



CHAPTER 14

The Ethics of Caring for People With Disabilities

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“Disability doesn’t make you exceptional, but questioning what you think you know about it does.” (Young, 2014)

THERE IS CONSIDERABLE EVIDENCE that disabled people experience stigma, exclusion, and discrimination when accessing health care. Many highly contested and debated issues in health care have their origins in the treatment of people with disabilities. Policies and procedures rooted in eugenics—including forced sterilization, rationing of care services, institutionalization, “mercy killings,” and more recently, prenatal testing—are past and current issues impacting this population. These disability-related issues are a result of cultural assumptions and biases about disability and disabled people. How people think of disability affects how disabled

people are treated in the health care system. Drawing upon the words of Stella Young, the Australian comedian, journalist, and disability rights activist quoted at the beginning of this chapter, we contend first that nursing practice and leadership in the health care of disabled people requires education regarding disability. Currently, the lack of disability content in nursing curricula is well-documented. Secondly, nurses must apply this knowledge to interrogate cultural norms and biased health care practices surrounding disability.

We start this chapter by describing language used to refer to disability and disabled people. We then discuss definitions of disability and prominent models of disability that will form a foundation for understanding how disabled people are treated in the health care system. Next, we consider disability in the context of a number of health-related issues throughout a disabled person's life. Finally, we consider ways to move forward in partnership with disabled people to address harms they have experienced individually and as a community in relation to health and health care services.

Speaking of Disability: The Importance of Language

The terminologies and language surrounding disability are important and have evolved over time. In the past, terms such as “slow,” “idiot,” “moron,” “handicapped,” “impaired,” and “retarded” (the “r” word) have been socially acceptable and included in medical terminology. These terms are no longer acceptable and are considered offensive (Degeneffe & Terciano, 2011; Special Olympics, n.d.). Currently, three main types of language are used to refer to disabled people: person-first language, identity-first language, and terms used when people reject or modify the term “disability” entirely (for example, “diversability”).

In North America there is often an emphasis on person-first language. Person-first language arose in relation to the *Americans With Disabilities Act* in the United States (Burgdorf, 1991). Person-first language refers to identifying the person first and then the disability, making the point that the person is a “person first.” Using this language, people are referred to as “a person with a disability,” “a

person who has Down syndrome,” or “a person who has schizophrenia.” Terms which forefront or primarily define the person by their impairment—such as referring to someone as “an autistic boy” or “a schizophrenic”—are not acceptable in person-first language.

Identity-first language is used outside of North America. Identity-first language is used to emphasize that people are disabled by their social and physical environment, not by their individual impairment. While someone’s impairment (for example, having a spinal cord injury) is an individual property, disability is created by external societal factors, such as a lack of wheelchair access to the workplace. In identity-first language, the term “disabled people” is acceptable, as a person’s disability is seen as an important and persisting aspect of their life. Within North America the use of person-first language has become contentious, with advocates maintaining that rather than equalizing treatment of disabled people, it contributes to stigma (Gernsbacher, 2017). This debate, plus a growing emphasis on disability pride, and on claiming disability as a vital part of a person, have contributed to the increased use of identity-first language over person-first language in North America.

In British Columbia, a third type of language is used in relation to people who have intellectual/developmental disabilities (IDD). The term “diversability” was coined in 2007 by Tiffany Yu (Yu, 2022) to refer to people with all types of disabilities, and was adopted in 2012 by self-advocate Shelley DeCoste to refer to people with developmental disabilities (Community Living British Columbia, n.d.). The term “diversability” has grown in popularity across British Columbia. The Deaf community also resists the label of disability and considers themselves to be a distinct culture with their own language (sign language) and values (Canadian Association of the Deaf - Association des Sourds du Canada, n.d.). In this chapter, we have chosen to use identity-first language to emphasize the importance of disability for individuals. However, when nurses are interacting with an individual, it is important to ask them about their language preference.

There are other important language issues to consider. Referring to people who do not have disabilities as “normal” or “typical” implies that disabled people are not normal or typical; therefore, a better term for people who do not have disabilities is “non-disabled

people.” The framing of a person’s adaptive equipment, such as crutches, wheelchairs, or walkers, is also important. Equipment should be described as something that assists but does not limit the person. For example, “uses a wheelchair” is acceptable, while phrases such as “confined to a wheelchair” or “wheelchair-bound” are not (McCain, 2017). In addition, describing disabled people as “victims” or “suffering” (for example, the patient is “suffering” from blindness) is inappropriate (Laithland, 2019). When using these terms, people assume that the disabled person has a poor quality of life; such assumptions are based on biases that are often incorrect.

The terms “ableist” and “ableism” are used to refer to societal biases (Harpur, 2012). Ableism has been defined as discrimination in favour of the able-bodied, and includes the idea that disabled people are inferior to non-disabled people (Linton, 2006). Ableism is a type of discrimination, just as sexism and racism are. Ableism can be found in every facet of society, including language, media portrayals of disabled people, the built environment, political structures, economics, education, and health care. Nurses, too, are influenced by societal biases. Nurses should be aware of how they refer to disabled people and their assistive devices in their speech, and in health records and documentation. In sum, nurses need to understand how disabled individuals self-identify and take up the appropriate language of disability in order to provide and promote person-centred care.

Defining Disability

Defining disability is complex. Is disability an illness, an impairment, a result of social stigma, or a cultural construct? The *Oxford English Dictionary* defines disability as “lack of ability; inability, incapacity; weakness or a physical or mental condition that limits a person’s movements, senses, or activities” (“Disability,” 2021). This definition is premised on the idea that disability represents a personal lack of something (physical, developmental, etc.), and is primarily based on a medical view of disability, which relies upon a diagnosis obtained from a trained professional. (Please read a further discussion about this in the section below under the heading “The Medical Model.”)

The United Nations has a more complex and nuanced definition of disability. According to the Preamble to the *United Nations Convention on the Rights of Disabled Persons* (2008), disability “is an evolving concept and disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others[.]” (United Nations, 2008, para. 5). To reflect the complexity of defining disability, the WHO (n.d.) has provided an International Classification of Functioning, Disability and Health (ICF). Replacing the OED’s definition of disability as a condition causing mental or physical limitation, the ICF provides a broader functional definition of disability that includes individual body functions and structures, and distinguishes between individual activity limitations and participation restrictions imposed by society.

Using the terminology in the ICF, an impairment is defined as 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 hampers an individual’s involvement in life situations. Since everyone’s functioning occurs in a context, the ICF also includes recognition of a wide variety of environmental factors that can influence the experience of disability. These environmental factors include physical factors such as terrain and building design, as well as social factors such as laws and societal attitudes. By including these factors, the authors of the ICF also take into account the social aspects of disability and do not see disability as a “medical” or “biological” issue alone. The ICF authors stress that disability is not something that only happens to a minority of humanity, but instead recognize disability as a universal human experience.

Conceptual Models of Disability

Many conceptual models have been proposed as a way to better understand how disability has been framed in Western culture. In this chapter, we discuss five of these models: the tragedy/charity model, the economic model, the medical model, the social model, and the biopsychosocial model. The tragedy/charity and economic

models, although now considered dated, continue to underpin many current structural inequities in care and personal exchanges between health care professionals and disabled people. In the last century, the two most influential models have been the medical model and the social model. We also acknowledge that there are other world views, such as Indigenous perspectives, which foster alternative understandings of disability.

The Tragedy/Charity Model

The tragedy/charity model of disability is used frequently in Western culture to frame disabled people as victims to be pitied. Disability as tragedy is a common theme in many stories, movies, and social media interactions. This model is also often used in fundraising campaigns and to justify services for disabled people; for centuries, sick and disabled children have been exploited for fund-raising (Longmore, 2013). In British Columbia, for example, the BC Lions Society for Children with Disabilities raised money for decades by portraying children with disabilities as pitiful during their annual Timmy Christmas Telethon fundraisers. However, this perspective does not account for the rights of disabled people, the strengths of disabled people, or for the role of society in disabling people.

The tragedy model is also evident in what Young (2014) described as “inspiration porn” (Young, video introduction). Inspiration porn refers to images and stories that portray disabled people as inspirational *because* they are disabled. It is based upon stereotypes of disabled people and is designed to inspire non-disabled people by creating a narrative that focuses on their apparent lack of limitation in comparison (that is, “if that poor disabled person can do it, so can I”). While inspiration porn and stereotypes contribute to a limited view of disability and disabled people that affects how they are treated, disabled people are counteracting this narrative. As Young (2014) states, “I am not your inspiration, thank you very much.” The WeThe15 international coalition of organizations is also working to change attitudes regarding disability. We encourage readers to watch their video (WeThe15, 2021).

The Economic Model

The economic model is used to describe disability in terms of an inability to be “productive,” depicting disabled people as a burden on society’s resources. In North America, people are valued for their autonomy and independence (Macpherson, 1962; Stramondo, 2016), and according to theories of utilitarianism, for their contributions to society (Sullivan, 2009). Individualism and independence are idolized in media, myths, and societal emphases on attainment. This creates a cultural bias against disabled people, as many are not independent in the ways that the dominant North American culture defines independence (Davis, 2013; Reinders, 2000). They also may not be “productive” in the traditional economic sense, such as following a particular career path or earning a large wage. Independence for disabled people may mean the use of devices, such as wheelchairs and feeding tubes, and having supported decision making. For disabled people, realizing independence is about securing the necessary tools (for example, wheelchairs, feeding tubes or supported decision-making) to be “able to achieve goals and have control over one’s life” (Stienstra, 2012, p. 104).

The cultural bias against people who are not perceived as independent and who do not “contribute” to society is also evident in hierarchies of disability. Researchers over the years have consistently found that both disabled and non-disabled people view disability as a hierarchy of impairments (Deal, 2003; Tringo, 1970), with the most negative attitudes focused on people with IDD (Irish Social Science Data Archive, 2017; Scior, 2011). This hierarchy of attitudes also exists among health care professionals. For example, Lewis and Stenfert-Kroese (2010) found that nursing staff had less positive attitudes about caring for a patient with an IDD than for a patient with a physical disability.

Parmenter (2001) argued that the emphasis on independence, even within disability advocacy, contributes further to the view of disabled people (especially those who have an IDD) as having lower status and less value than non-disabled people. Many disability advocates have turned instead to stressing the importance to

humans of interdependence and community; see, for example, the video *Examined Life* (Butler & Taylor, 2010).

The Medical Model

The medical model of disability is prevalent in Western medicine and society, and has had the largest impact on shaping both overall attitudes towards disabled people and health care for disabled people. In this model, disability is considered to be a health problem or abnormality caused by disease, genetics, or trauma that requires individual diagnosis and treatment. The focus is on the disabled individual's limitations and the work required to "cure" the disability or to reduce the individual's impairments so that the person can fit into society; in other words, to "normalize" the person (Davis, 2006). Use of the medical model assumes that there is a "normal" state of being, from which disabled people deviate. Davis pointed out that in North America and Europe, those who are part of the dominant culture have a cultural understanding of what "normal" means, and that acceptance of "normal" stigmatizes disabled people.

The medical model has contributed positively in the areas of prevention, cure, and reduction of disability. Examples of this include the discovery of a cure for leprosy and the introduction of seizure control medications. However, the medical model of disability has been criticized for its limitations and for its focus on individual cure or treatment (Goering, 2015; Roush & Sharby, 2011). Disability advocates argue that despite the many benefits of medicine and individualized services, use of this model often negatively affects the lives of disabled people. Negative effects include narrow definitions of disability, assumptions that disability is synonymous with "suffering" and a poor quality of life, an artificial emphasis on "normal," control by professional service providers, segregation, and relationships of dependency in which the disabled person is the passive recipient of professional expertise (Goering, 2015; Hayes & Hannold, 2007; Roush & Sharby, 2011).

The Social Model

The development of the social model signalled a profound shift in disability discourse. In contrast to the medical model, in the social model, disability is conceptualized as socially constructed, not as an individual problem. The social model was developed in the United Kingdom in the 1970s as a direct rejection of the medical model and the “tyranny of the norm” (Shakespeare, 2006, p. 198). Advocates of this model focus on social oppression and environmental barriers (Oliver, 2009). They maintain that most problems encountered by disabled people are not a result of their bodies or capabilities, but, rather, are the result of a lack of acceptance by society, including society’s failure to provide the necessary supports. Key elements of the model are (a) a distinction between disability (defined as social exclusion caused by, for example, a lack of accessible buildings, or policies that create barriers to inclusion) and individual impairment (defined as a physical or intellectual limitation); (b) a recognition of disabled people as a stigmatized group; and (c) an emphasis on the removal of barriers (through anti-discrimination legislation, etc.) that cause disability (Shakespeare, 2006).

Use of the social model involves identifying systemic barriers, negative attitudes, and exclusion by society (either purposeful or inadvertent), thus emphasizing that society is the main contributory factor in disabling people. While individual impairments may be caused by physical, emotional, or intellectual differences, these do not have to lead to disability unless society fails to include all people (Withers, 2012). This emphasis on social exclusion shifts responsibility for change from a focus on the individual (curing or normalizing people using the medical model) to a focus on society (making society more inclusive).

The Biopsychosocial Model

The biopsychosocial model allows users to conceptualize disability as universal, and as an interaction between intrinsic factors (impairments) and environmental factors (activity limitations and participation restrictions) (Bickenback, 2012). This model is reflected in the ICF classifications of disability discussed earlier in this chapter. The biopsychosocial model was developed as a

response to the limitations identified for both the medical model and the social model of disability (Shakespeare & Watson, 2001), and through attempts by professional groups to distance themselves from the medical model and to include social aspects of disability (Hayes & Hannold, 2007; Roush & Sharby, 2011).

An important aspect of the biopsychosocial model is its emphasis on the universality of disability. Disability is not rare, nor is it an abnormality. For example, the disability rate in 2006 in Canada was reported as 14.3%, which represented 4.4 million Canadians. This disability rate steadily increased with age; Canadian seniors aged 65 and over had a disability rate of 43.4% (Statistics Canada, 2011). In *The Canadian Survey on Disability* (Statistics Canada, 2017), it was estimated that the prevalence of disability was one in five Canadians (or 6.2 million) aged 15 years and over. This is a marked increase over the 2006 data. The United Nations estimates that individuals in developed countries spend on average about 8 years, or 11.5% of their lifespan, living with disabilities (United Nations, 2008).

Each of the models of disability discussed in this chapter provides insight into how disability is viewed and how disabled people are treated. However, each model has limitations. For example, some disability theorists have maintained that the biopsychosocial model does not account for the oppression imposed on people with disabilities by societal norms and values (Thomas, 2004), and does not include a life course perspective of disability (Smith, 2002). Advanced practice nurses need to question and reflect upon how they may unconsciously be taking up the negative aspects of these various models in their practice.

Additional World Views of Disability

All of the previously discussed models of disability come from predominantly White, Western cultural perspectives. Disability is viewed differently by people in other cultures. Meyer (2010) described differences in terms of individualistic versus collectivist societies, with individualistic societies emphasizing individual resources and support and individual human rights, and collectivist societies emphasizing the importance of the family or cultural

group. There is evidence, for example that traditionally, many North American Indigenous Peoples did not define disability as a separate entity (Senier, 2013) and did not use concepts of “ideal” or “normal” in describing people (Gilroy et al., 2021). Lovern (2008) described a North American Indigenous world view as involving an “understanding of the wholeness of existence” (p. 113) in which an individual is expected to care for the whole community. In this world view, individual differences are “natural and create opportunities for both individual and community balance leading to wellness” (Gilroy et al., 2021, p. 2086).

Examples of Disability-Related Ethical Issues in Health Care

Building on the foundational content of this chapter, we now consider some prominent ethical issues in practice related to disability. As we have indicated earlier, many of the issues faced by disabled people in the health care system stem from how disability is defined and understood in dominant cultures and, subsequently, how these values become ingrained in the structure of health care systems. Health care programs, services, and decisions are often based upon the medical model of disability, with assumptions that disability is synonymous with a poor quality of life, that disabled people are a burden, and that some disabilities are more acceptable than others.

These assumptions are particularly evident in the relationship between disabled people and eugenics. Wilson (n.d.) defined eugenics as “the selection of desired heritable characteristics in order to improve future generations.” Wilson explained that eugenics was first described in 1883 and was influenced by Social Darwinism, including the concept of the “survival of the fittest.” Ideas about eugenics continued to expand until, by World War II, the Nazis were using eugenic theories to justify their extermination programs.

Policies and practices explicitly rooted in eugenics theory have existed in Canada for many years. *Sexual Sterilization Acts* were passed in Alberta in 1928 and in British Columbia in 1933 (Leung, 2012). These Acts allowed for the surgical sterilization of “defectives” without the person’s knowledge or consent. The aim was to promote a “healthy population while reducing the cost of these individuals

on the state” (Leung, 2012). “Defectives” included people with IDs, people with physical disabilities, single mothers, Indigenous people, Métis, and Eastern Europeans (Leung, 2012). These Acts were finally repealed in 1972 (Alberta) and 1973 (British Columbia). In Alberta, 2,832 people were forcibly sterilized (Park & Radford, 1998). Forced sterilization of disabled girls and women continues to be legal in some countries, including Australia (Elliott, 2017; Simhan, 2019).

Eugenic ideas remain prevalent in current issues surrounding human reproduction and death, and have given rise to discussion of “new eugenics” (Brown, 2019; Reinders et al., 2019; Rembis, 2009). These authors maintain that there is very little difference between the old eugenics and new eugenics. New eugenics simply uses new techniques to obtain the same goal: the selection of particular human characteristics. Debates regarding new eugenics now centre on health-related issues, including gene manipulation (Benston, 2016), perinatal medicine (Garrett et al., 2017; Grue, 2010), selective abortion (Thomas & Rothman, 2016; Ville, 2011), do not resuscitate orders (Dyer, 2012; Neville, 2021), health care rationing (Andrews et al., 2021; Lund & Ayers, 2020), and medically assisted death (Duong, 2021).

Perinatal and Neonatal Care

Questions around perinatal practice—such as selective abortion and care of disabled newborns—epitomize many of the current ethical concerns regarding eugenics and disability. These issues are centred on the common cultural assumption that disabled children are a “burden from birth” (Rubeis & Steger, 2019). There are a number of ethical issues that advanced practice nurses should be aware of and consider through a disability lens. These issues include (a) the implications of reproductive genetic carrier screening, that is, testing people to determine their likelihood of having a child with certain disabilities (Dive & Newson, 2021); (b) prenatal screening and counselling; (c) selective abortion; and (d) discussions about whether or not extremely preterm newborns should be resuscitated (Garrett et al., 2017; Grue, 2010).

Ville (2011) pointed out that perinatal medicine plays an active role in the social treatment and perspectives of disability. The

selective abortion of Down syndrome fetuses is an example of this phenomenon (Zhang, 2020). Thomas (2016) reported that assumptions that Down syndrome reduces quality of life affect how HCPs provide information during prenatal screening consultations. Specifically, Down syndrome was a topic often avoided during consultations, as health care professionals believed they had minimal knowledge of the subject. In a study by Kellogg et al. (2014), 48% of mothers of children with Down syndrome believed that HCPs gave biased or incorrect information. Williams et al. (2002) questioned whether or not counselling attached to prenatal screening could be truly non-directive and unbiased, given cultural biases about disability and assumptions about the quality of life of disabled people and their families. As a result, disability activists have condemned selective abortion of disabled fetuses as evidence of the devaluing of disabled lives (Brown, 2019; Reinders et al., 2019). In Ethics in Practice 14-1 we present a scenario in which the biases of HCPs and their judgments about quality of life negatively affect the relationship between a mother and her newborn.

ETHICS IN PRACTICE 14-1

A Common Experience of Parents of Newborns with Genetic Differences

Working on a maternity unit, you enter your patient's room to check on her and her newborn. The mother is lying on her side, facing away from the baby, and is crying. You gently ask how she is doing. She replies, "The doctor was just here and said 'I'm sorry, your baby has Down syndrome.' This didn't come up in the prenatal testing. What am I going to do?"

In this Ethics in Practice scenario, the new parent is confronted with an unexpected diagnosis for her newborn, but the way the information was communicated—as an apology, implying that the baby is a burden—contributes to their distress (Canadian Down Syndrome, 2017). As advanced practice nurses, how do we support care for patients who receive unexpected news, and also support them to readjust their perspective on disability? How can we

address this situation with the provider who shared the diagnosis, as well as with other team members?

Quality of Life and End-of-Life Care

Cultural assumptions that disabled people have a poor quality of life commonly affect health care practices. “I would rather be dead than live with a disability” is a sentiment that disabled people, particularly those with severe disabilities, hear from people without disabilities” (Wiebe & Derksen, 2010, Executive Summary, para. 1). Wiebe and Derksen add, “Incorrect assumptions about quality of life have the power to trigger responses that harm people with disabilities” (Executive Summary, para. 1). This sentiment of fear stands in stark contrast with the actual lives and experiences of many disabled people. As Withers (2012) explains:

Our disabled identities are important to many of us. While I am in incredible pain at times, I value the things that I get from my body—a body that is considered disabled. I appreciate my slow labored walk because I notice things that many other people don’t. My pain and my inability to do certain things also makes me very efficient, skilled at delegation and thoughtful about help and asking for it. These are parts of my personality that I am proud of and couldn’t imagine living in the world without. (p. 48)

Evidence of incorrect assumptions about quality of life that harm disabled people can also be found in the history of “do not resuscitate orders” being applied to disabled people without their consent or knowledge (Dyer, 2012; Neville, 2021; Wagemans et al., 2017). Disabled people have also expressed fears that decisions regarding medical assistance in dying (MAID) will be influenced by cultural biases that regard disabled people as suffering, having a poor quality of life, and being a burden on the health care system (Duong, 2021). The protection of vulnerable persons regarding MAID has generated much concern among disabled people and disability advocates (Council of Canadians with Disabilities, 2021; Philpott & Wilson-Raybould, 2020; Vulnerable Persons Standard,

2017). In end-of-life care, there is also evidence of the devaluing of disabled lives. In general, disabled people experience poor access to palliative care services in comparison to the non-disabled population (Adam et al., 2020; Tuffrey-Wijne et al., 2016). In Ethics in Practice 14-2, we present a scenario in which a frightened patient expresses the common attitude of “better dead than disabled.”

ETHICS IN PRACTICE 14-2

Responding to Traumatic, Disabling Life Events

While working on a surgical ward, you have a 21-year-old patient who has been in a snowboarding accident and has been diagnosed with a spinal cord injury that will limit his mobility. He appears depressed and refuses to speak to his physicians or to his family. When you come into the room he yells “I want to die! Why didn't you let me die? Someone help me die!”

In Ethics in Practice 14-2, you are confronted with despair and suicidal ideation that can be common among people newly diagnosed with spinal cord injuries (Spinal Cord Injury Canada, 2020; Tchajkova et al., 2021). According to Rodríguez-Prat et al. (2017), some of the most common reasons that people consider physician-assisted death include fears regarding loss of independence, uncertainty regarding the future, and concern that they will be a burden for their loved ones. As advanced practice nurses, we can provide much needed support for patients as they adjust to changed life circumstances and fear of the unknown. We can help patients navigate these fears and consider how they may stem from cultural concepts and biases about disability rather than the lived experience of many disabled people.

Inequities in Health Care Throughout the Life Course

Disabled people experience well-documented inequities in access to and provision of health care throughout their lives. This is particularly evident for those disabled people who are considered to be lower on the hierarchy of disabilities; that is, people with (IDD). One

well-documented issue is screening for common medical conditions. Compared to people without IDD, those with IDD experience lower rates of screening for hypertension (Hanley et al., 2021; O'Brien et al., 2021; Schroeder et al., 2020), osteoporosis (Burke et al., 2017), breast cancer (Cuypers et al., 2020), cervical cancer (Brown et al., 2016; Cuypers et al., 2020), and colon cancer (Cuypers et al., 2020). In addition to lower rates of screening and under-diagnosis of cancers, Cuypers et al. (2020) found that people with IDD who were diagnosed with cancer were under-treated.

Additional examples of inequity in health care for people with IDD include poor hospital experiences and neglect of pain management. Several authors have documented poor hospital care, including delays in care, lack of consistent care, and poor communication among staff regarding hospitalized patients with IDD (Iacono et al., 2014; Tuffrey-Wijne et al., 2014). Neglect of pain management occurs frequently in adults with IDD. Weissman-Fogel et al. (2015) found that 48% of adults with IDD experienced chronic pain, and 10% experienced high levels of chronic pain. This chronic pain was due to a need for adaptation of wheelchairs; lack of care for digestive, oral/dental, and orthopaedic conditions; and a lack of availability of analgesics for menstrual pain. Further, Rush (2013) noted that poor dental care has been a well-documented source of pain for disabled people, particularly people with IDD.

In Ethics in Practice 14-3, we illustrate some of the difficulties in providing accessible care and offer some suggestions to increase one aspect of accessibility.

ETHICS IN PRACTICE 14-3

Making Emergency Care Accessible

A mother takes her seven-year-old autistic son into the emergency department because he has cut his hand on a piece of glass. It is not a deep or serious wound, but it is continuing to bleed. The child is visibly agitated. He paces in the waiting area, giving intermittent cries and waving his bleeding hand. It is Friday evening, the waiting area is full, and the wait times are four hours or more. As time passes, the child becomes more and more agitated. He lies on the floor and starts to emit an ear-piercing scream. Other patients in the waiting area are complaining about the noise.

In this scenario, you are confronted with issues of long wait times for emergency care and a patient who does not physically need immediate care. However, the longer this patient has to wait in the emergency area, the more difficulty he will have accepting treatment. Some people with autism are affected by changes in routine, unfamiliar environments, and environmental stimuli, such as flickering fluorescent lights, noises, bright colours, and other stimuli. In addition to considering how to reduce emergency wait times and how to triage less urgent cases, advanced practice nurses need to consider the many other aspects of “accessible” care. There are a number of resources that can be used to reduce environmental triggers for behaviour issues for autistic people and to create more calming and welcoming environments for everyone (Simpson, 2020; Wolpert, 2022). As an advanced practice nurse, you might institute these recommendations in your place of work.

There is evidence that existing disparities in health and health care for disabled people have been exacerbated during the COVID-19 pandemic. For example, in Canada, COVID-19 positivity rates were 1.28 times higher for adults with IDD, and 1.42 times higher for adults with Down syndrome, compared to non-disabled adults (Lunsky et al., 2021). Lunsky also reported that adults with IDD were more than twice as likely to be hospitalized and to die following a COVID-19 diagnosis. For adults with Down syndrome, mortality rates were 6.59 times higher than those without IDD. This inequality has also been reported in other countries (Clift et al., 2021; Landes et al., 2021). In England, for example, researchers found that compared to non-disabled people, people with intellectual disabilities had a 56% increased risk of dying from COVID-19 after they were hospitalized (Baksh et al., 2021). These authors attributed this increase in death rate to bias and discrimination that lead to disparities in care. They found that people with intellectual disabilities admitted to hospital with COVID-19 were 37% less likely to receive non-invasive respiratory support, 40% less likely to receive intubation, and 50% less likely to be admitted to the ICU.

During the COVID-19 pandemic, disabled people also experienced greater barriers in accessing services for their ongoing health care needs. In a study of children with medical complexity in British Columbia, Canada, Baumbusch and colleagues (2022) found that children had a significant decline in access to allied health therapies

(for example, physiotherapy, occupational therapy, speech and language therapy) and medical specialists during the initial wave of the pandemic. Additionally, Baumbusch and colleagues found that single-parent families were less likely to take their children to the emergency department than they would have prior to COVID-19. This reluctance to access emergency department services reflected the impact of public health measures, which, at the time (March to August 2020), severely restricted the number of essential care partners who could be with a patient in the hospital. One tragic outcome of these restrictions was the death of Ariis Knight, a disabled woman in BC whose family and support workers were not permitted to be with her during a hospitalization early in the pandemic (Bains, 2020).

Responses from Nurse Leaders

Addressing health inequities and preventing harm to disabled people will require intentional and authentic engagement by the nurses providing direct care, as well as nurse leaders. Two core practices that form the basis for this engagement include understanding common cultural views of disability and their effects on disabled people, and partnering with disabled people to work towards transformation of individuals' health care practices, as well as health care systems and policy. "Nothing about us without us" (Charlton, 1998, p. 1) is a well-known disability rights slogan, and must be central when considering how to move forward. Disabled people should have increased visibility, both as advisers to health care policy and practices and as teachers in health care education settings. Building on these core practices, we follow through with a discussion focusing on nursing education.

Nursing Education

The lack of disability content in nursing curricula is well-documented, and contributes to critical inequities that arise from inadequate education of nurses and other HCPS (Cashin et al., 2021; Lewis & Stenfert-Kroese, 2010; Ndengeyingoma & Ruel, 2016). Nursing curricula should include disability-related topics in undergraduate, graduate, and continuing education programs. We need

to question how we perceive disability—for example, we need to ask whether we are using a tragedy/charity or medical model lens—and consider how our perceptions impact our interactions with disabled people and provision of their health care. In addition, nurse educators ought to provide opportunities for students to meaningfully engage with disabled people in both clinical settings and the classroom.

We also need to consider barriers to the inclusion of disabled nursing students that shape the processes used for admission to academic programs, provision of academic programs, and assignment to workplaces. Frain et al. (2007) reported that disabled nurses experienced stigma and a lack of acceptance in the workplace. Disabled nurses and physicians have reported having fewer career choices and opportunities for advancement compared to their non-disabled peers (Neal-Boylan et al., 2012). We should encourage nurse educators to reflect on the presence (or absence) of students with disabilities in their programs. Based upon human rights legislation in Canada, nursing schools cannot discriminate against students based upon disability. It is, therefore, the responsibility of nursing programs to facilitate inclusion of disabled people by providing appropriate and necessary accommodations. Nurse educators have a central role in identifying and addressing ableism in nursing, beginning with educational practices. The video *What's Disability to Me? Rachael's Story* features a powerful message from the perspective of a disabled nurse (WHO, 2011).

Nursing Practice

Nurses in practice also need to have an understanding of the implications of ethno-cultural assumptions regarding disability when caring for patients, families, and communities. As we have articulated in this chapter, discrimination and stigma within health care are commonly experienced by disabled people, particularly those with IDD (Pelleboer-Gunnink et al., 2017; Walsh et al., 2020). Further, discrimination and stigma experienced by disabled people can be exacerbated by race and ethnicity (Krahn et al., 2006; Magaña et al., 2012).

One particular area in nursing practice that needs improvement is access to services. Access issues may include physical barriers in buildings, as well as organizational barriers, such as inflexible policies and procedures (Bailey et al., 2019). Barriers caused by low incomes in the face of high costs of health services, equipment, and therapies also need to be addressed (Karpur et al., 2019; Raymaker et al., 2017).

Another area of nursing practice requiring attention is communication. Poor communication between disabled people and HCPS is reported frequently (Baumbusch et al., 2014; Redley et al., 2019; Sharby et al., 2015). Communication problems can be related to a range of factors, including (a) lack of appropriate interpreters; (b) the patient's use of communication techniques and devices that are unfamiliar to HCPS; (c) noisy and distracting environments; and (d) lack of time for interactions.

To begin to address these issues, one approach nurses should take is to use trauma-informed care practices (Center for Substance Abuse Treatment, 2014). By using this approach, nurses acknowledge the trauma many disabled people experience. Trauma-informed care is characterized by:

- realizing the prevalence of trauma;
- recognizing signs and symptoms of trauma exposure;
- responding by integrating this knowledge into practice, procedures, and policy; and
- resisting re-traumatization or replication of prior trauma dynamics. (Center for Substance Abuse Treatment, 2014)

Trauma-informed care can be taken up by nurses at the individual level and by leaders at the organizational level to create systems-level changes. Importantly, researchers have indicated that when nurses integrated trauma-informed care into their practice, they were less likely to re-traumatize individuals (Lewis et al., 2019).

Nursing Leadership

As nurse leaders plan health care services and develop policy, it is imperative that they use a disability-inclusive approach. A central tenet of this approach is ensuring active and meaningful involve-

ment of people with disabilities in all aspects of planning, implementing, and evaluating services and policies. It is also important to raise awareness of the rights and needs of disabled people among everyone on the health care team; that is, regulated health care professionals as well as other staff on the team. Finally, careful examination of accessibility as it relates to services and policies is key. As part of this accessibility, nurse leaders ought to consider additional social factors that may be influencing an individual's experiences, such as gender, sexual orientation, race, class, and age.

Conclusion

In this chapter, we provided foundational content about disability, including definitions, models, and current terminology and language. Many nurses have not had access to this type of knowledge in their pre-licensure education, and in order to provide appropriate care for disabled people across the life course, it is imperative that nurses understand how disability has been viewed in Western society over time. The influences of the tragedy/charity model and the medical model continue to shape health care delivery. Disabled people experience many inequities in health care, from value judgments about their very existence to barriers to recommended health care services, such as cancer screening. Advanced practice nurses are ideally situated across diverse practice settings to provide leadership by challenging and helping to address these inequities. Working with disabled people, nurses can contribute to the transformation of the health and health care of this large and diverse population.

QUESTIONS FOR REFLECTION

1. *How can a disability lens be integrated into nursing education in order to foster a more equitable experience for disabled people?*
2. *What are the implications of the medical model of disability and the social model of disability for the delivery of health care?*
3. *In your experience, what evidence is there of negative attitudes and biases against people with IDD in hospital care? How can these be addressed?*

4. *How can the inclusion of disabled people in public health screening programs be increased?*
5. *What strategies can advanced practice nurse leaders implement to create disability-inclusive health care systems?*

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