Nurses With Disabilities
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Nurses With Disabilities
Professional Issues and Job Retention

Leslie Neal-Boylan, PhD, RN, CRRN, APRN, FNP-BC
This book is dedicated to registered nurses everywhere who devote their lives to improving the lives of others.

To a particularly special nurse, my mother: Natalie Rotkoff, nurse (and mother) extraordinaire!
Contents

Foreword by Geraldine Polly Bednash, PhD, RN, FAAN ix
Foreword by Suzanne C. Smeltzer, EdD, RN, FAAN xi
Preface xiii
Acknowledgments xv

1. Who Are Nurses With Disabilities? 1
2. Why Are Nurses With Disabilities Leaving Nursing? 19
3. Hiding the Disability 37
4. Disability, Job Longevity, and Career Choice 63
5. Does Having a Disability Compromise Patient Safety? 95
6. Nurses With Disabilities and the Health Care Environment 117
7. Nurse Heroics 145
8. Retaining Nurses With Disabilities 167

Appendix 201
Index 205
The term “disability” is fraught with social and moral connotations reflecting society’s belief that the disabled individual has lost significant cognitive, motor, sensory, or other functions. This perception of the term disabled has often led to a differentiated life or work experience for the disabled individual that is often not based on real assessment of that individual’s capacity to contribute to the work of a profession, a community, or a society and can create a tremendous loss to both the individual who is disabled and our society as a whole.

This book challenges some of these preconceived notions and tells the real-world experience of nurses who have faced barriers that are not fact based and that in some cases deprived the profession or society of their capacity as fully contributing and functioning members. In the United States, and many other nations, discrimination based upon disability is outlawed. In 1990, President George W. Bush signed into law the Americans with Disabilities Act, adding disabled to the list of other protected categories in the U.S. Civil Rights Act of 1964.

The primary intent of this law was to ensure that inappropriate perceptions of an individual’s capacity to be a contributing worker, professional, or member of society would not be used to limit that individual’s opportunities. The law was also an example of our society’s belief that in a just society, an individual should be judged by his or her contributions and work, not by appearance or perceived limitations.

This book will provide nurses with the information to make objective and fact-based assessments on this important issue. Moreover, it will arm nursing professionals with an understanding of how the issue of disability is affecting workforce supply in nursing, how accommodations can provide assistance to individuals with disabilities, and how a balanced and thoughtful approach can allow nursing professionals to function to their fullest.

Clearly, disabilities are not solely a concern for the working nursing professionals. Another, and perhaps just as important, outcome of this book will be the capacity for nurses to also understand more fully the disabled individuals for whom they provide care. The unique physical,
emotional, and social needs of disabled patients will also surely be addressed more fully from this important perspective.

Geraldine Polly Bednash, PhD, RN, FAAN
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Foreword

It has been estimated that between 54 million and 60 million people in the United States live with one or more disabilities; the number exceeds 1 billion globally. Many studies have demonstrated that the health care of people with disabilities is of poorer quality than care provided to people without disabilities, and people with disabilities are less satisfied with their health care than other patient populations. Numerous physical, structural, and attitudinal barriers to obtaining quality health care have been reported by people with a variety of disabilities. As a result they receive less health care screening and primary care, and experience repeated negative encounters in their efforts to obtain appropriate health care and to receive high-quality care during hospitalization.

The U.S. Surgeon General’s office issued several calls to action to improve the situation, in part by calling for inclusion of the topic of disability in educational programs for nurses, physicians, and dentists. Some efforts are underway to respond to these calls to action. Often overlooked, however, are strategies to increase the number of health care providers with disabilities by examining program admissions criteria, opening admissions procedures to qualified candidates with disabilities, and undertaking strategies that allow health care professionals who acquire disabilities as adults to continue their work in health care. They are often not provided with the accommodations that are mandated by the Americans with Disabilities Act of 1990 that would enable them to continue their contributions to their profession and to patient care. As a result, many health care professionals with disabilities end up leaving the work setting and often their profession, even when the need for providers with expertise is growing and a shortage of experienced health care professionals is acute.

Fearing discrimination and other negative reactions from their employers, coworkers, and peers, some health care providers with disabilities hide their disabilities, depriving them of accommodations that could make their work easier and allow them to continue working. This also deprives the profession, employers, and patients of the expertise of nurses who could have a major impact on the care of patients, including those with disabilities.
Despite the call to integrate disability-related content and issues in the education of health professionals, the profession and educational programs have been slow to respond. Although faculty in health professions education have been encouraged to develop and implement strategies to improve preparation of their students for caring for patients with disabilities, there has been little attention to what people with disabilities who are students in the health care professions bring to the educational setting. In addition to joining the ranks of health care professions, their presence in the classroom and clinical environment can change the negative attitudes and stereotypes held by other students and faculty as well as society as a whole. Further, they can utilize their own personal experiences and views as a person with a disability to improve the care given to patients with disabilities.

*Nurses With Disabilities: Professional Issues and Job Retention* has brought together information and real-life experiences of nurses who have disabilities. It will serve as an invaluable source of information on the impact of disability on the employment and retention of registered nurses.

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Preface

I first learned of the scarcity of literature regarding nurses with disabilities when a graduate student of mine mentioned that she had come across a lot of work on students with disabilities but none on nurses. This was several years ago and I didn’t pursue doing anything about it until the idea had germinated for a while. When my close friend and colleague, Dr. Sharron Guillett, and I decided to explore the experiences of nurses with disabilities, we asked the student if she would like to be included. She declined and wished us luck in exploring this new territory.

Sharron and I were fascinated with the topic: Sharron, because she has a family member with a disability, and I because of my work as a rehabilitation nurse. As we talked to nurses with disabilities we learned how our supposedly compassionate profession had mostly turned its back on these nurses. Although invaluable work has been done about the experiences of student nurses with disabilities, when we sought collaboration on our work about nurses with disabilities, to our amazement we were refused because Sharron and I were not disabled. The perspective was that we had no right or ability to shed light on the experiences of nurses with disabilities if we were not, ourselves, disabled.

Neither of us ever claimed to know what it was like to be personally disabled but we did know about caring for people with disabilities and we did know that someone had to bring their experiences to light. But this book is much more than the four research studies that buttress it. It was also informed by the many nurses who have come up to us at conferences and otherwise shared their stories, so similar in experience and outcome to those of our research participants. It has become clear, over time, that the issues nurses with disabilities face are serious and irredeemable unless we decide to act.

The experience of being a nurse with a disability, according to the voices of these nurses, exemplifies the experience of anyone with a disability who is trying to work without discrimination. It also exemplifies the experience of simply being a nurse in this day and age because, as nurses, we often sacrifice ourselves physically and mentally in the course of doing our jobs. Chapter 7, “Nurse Heroics,” discusses how the expectation of nurses is to work above and beyond regardless of our own health and well-being. We tend to look down on nurses who are not willing to
miss breaks, meals, and days off in service to the profession. I say “in service to the profession” and not “in service to our patients” because we don’t do our patients any favors by being angry and resentful or sick and tired when we are at work. We also don’t benefit them when we don’t role model all of the healthful behaviors we preach to them.

The intention of this book is not to scold but to present the issues facing nurses with disabilities using their own voices and to attempt to offer potential solutions. Chapter 1 lays a foundation by introducing to or reminding the reader about legislation that affects persons with disabilities and by briefly describing the research studies that ground the book. Chapter 2 describes why nurses with disabilities are leaving nursing. Chapter 3 continues the dialogue by discussing the interesting phenomenon of many nurses with disabilities attempting to hide their disabilities and the perspectives of nurse recruiters and managers regarding hiring nurses with disabilities.

Job longevity and career decisions are analyzed in Chapter 4. Nurses with disabilities often leave the profession, sometimes of their own accord, but more often because they feel pushed out. How do they decide to leave and what do they do next? Chapter 4 addresses these questions.

Chapter 5 explores the common perception that nurses with disabilities jeopardize patient safety. There are no data to support this perception, yet it is pervasive. Nurses are trained to think scientifically yet that is not demonstrated in this case.

Chapter 6 illustrates how the nurse with a disability interacts within his or her environment with colleagues, administrators, and patients. Nurse testimonials describe how these interactions affect the work life of these nurses. Managers and patients lend their voices as well to this discussion.

Following Chapter 7, “Nurse Heroics,” Chapter 8 attempts to provide solutions to the issues presented throughout the book. Specific suggestions are given for altering the way we educate nurses and what nurse educators and clinicians with disabilities should consider as they plan their careers. Nurse leaders and administrators are advised about specific approaches they can use to minimize the hemorrhage of nurses with disabilities from the profession.

I hope readers will see that as many perspectives as possible were presented in the writing of this book. Furthermore, many of the experiences described were positive and serve to further illustrate that we can approach the issues in positive ways and that it is possible to be open minded, compassionate, and creative when necessary to support our colleagues, whether or not they are disabled.
Acknowledgments

I’d like to thank my beloved friend and colleague, Dr. Sharron E. Guillett, for her work regarding nurses with disabilities. I admire her for her keen intelligence, incredible strength, and dedication to nursing and nurses.

I also want to thank my husband for his enduring love, support, and editing assistance while writing this book.

Most importantly, I am supremely grateful to all of the nurses who shared their stories and experiences with me and had faith that by exposing the issues that they live with day to day, the profession might make changes that would benefit all of us.

Finally, I’d like to sincerely thank every nurse who reads this book through, because in doing so you show that you are willing to hear about the sometimes ugly side of our beloved profession, and awareness is the first step toward meaningful change.
Who Are Nurses With Disabilities?

Sue is a 54-year-old registered nurse with 30 years of nursing experience. She has always been a hard worker and she has extensive expertise and experience as a critical care nurse. She has always prided herself on being able to care for her patients without needing to ask her colleagues for help, except in extreme situations. Sue was diagnosed with rheumatoid arthritis 5 years ago but never mentioned this to her supervisor or colleagues. However, in the past year, she began to feel very fatigued and in frequent pain. She found herself asking other staff to help her with tasks she could previously manage on her own. She has also been using her sick leave and taking more time off than she has ever taken before. Her manager suggested that Sue might not be capable of doing this kind of work anymore and asked if it might not be best for her to leave critical care and work in another area of nursing. Sue was shocked and dismayed to hear her manager speak to her this way and assured her that she could do the work and that she wanted to stay on the unit. Sue found her own ways of compensating for what she could no longer easily do but sensed that her colleagues did not approve of her compensatory techniques even though they worked well and did not compromise patient safety. Not long after this, Sue had her annual review. Despite having had excellent reviews every year, this review indicated that her manager was not pleased with her work. Sue decided to leave the job. Sue was not given any information by the manager or by a Human Resources representative regarding her disability rights before she left. Nor was she given any specific options for working in another area of the facility in order to stay there.

Registered nurses with disabilities appear to be facing discrimination of one form or another in the work place. This discrimination is occasionally blatant but more often masked by disapproval of how the nurse is performing even if the care he or she is providing does not differ significantly from the care the nurse has always provided. Nurses with disabilities tend
to leave nursing or find jobs that are not physically demanding or they go back to school to move further from the bedside. These nurses have expertise and are often very experienced. They tend to love nursing and they grieve when they cannot continue to be part of the profession. The profession has undergone many shortages as it ebbs and flows from decade to decade. It is important to the profession to try to understand why nurses with disabilities often perceive themselves as being pushed out of the profession and what can be done to retain them.

To date, several research studies have been done to explore the work life experiences of nurses with disabilities, to learn who these nurses are, the settings in which they work, and their successes and struggles. This chapter explores the data about people with disabilities, in general, and about nurses with disabilities, in particular. This will set the stage for the rest of the book as it explores the work life experiences of nurses with disabilities.

**BACKGROUND**

It is currently unknown how many registered nurses have physical and/or sensory disabilities. However, according to the most recent data from the Census Bureau which gets its data from the American Community Survey (ACS), approximately 41 million nonmilitary, noninstitutionalized people in the United States considered themselves disabled in 2006. Of these people, approximately 4% had a sensory disability (hearing, vision, or communication) and 9% had a physical disability. Of those 16 years old or older, 7% described themselves as having an employment disability. Within the working age population (16 years to 64 years), 12% reported having a disability.

The rate of disability increases to almost 16% of the total population when people in the military and those living in group homes, whether institutional or in the community, are included (Brault, 2008; U.S. Census Bureau, 2006a, 2006b). The Centers for Disease Control and Prevention (CDC) estimates that 71.4 million people in the United States have disabilities (CDC, 2011; www.cdc.gov/nchs/fastats/disable.htm). Approximately 16 million of these have problems with mobility, 35 million have trouble hearing, and 19 million have difficulty with vision (CDC, 2011).

**DEFINING DISABILITY**

There are many definitions of disability. The Americans with Disabilities Act (ADA) of 1990 (Public Law 101-336) defines disability as “with respect to an individual, a physical or mental impairment...
that substantially limits one or more of the major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment.

The phrase “physical or mental impairment” means—

- Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive; digestive; genitourinary; hemic and lymphatic; skin; and endocrine
- Any mental or psychological disorder such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities
- The phrase physical or mental impairment includes, but is not limited to, such contagious and noncontagious diseases and conditions as orthopedic, visual, speech, and hearing impairments; cerebral palsy; epilepsy; muscular dystrophy; multiple sclerosis; cancer; heart disease; diabetes; mental retardation; emotional illness; specific learning disabilities; HIV disease (whether symptomatic or asymptomatic); tuberculosis; drug addiction; and alcoholism (http://www.ada.gov/regs2010/titleIII_2010/titleIII_2010_regulations.htm#a104)

This definition supports the concept of a chronic illness as a disability. Such has been the case with many of the nurses studied who self-identified as having a disability. The research on which this book is based did not include nurses with cognitive or behavioral disabilities.

The World Health Organization (WHO) states that:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. (http://www.who.int/topics/disabilities/en)

This definition applies to a discussion of nurses with disabilities because they may have self-imposed restrictions or restrictions imposed or suggested by others related to their work. Many of the nurses studied found safe ways to compensate for what they could no longer do in the traditional way, so according to the WHO definition, they would not be viewed as having an activity restriction. Despite this, colleagues and administrators do not always support compensatory
methods and therefore may make it appear as if the nurse has an activity limitation.

The United States Equal Employment Opportunity Commission’s (EEOC) definition of disability is a physical condition that significantly limits one or more major life activities, such as seeing or walking. A history of disability may allow the person to be considered disabled if the person has an impairment (mental or physical) that is expected to last more than 6 months. In other words, this qualifies someone who has a medical condition that may cause disability to be considered disabled, even if they don’t currently have the disability.

The definition of disability that is used will ultimately impact how issues regarding disability are approached and viewed (Neal-Boylan, in press). What one person may view as a disability, another may not view as a disability. To retain nurses with disabilities, it is important that nursing not define disability in such a way as to be used as an excuse to push out a nurse who is simply not wanted in the setting for other reasons.

The ADA does not permit prospective employers to ask applicants questions about the disability before offering the job. Employers are required to make “reasonable accommodation” to “otherwise qualified individuals . . . unless it results in undue hardship.” According to the ADA, the prospective employer must be aware of the disability in order to respect the rights of the person with disabilities. This seems self-evident. However, as will be explained later in this book, nurses often feel the need to hide their disabilities in order to obtain employment in nursing (http://www.ada.gov/cguide.htm#anchor62335).

For the purposes of the research studies upon which this book is based, the nurses involved self-identified as having a physical and/or sensory disability. The nurses often discussed the handicapping aspects of their disabilities. It is important to distinguish a disability from a handicap. Someone may have a disability but because they can compensate in some form or another, or in cases when they are doing something that has no relevance to whether or not they have a disability, they would not be considered handicapped. The disability contributes to a handicap when the person is unable to perform a task or do something they might otherwise do because they have a disability. However, anyone, whether or not they have an identified disability, might be judged as conceivably having a handicap depending on the situation. A student who has stayed up all night partying instead of studying, for instance, might be handicapped by lack of sleep and might be unable to take the test to the best of his or her ability if the student had gotten a full night’s sleep.
For the purposes of this book, disability is defined the way the nurses in the research studies defined it. Nurses who participated in the research studies on which this book is largely based self-identified as having chronic illnesses, severe allergies, difficulties with mobility, sensory impairments, and many “hidden disabilities.” Many nurses who participated had multiple disabilities. Table 1.1 includes the various disabilities self-identified by nurses in these studies.

It is important to note that nurses may have cognitive or emotional disabilities that can significantly impact nursing work. The research on which this book is based specifically excluded nurses who self-identified as having cognitive or emotional disabilities except when one of these occurred concomitantly with a physical and/or sensory disability. This decision was made because it is very hard to distinguish whether the way in which a nurse perceives he or she is treated on the job is directly attributed to the disability or is because the nurse is angry or cognitively impaired. In the course of the research, the author received several phone calls from nurses who said they wanted to participate and reported that they had cognitive or emotional disabilities. These nurses tended to sound very angry and it was hard to elicit specific details of their experiences. Clearly, this is a population that should also be studied as it is probable that these nurses have been the recipients of discriminatory practices. Their voices should also be heard. However, doing so was not within the scope of the studies that were done and therefore the experience of having a cognitive or emotional disability will not be discussed in this book.

**TABLE 1.1**

<table>
<thead>
<tr>
<th>Self-Identified Disabilities</th>
<th>Joint pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatoid arthritis</td>
<td>Epilepsy or other seizure disorder</td>
</tr>
<tr>
<td>Back pain</td>
<td>Post polio syndrome</td>
</tr>
<tr>
<td>Crohn’s disease</td>
<td>Spinal cord injury</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>Multiple sclerosis</td>
</tr>
<tr>
<td>Herniated disc</td>
<td>Latex allergy</td>
</tr>
<tr>
<td>Psoriatic arthritis</td>
<td>Stroke</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>Diabetes mellitus</td>
</tr>
<tr>
<td>Status post brain tumor</td>
<td>Muscular dystrophy</td>
</tr>
<tr>
<td>Fibromyalgia</td>
<td>Visual impairment</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>Speech disorder</td>
</tr>
<tr>
<td>Ureterostomy</td>
<td>Wrist joint removal</td>
</tr>
<tr>
<td>Deafness</td>
<td>Missing joints</td>
</tr>
<tr>
<td>Paraplegia</td>
<td>Amputation</td>
</tr>
<tr>
<td>Chronic pain</td>
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</tbody>
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EMPLOYMENT

According to the U.S. Department of Labor, Bureau of Labor Statistics (2012; http://www.bls.gov/news.release/empsit.t06.htm), as of October 2011 the number of civilian, noninstitutionalized people aged 16 years and older with disabilities who were employed was 5,037 (in thousands) out of 27,214 (in thousands) as opposed to 135,949 (in thousands) out of 213,055 (in thousands) of those not disabled. This demonstrates that while approximately a quarter of people with disabilities are employed, closer to half of those without disabilities are employed. The unemployment rate for those with disabilities was approximately 13%, which is a slight decrease from the year before and is approximately 8% which is largely the same as the year before for those without disabilities. The unemployment rate for women with disabilities was slightly lower than that for men with disabilities. These data included people with cognitive, sensory, and physical disabilities.

People with disabilities are often self-employed as compared to people without disabilities and are more likely than those without disabilities to work part time. People with disabilities are less likely than those without a disability to work in professional or management jobs (Bureau of Labor Statistics/news.release/disabl.nr0.htm). It costs the United States government approximately $232 billion every year to support employable adults with disabilities who are not employed (Office on Disability Prevalence and Impact fact sheet; http://www.hhs.gov/od/about/fact_sheets/prevalenceandimpact.html).

Impairments in physical function increase as one ages. The number of people with disabilities is significantly higher for adults aged 65 years and older than for younger populations (Brault, 2008). As the population of nurses age, it is expected that those with functional impairments will increase (Bristo, Ciotti, McCulloh, Lyons, & Carroll, 2005; Neal-Boylan, 2012; Wray, Aspland, Gibson, Stimpson, & Watson, 2009). Older nurses may find that the physical aspect of nursing becomes more difficult with age (Mion et al., 2006; O’Brien-Pallas, Duffield, & Alksnis, 2004). Aging nurses are needed to remain in nursing as they have experience (Fitzgerald, 2007) and can mentor younger nurses as well as strengthen the nursing workforce during times of shortage (Cocca-Bates & Neal-Boylan, 2011). This fact that nurses are aging and are sought after to remain in the nursing workforce further validates the need to learn how to retain nurses with disabilities in nursing.

As one 67-year-old nurse said:

I realize that I can’t be lugging patients around. . . . It is the realization that I have my limits and the expectation that really all nurses have health limits for lifting patients. I have to speak up and let
them know what my limits are and how I’m going to accommodate my limits and how I’m going to accommodate the unit and safety.

**DISABILITY BENEFITS**

Interestingly, not all of the nurses studied knew about or applied for disability benefits from their workplace or sought legal counsel to try to get any benefits or accommodations for which they were eligible. It is worth reviewing what legal options may be open to nurses with disabilities if they choose to access them.

The Social Security Administration states that persons eligible for disability benefits have a medical problem that will last at least one year or could result in death. Their definition does not include short-term disability or partial disability. A “recent work test” and a “duration of work” test are necessary to meet the Social Security Administration’s strict guidelines for receiving disability benefits (http://www.ssa.gov/pubs/10029.html).

There are also short-term disability benefits that one can obtain through their work. Depending on the employer, the employee may need to use up all sick days before the employee can access short-term disability benefits. Typically the employee needs to have worked for the employer for a specified period of time before they have access to this benefit and they have to work near full time (30 hours) or full time. Typically the employer pays the benefit but states differ regarding whether employers are required to offer this benefit. The percentage of pay and the length of time the employee may receive disability pay vary depending on the plan (http://employeebenefits.about.com/od/ancillaryinsurance/a/STDBasics.htm).

The Family and Medical Leave Act (FMLA) allows employees to take unpaid leave from work for a medical condition or a family reason. A medical condition that is serious enough to render the employee “unable to perform the essential functions” of the job is one of the requirements that makes someone eligible to receive FMLA. The Act allows for 12 weeks off within 12 months and includes job and insurance protection during that period. The employee must receive medical certification that they are eligible for FMLA (http://www.dol.gov/whd/fmla/USDeptoOfLabor).

Many nurses seem reluctant to apply for or request these benefits. This may be because they feel they should work through their pain or disability (see Chapter 7) or they may not see themselves as disabled and therefore eligible for these benefits. Others may think that acquiring these benefits may stigmatize them or effect their future work opportunities. It is important that employers make sure that nurses are not only aware of the options if they are disabled or ill or become so, but that they clearly understand them.
DISCRIMINATION

The Rehabilitation Act of 1973 (Americans with Disabilities Act, 2005) prohibits employers who receive federal monies, work within federal agencies, or hire federal contractors from discriminating against anyone because of their disability (http://www.ada.gov/cguide.htm#anchor65610).

According to the EEOC, if an employee is treated in a way that violates the ADA or the Rehabilitation Act (1973), then they have suffered disability discrimination. According to these laws, persons with disabilities (this includes a history of disability or chronic illness) must be provided with “reasonable accommodation.”

A reasonable accommodation is any change in the work environment (or in the way things are usually done) to help a person with a disability apply for a job, perform the duties of a job, or enjoy the benefits and privileges of employment. (http://www.eeoc.gov/laws/types/disability.cfm)

The law requires that access be provided (such as with wheelchairs) and that assistance in some cases (such as for someone who is blind) be offered. The employer is not expected to have to undergo “undue hardship” or expense to provide reasonable accommodation. According to the EEOC:

Undue hardship means that the accommodation would be too difficult or too expensive to provide, in light of the employer’s size, financial resources, and the needs of the business. An employer may not refuse to provide an accommodation just because it involves some cost. An employer does not have to provide the exact accommodation the employee or job applicant wants. If more than one accommodation works, the employer may choose which one to provide.

It is also unlawful to discriminate against people because they are related to someone who has a disability. People with disabilities must not suffer discrimination in the hiring or firing processes through pay, jobs to which they are assigned, promotions, or in anything else related to their employment. It is also unlawful to harass anyone with a disability or who once had a disability. Offensive comments that pertain to the disability and remarks that serve to foster a work environment that is hostile to the person with the disability are illegal. Supervisors, coworkers, and clients are all subject to this law.

Interestingly, nurses applying for a job cannot, by law, be asked medical questions or be required to take a physical examination before the job offer is made. They may not be asked about their disability or
the extent of the disability. However, one can ask the nurse if he or she can do the job whether or not there are accommodations. If the nurse is offered the job and has the medical exam, the employer may decide to make the job conditional on certain health-related questions or the passing of the medical exam as long as all employees new to that same type of job are required to do the same. After the nurse has started in the job, medical questions and a medical exam are allowed only if documentation is needed to support accommodation or it is perceived that the nurse cannot do the job safely or effectively (http://www.eeoc.gov/laws/types/disability.cfm).

NURSES WITH DISABILITIES

Despite the higher incidence of disability in older adults, nurses of all adult ages have disabilities. Nurses with disabilities work in all settings both community and institution based. However, they appear to be least likely to remain in the hospital. Perhaps this is because hospital work tends to be very demanding physically. Interestingly, difficulty hearing in hospital nurses is associated with an increased risk of leaving the job when compared with nurses with hearing disabilities who work outside of the hospital (Neal-Boylan, Fennie, & Baldauf-Wagner, 2011). Table 1.2 lists work settings of the nurses with disabilities who were studied. However, this is by no means a complete list of settings in which nurses with disabilities work.

### TABLE 1.2
Settings and Jobs in Which Nurses With Disabilities Practice

<table>
<thead>
<tr>
<th>Setting/Job</th>
<th>Setting/Job</th>
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</thead>
<tbody>
<tr>
<td>Dialysis center/clinic</td>
<td>Skilled nursing facility</td>
</tr>
<tr>
<td>Insurance company</td>
<td>Medical-surgical nursing</td>
</tr>
<tr>
<td>Legal nurse consultant</td>
<td>Occupational health</td>
</tr>
<tr>
<td>Nurse manager (telephonically)</td>
<td>Orthopedics</td>
</tr>
<tr>
<td>Pregnancy care clinic/maternal child health unit</td>
<td>Home care</td>
</tr>
<tr>
<td>Private practice</td>
<td>Office nursing</td>
</tr>
<tr>
<td>Psychiatric/mental health</td>
<td>Rehabilitation</td>
</tr>
<tr>
<td>Public health</td>
<td>Gerontology</td>
</tr>
<tr>
<td>School</td>
<td>Education</td>
</tr>
<tr>
<td>Surgery center</td>
<td>Oncology</td>
</tr>
<tr>
<td>Telephonic diseases management</td>
<td>Informatics</td>
</tr>
<tr>
<td>Online education</td>
<td>Pediatric primary care</td>
</tr>
<tr>
<td>Emergency, oncology center</td>
<td>Professional membership organization</td>
</tr>
<tr>
<td>Hospice</td>
<td>Day surgery</td>
</tr>
<tr>
<td>Women’s health</td>
<td>Intensive care unit (ICU)</td>
</tr>
<tr>
<td>Travel nursing</td>
<td>Nurse anesthesia</td>
</tr>
<tr>
<td></td>
<td>Health counseling</td>
</tr>
</tbody>
</table>
Nurses may begin their careers in any setting that utilizes nurses. However, once the disability is acquired or once it begins to cause a handicap to the nurse at work, nurses are often made to feel that they are no longer fit to work in that setting or the nurses themselves may choose to leave that setting. Nurses may leave because they fear they will jeopardize patient safety or because they feel that the compensatory techniques they use to do their jobs are not sufficient in their view or in others’. Frequently, fatigue, reduced stamina, and the inability to float to other units or to work nights or 12-hour shifts interfere with the ability to remain in the job.

When nurses leave an inpatient position, for instance, they may go back to school to prepare them for a position that will move them further away from physical care or a position that requires or puts less emphasis on the need to do physical work. This is an important distinction as job descriptions don’t always match the work of the job and while the expectation may be for physical labor such as lifting patients, the nurse often has assistance from nurses’ aides and others to perform the physical work. Infrequently, the organization for which the nurse works will assist the nurse to remain in the facility in a different position, thereby retaining a loyal and valuable employee.

Nurses who leave a position they love or leave the profession tend to grieve the loss and search for ways to remain in nursing despite the disability. Interestingly, they are not as likely as one might suppose to pursue disability benefits or to lodge formal complaints about discrimination. In a study of physicians with disabilities, this was also found to be true (Neal-Boylan et al., 2012)

Many nurses come to nursing with disabilities but more appear likely to acquire a disability once they become nurses. This is easily explained by the fact that most nursing schools are still reluctant to permit students with disabilities that affect physical functioning to either be admitted or to remain in school. There appears to be a common traditional belief that nursing students must be able to engage in the physical labor of caring for patients in order to become nurses. This is counterintuitive to the image that nursing is eager to portray; that is, a profession that should be valued for critical thinking and the ability to make sound and decisive judgments that direct patient care. In addition, many nurses acquire disabilities after they begin working either from injuries suffered on the job, such as back injuries, or from aging. Life in general contributes to some injuries. Further, some chronic illnesses that may not initially cause functional disability may do so as one ages or as one is exposed to a job, such as nursing, that may require physical labor, long work hours, and stamina.

Both male and female nurses have disabilities, although women have been more likely to participate in the research studies on nurses with disabilities than men. In addition, female nurses still outnumber male
nurses, in general. Nurses who participated in the studies ranged in age from 26 to 77 years. Many of these were working when they participated in the research. Others were not working because they left nursing for reasons related to their disabilities. Recruiting nurses with disabilities to participate in research studies is not hard. However, finding nurses with disabilities who are still working as nurses is.

**THE RESEARCH**

This book is based upon four research studies and several anecdotal encounters with nurses with disabilities. All of the studies were grounded by a conceptual framework, “the integrative model of health care working conditions on organizational climate and safety” (Stone et al., 2005) (see Figure 1.1).

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FIGURE 1.1

An integrative model of the relationships between health care working conditions and organizational climate and safety.
The first study (Guillett, Neal-Boylan, & Lathrop, 2007; Neal-Boylan & Guillett, 2008a, 2008b, 2008c) included 10 registered nurses who self-identified as having a physical and/or sensory disability and 10 nurse recruiters/managers. The study was done in Maine, Washington, DC, and Virginia. The nurses were interviewed using rigorous qualitative research methods, the data were transcribed verbatim and then analyzed. Table 1.3 lists the research questions that guided the first study and Table 1.4 includes the unstructured interview guide that was used to explore the experience of having a disability.

The second study (Neal-Boylan, Fennie, & Baldauf-Wagner, 2011) sought to focus on nurses with sensory disabilities: hearing communication and/or visual disabilities. Working nurses were sought but it soon became clear that many nurses with disabilities are not working. Nurses with visual problems who were able to accommodate by wearing glasses did not perceive themselves as being disabled. The majority of participants

### TABLE 1.3
Research Questions Research Study #1

<table>
<thead>
<tr>
<th>Question</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>How does the work of an RN change once he/she becomes disabled?</td>
<td></td>
</tr>
<tr>
<td>Does his/her perception of nursing change once the RN becomes disabled?</td>
<td></td>
</tr>
<tr>
<td>What are the barriers to the profession for the RN with disabilities?</td>
<td></td>
</tr>
<tr>
<td>What are the facilitators to the profession once the RN becomes disabled?</td>
<td></td>
</tr>
<tr>
<td>What modifications could be made to the profession to enhance the ability of the RN with disabilities to participate in the nursing profession?</td>
<td></td>
</tr>
</tbody>
</table>

### TABLE 1.4
Unstructured Interview Guide Research Study #1

**For the RN with a disability**

<table>
<thead>
<tr>
<th>Question</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>In what way do you consider yourself to be disabled?</td>
<td></td>
</tr>
<tr>
<td>How has your condition influenced your ability to practice as an RN?</td>
<td></td>
</tr>
<tr>
<td>Has having a disability changed the way you feel about nursing?</td>
<td></td>
</tr>
<tr>
<td>What, if any, barriers do you see to practice as an RN with a disability?</td>
<td></td>
</tr>
<tr>
<td>What, if any, facilitators do you see to practice as an RN?</td>
<td></td>
</tr>
<tr>
<td>Tell me about them.</td>
<td></td>
</tr>
<tr>
<td>What could be done to facilitate practice for RNs with disabilities?</td>
<td></td>
</tr>
</tbody>
</table>

**For the nurse who hires other nurses**

<table>
<thead>
<tr>
<th>Question</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you hire or have you hired RNs with physical disabilities? Tell me about that.</td>
<td></td>
</tr>
<tr>
<td>Are there conditions that would affect an RNs ability to practice if he/she had a disability?</td>
<td></td>
</tr>
<tr>
<td>What would be a condition that might limit their practice?</td>
<td></td>
</tr>
<tr>
<td>Do you see barriers? Facilitators?</td>
<td></td>
</tr>
<tr>
<td>What does and could your organization do to reduce the barriers, if there are any?</td>
<td></td>
</tr>
</tbody>
</table>


had hearing disabilities. However, there were some participants with visual and communication disabilities. This study used the United States Census Questions on Disability (Table 1.5) to determine if someone had a sensory disability and the extent of that disability. Nurses were surveyed using the Nurse Work Instability Scale (Nurse WIS; Gilworth et al., 2007), which measured the risk of leaving the job. The tool was originally designed for nurses with musculoskeletal impairments but this study also evaluated its reliability with nurses with sensory disabilities and most of the questions were found to be reliable. Table 1.6 includes the research aims for this study.

The third research study (Neal-Boylan, 2012; Neal-Boylan et al., 2012) explored and compared the work life experiences of nurses and physicians with self-identified physical and/or sensory disabilities. Ten RNs and

### TABLE 1.5
Census Questions on Disability Research Study #2

The next questions ask about difficulties you may have doing certain activities because of a health problem.

1. Do you have difficulty seeing, even if wearing glasses?
   - a. No – no difficulty
   - b. Yes – some difficulty
   - c. Yes – a lot of difficulty
   - d. Cannot do at all

2. Do you have difficulty hearing, even if using a hearing aid?
   - a. No – no difficulty
   - b. Yes – some difficulty
   - c. Yes – a lot of difficulty
   - d. Cannot do at all

3. Using your usual (customary) language, do you have difficulty communicating, for example, understanding or being understood?
   - a. No – no difficulty
   - b. Yes – some difficulty
   - c. Yes – a lot of difficulty
   - d. Cannot do at all

*Source: www.census.gov/prod/2006pubs/p70-107.pdf*

### TABLE 1.6
Research Aims for Research Study #2

To determine the demographic characteristics of RNs with hearing, visual, or communication disabilities.

To explore work instability and the risk of job retention problems among nurses with sensory disabilities.

To determine whether the Nurse Work Instability Scale (Nurse-WIS) is a reliable tool to measure work instability in nurses with hearing, visual, or communication disabilities.
10 physicians were interviewed. The nurses were interviewed (Table 1.7) by a nurse and the physicians were interviewed by a physician. The coding team that analyzed the results consisted of three nurses, one of whom was disabled, and two physicians, one of whom was also disabled. Interestingly, physicians and nurses with disabilities had very similar work-life experiences. The research questions that framed the study are in Table 1.8.

The fourth study (Table 1.9) explored the match or mismatch between nurse job descriptions and the actual work of the job for registered nurses with disabilities. A purposive, theoretical sample of RNs from throughout the United States was sought. Seventeen nurses were interviewed and the interviews were transcribed verbatim. The idea for this study arose out of the previous findings that many nurses with disabilities felt discriminated against due to the perception that they were not performing their jobs as they should be. The question then arose as to whether nurses were always provided with job descriptions when they were hired and then whether the actual work they did was aligned with what was proscribed in the job descriptions. If nurses were hired with the idea that they would lift

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**TABLE 1.7**

*Unstructured Interview Guide Research Study #3*

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>In what way do you consider yourself to be disabled? Or could you describe your disability?</td>
</tr>
<tr>
<td>How has your condition influenced your ability to practice as a physician/RN if at all?</td>
</tr>
<tr>
<td>Have you needed to compensate for your disability in any way?</td>
</tr>
<tr>
<td>How has/does your disability influence interactions at work, if at all? With patients?</td>
</tr>
<tr>
<td>With colleagues?</td>
</tr>
<tr>
<td>What, if any, barriers do you see to practice as a physician/RN with a disability?</td>
</tr>
<tr>
<td>What, if any, facilitators do you see to practice as a physician/RN with a disability?</td>
</tr>
<tr>
<td>Given your disability, what organizational (or professional) changes would facilitate your ability to practice successfully?</td>
</tr>
<tr>
<td>How has your disability influenced your career choices to date? How might it influence future career choices?</td>
</tr>
<tr>
<td>Have you experienced discrimination because of your disability?</td>
</tr>
</tbody>
</table>

**TABLE 1.8**

*Research Questions Research Study #3*

<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is it like to be a physician/RN with a physical disability?</td>
</tr>
<tr>
<td>How does the work change, if at all, in light of the physical disability?</td>
</tr>
<tr>
<td>What barriers does the physical disability present to the physician/RN with a disability?</td>
</tr>
<tr>
<td>How does the physical disability influence career decisions of the physician/RN?</td>
</tr>
<tr>
<td>Does the disability jeopardize the ability of the physician/RN to practice medicine/nursing safely?</td>
</tr>
<tr>
<td>How do the experiences of the RNS and physicians compare with regard to having a physical disability?</td>
</tr>
</tbody>
</table>
and move patients and do other very physical activities, then it would be reasonable to assume that they should be able to do these things while they were working. However, if physical activity with patients was not included in their original job descriptions, then how could they be pushed out of their jobs for not being able to perform those activities? Interestingly, the nurses who were recruited for this study were working in areas that they sought out and that were willing, for the most part, to accommodate them.

Overall, while doing the research, it was a challenge to find nurses with disabilities who either felt comfortable and accommodated in their work (if they did, they typically had sought that work themselves or were employed by others with disabilities) or who were working as nurses at all. The profession should want to recruit and retain nurses who think well and who can contribute their intelligence to the profession and, as well, should seek to practice what it preaches to patients by seeking ways to use nurses with disabilities in some form or capacity. This book hopes to make that possible.

It is interesting to examine the comments and experiences of the nurses who participated in the research studies and of nurses who have anecdotally contributed their comments regarding their experiences at work. In light of the laws regarding the prevention of discrimination and the necessity for reasonable accommodation, it is confusing and disheartening that many nurses with disabilities have expressed that they were not met with lawful responses to the challenges they faced in the workplace.

It is clear that Sue, the nurse described in the case at the beginning of the chapter, is only one example of a nurse who feels pushed out of the job and does not know where to turn to be able to remain in nursing. The purpose of this book is to enlighten readers regarding the experience of these nurses and to suggest ways we can retain nurses with disabilities and not deter them from staying in nursing either from outright discriminatory practices or from ignorance of what a person with a disability can bring to their work.

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**TABLE 1.9**

**Research Questions and Unstructured Interview Guide for Research Study #4**

1. How is the description of nurse responsibilities managed during the hiring interview?
2. In actuality, what is the experience of the nurse with regard to fulfilling all of the duties listed in the job description?
3. If the nurse’s disability impacts the nurse’s ability to perform the work, then what is the experience of the nurse regarding the need to compensate in order to fulfill her/his responsibilities?
4. What are the perceptions of the nurse regarding the outcomes/responses of others to the nurse’s inability to perform a skill/task or the nurse’s attempts to compensate?
REFERENCES


Neal-Boylan, L. (in press). Rehabilitation clients in the community. In F. A. Maurer & C. M. Smith (Eds.), Community/public health nursing practice: Health for families and populations (5th ed.).


