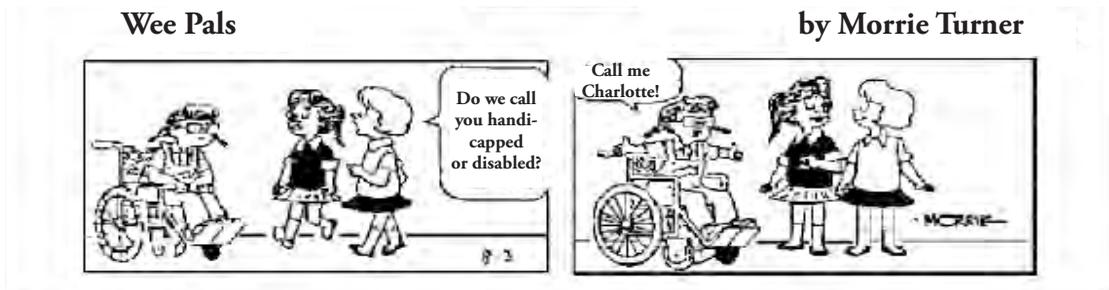
Nearly every professional and advocacy group in the United States and Canada has provided strong leadership in the promotion of positive language in the disability movement.

CREATE POSITIVE IMAGES

In addition to using "people-first" language, we should be careful not to use negative or pejorative words. Certain terms can be dehumanizing and can perpetuate negative stereotypes about people with disabilities. The way a society refers to persons with disabilities shapes its beliefs about and responses to them. While not written in people-first language, the National Recreation and Park Association in its publication, *Trends*, illustrates this point: "the way in which a society responds to the needs of the handicapped is a good measure of civilization itself. We are more aware today than ever before of the interdependence of human beings. We understand that whatever diminishes anyone diminishes everyone" (Third Quarter, 1974).

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

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TABLE 1.1
Examples of Appropriate/Inappropriate Technology

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

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.

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). Recently (August 2008) the movie, *Tropic Thunder*, 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 sentence on the reference being made to a person. 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. Hutchinson and McGill (1992, p. xvi) suggest 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. Kim Brown from Therapy Animals Assisting People of St. George, Kansas,

uses cats in addition to dogs to assist people with emotional disabilities (personal communication, 10/21/08).   Also, the National Primate Research Center of the University of Wisconsin-Madison provides research and information about using monkeys to assist people with disabilities on the Primate Info Net (http://pin.primate.wisc.edu).

- 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.

Cole (2008) briefly discusses the issue of "people-first" language in an article published by Diversity, Inc. on their website. The article supports the main principle of this cornerstone in the discussion of how to refer to a person with a disability. In addition, as a part of Diversity, Inc.'s promotion of National Disability Employment Awareness Month, provides "7 Things NEVER to Say to a Person With Disabilities." Those "things" include, according to Daryl Hannah (2008):

1. "What's wrong/what happened?" or "Were you born that way?"
2. "Oh, if you just have faith, you can be healed."
3. Speaking slowly or loudly to someone who is in a wheelchair.
4. "I don't even think of you as a person with a disability."
5. "How do you go to the bathroom?"
6. "But you look so good."
7. "Oh, you're here, you must feel better."

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

How Many People Have Disabilities?[1]

It is difficult to say exactly how many people have disabilities in the United States or Canada. The United States Census Bureau's Survey of Income and Program Participation (SIPP, 2005) estimated that there are 54.43 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 is not that easy.

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 (ICD survey, 1986, p. 14). Americans with disabilities are evenly divided between those who do and those who do not consider themselves disabled (handicapped). About 49% of people with disabilities said they consider themselves disabled (handicapped), while 50% said they do not. However, there are dramatic differences in self-perceptions between slight or moderately disabled people and those who are severely disabled. Only 19% of people who identify themselves as slightly disabled and 32% of those who identify themselves as moderately disabled consider themselves disabled. Large majorities of those who identify themselves as severely disabled (58%) or very severely disabled (77%) consider themselves disabled (handicapped) people. People most likely to consider themselves disabled (handicapped) 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. But 23% of people who identify themselves as very seriously disabled do not consider themselves disabled (handicapped). Many factors clearly influence self-perceptions about disability (handicap).

The way surveys are constructed dictates the populations that will be solicited as well as the responses that will be given by those surveyed. Already clear is that the very definition of the term disability varies depending on who asks the questions and what information is sought. As such, the statistics on the size of the population of individuals with disabilities depend on various program statistics serving selected eligible people, on information collected in surveys addressing broad social issues, or on interpretations of data designed to achieve particular programmatic purposes (*Rehab Brief*, 1993).

Indeed, there are many different answers to the question: "How many people with disabilities are there?" It is important to realize that estimates vary given the specific use for the data. For example, in pushing for legislation, advocates may adopt a larger, more general number, such as the NHIS (2007) 36 million number used in the Americans with Disabilities Act (ADA) or the 2005 SIPP estimate of 54.43 million. On the other hand, a person doing a more targeted study may use a different number to refer to more specific information on particular populations or particular needs. It is safe to say that the more broadly disability is assessed, the larger the number of persons counted. For example, the 2005 SIPP estimate is 54.43

million, while the 2007 ACS estimate is only 41.2 million. The reason for such a disparity is that the more current ACS survey uses a short list of six questions, whereas the SIPP uses many more questions and gets a larger group of people (personal communication with Mitch LaPlante, Ph.D., Director, Disability Statistics Center, University of California, San Francisco, May 16, 2005).

Clearly, 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 suggested the 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).

In the United States, there are four frequently cited surveys that measure the extent of disability in the U.S. They are: the Census Bureau's Survey of Income and Program Participation (SIPP); 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 extensive set of disability questions that have been asked in SIPP makes it the preferred source for examining most disability issues in the U.S. In Canada, the main source of data is the Participation and Activity Limitation Survey (PALS).

The CPS is a more limited measure of disability, says bureau statistician Jack McNeil, because it specifically asks people only about work-inhibiting disabilities. Respondents are asked if they have a condition that prevents them from working or limits the kind or amount of work they can do. "That could be responded to in various ways by a person with a disability," says McNeil. "If a person uses a wheelchair, but has a satisfactory job, then there wouldn't be a particular reason for that person to report that he has a disability."

The CPS question concerning work disability dates back to the 1960s when the Social Security Administration wanted to identify the number of people who might eventually apply for Social Security disability benefits. In contrast, the newer SIPP questions explore issues of functionality across the life span and therefore provide a much broader estimate.

The SIPP defines functional disability as difficulty with or inability to perform age-appropriate activities due to a physical or mental condition or impairment. This includes those who have trouble seeing ordinary newsprint even with corrective lenses; those who can't hear normal conversation or whose speech can't be understood; those who have trouble lifting ten pounds, climbing a flight of stairs, walking three city blocks, or getting around in their homes; or those who have difficulty with at least one of the five Activities of Daily Living (ADL)—getting into or out of bed or a chair, bathing, dressing, eating, and using the toilet.

The SIPP also asks about people's ability to perform Instrumental Activities of Daily Living (IADL). These include: going outside the home, keeping track of money and bills, preparing meals, doing housework, and using the telephone. The survey also collects information about those who use wheelchairs, canes, crutches, or walkers, as well as those who have certain mental conditions. Finally, the SIPP asks about people's ability to work at a job.

With this set of questions, the SIPP data reveal links between disabilities and employment status as well as disabilities and functional living. Some people who are paraplegic don't find their condition a hindrance to full-time work, while others do. With this survey, analysts can tease out the differences.

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; non-major 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.

Acute conditions that could cause temporary disability include all types of illnesses and injuries. Sometimes the lasting effects of injuries become chronic impairments. Chronic conditions include the same congenital and acquired impairments tallied in the SIPP, such as visual and hearing problems, as well as paralysis and limb loss. They also include mental illness and intellectual disability, immunity disorders, and diseases of the

respiratory, circulatory, digestive, and other body systems. In other words, 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.

The value of the SIPP and NHIS questions is that they permit customized definitions of disability. After all, the label is largely contingent on people's expectations of what they can, should, or want to do in their particular situations. If a construction worker suffers a back injury that prohibits him from doing heavy labor the rest of his life, he's permanently disabled in that line of work. An office worker with the same back problem may require ergonomic equipment and flextime for physical therapy, but she might be otherwise unaffected as far as work goes. On the other hand, she might be unable to do certain home-maintenance tasks, like lifting children and bags of groceries (Mergenhagen & Crispell, 1997).

The choice of how to define disability is more than merely a semantic issue. In fact, the definition determines who is included and who is not. For example, for state or federal entitlement programs that commission a survey of the numbers of people with disabilities, cost containment issues limit the population count. On the other hand, larger numbers will be solicited and subsequently used by advocacy groups attempting to affect local, state, or federal policy. The definition, as a result, has a direct impact on the statistical estimates of people with disabilities. The range of estimates varies depending on the source of data and the concept to be measured. See Table 1.2 for selected disability statistics.

We must note that most national surveys cover only the non-institutionalized population. In the United States, 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 who are mentally retarded. 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. The figure in the United States that currently is popularly accepted is the SIPP survey that states that 54.43 million Americans have at least one impairment.

People 15 years old and over were identified as having a disability if they met any of the following criteria:

- Used a wheelchair or were a long-term user of a cane, crutches, or a walker
- Had difficulty performing one or more functional activities (seeing, hearing, speaking, lifting/carrying, using stairs, or walking)

TABLE 1.2
Selected Disability Statistics

54.43 million (18.7%) Americans live with some type of disability in the U.S.	SIPP, 2005
34.95 million (12%) of people of all ages have a severe disability	SIPP, 2005
18.13 million (51.8%) of people aged 65 and older have some type of disability	SIPP, 2005
12.94 million (36.9%) of people aged 65 and older have a severe disability	SIPP, 2005
41.2 million (15%) of people have some level of disability (data from a much smaller set of questions than SIPP)	ACS, 2007
20.8 million (9%) of people over 15 have a physical limitation	SIPP, 2005
2.0 million (10%) of people living in Canada between the ages of 15 and 64, have some type of disability	PALS, 2001
36 million (12 %) of U.S. residents have a limitation in activity	NHIS, 2007
13.3 million (7%) of 16- to 64-year-olds, reported a medical condition that made it difficult to find or hold a job	ACS, 2007
Unemployment rate of persons with a disability was 14.3%	*CPS Monthly*, June 2009
Unemployment rate of persons with *no* disability was 9.5%	*CPS Monthly*, June 2009
Employment-population ratio for persons with a disability was 19.4%, compared with 65% for persons with *no* disability	*CPS Monthly*, June 2009

- Had difficulty with one or more activities of daily living (the ADLs included getting around inside the home, keeping track of money and bills, preparing meals, doing light housework, taking prescription medicines in the right amount at the right time, and using the telephone)
- Had one or more specified conditions (a learning disability, intellectual disability or another developmental disability, Alzheimer's disease, or some other type of mental or emotional condition)
- Were limited in their ability to do housework
- Were 16 to 67 years old and limited in their ability to work at a job or business

• Were receiving federal benefits based on an inability to work

People age 15 and over were identified as having a severe disability if they were unable to perform one or more functional activities; needed personal assistance with an ADL or IADL; used a wheelchair; were a long-term user of a cane, crutches, or a walker; had a developmental disability or Alzheimer's disease; were unable to do housework; were receiving federal disability benefits; or were 16 to 67 years old and unable to work at a job or business.

Canadian information comes from the 2001 Participation and Activity Limitation Survey (PALS). PALS provides information every 10 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.

Disability and the Social System

People with disabilities are typically a part of a number of social systems. Howe-Murphy and Charboneau (1987, p. 12), in their text *Therapeutic Recreation Intervention: An Ecological Perspective*, define a system as

> ... a complex of elements or components directly or indirectly related in a causal network, such that each component is related to at least some others in a more or less stable way within a particular period of time.

They identify six systems of which a person with a disability is often a part. The systems they identify include the following:

• the total person   • an agency system
• the biological system   • a neighborhood system
• the family system   • a community system

Figure 1.3 represents graphically what is included within each of these systems. All of the systems described in Figure 1.3 compose what may be referred to as a multiple supra-system. Every component of each system interacts with other components of other systems. For example, the spiritual component of the total person system will quite likely interact with a family component such as mother or grandfather. Howe-Murphy and Charboneau suggest that it is important to understand the boundaries of each of the

FIGURE 1.3
Howe-Murphy and Charboneau System
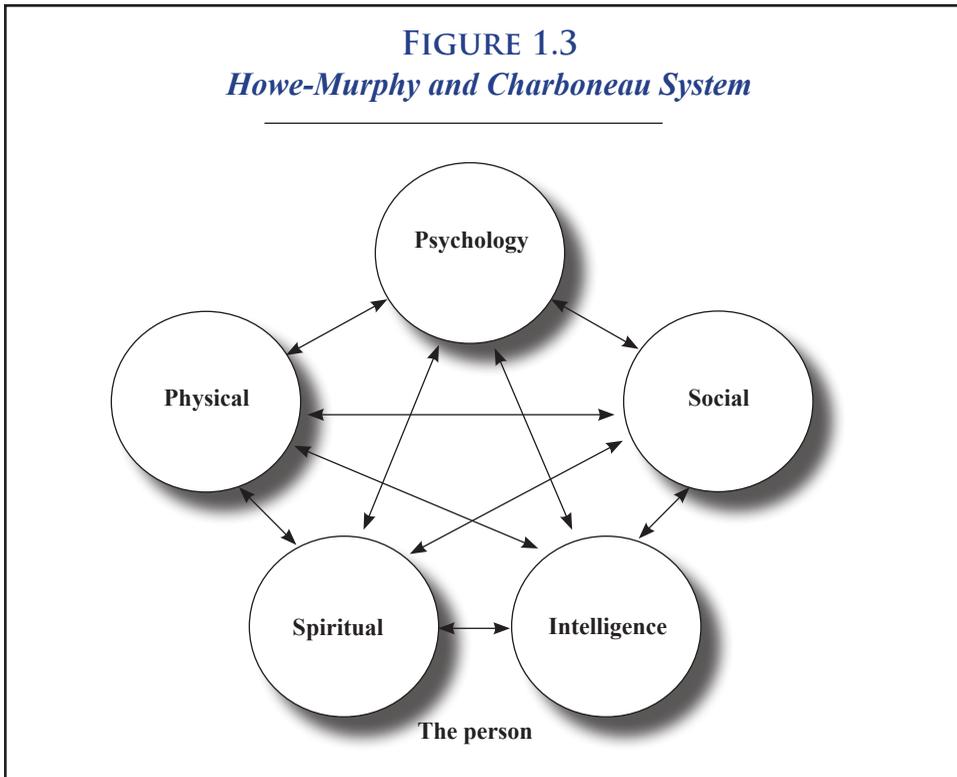
systems for a particular person in order to design interventions and to determine how recreation interacts with each system. At the same time, it is also necessary to recognize that within every system, there is a constant flow of information, resources, and effect within and between systems that Howe-Murphy and Charboneau describe as the energy of the social system. It is particularly important to understand that each of the subsystems portrayed in Figure 1.3 may differentially interact with a person with a disability. In considering how recreation relates to the systems described above, we must understand that each of the systems is in a constant state of flux.

For example, the family system that includes a child with a disability will continuously undergo change. As the child moves from childhood to adolescence, she will undergo physical and social changes that will have an impact on her relationships with other family members. Sexuality will become an important consideration for the child, her parents, and quite likely other family members. These changes may have a positive or a negative effect on the overall family system. The child's growing awareness of her sexuality may cause the parents to be uncomfortable and may introduce stress into their relationship with their daughter. In this case, the family

system will be undergoing negative change. In contrast, the child and family may deal with the issue of sexuality in a positive way and their relationship may be enhanced by communicating about such life changes. This would suggest that the system would undergo a positive change.

Each of the systems will continuously undergo similar types of changes. The significance of these systems and their ongoing changes to our central focus is that the recreation delivery system must maintain itself within all of these systems and recognize the place of recreation in relation to each system and the overall supra-system. In the case of the child experiencing sexual growth, any recreation intervention or facilitated experience must be sensitive to the child's present social system.

Beyond understanding the need for recreation services to be framed within the context of the social system of the individual with a disability, it is important to address more specifically the need for recreation services to be framed within the scope of the overall human service delivery system. This system in some ways is a combination of the agency, neighborhood, and community systems described by Howe-Murphy and Charboneau. In Figure 1.4, the most common services for people with disabilities are presented.

The extent to which these services are available within a given community will vary across the United States and Canada. Existing and new recreation services must be framed within the context of these other systems. For example, a therapeutic recreation program designed to facilitate the transition of an individual from a rehabilitation setting must function in an interdependent manner with employment services, schools, and social services in order to create a transitional process that meets the overall needs of the individual. In this way, the chance of duplication or lack of services in a particular area will be diminished, and the needs of the individual will be met.

Summary

There are noteworthy differences between the old and new paradigms of disability perspective, particularly in the way that disability is measured, defined, and understood. The new paradigm emphasizes the dynamic intersection of environmental factors and individual characteristics and the role this intersection plays in shaping the disability experience. In contrast, the old paradigm of disability is reductive to pathology and emphasizes individual disability characteristics and deficits (Pledger, 2003, p. 279). Throughout this book, we will focus on the new paradigm that stresses ability over *dis*-ability as we encourage you to do everything to make all
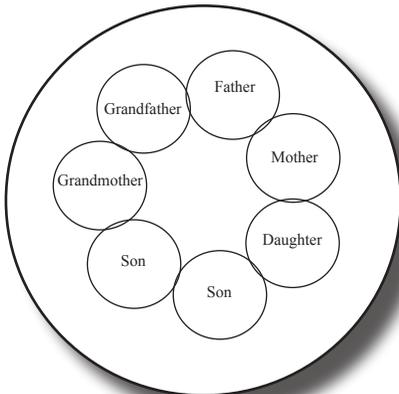
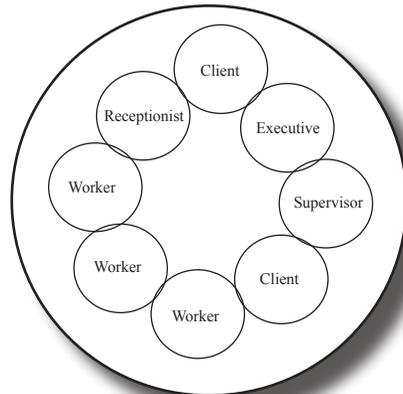## FIGURE 1.4
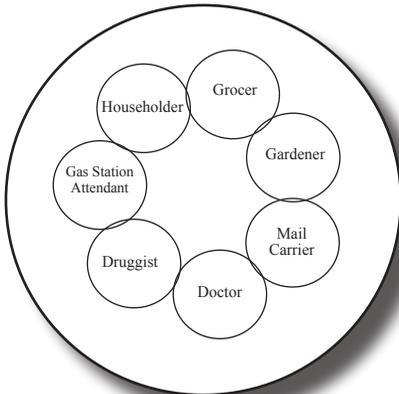### *Common Services for People with Disabilities*
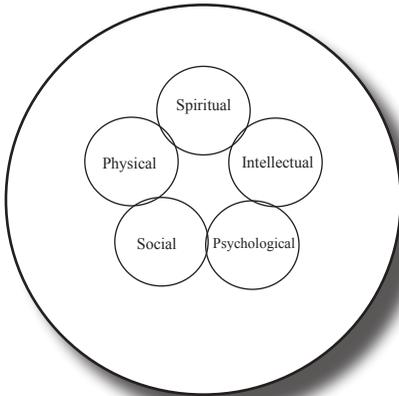
Total person, a system
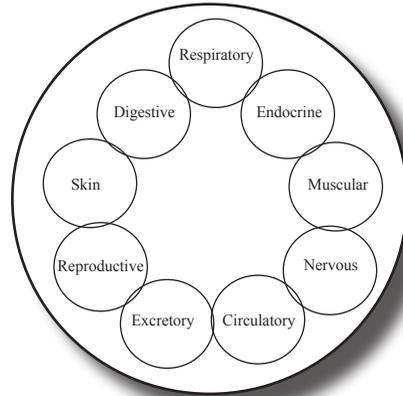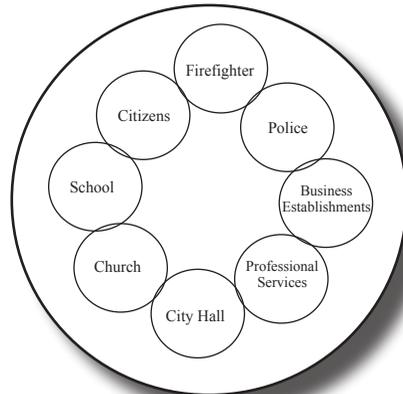
Person, a biological system

A family system

An agency system

A neighborhood system

A community system

persons part of and not apart from the communities in which they live.

In the next chapter, we will look at how people with disabilities have been treated throughout time.

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 ICIDH2 classification for a person who has become blind in her late teenage years from a degenerative eye disease, describe what might be her
    - Impairment
    - Activity
    - Participation
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

Allen, S. N., & Mor, V. (1998). *Living in the community with disability.* New York: Springer.

Auslander, G. K., & Gold, N. (1999). Disability terminology in the media: A comparison of newspaper reports in Canada and Israel. *Social Science and Medicine, 48*(10), 1395-1405.

Beadles, R. J., Jr. (2001). How to refer to people with disabilities: A primer for lay people. *Review (Washington), 33*(1), 4-7.

Cole, Y. (2008). "Terminology: What Should You Call a Person With a Disability?" Diversity, Inc. website. Retrieved October 9, 2008. Available: http://www.diversityinc.com

Costa, A. J. L., Massad, E., Ortega, N. R. S., & Araujo, A. (2004). Perception of disability in a public health perspective: A model based on fuzzy logic. *International Journal of Medical Informatics, 73*(7/8), 647-656.

Devlieger, P. J. (2000). From handicap to disability: Language use and cultural meaning in the United States. *Disability and Rehabilitation, 21*(7), 346-354.

Discover together: A disability awareness resource. (1992). Ottawa: Department of the Secretary of State of Canada.

"Dispelling myths about people with disabilities." (1995). Online. Internet, retrieved 1 March 1999. Available: http://www.50.pccpd.gov/pcepd/pubs/fact/ dispel.htm

Frey, L. R., & Upchurch, C. M. (2000). Walking the en-abling dis-ability symbolic tightrope: Towards a constitutive, dialectical view of disability symbolism. *Disability and Rehabilitation, 22*(11), 509-512.

Hannah, D. (2008). 7 Things NEVER to Say to People With Disabilities. Diversity, Inc. website. Retrieved October 23, 2008. Available: http://www.diversityinc.com

Helander, E., Mendis, R., & Nelson, G. (1989). *Training disabled people in the community (RHB184)*. Geneva: World Health Organization.

Howe-Murphy, R., & Charboneau, B. (1987). *Therapeutic recreation intervention: An ecological perspective.* Englewood Cliffs, NJ: Prentice-Hall.

Hutchinson, P., & McGill, J. (1992). *Leisure, integration, and community.* Concord, Ontario: Leisurability Publications, Inc.

ICIDH and Environmental Factors International Network (2001). *ICIDH 2* (WHO, 2001).

Imrie, R. (2004). Demystifying disability: A review of the International Classification of Functioning, Disability and Health. *Sociology of Health and Illness 26*(3), pp. 287-305.

"Language and disability." (1998). Online. Internet, retrieved, 28 February 1999. Available: http://www.austlii.edu.au/au/orgs/uts/roles/policy/aa_policy/ ablist.html

Linton, S. (1998). *Claiming disability, knowledge, and identity.* New York: New York University Press.

Lord, J. (1981). Opening doors, opening minds! *Recreation Canada*, Special Issue, 4-5.

Louis Harris & Associates, Inc. (1986). *The ICD survey of disabled Americans. Bringing disabled Americans into the mainstream.* Washington, D.C.: Author.

Masala, C., & Petretto, D. R. (2008). From disablement to enablement: Conceptual models of disability in the 20th Century. *Disability and Rehabilitation, 30* (17), pp. 1233-1244.

Mergenhagen, P., & Crispell, D. (1997). Who's disabled? American Demographics On-line. Internet, retrieved, 6 December 1998. Available:http://www.demographics.com/publications/ad/97_ad/9707_ad/ad970712.htm .

Olkin, R. (2002). Could you hold the door for me? Including disability in diversity. *Cultural Diversity and Ethnic Minority Psychology, 8*(2), pp. 130-137.

Pfeiffer, D. (2000). The devils are in the details: The ICIDH2 and the disability movement. *Disability and Society, 15*(7), 1079-1082.

Pfeiffer, D. (1999). The problem of disability definition: Again. *Disability and Rehabilitation, 21*(8), 392-395.

Pledger, C. (2003). Discourse on disability and rehabilitation issues: Opportunities for psychology. *American Psychology, 58*(4), 279-284.

Rehab Brief. (1993). Bring research into effective focus. National Institute on Disability and Rehabilitation Research, Office of Special Education Research Services, U.S. Department of Education. (Vol. 14),8.

Scotch, R. L. (1990, Summer). The politics of disability statistics. In I. Zola (Ed.), *Disability Studies Quarterly, 10*(3).

Shapiro, J. P. (1993). *No pity: People with disabilities forging a new civil rights movement.* New York, NY: Times Books.

Smedby, B. (2001). ICF approved as the successor of ICIDH. *Journal of Rehabilitation Medicine, 33*(5), 193-195.

Titchkosky, T. (2001). "Disability: a rose by any other name? people-first language in Canadian society." *Canadian Review of Sociology and Anthropology, 38*(2), 125-140.

Trotter, R. T., Ustun, B., Chatterji, S., Rhem, J., Room, R., & Bichenbach, J. (2001). Cross-cultural applicability research on disablement: models and methods for the revision of an international classification. *Human-Organization, 60*(1), 13-27.

Williams, C. (2006). *Disability in the workplace.* Statistics Canada–Catalogue no. 75-001-XIE.