

DELIVERING QUALITY HEALTHCARE FOR PEOPLE WITH DISABILITY

SUZANNE C. SMELTZER



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THIS BOOK IS based on the principle and belief that all healthcare professionals—regardless of discipline, level of education, or position within the healthcare system—have a role in caring for individuals with disability.

Disability is a universal aspect of the human experience. It will affect all of us, either directly or indirectly, at some point in our lives. Healthcare professionals frequently provide care for and communicate with people who have disability. Many care providers have acknowledged that additional education would help them deliver optimal evidence-based care. The educational gap has broad implications and repercussions for the care of this population.

Delivering Quality Healthcare for People With Disability provides a road map for nurses, nursing students, and other healthcare professionals to deliver quality healthcare for individuals with disability. From social determinants of health to disability models to an understanding of different types of disability, author Suzanne Smeltzer helps nurses take the lead in redefining education and addressing the needs of people with disability.

“Dr. Smeltzer masterfully synthesizes theory, research, and practice and provides clear strategies nurses can use to improve and humanize healthcare for people with disability.”

—**ALEXA STUIFBERGEN, PhD, RN, FAAN**
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SUZANNE C. SMELTZER, EdD, RN, ANEF, FAAN

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Smeltzer has received multiple awards for her work related to disability, including the 2016 Nurse.com/Gannett Foundation Lecture-ship Award for Diversity, Inclusion, and Sustainability in Nursing Education from the American Association of Colleges of Nursing. She was the first author/editor of *Brunner & Suddarth's Textbook of Medical-Surgical Nursing*, published by Lippincott Walters-Kluwer from 1992 to 2014, and continues to write the textbook's chapter on disability and chronic illness. This remains the only widely used medical-surgical nursing textbook that includes a section specifically on disability as well as disability-related issues throughout the book. The textbook has been translated into multiple languages and is used around the world. She was inducted into the American Academy of Nursing in 1992 and the Sigma International Nurse Researcher Hall of Fame in 2019 for her work on disability.

Smeltzer has been the driver of the standardized patients with disabilities project at Villanova University's College of Nursing, which ultimately resulted in the development of the Advancing Care Excellence for Persons with Disabilities (ACE.D) component of the National League for Nursing's series on advancing care excellence for vulnerable populations. She has had an active role in the development of competencies related to disability for nurses and other

healthcare professionals. In addition, she has received research and programmatic funding related to disability and published widely on the issue. Her research has focused on attitudes of nurses toward individuals with disability, inclusion of disability-related content in nursing curricula and textbooks, and health issues of women with disability, including those related to pregnancy.

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Marks has addressed the lack of disability-related content and experiences in the education of most healthcare professionals and has had a prominent role in advocating for the inclusion of individuals with disability in nursing and nursing education. Many schools of nursing have automatically excluded from consideration applicants to their programs who disclose a disability. She views the inclusion of individuals with disability in nursing education and the retention of nurses with acquired disabilities in nursing practice as important strategies to increase nurses' understanding and knowledge about caring for individuals with disability they encounter in their practice. Marks's advice has been invaluable in working with faculty and administrators to determine what steps and strategies they should take to be fair to applicants and compliant with the law.

Marks coproduced *Open the Door, Get 'Em a Locker: Educating Nursing Students With Disabilities*, an award-winning documentary about the experiences of nursing students with disability. The documentary serves as a forum for voices of nursing students, faculty, academic administrators, and agency nursing staff to discuss the trials and triumphs of shifting perspectives and transforming nursing practice by healthcare providers with disability.

Marks has published and presented widely on the topic of disability and health professionals with disability, in journals and at conferences that reach multiple disciplines. She has been recognized for her contributions through a number of awards. She was inducted into the American Academy of Nursing for her contributions to nursing.

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FOREWORD

Delivering Quality Healthcare for People With Disability, by Suzanne Smeltzer, with contributing author Beth Marks, is a must-read for nurse educators, advanced practice nurses, and students of the profession. Schools of nursing and medicine have not engaged in meaningful education about care of people with disability, and few schools of nursing or their graduate programs adequately address the health and healthcare issues of individuals with disability. At the undergraduate level, care of people with disability may be discussed in courses that address infants, children, and adults with genetic illnesses. In the care of the adult or in geriatric nursing, students learn about movement disorders associated with neurological or cardiovascular diseases and the impact of traumatic injuries such as motor vehicle crashes, falls, and gunshot wounds on mobility and cognition. Some schools offer simulations programs in which students are “given” disabilities and asked to navigate their environment with blindfolds, padded earphones, crutches, or with one arm in a sling, a practice discouraged by the disability community and disability advocates.

Although nursing students care for people with disability, the focus of care is usually on the management of acute or chronic illness and the provision of safety or comfort measures. Few nursing course objectives emphasize the Alliance for Disability in Health Care Education’s Core Competencies on Disability for Health Care Education (2019). Course readings seldom mention global and national reports on the scope of disabilities by the World Health Organization, the International Council of Nurses, or the National Academy of Medicine. Few nursing education programs address the interaction of disability and healthcare or the barriers to quality healthcare experienced by individuals with disability.

This book covers disability as an inequity and a health disparity within the context of social determinants of health, noting that disability can be intellectual, developmental, or physical, as well as expressions of neurological disorders, mental illnesses, or sensory impairments. One significant chapter of the book speaks to the fact that nursing students can also be living with disabilities.

Globally, more than a billion people, about 15% of the world's population, live with some form of disability (World Health Organization, 2018). In the United States, one in four persons have a disability (Centers for Disease Control and Prevention, 2018). Yet definitions, classifications, and the epidemiology of disability do not receive adequate attention in nursing education and practice. Dr. Smeltzer not only identifies this problem but also provides strategies to bring about curriculum change. Given the number of people with disability, the gaps in nursing education must be addressed.

People with disability are the largest group of vulnerable persons in the United States. Most Americans have or know someone with a disability. Dr. Smeltzer gives a face to the statistics by describing how disabilities are commonly associated with mobility, cognition, hearing, vision, and the ability to live alone or engage in self-care.

The book also charts how the US has changed its approach to people with disability. Some live with their parents or relatives. Others live in group homes with other adults with mobility issues or cognitive difficulties. In the past, some people with disability were placed in institutions—often long-term psychiatric hospitals. Some became homeless or found themselves in jail.

Today most young people with disability are successfully mainstreamed in primary and secondary schools. Students assisted by mobility devices and students who rely on interpreters to help them understand what their teachers and classmates are saying graduate higher education. Despite these successes, healthcare for those with disability often remains problematic and inadequate.

This book is more than a textbook. It is a road map to overcoming a noticeable gap in the education of health professionals. It increases awareness and deepens the knowledge base of professional nurses and students. Knowledge and physical barriers can be improved, and

FOREWORD

I encourage you to read and have your students and colleagues read *Delivering Quality Healthcare for People With Disability*.

—Sr. Rosemary Donley, PhD, APRN, FAAN
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INTRODUCTION

“Disability is a universal aspect of human experience, affecting nearly everyone at some point in his or her life span.”

–Kirschner & Curry, 2009

In 2009, in a commentary published in the *Journal of the American Medical Association*, Kirschner and Curry stated what should be obvious to all of us: Disability is a universal aspect of human experience, and it will affect all of us, either directly or indirectly, at some point in our lives. Despite its universality and the inevitable encounters with disability that nurses and other healthcare professionals will have—personally and as part of their role as health professionals—the health professions’ educational programs do not adequately prepare students to provide quality care to individuals with disability.

Those with disability—be it mild and a mere inconvenience, or one that necessitates the use of high-tech support for survival—have repeatedly reported that their healthcare needs are not adequately addressed by healthcare providers. Most healthcare professionals, including nurses, are unfamiliar with the consequences of disabling conditions in the lives of individuals with disability. They lack knowledge about how to communicate effectively with those with all types of disability, do not consider the effect of individuals’ disability on their ability to participate in health-promotion efforts, harbor negative attitudes and bias toward them, stereotype them, and often perceive them as unable (or unwilling) to take an active part in their own care.

Healthcare professionals have reported that disability is not a very important issue, despite the statistics that indicate that people with disability comprise the largest minority group in the US. Some healthcare providers have indicated that they are unlikely to be in roles or settings in which they will care for individuals with disability, when in fact, based on the large and growing number of people

with disability and their need and desire for healthcare, they are very likely to encounter individuals with disability in their practice.

Many healthcare professionals recognize and acknowledge that they lack knowledge, expertise, and experience to provide quality care for this population, despite years of education to prepare them to provide quality healthcare to diverse populations. Because of this lack of knowledge and expertise on the part of healthcare professionals across healthcare settings, communication and interaction of healthcare providers with individuals with disability, and the healthcare they receive, remain very problematic.

Ineffective communication on the part of healthcare professionals when interacting with individuals with disability has broad implications and repercussions. Healthcare providers who believe they know best, and are the experts on disability (despite their acknowledged lack of expertise on the topic), will continue to ignore the wishes and preferences of individuals with disability and their desire to make decisions about their own lives and healthcare. Many healthcare professionals presume people with disability are reluctant to participate in health promotion. Many healthcare professionals are unaware of barriers to accessible healthcare and screening experienced by individuals with disability, and as a result are unable to identify ways to address or overcome those barriers. Healthcare professionals who do not understand disability and the contributions that those with disability make to their families, to the lives of others, and to society as a whole, may consider preventive health screening and health promotion efforts to be not worth the effort for someone who already has a disability.

Individuals with disability have reported that healthcare providers are uncomfortable and unwilling to discuss issues related to sex and sexuality with them. They have further reported that healthcare providers assume that they are uninterested (or perhaps believe that they should be uninterested) in sexual relationships, intimacy, pregnancy, and childbearing. Women with disability who have elected to become mothers and have sought out prenatal care have reported that their healthcare providers' first assumption was that the reason

for their healthcare visit was to terminate their pregnancy, even if the pregnancy was well-thought-out and planned. Women with disability who have successfully become pregnant have been questioned and chastised by healthcare professionals about their decision to bear children, and have even been blatantly accused of being irresponsible for becoming pregnant and having children. Women with disability have expressed fear that someone will attempt to remove their children from them based solely on their having a disability, regardless of how well they have cared for their children and been very successful and effective parents.

Most studies that have addressed the healthcare experiences of individuals with disability have focused on their interactions with physicians. However, studies of nurses indicate that nurses' attitudes and knowledge level mirror those of physicians and reflect those of greater society. Numerous national and global organizations and agencies have issued calls for the healthcare disciplines to address the inadequate healthcare experienced by individuals with disability; these agencies and organizations have identified changing the educational preparation of healthcare professionals as a primary strategy and an important first step.

Several organizations, with input from individuals with disability, have developed competencies that should be expected of all healthcare professionals who interact with individuals with disability. The Alliance for Disability in Health Care Education has urged nursing, medicine, and other healthcare professions to endorse these competencies with the goal of moving forward in the effort to improve the healthcare of individuals with disability. Nurses have been very involved in the development of these competencies from the beginning of the process. Several nursing

Throughout this book, the authors use the term *people with disability* rather than *people with disabilities*. The singular disability is used as a collective noun to note commonalities rather than differences among individuals with different types of disability or groups of individuals with disability. The term *disabilities* has been avoided because it suggests differences and fragmentation rather than the similarities that this book is intended to address (McDermott & Turk, 2014).

organizations, including Sigma, have endorsed the cross-discipline competencies developed by the Alliance for Disability in Health Care Education (2019).

This book is based on the principle and belief that all healthcare professionals—regardless of discipline, level of education, or role within the healthcare system—have a role in caring for individuals with disability. As such, they need a basic understanding of the issue of disability to provide appropriate, optimal, and sensitive healthcare to those with disability. These issues and more are addressed in the chapters of this book. It is intended to provide information to nurses, nursing students, and other healthcare professionals to enable them to communicate with and provide quality healthcare to individuals with disability.

The first three chapters of this book provide essential background information intended to put the topic of disability in context. Often, disability is not the reason that an individual with a disability seeks healthcare. However, the presence of a disability often has a negative effect on the individual's interaction with healthcare clinicians. The goal of this book's first three chapters is to provide background to ensure that interactions with those with disability are positive and of high quality. The first three chapters also provide definitions of important terms and an explanation of what terms are considered acceptable by individuals with disability and their community.

Key information addressed in Chapter 1 includes the epidemiology of disability and an explanation of the major categories of disability. This illustrates that types of disability have been categorized in many ways over time, and some terms have been discarded as objectionable.

Chapter 2 discusses the social determinants of health. These can have a very significant impact on how individuals with disability are perceived and are treated within the healthcare system. A historical view of models of disability and the role of these models in framing the views of healthcare professionals and the broader society are also discussed. In addition, an important distinction is made

between “disability” and “disabling condition.” Nurses and other healthcare professionals can be very knowledgeable about a disabling condition without considering the day-to-day experience of individuals with disability as they try to navigate a healthcare system that frequently throws barriers in their way to obtaining care. To put today’s approaches to disability in historical perspective, a brief history of disability through the ages is included. Finally, strategies for communicating with individuals with various types of disability are discussed.

Chapter 3 introduces barriers to access to healthcare for individuals with disability. These have been identified by multiple agencies, researchers, and individuals with disability and their advocates. Specific categories of barriers are addressed, along with the consequences of those barriers on access to healthcare. Strategies to address these barriers are suggested. Important federal legislation related to the rights of individuals with disability is also addressed.

Each of the next five chapters discusses a major category of disability. This is to provide nursing students and nurses in practice with the necessary background to communicate with and care for individuals with that disability. Each chapter provides information about the disability category; appropriate terminology; and information about the prevalence, causes, and consequences of disabilities in that category. They also provide examples of specific disabling conditions within the category of disability, along with specific points about caring for individuals with disabilities in that category. Finally, each chapter includes links to informative and helpful resources. It is not the author’s intention to make readers experts or specialists in disability. Rather, it is to arm them with information that will enable them to provide high-quality and sensitive care to individuals with disability they see in their practice across various settings. These include but are not limited to outpatient settings, acute and long-term care facilities, maternity settings, and home- and community-based settings.

The last chapter of the book, Chapter 9, addresses the inclusion of individuals with disability in nursing education. The discussion is based in part on the principle that nursing care—and, more generally, healthcare—could be improved and made more accessible, more welcoming, and more effective for individuals with disability if healthcare providers knew about disability from their own personal experience and perspective. Hopefully, the information included in this chapter will result in more open, welcoming, and supportive admission policies to enable individuals with disability to become nurses and other healthcare professionals and to improve the health and nursing care of this population in the future.

This book is based on the principle and belief that all healthcare providers have a role in caring for people with disability and need a basic understanding of the issue of disability to provide appropriate, optimal, and sensitive healthcare to those with disability. The hope is that this book will serve as a starting point for nursing students, nurses in practice, nursing faculty, and others interested in the topic of disability to consider the healthcare issues experienced by individuals with disability, at least in part because of barriers to quality care. I want the nursing discipline in general and nurses in particular to take the lead in addressing the needs of people with disability in our care. Nursing and nurses must become the solution, rather than part of the problem, for individuals with disability seeking healthcare.

COVID-19 AND PEOPLE WITH DISABILITY

This book was written in part during the worldwide coronavirus (Covid-19) pandemic that surged in 2020. The pandemic raised important issues for individuals with disability, their families, and other support persons, as well as for nurses and other healthcare providers who provide healthcare to all populations. The Covid-19 pandemic has affected individuals with disability more than many other populations.

In the best of circumstances—that is, in the absence of a pandemic like Covid-19—people with disability experience healthcare inequities. They have a difficult time obtaining the kind of healthcare they need and deserve. Some healthcare providers fail to recognize the desire and ability of individuals with disability to have a say in what happens to them when they seek healthcare and do not treat individuals with disability with the dignity and respect they deserve. Although the Americans with Disabilities Act was passed more than 30 years ago, in 1990, many changes and policies are still needed to ensure that healthcare for this population is available, accessible, respectful, and sensitive to their needs.

The Covid-19 pandemic uncovered even more issues that need to be addressed. One of these is that in many cases, people with disability are at increased risk for Covid-19 infection because of preexisting health conditions—often multiple health conditions. Some of these preexisting conditions put people with disability at high risk in ordinary circumstances because many have what could be considered a narrow margin of safety or health. Although disability cannot and should not be equated with poor health, this narrow margin of safety may make it more likely that someone with disability will experience health issues earlier or more easily than others. For example, if someone has a high spinal cord injury, that person’s respiratory status may be good in normal circumstances, enabling him or her to breathe without difficulty. But if that individual has a simple respiratory infection (or cold), his or her respiratory status may become compromised more easily. Then, when the severe respiratory symptoms that often occur with Covid-19 develop, the likelihood of severe respiratory failure increases dramatically.

The Covid-19 pandemic has created other problems for people with disability. For example, during the pandemic, people with disability have been justifiably concerned that they might not be seen as deserving of hospitalization and ICU care, including treatment with ventilators, if needed. The pandemic has also made it increasingly more difficult for individuals with disability to obtain other treatments they might need, as well as food, medication, and other products required to maintain their well-being.

The ability of individuals with mobility limitations to wash their hands may be reduced. Although hand sanitizers can be used in these situations, the limited supply or availability of such sanitizers may prevent individuals with disability from using them as often as recommended. Further, handwashing with soap and water is preferable and more effective than using hand sanitizers.

During the Covid-19 pandemic, some healthcare facilities established policies prohibiting family members or other support persons from staying with patients during hospitalization in an effort to decrease the risk of virus transmission. This was devastating for many individuals who required hospitalization, including those with disability—particularly for those with intellectual or cognitive disability and those who have difficulty communicating with healthcare team members. These individuals often require additional time to communicate and frequently rely on family members or support persons to assist them. Family members or support persons are also often needed to minimize the stress and anxiety that arises in hectic or chaotic situations, such as acute care or emergency room visits.

The pandemic has also affected people with hearing loss because of the need for healthcare providers—and everyone else—to wear masks. Masks prevent people with hearing loss who rely on facial expressions and lip/speech reading from understanding what others are saying. When wearing a mask, healthcare providers must use new strategies to communicate with people with hearing loss.

The effects of Covid-19 in nursing homes and other long-term care facilities during the pandemic have been tragic and distressing. The pandemic has placed individuals with disability who live in nursing homes or long-term facilities at increased risk due to their close proximity with others and an inability to maintain social distancing. Employees in nursing homes and other long-term care facilities—which are often understaffed—are also at increased risk for infection. This is due to their own health issues, a lack of personal resources, the fact that many of them are underserved in their own communities, a lack of personal protective equipment (PPE), and the frequency with which they provide close physical care to

residents. Moreover, many staff members use public transportation to get to their jobs, increasing their exposure to people who may be infected. All these factors contribute to the risk of transmission of Covid-19 to both residents and caregivers, resulting in the tragic events that have occurred in nursing homes and long-term care facilities nationwide.

The lack of preparation for the Covid-19 pandemic in 2020 has taken many people and organizations by surprise. Going forward, analyses of what went wrong and what can be done to prevent the recurrence of the devastation experienced in nursing homes and long-term care facilities, and by society as a whole, are crucial. As a country and as healthcare professionals, we must recognize that pandemics are possible and prepare for them accordingly. We must also ensure that organizations such as the Centers for Disease Control and Prevention and healthcare departments across the country have the resources they need to conduct appropriate surveillance and to develop evidence-based policies needed to contain pandemics. Simply put, we must have a coordinated response within healthcare and across the country.

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3

STRATEGIES TO ADDRESS BARRIERS TO HEALTHCARE FOR PEOPLE WITH DISABILITY

INTRODUCTION

As discussed in Chapter 1 and Chapter 2, people with disability often experience inadequate healthcare. As a result, they are at high risk for chronic conditions, poor quality of life, and increased morbidity and mortality. Causes of inadequate healthcare for this population have been attributed to many barriers that affect healthcare access. Nurses and other healthcare professionals must be aware of these barriers and either take steps to eliminate them (when possible) or work around them until they can be removed entirely.

The social determinants of health (refer to Chapter 2) are just some factors that affect access to healthcare for this population. There are also generic barriers that affect this population as a whole. The Centers for Disease Control and Prevention (CDC) describes these barriers as factors in an individual's environment that, through their absence or presence, limit functioning and create disability. They are as follows (CDC, n.d.-a):

- A physical environment that is not accessible
- A lack of assistive technology (assistive, adaptive, and rehabilitative devices)
- Negative attitudes toward disability and people with disability
- Services, systems, and policies that are either nonexistent or hinder the involvement of all people with a health condition in all areas of life

Experts identify five major categories of barriers. These categories are as follows:

- Attitudinal barriers
- Communication barriers
- Structural and physical barriers

- Programmatic barriers
- Transportation barriers

All these barriers are related. Even if only one category of barrier currently exists, that single barrier can cause other barriers. Moreover, addressing one type of barrier may have little effect on access to healthcare if other barriers are not also addressed. For example, even if physical barriers are removed, attitudinal barriers in the form of negative attitudes of healthcare professionals toward those with disability might remain. Finally, barriers often result in a negative snowball effect. For instance, the existence of physical or structural barriers can cause people with disability to be dependent on others, which in turn limits their participation in everyday life (World Health Organization [WHO], 2011).

ATTITUDINAL BARRIERS

The most difficult barriers to overcome are *attitudinal barriers*. These describe the negative attitudes of others, including healthcare professionals, toward people with disability. Examples of attitudinal barriers in healthcare include the following:

- Negative attitudes toward people with disability, resulting in stereotyping, bias, stigma, prejudice, and discrimination
- A lack of knowledge about the abilities and strengths of people with disability
- The assumption that people with disability are dependent, unaware of or uninterested in events around them, and unable to make decisions or otherwise participate in life activities
- The belief that all health issues that affect people with disability are due to their disability

- The failure to recognize, prevent, and treat common health issues that affect people with and without disability
- The assumption that the quality of life of people with disability is poor

Negative attitudes are often due to implicit or unconscious biases, which may be triggered without our even being aware of them. They result in attitudes about and preferences for others based on factors such as age, gender, race, ethnicity, national origin, socioeconomic status, sexual orientation, religion, body weight, and disability status (American Bar Association Commission on Disability Rights, 2019).

Lack of contact with and lack of knowledge about others—in this case, people with disability—tend to reinforce the negative attitudes that we hold.

Implicit biases generally reflect our personal experiences; the attitudes of people we grew up with; the attitudes of our friends, acquaintances, and broader community; our culture; the media; and books and movies. We tend to harbor negative attitudes toward those who are different from us, who do not belong to the same groups as we do, or who do not share our characteristics. Consequences of implicit bias can include stereotyping, prejudice, and discriminatory behaviors or actions—although we may be unaware that we are exhibiting these behaviors or taking these actions.

Studies show that the negative attitudes of healthcare professionals and students toward people with disability do not differ significantly from the attitudes of society at large and in some cases are even worse (Tervo, Palmer, & Redinius, 2004). Further, health professionals and society at large tend to view people with certain disabilities more negatively than those with other disabilities. For example, people with intellectual or cognitive disabilities and those with psychiatric or

Most calls to improve the healthcare of people with disability (refer to Chapter 1) have identified the need to include disability content and to increase the attention on disability in health professions curricula. Movement in that direction, however, has been slow.

mental health disabilities are viewed more negatively than people with physical disabilities (Pelleboer-Gunnink, Van Oorsouw, Van Weeghel, & Embregts, 2017).

A lack of attention to disability in the curricula of most health professions education (nursing, medicine, dentistry, and others) contributes to the negative attitudes of healthcare professionals toward people with disability. So, too, does a lack of opportunities for students in those professions to interact with people with diverse types of disabilities.

CONSEQUENCES OF ATTITUDINAL BARRIERS

The negative attitudes of healthcare professionals toward people with disability can have significant consequences. For example:

- Healthcare providers who believe that people with disability make no contribution to society will likely provide low-quality care or no care at all.
- Healthcare providers who believe that women with disability are (or should be) sexually inactive—or that they have no right to bear children—will likely make women with disability extremely uncomfortable during interactions with them. They might even provide substandard care to women with disability, refuse to provide reproductive healthcare to pregnant women with disability, or withhold information from women with disability about caring for their infants.
- Healthcare providers who believe that people with disability are incapable of making informed decisions might determine what care and treatment are warranted for patients with disability without consulting them, without offering any explanation, and without proposing treatment options.

The healthcare providers in these examples would likely be unaware of their negative attitudes and biases, and unaware of the discriminatory and prejudicial practices and behaviors that resulted.

STRATEGIES TO ADDRESS ATTITUDINAL BARRIERS

Strategies for healthcare professionals and educators to address attitudinal barriers include the following:

- Providing students with firsthand experiences interacting with people with disability during medical, nursing, and dental school (Shakespeare & Kleine, 2013; Symons, Morley, McGuigan, & Akl, 2014; Woodard, Havercamp, Zwygart, & Perkins, 2012)
- Including standardized patients with actual disability in health professions education (Long-Bellil et al., 2011; Smeltzer et al., 2018; Vest et al., 2016)
- Including people with disability on the educational team

Including people with disability on the educational team conveys that people with disability are experts on their disability. It also increases students' comfort interacting with people with disability and enables them to ask questions that they may otherwise be reluctant to ask about their disability and their daily lives. Finally, it provides an authentic learning experience and helps prevent stereotyping that often occurs when people pretend to have a disability for educational purposes. This practice should be avoided by inclusion of individuals with actual disability.

- Modeling positive behaviors, including communication, when interacting with people with disability
- Educating healthcare professions students about the health issues experienced by people with disability and the need to provide them with the same quality of healthcare, including health promotion and preventive screening, that is provided to others
- Educating people without knowledge or exposure to people with disability
- Not ignoring others' negative behaviors toward people with disability

Because of the tenacity of lifelong mindsets, strategies to address negative attitudes must be multiple, persistent, and repeated over time.

US FEDERAL LEGISLATION ON THE RIGHTS OF PEOPLE WITH DISABILITY

Healthcare professionals and organizations should be aware of national policy and legislation that protects the rights of people with disability and ensures that they are included in all aspects of society, including healthcare. Knowledge of the legal rights of these individuals helps ensure the provision of quality healthcare for this population now and in the future. Several of the most relevant federal laws are described briefly here (Bersani & Lyman, 2009; Institute of Medicine, 2007):

Section 504 of the Rehabilitation Act of 1973: This federal law protects people from discrimination based on disability by employers and organizations that receive financial assistance from federal departments or agencies. Section 504 of the Rehabilitation Act forbids organizations and employers from denying people with disability an equal opportunity to receive program benefits and services. Further, the act defines the rights of individuals with disability to participate in, and have access to, program benefits and services.

The Americans with Disabilities Act (ADA) of 1990: The ADA (and the ADA Amendments Act of 2008, discussed in the next bullet) protects the civil rights of people with disability and seeks to eliminate discrimination against them. Although there is further progress to be made, the ADA has helped to remove or reduce many barriers for people with disability. The ADA has also expanded opportunities for people with disability by changing perceptions and increasing participation of people with disability in community life. Specific areas identified in the ADA as guaranteed for people with disability include employment and public accommodations (e.g., at restaurants, hotels, theaters, doctors' offices, pharmacies, stores, museums, libraries, parks, private schools, and daycare centers). The ADA also requires that transportation, state and local government agencies, and telecommunications (e.g., telephones, televisions, and computers) be accessible to people with disability.

ADA Amendments Act (ADAAA) of 2008: This law was enacted to restore the original intent of the ADA after several Supreme Court decisions that limited the rights of people with disability. The ADAAA increased the number of people protected by the ADA and other nondiscrimination laws by broadening the law and redefining disability.

Patient Protection and Affordable Care Act (ACA) of 2010: This law increased healthcare choices and protection for people with disability. It also allowed for new healthcare options for long-term support and services; improved Medicaid home- and community-based services; increased access to high-quality and affordable healthcare for many people with disability; and enabled accessible preventive screening equipment. In addition, it designated disability as a demographic category to establish the inclusion of people with disability in the US census and in national studies. This will improve data about this population that have been missing from many governmental and other reports.

A CAUTION AGAINST DISABILITY SIMULATIONS

Disability simulations (or disability experiences) have been suggested and implemented as a strategy to increase the understanding of nondisabled people about disability. In a disability simulation, students might be placed in wheelchairs, or their hands and feet might be restrained to simulate a loss of mobility; they might be given opaque glasses or blindfolded to simulate vision loss; or their hearing might be modified to simulate hearing impairment.

People with disability and disability advocates caution that these simulations do not have long-lasting positive effects on learners and do not provide a realistic view of living with a disability. In some cases, after participating in such simulations, students indicated that they did not think having a disability was "so bad." In others, students left with a false sense and negative view of what living with a disability would be like (VanPuymbrouck, Heffron, Sheth, The, & Lee, 2017). Other negative outcomes include a lack of improved attitudes about interacting with people with disability, an undermining of efforts to improve the integration of people with disability, and increased stereotyping (Nario-Redmond, Gospodinov, & Cobb, 2017; Silverman et al., 2017).

Because of these negative reactions and responses, these simulations are generally *not* recommended. Instead, it is more effective to have students get to know people with disability who can share their experiences and give students more realistic and positive views of people with disability.

COMMUNICATION BARRIERS

Communication between healthcare professionals and their patients or clients is essential to the therapeutic relationship. Yet, communication barriers are among the most common types of barriers experienced by people with disability (as reported in

studies by Smeltzer, Avery, and Haynor [2012] and many others). Communication barriers might include the following:

- Talking to an accompanying person rather than the person with a disability
- Failing to provide people with disability the information about health issues they need and consider important
- Communicating with and treating people with disability as if they were children
- Failing to ask people with a disability what is the best way to communicate with them
- Failing to use alternative communication strategies for people with disability
- Pretending to understand what a person with disability has said
- Failing to include people with disability in discussions and decisions about their own care
- Failing to recognize that some people with disability have a low reading level or low health literacy

Communication barriers affect all persons with disabilities, not only those with hearing, vision, and communication impairment.

Another communication barrier is the discomfort some healthcare professionals feel about asking patients about their disability and its effects on their health and everyday lives. This is often because healthcare professionals lack knowledge about disability, have had little previous contact with people with disability, or fear they will offend or upset patients with disability. Although asking a stranger such questions in a social setting would indeed be inappropriate and insensitive, doing so in a health-related interaction is appropriate. This is because the presence of a disability may have a direct impact on a patient's health as well as that patient's ability to participate in health-promotion activities, follow a treatment regimen, or undergo preventive screening. Indeed, *not* asking about the effects of

a disability on a patient's life and activities may distress the patient because it suggests that the healthcare provider has not considered the disability and its possible effects on the patient's health. A simple approach is to say to the individual with a disability, "Please tell me about your disability." Patients with disability are often the most knowledgeable and most expert persons about their disability. They are usually able and eager to explain their health issues and to provide useful information to healthcare professionals. They just need to be asked.

One of the most challenging scenarios for healthcare providers involves interacting with patients who are nonverbal or whose speech is difficult to understand. This may occur with people with severe intellectual or developmental disabilities or adults with aphasia due to stroke or other neurological disorders. Speech and language therapists can often help healthcare providers (and individuals with disability and their family members) in this scenario by identifying or establishing alternate communication methods. In any case, it is critical that healthcare providers recognize that absence of verbal language does not mean that a patient is unable to hear or understand what is being said, so they should speak to these patients directly.

CONSEQUENCES OF COMMUNICATION BARRIERS

Communication barriers have several critical consequences. For example:

- They can lead to misinformation, an incomplete picture of the health status of the patient, unaddressed or unmet healthcare needs, errors, unsafe practices, and increased morbidity and mortality.
- Healthcare professionals who fail to use effective communication strategies with patients with disability can cause these individuals to feel angry, frustrated, or dissatisfied with their care, resulting in their reluctance or even refusal to seek care in the future.

- Healthcare professionals who fail to use alternative modes of communication with people who require accommodations because of a disability can compromise care.
- Asking family members or others accompanying the patient to provide information about a patient with disability or serve as interpreters without the patient's explicit permission is demeaning, violates the patient's privacy, and ignores the rights of people with disability to self-determination.

Healthcare professionals must talk directly to patients with disability. Talking to accompanying persons rather than those with disability fails to acknowledge that those with disability are individuals who are capable and interested in the world around them.

STRATEGIES TO ADDRESS COMMUNICATION BARRIERS

Strategies for healthcare professionals and educators to address communication barriers include the following:

- Assuming that people with disability are capable of understanding and addressing their own needs
- Communicating with and treating adult patients with disability as such
- Recognizing that the presence of a disability, no matter how severe, does not mean that people with disability are unable to identify or communicate their needs
- Understanding that most people with disability are intelligent and knowledgeable about their health and disability and capable of making their own decisions about their care
- Speaking directly to people with disability rather than about them to family members or others who are accompanying them

- Referring to people with disability with person-first language (unless the person prefers otherwise)—for example, saying “person with a disability” rather than “disabled person” or “the disabled”
- Using the preferred method of communication for people with communication impairment
- If necessary, obtaining input from family members or other caregivers about the best way to communicate with a patient whose communication or cognition is impaired
- Recognizing that some people with disability might not be able to decipher handwritten notes or instructions
- Using plain and simple wording to make information available to people with or without disabilities—for example, people with low literacy levels or whose first language is not English
- Not pretending to understand what people with impaired speech have said and instead asking them to repeat themselves or to use an alternative method of communication
- Learning and using accommodations for people with disability
- Asking people with disability their views on the topic being discussed
- Educating other healthcare providers about the disability-related competencies expected of them
- Using communication boards

Using person-first language emphasizes the person rather than the disability. When we think of the person first, we are more likely to see people with disability in a positive light and be more effective in our communication with them (Tennessee Disability Pathfinder, n.d.).

Patients with some disabling conditions such as hearing loss, vision impairment, and cognitive impairment require special communication strategies. When interacting with a patient with hearing loss, the method of communication used will depend on the type and severity of the impairment. It is important to keep these points in mind:

Some patients have more than one type of communication impairment. In this case, healthcare professionals must adjust communication efforts to meet the patient's needs, preferences, and abilities.

- As people age, they often develop hearing loss. Most of these people communicate with spoken language, which may be assisted with hearing aids.
- People with profound hearing loss that was present at birth or before they developed language skills will likely use sign language or speechreading. Communication must match the severity and type of hearing loss and the person's ability to communicate using alternate approaches.
- For many people who are Deaf (the uppercase "D" indicating hearing impairment from a very early age), sign language is their first language. This makes reading English more difficult for some.

Recommendations for communicating with people with hearing loss include the following:

- Use videos with closed captioning.
- Provide written materials.
- Provide audio-induction loops.
- Provide text telephones (TTY or TDD).
- For people whose first language is sign language, provide a sign-language interpreter or use pictures instead of words.

Like hearing impairment, vision loss varies in type and severity. When communicating with people with vision loss, it is important to consider the following points:

- When meeting a person with vision loss, announce your presence, address the person by name, and explain who you are, your role, what you will be doing, and what you will ask the individual to do.
- Speak directly to the person in a normal tone and volume. Do not shout and don't exaggerate or over-articulate when speaking.
- Do not rely on gestures (including head shakes or nods) to communicate with people with vision loss. They may be unable to see them.
- Use large-print documents for people with some vision loss.
- Provide or allow audio recordings of discussions. This enables the person to relisten to the discussion and to any instructions given.
- Offer Braille versions of written materials.

Effective communication with people with cognitive impairment can be challenging for many healthcare professionals, especially if they have little experience interacting with patients with cognitive issues. Cognitive impairment can occur in people with intellectual disability, developmental disability, head injury, neurological disorders, and dementia. Because some patients with intellectual disability may have difficulty communicating their needs, nursing staff must be especially attentive to them and perhaps use alternative communication strategies (e.g., the use of pictures) to provide quality nursing care (Ailey, Johnson, Fogg, & Friese, 2015).

Demonstrating patience is important when interacting with any patient, whether that patient has a disability or not. However, it is especially critical when communicating with patients with cognitive impairment.

Factors that determine the effectiveness of communication with people with cognitive disability include the following:

- The ability of the healthcare provider to establish trust
- Treating the person with dignity
- Communicating in a way that promotes comprehension at the person’s level—for example, using short sentences and language the individual will understand
- Giving the person sufficient time to respond
- Using the person’s name
- Treating persons with disability as adults even if their behavior or intellectual level is that of a child

For any person who has difficulty communicating, regardless of the reason why, a communication board can be an effective tool. A communication board is a device with a series of symbols, letters, words, and pictures from which persons with impaired communication can select to communicate with others. Speech-to-text and text-to-speech computer devices are also available to promote communication.

Additional strategies to communicate with individuals with hearing loss, vision loss, or cognitive impairment are discussed in more detail later in this book.

STRUCTURAL AND PHYSICAL BARRIERS

Structural and physical barriers in the built environment are perhaps the most visible and recognizable barriers. These include the following:

- Inaccessible parking areas
- The absence of ramps and curb cuts
- Steps outside buildings that hamper entry and steps inside buildings that prevent movement from floor to floor

- Narrow doorways that do not accommodate wheelchairs or other mobility devices
- Heavy doors or a lack of automatic doors
- Doorknobs that cannot be used by people with limited hand function
- Inadequate space
- The absence of height-adjustable examination tables, scales, and imaging equipment
- A lack of grab bars
- The absence of ramps or ramps that are too steep
- A lack of accessible restrooms
- Reception desks that are too high to permit people with disability to speak easily with receptionists
- Poor signage
- Forms (consent and otherwise) with small print or complex language
- A lack of knowledge about legal requirements for health-care and other settings to accommodate people with disability

CONSEQUENCES OF STRUCTURAL AND PHYSICAL BARRIERS

The presence of structural and physical barriers limits access to both healthcare settings and healthcare in general—a major cause of poor healthcare among people with mobility limitations and similar types of disability.

STRATEGIES TO ADDRESS STRUCTURAL AND PHYSICAL BARRIERS

The Americans with Disabilities Act (ADA) requires that sites, settings, and facilities that are likely to be frequented by people with disability—for example, hospitals, clinics, private offices, imaging centers, clinical laboratories, urgent care centers, and so on—be accessible. Legal mandates also require that new construction and structures undergoing renovation be made accessible.

Even sites that are ADA compliant may still be inaccessible. To identify structural barriers to care, facilities must perform an accessibility assessment. Often, people with disability are the only ones able to provide an accurate assessment of a facility. Thus, they must be part of the assessment. The following sidebar offers additional information about accessibility assessment as well as on universal design, whose principles can be applied to increase accessibility for people with disability.

The US government offers tax breaks to remove structural and physical barriers from facilities to enable people with disability to use health-related and other facilities

In addition to the accommodations mandated by the ADA, there are several low-cost strategies for reducing structural and physical barriers to care (especially for people who use wheelchairs):

- Moving chairs that obstruct pathways
- Removing deep-pile rugs or carpets
- Providing rooms with accessible tables and weight scales
- Using height-adjustable exam tables (some are expensive, but less costly options exist)
- Ensuring staff are available to help patients transfer to and from exam tables
- Modifying doors to easily swing both ways
- Installing grab bars in restroom stalls
- Placing hooks low on the back of restroom stall doors

SOURCES OF INFORMATION ON ACCESSIBILITY ASSESSMENT AND UNIVERSAL DESIGN

Multiple assessment guides exist. These can be used to ensure that sites are accessible. Following are links to useful resources for accessibility assessment:

- ADAAG Manual: A Guide to the Americans with Disabilities Act by the Access Board: <https://www.adainfo.org/sites/default/files/ADAAG-Manual.pdf>
- Survey Instruments to Assess Patient Experiences with Access Coordination Across Healthcare Settings: Available and Needed Measures by Quinn et al.: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5509356/>
- Web Accessibility Evaluation Tools List by the Web Accessibility Initiative: <https://www.w3.org/WAI/ER/tools/>

For information about universal design, see the following resources:

- The 7 Principles by the National Disability Authority Centre for Excellence in Universal Design: <http://universaldesign.ie/What-is-Universal-Design/The-7-Principles/>
- Principles of Universal Design by the United States Access Board: <https://www.access-board.gov/guidelines-and-standards/communications-and-it/26-255-guidelines/825-principles-of-universal-design>
- The Seven Principles of Universal Design by Rosemarie Rossetti: <https://www.udll.com/media-room/articles/the-seven-principles-of-universal-design/>

Accessible sites and equipment also make life easier for certain people without disability—for example, people pushing children in strollers, people carrying groceries or making deliveries, older people, and people who are short in stature.

Healthcare professionals might consider elimination of physical and structural barriers to be beyond their expertise and outside their area of responsibility. But these barriers affect patient care, so addressing them is relevant to their role. In collaboration with people with disability, healthcare professionals are in a position

to inform administrators when barriers exist and advocate for the adoption of strategies to minimize them.

Healthcare professionals must also understand and advocate for *reasonable accommodations*. This term refers to modifications made to tasks and to the environment to allow people with disability an equal opportunity to participate. This concept, often discussed in the context of employment and education, also applies in healthcare settings (Institute of Medicine, 2007).

To ensure that accessibility requirements are met, healthcare professionals must understand and educate others about accessibility.

PROGRAMMATIC BARRIERS

Examples of programmatic barriers in healthcare include the following:

- Inconvenient scheduling of healthcare visits
- Allowing too little time to accomplish needed assessments and healthcare interventions
- A lack of knowledge and expertise on the part of healthcare providers about the health-related needs of people with disability
- A lack of training for healthcare staff to assist patients with disability so that both patients and healthcare personnel are safe

CONSEQUENCES OF PROGRAMMATIC BARRIERS

People with mobility limitations might need more time to travel to a healthcare facility—especially if they rely on paratransit services. (These are discussed in more detail in the later section

“Transportation Barriers.”) They might also need more time and assistance during appointments to compensate for difficulties with undressing and transferring to the exam table. Scheduling appointments at inconvenient times (e.g., early in the day) and failing to allot adequate time to complete needed assessments and interventions increase stress on both patients and healthcare providers. Such scheduling issues can also result in patients missing important services (such as diagnostic tests or physical therapy sessions).

A lack of training and knowledge among staff as to how best to communicate with and to assist patients with disability may put these patients at risk of receiving misinformation and of experiencing falls or injuries. They can also increase risk of injury to staff.

STRATEGIES TO ADDRESS PROGRAMMATIC BARRIERS

Programmatic barriers are comparatively easy to address. Strategies include the following:

- Providing healthcare professionals with educational and training resources as well as teaching materials on disability (including information on the increased health risks associated with having a disability), caring for people with disability, and communication strategies
- Being aware of transportation barriers facing some patients with disability and scheduling them accordingly
- Scheduling multiple appointments for each visit to the healthcare setting to minimize the need for multiple trips
- Having alternative formats of materials available (e.g., large print, Braille, audio, consistent with patients’ cognitive abilities)

PROVIDING QUALITY CARE FOR HOSPITALIZED PATIENTS WITH DISABILITY

People with disability who have been hospitalized have reported poor communication on the part of nursing staff and other healthcare providers, a lack of competence, compromised care, negative attitudes among staff, and a feeling of vulnerability (Smeltzer et al., 2012). Things are even worse for hospitalized patients with intellectual disability, who are at higher risk than other patients for complications (many of which are preventable) and require careful monitoring.

Patients with disability who require hospitalization need nurses and other healthcare providers to be knowledgeable about how to provide quality care. However, most healthcare professionals currently in practice have received little education about disability and have had limited opportunity to interact with patients with disability. Instruction and training can help with this. It can also allay providers' concerns and fears about working with patients with disability, uncover and dispel any implicit biases they may have, and learn techniques to ensure their safety as well as that of the patient. Finally, it can help them identify useful communication strategies for interacting with patients with disability. (Refer to the earlier section "Strategies to Address Communication Barriers" for more information.)

TRANSPORTATION BARRIERS

Multiple studies cite a lack of reliable and accessible transportation as one of the most common barriers to healthcare identified by people with disability. Despite an increase in the availability of public transportation since the passage of the ADA, transportation systems often fail to meet the needs of people with disability.

There are various reasons for this, including limited number of stops, inaccessible stations, and drivers who lack knowledge or harbor negative attitudes toward people with disability. In addition, *paratransit systems*—which are public transportation services designed for people with mobility limitations—are notoriously unreliable, arriving late or not at all (Bezyak, Sabella, & Gattis, 2017).

These problems have a disproportionate effect on people who are blind or have low vision and people who have mobility issues—particularly those who use wheelchairs. People who live in rural areas are at an even greater disadvantage due to a lack of public transportation options (National Council on Disability, 2015).

CONSEQUENCES OF TRANSPORTATION BARRIERS

People with disability who rely on paratransit systems are at risk for missed appointments, long wait times, missed pickups at the end of the day, and lengthy travel times. This causes many patients to give up on trying to obtain healthcare. As a result, health problems may be missed, or they may be diagnosed and treated late in their course. As a result, their health status and quality of life may suffer.

STRATEGIES TO ADDRESS TRANSPORTATION BARRIERS

Nurses and other healthcare professionals cannot remove transportation barriers. However, they can recognize these barriers and consider the difficulties they cause patients with disability who must depend on others for transportation in scheduling health-related appointments. Healthcare providers can also advocate for improved and more reliable transportation services for these patients, identify and recommend the use of more reliable accessible van services, and push for policy changes to address these barriers.

PUTTING IT ALL TOGETHER

Table 3.1 summarizes major categories of barriers, examples, and corrective practices to minimize them.

DISABILITY-RELATED COMPETENCIES FOR HEALTHCARE PROFESSIONS AND PROVIDERS

In an effort to ensure that healthcare professionals—including nurses, physicians, occupational and physical therapists, speech pathologists and therapists, and others involved in patient care—are adequately prepared to provide high-quality care to individuals with disability, several organizations have developed specific competencies. Several of these sets of competencies are described briefly here:

- **Alliance for Disability in Health Care Education, Inc. (ADHCE):** This organization, whose goal is the integration of disability-related content and concepts into the healthcare professions, developed *Core Competencies on Disability for Health Care Education*. The competencies are not discipline specific and are intended to be applicable to all healthcare professions and to all categories of clinicians (Alliance for Disability in Health Care Education, 2019).
- **American Nurses Association (ANA):** The ANA develops and publishes the scope and standards of practice related to intellectual and developmental disabilities nursing (American Nurses Association, 2013).
- **American Rehabilitation Counseling Association (ARCA):** The ARCA Task Force on Competencies for Counseling Persons with Disabilities has put forth a set of competencies for counselors who work with persons with disability in school, employment, community, and clinical settings (Chapin et al., 2018).

TABLE 3.1 BARRIERS TO HEALTHCARE ACCESS FOR PEOPLE WITH 

CATEGORY	EXAMPLES
Attitudinal barriers	<p>Negative attitudes among healthcare professionals toward people with disability, resulting in stereotyping, bias, stigma, prejudice, and discrimination</p> <p>A lack of knowledge about the abilities and strengths of people with disability</p> <p>The assumption that people with disability are dependent, unaware of or uninterested in events around them, and unable to make decisions or otherwise participate in life activities</p> <p>The belief that all health issues that affect people with disability are due to their disability (diagnostic overshadowing)</p> <p>The failure to recognize, prevent, and treat common health issues that affect those with and without disabilities</p> <p>The assumption that the quality of life of people with disability is poor</p>
Communication barriers	<p>Talking to an accompanying person rather than person with a disability</p> <p>Treating and communicating with people with disability as if they were children</p> <p>Failing to ask people with disability the best way to communicate with them</p> <p>Failing to use alternative communication strategies for people with disability</p> <p>Pretending you understand what a person with disability has said even if you do not</p> <p>Failing to include people with disability in discussions or decisions about their own care</p> <p>Failing to recognize people with disability with a low reading level or low health literacy</p> <p>Feeling uncomfortable asking patients about their disability and its effects on their general health for fear of offending the patient</p> <p>Failing to provide people with disability the information about their health issues they need and consider important</p>

DISABILITY, EXAMPLES, AND CORRECTIVE PRACTICES

CORRECTIVE PRACTICES

Educate people without knowledge or exposure to people with disability.
Provide experiences with people with varied disabilities to increase knowledge and comfort level.
Model positive behaviors when interacting with people with disability.
Educate others about the need for people with disability to receive the same quality of care, including health promotion and preventive screening, as that provided to others.
Do not ignore others' negative behaviors toward people with disability.
Include standardized patients with disability in health professions education.
Include people with disability on the education team.

Learn and use accommodations for people with disability.
Obtain input from family caregivers about the best way to communicate with people with communication or cognitive impairment.
Ask people with disability their views on the topic being discussed.
View people with disability as the decision-makers for their own care.
Involve people with disability in decision-making about their health and well-being.
Educate other healthcare providers about the disability-related competencies expected of them.
Use person-first language when referring to people with disability.
Increase own knowledge about health issues of those with disability.
Assume people with disability can understand and address their own needs.
Treat and communicate with adult patients as such.
Recognize that the presence of a disability does not mean people are unable to identify or communicate their own needs, and that most people with disability are intelligent and knowledgeable about their own health and disability.
Speak directly to people with disability rather than about them to those accompanying them.
Understand that some people with disability might not be able to decipher hand-written notes or instructions.
Use plain and simple wording.

continues

TABLE 3.1 BARRIERS TO HEALTHCARE ACCESS FOR PEOPLE WITH

CATEGORY	EXAMPLES
Communi- cation barriers (continued)	

DISABILITY, EXAMPLES, AND CORRECTIVE PRACTICES (CONT.)

CORRECTIVE PRACTICES

Do not pretend to understand what people with impaired speech have said. Instead, ask them to repeat themselves or use an alternative method of communication.

Use a communication board, text-to-speech, and speech-to-text devices.

For people with hearing impairment:

Use videos with closed captioning.

Provide written materials.

Provide audio-induction loops.

Provide text telephones (TTY or TDD).

For people whose first language is sign language, provide a sign-language interpreter or use pictures instead of words.

For people with vision impairment:

Use large print in documents.

Use audio recordings.

Offer Braille versions of written materials.

Employ tools available on smartphones and other technological devices.

When meeting a patient with vision loss, announce your presence, address the patient by name, and explain who you are, what your role is, what you will be doing, and what you will ask the patient to do.

Speak directly to the patient in a normal tone and volume. Do not shout.

Do not rely on gestures (including head shakes or nods) to communicate with people with vision loss. They may be unable to see them.

For people with cognitive impairment:

Use reading and language levels appropriate for the individual.

Use pictures instead of words.

Establish trust.

Treat patients with dignity.

Communicate in a way that promotes comprehension at the patient's level—for example, using short sentences and language the individual will understand.

Give patients sufficient time to respond.

Use the patient's name.

Treat patients as adults even if their behavior or intellectual level is that of a child.

continues

TABLE 3.1 BARRIERS TO HEALTHCARE ACCESS FOR PEOPLE WITH

CATEGORY	EXAMPLES
Structural and physical barriers	<p>Inaccessible parking areas</p> <p>The absence of ramps and curb cuts</p> <p>Steps outside buildings that hamper entry and steps inside buildings that prevent movement from floor to floor</p> <p>Narrow doorways that do not accommodate wheelchairs or other mobility devices</p> <p>Heavy doors or a lack of automatic doors or door openers</p> <p>Doorknobs that cannot be used by people with limited hand function</p> <p>The absence of height-adjustable examination tables, scales, and imaging equipment</p> <p>A lack of grab bars</p> <p>A lack of accessible restrooms</p> <p>Poor signage</p> <p>A lack of knowledge about legal requirements for healthcare and other settings to accommodate people with disability</p> <p>Inadequate space</p> <p>The absence of ramps or ramps that are too steep</p> <p>Reception desks that are too high to permit people with disability to speak easily with receptionists</p> <p>Forms (consent and otherwise) with small print or complex language</p>
Programmatic barriers	<p>Inconvenient scheduling of healthcare visits</p> <p>Allowing too little time to accomplish needed assessments and healthcare interventions</p> <p>A lack of knowledge and expertise on the part of healthcare providers about the health-related needs of people with disability</p> <p>A lack of training of healthcare staff to assist patients with disability so that both patients and healthcare personnel are safe</p>
Transportation barriers	<p>Lack of accessible public transportation</p> <p>Unreliable transportation</p>

(CDC, n.d.-a, -b)

DISABILITY, EXAMPLES, AND CORRECTIVE PRACTICES (CONT.)

CORRECTIVE PRACTICES

Advocate for accessible entrances into and within buildings used by the public.

Ask a person with disability to evaluate sites for accessibility.

Inform administrators of a lack of accessible site and equipment.

Become knowledgeable about laws that address the legal rights of people with disability to accommodations and accessible facilities.

Educate and advocate for greater understanding of legal requirements to make reasonable accommodations for people with disability.

If the accessibility of a site or setting is questionable, use an accessibility form to evaluate it.

Move chairs that obstruct pathways.

Remove deep-pile rugs or carpets.

Provide rooms with accessible tables and weight scales.

Use height-adjustable exam tables. (Some are expensive, but less costly options exist.)

Ensure staff are available to help patients transfer to and from exam tables.

Modify doors to easily swing both ways.

Install grab bars in restroom stalls.

Place hooks low on the back of restroom stall doors.

Provide educational and training resources as well as teaching materials about caring for people with disability to all providers across the healthcare continuum.

Modify scheduling to allow for adequate time and assistance (if needed) to ensure high-quality care for people with disability.

Train staff to assist and transfer patients in a way that is safe for both patients and staff.

Offer alternative formats of materials (large print, Braille, audio) consistent with patients' cognitive abilities.

Educate healthcare professionals about the increased health risks associated with having a disability.

Advocate for accessible transportation systems.

Identify and recommend use of *reliable* accessible van services.

Push for policy changes to address transportation barriers.

- **Council on Social Work Education (CSWE):** The CSWE's Council on Disability and Persons with Disability has developed competencies for disability-competent care and identified resources to support the inclusion of disability-related content and concepts in social work education. The resources could be useful for other disciplines interested in ensuring the preparation of health professions students to care for individuals with disability (Council on Social Work Education Disability Competent Care Curriculum Workshop, 2018).
- **Developmental Disabilities Nurses Association (DDNA):** This organization has developed practice standards to promote quality nursing care of people with developmental disabilities. The organization provides support to nurses who specialize in caring for individuals with developmental disabilities.

Although several of these sets of standards and competencies were developed to be specific to one profession or another, much could be gained by examining how various healthcare disciplines address the health issues and care of individuals with disability. This is particularly important because of the interprofessional collaboration that is needed to ensure a high level of healthcare to individuals with disability. Several of these sets of competencies also identify resources to promote the integration of disability-specific content in educational curricula. These resources could be useful for any discipline or healthcare professional interested in disability.

SUMMARY

This chapter has discussed in detail barriers facing many people with disability. Some of these barriers make it difficult for people with disability to obtain quality healthcare; others make it impossible. Implicit bias has been identified as an underlying factor in attitudinal barriers that result in negative attitudes toward people with disability. This bias also prevents healthcare professionals from recognizing the

stereotyping, prejudice, and discriminatory practices that affect the quality of care provided to this population. Another major factor underlying the barriers addressed here is inadequate attention to disability and its impact on health and healthcare in the educational preparation of healthcare professionals. This chapter identified strategies to address the various barriers to healthcare; they will be discussed further in subsequent chapters that address specific categories of disabilities.

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