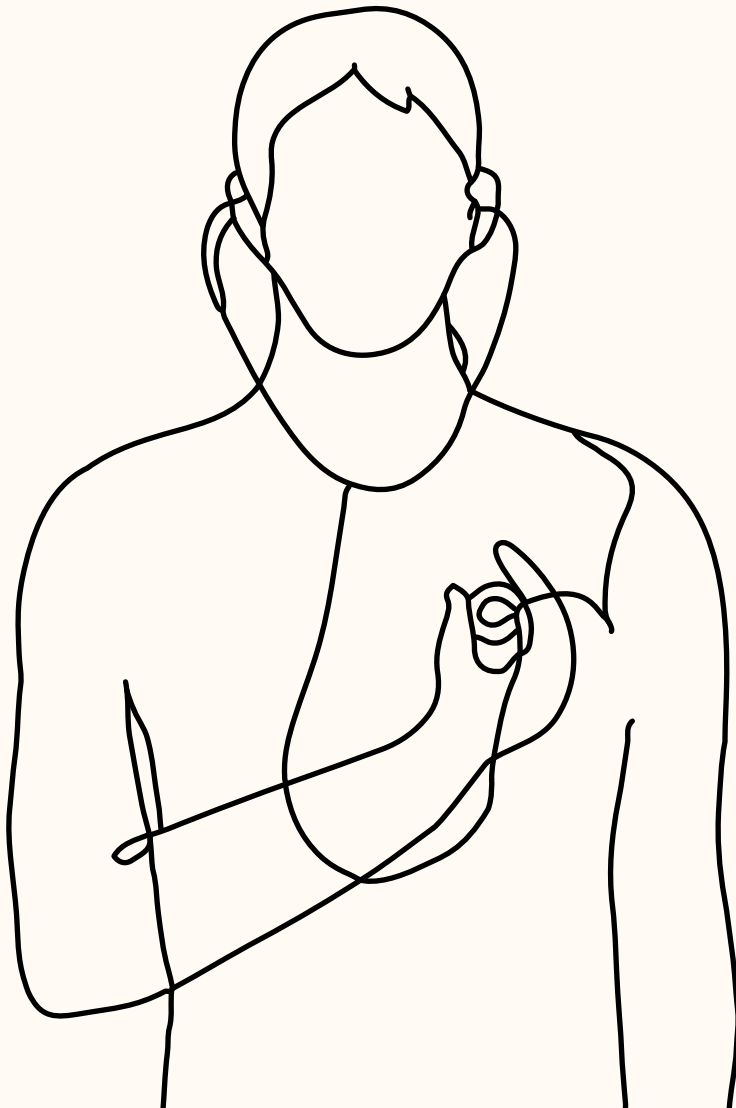


AMMI ABLEIST?

Disability Awareness in Healthcare



Marihan Farid
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The authors of this book want to acknowledge that we cannot speak for disabled people. We've collaborated with various disability advocates to strive to create material that was thoughtful, accurate, and educational for our fellow healthcare students. We recognize within disability communities, there are diverse experiences, histories, and ways to provide competent care as healthcare providers. Our goal is for students and professionals to start to have access to a more intentional perspective while going through their training; however, take this book within its necessary context.

Many of the perspectives and examples provided in this resource are specific to medical education and patient-physician relationships. We recognize that various professions may refer to individuals as clients, participants, or more broadly people supported.

For more examples and further discussions, please email us at disabilityinmedicaleducation@gmail.com or visit our website at <https://sites.google.com/view/amiableist/>

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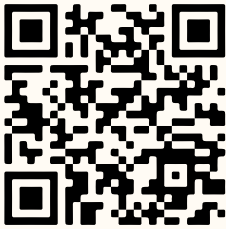
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Why Should We Care?

Disability-based discrimination in healthcare can lead to substandard care, limited access, and negative health outcomes, particularly for people with medical complexity. A recent study identified key drivers of such discrimination, including clinician assumptions, apathy, and lack of knowledge¹. These factors result in limited accessibility, substandard care, and dehumanization of patients. For many of us, our education about disability began before our training with what we see in the media, how the people around us talk about disability, or people we know that have disabilities. The view of disability that society shows you will likely be reinforced in training, often focusing solely on clinical manifestations of disabilities².

This means views surrounding disability could be missing a balanced and thoughtful lens of what disability means for an individual and for communities on a societal level. Without reflection and understanding, this perspective can cause clinicians to have harmful biases, leading to adverse health outcomes and societal consequences among disabled patients. Healthcare providers have enormous power over access to resources for people with disabilities. We must continue to learn about these resources and inform patients how to access them.

Scan the QR code to answer on your phone!



- How do you define disability?
- What experiences did you have with disability prior to starting training?

Healthcare professionals must begin to recognize their role within the medical institution when it comes to their ideas about disability and realize at an individual and systems-level we collectively have a lot of work to do to provide competent and equitable care. We decided to put together a starting point for what we think fellow healthcare students should begin to think about before caring for people with disabilities.

Interactive Questions

- How comfortable would you feel, as a student, interacting with patients without disabilities?



- How comfortable would you feel, as a student, interacting with patients with disabilities?



- How much do you trust your training to provide competent care to patients without disabilities in the future?



- How much do you trust your training to provide competent care to disabled patients in the future?



Interactive Activity

Scan the QR code to answer on your phone! ↴



Privilege Checklist

Before reading this chapter, review the following statements and see which ones apply to you regarding your own privilege when it comes to learning about disability...

- I'm not considered by some individuals a burden on my family or all of society for being born.
- I can reliably trust whatever researchers and scientists say about people whose bodies and brains are like mine.
- I don't have to worry about being sent to an institution or having all my legal and political rights taken away as a legal adult.
- I don't feel like I'm part of a dying species or the target of modern-day eugenics programs because of how my brain or body works.
- If I do have children, some people won't question whether it was responsible or ethical to add another person to the world who might end up being like me.
- My type of body or brain is not used as a metaphor by some for brokenness, awfulness, mediocrity, or ignorance.
- I can choose whether or not to be part of the fight for disability justice, or to take breaks from it.

A lot of research conducted by physicians and researchers with these ideas in mind played a huge role in our society's historical understanding of disability. Healthcare providers also played an important role in advocating for the institutionalization of disabled people due to their potential "burden" on society, ultimately resulting in forms of neglect, abuse, and trauma while people attended these institutions.

Many disabled people were sterilized without their consent, and Canadian laws were passed to promote the sterilization of disabled people and the use of their tissues in research without their consent.

Many of the terms that scientists and physicians coined to describe disabled people are still used today as harmful slurs.

If you don't have to live this every day if you do not want to, then this book definitely applies to you! Keep reading!

This list is adapted from the Autistic Hoya Privilege Checklist

Chapter 1

Knowing Your Role in Healthcare

“An institution is not just a place, it is the way people think”

—Pat Worth, a founder of People First

Throughout Chapter 1, we may use language from the time period for the relevant context in quotations, however, these terms are oppressive and harmful. Please refer to [Chapter 2](#) for details on the correct current-day language.

In this chapter, we examine how the foundation of the profession we are a part of today was built on the oppression of disabled people. During clinical training, there is a brief mention, if at all, of the historical relationship between the medical profession and disability. There was a time not too long ago when doctors forcibly sterilized disabled women, locked up people with disabilities, and experimented on them without their consent⁶. Moreover, many doctors of that time felt that they were doing the right thing for the good of their patients and for society. So, how—as future healthcare providers wanting to do what is right and just—can we make sure we do better? First is by educating ourselves and recognizing our complicated role in history.

**What does the word ableism mean to you?
What do you think ableism in medicine
looks like?**

We start our brief history in the 19th century. At this time, provincial governments in Canada were trying to find solutions to provide law and order to society by criminalizing disability. Over time, people who were incarcerated solely for

Definitions

Eugenics: In 1883, Sir Francis Galton, cousin of Charles Darwin, coined the term “eugenics”, which he defines as: “the cultivation of race.” Indiana passed the first law allowing disabled people to be involuntarily sterilized³. This is considered to be the first such eugenic “law” to be passed in the world.

Sterilization: Defined by Ezra S. Gosney and Paul Popenoe in their book “*Sterilization for human betterment*,” chronicling 6,000 “successful” sterilizations in California of disabled people. Eugenic sterilization primarily, is applied to persons who would be likely to produce disabled children³.

mental illness or disability had separate jails, called “*asylums*”. Some of these early asylums existed with the goal of returning people with disabilities to community life as a form of rehabilitation; however, it soon became evident that most asylums were warehouses to provide custodial care for inmates⁷.

As time went on, these asylums became increasingly prevalent in Canada. Historical records of these asylums show the goals and motivations behind the development of these institutions were to improve both the living

conditions and capabilities of people housed there. Narratives at the time suggest that non-disabled people considered these asylums a “charitable response for the feeble-minded”⁸. These could be some of the early records of the charity model of disability (making disability out to be something to be “fought” or pitied)⁹. These incarcerated individuals were also used involuntarily for research, experimentation, and free labour. The Orillia Asylum for Idiots, located in Orillia, Ontario was Canada’s first institution for the disabled. It developed a closed-loop system where the most productive inmates (despite their likely successful rehabilitation or preparation for community living) were not discharged from the asylum as to ensure ongoing functioning of the asylum with their unpaid labour⁸.

Scientists played a huge role in the institutionalization of disabled people in these asylums as their research acted as “evidence” to suggest the belief that intelligence could be measured and people could be ranked based on intellectual capabilities. Research by these scientists provided supportive platforms for eugenics, ableism, racism, and class-based discrimination through the ability to identify individuals with disabilities through “intelligence” tests. The growing number of intelligence tests began to generate more and more new labels such as “moron, high grade-defective, idiot, imbecile” all continually growing the population that “qualified” for institutionalization⁸. An example of the power of these intelligence tests in Canada was used by Dr. Helen MacMurchy, an Ontario physician who pushed for intelligence testing with immigrants and to put children in institutions and other segregated settings. This same physician was named “Inspector of the

Definitions

Paternalism: An action that limits a person's or group's liberty or autonomy and is intended to promote their own good⁴. For example, a concept discussed in this chapter is the sterilization of disabled people by physicians without the patient's consent.

Ableism: Disability scholar Fiona Kumari Campbell defines ableism as “a network of beliefs, processes, and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human.” Disability then is cast as a diminished state of being human⁵.

Feeble-minded” and would identify children requiring institutionalization and advocate for the child’s removal from the family home and placement in Orillia. This physician’s research focused on the social concerns of intermingling non-disabled and disabled children in the school systems⁸. As a future healthcare provider, consider the power Dr. MacMurchy had in destroying hundreds of families’ relationships and labeling children in harmful ways that they and their loved ones would carry through their entire life. As a clinician-scientist with a responsibility to keep children safe and healthy, her research and advocacy were incredibly harmful with continued effects today.

It's important to realize that disabled children weren't admitted to institutions equally. Race played a role because those at the asylums were predominantly Eurocentric¹⁰⁻¹². This was because other groups were being segregated and oppressed in other ways, with Indigenous children already in residential schools and Black children in their own segregated schools.

Socioeconomic factors also played a prevalent role, with children in poverty more likely to be labeled as disabled. "IQ tests became a way to subject different groups of already marginalized people to diagnoses leading to life-long institutionalization⁷." Scoring lower on IQ tests (a type of testing primarily designed for educated, higher-class individuals of European descent) was used as a barrier to immigration, not to mention other specific immigration laws banning disabled people directly. These factors, among others at the time, resulted in a smaller diversity of individuals being in the community spaces in the first place to be identified for placement at these institutions. In addition to the discrimination and injustices people with disabilities experience, ableism continues to serve as a tool for disadvantaging ethnic minorities and people of lower socioeconomic status. Take the institution of education for example, even fast forward to today with the overrepresentation of minorities in special education in K-12 education, and the continued underrepresentation at the postsecondary level¹³. This overrepresentation demonstrates the complex intersectionality between ableism and racism and its influence at institutional levels such as education.

How can individuals in healthcare be ableist? How can systems in healthcare promote ableism?

Similarly, gender was used to determine if someone should be institutionalized, as disabled women of childbearing age were thought to generate higher rates of pregnancy through "promiscuity." In Canada, laws were passed

in Alberta and British Columbia (1928 and 1933, respectively) to limit reproduction among disabled women⁸. At the Michener Centre in Alberta, surgical sterilization parameters were loosened to allow for a rapid increase in procedures without consent or patient knowledge, with biological materials extracted during sterilization surgeries used by researchers and other individuals with authority within the institutions. For example, Leilani Muir, a young woman at 15 years of age was told she was having her appendix removed, but actually had a bilateral salpingectomy in 1959 in Alberta by the same physician, Dr. Le Vann, who was doing research on tissues removed during sterilization procedures. Later in life, when struggling to conceive and learning of what happened, she went to trial against the Alberta government in 1995, winning \$740,780 CAD in damages¹⁴. Despite this example occurring in the late 1950s, these eugenic policies were not officially changed until the 1970s¹⁵. Racialized women were impacted by sterilization at disproportionate rates, specifically among Indigenous women. The regulation of the sexuality of women (by undergoing forced or coerced sterilization) was using illogical, problematic reasoning in that it would minimize the detection of sexual exploitation by supposedly sparing these women the experience of pregnancy by rape¹⁶. Similarly, women with disabilities were institutionalized longer than men and often permanently to ensure they didn't have children¹⁷. This paternalistic logic, with doctors assuming they know what's best for other individuals, pretended to support the best interest of disabled women but did so by removing their autonomy^{8,16}.

As a future healthcare provider, how will you advocate for your disabled patients while prioritizing autonomy?

In the 1960s, countless physicians told families that sending their children with disabilities to these institutions would allow the children to be well cared for and it would be the best thing they could do for their child¹⁸. However, countless residents of these institutions experienced indescribable violence, abuse, and neglect at the hands of staff members and physicians while at these institutions. 1 in 33 children in Canada were sent to these institutions, to which the government coined the slogan “one on every street¹⁸.” It took more than 40 years for these institutions to begin to close, with the Huronia institution closing in 2009¹⁸. Despite Huronia’s closure, the Ontario Provincial Government argued that Huronia was managed in accordance with the “standard of care at the time” (a standard of care that resulted in the removal of disabled people from mainstream society).

This idea supports that “standard of care” could be deeply rooted in ableism within medicine and shows one of the many forms it can take. Standards of care are a fundamental component of delivering healthcare, and the fact that these were once the “guidelines” for providing “optimal” care is something to consider. A lawsuit in 2010 against the Ontario Provincial Government for abuse and oppression at these institutions by survivors was a huge step forward in a new chapter of self-advocacy by disabled people in a post-institution era. The Honourable Kathleen Wynne, the Ontario Premier at the time of the lawsuit, quoted during an official apology, “...residents

suffered neglect and abuse within the very system that was meant to provide them care¹⁸”.

Although many of these institutions physically closed, institutionalization still remains today. As of 2020, hundreds of individuals across Canada live in government funded facilities for individuals with intellectual and developmental disabilities³³. Countless disabled individuals in Canada are inappropriately placed in prisons, long term care, psychiatric hospitals, or nursing homes³³. Despite the physical closure or evolution of many institutions, it is important to acknowledge that the underlying thinking that opened them has not changed near as dramatically³³.

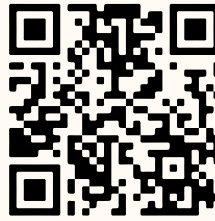
As students and trainees, we must consider that these same institutional systems still exist. The healthcare system we will work within has evolved significantly, but its foundations were built partially on models of thought that would be considered horrifying today. There were institutions like “Orillia Hospital School¹⁷” that were called “hospitals” and it makes us think about the relationship a disabled person might have in the present day with a “hospital” and the mistrust it could be built on. More directly, you very well could be caring for someone who has had traumatic experiences being institutionalized. Finally, as we conclude this chapter, we’d like to acknowledge how we’ve compiled this historical information from a variety of reputable sources; however, we hope you consider that what is known about this history is unfortunately shaped predominantly by historical discourse and not lived experience from people themselves that survived these institutions¹⁷.

Post-Chapter reflection questions:

- Where do you think themes of this history still exist in our health care system today?
- What does trauma-informed care look like?

Interactive Activity

Scan the QR code to answer on your phone!



Based on what you've just learned about historical treatment, how will you take more accountability to provide trauma-informed competent care to disabled patients?

This exercise was modified from the "Trauma Glasses On/Off Activity" from The National Center on Safe Supportive Learning Environments

Imagine a patient who...	Where is your accountability in this?
...does not agree with the treatment plan	<ul style="list-style-type: none"> • Maybe you haven't given sufficient evidence to them to trust your decisions about their health management •
...is late to appointments	
...interrupts you with questions	
...is reluctant to be examined	
...doesn't adhere to their medications	

Some potential answers:

Imagine a patient who...	Where is your accountability in this?
...does not agree with the treatment plan	<ul style="list-style-type: none"> ▪ Maybe you haven't given sufficient evidence to them to trust you about their health management ▪ Maybe you haven't empowered them sufficiently to participate in determining the treatment plan that works best for them ▪ Maybe there are barriers to these treatments that they are hesitant to bring up
...is late to appointments	<ul style="list-style-type: none"> ▪ Maybe their commute is inaccessible, resulting in delays ▪ Perhaps you only offer appointments at times that are not flexible for their schedule
...interrupts you with questions	<ul style="list-style-type: none"> ▪ Consider modifying your communication strategy ▪ Maybe you've been rushing your explanations ▪ Consider sensory barriers present in your interactions that could be distracting or resulting in communication barriers ▪ Maybe you've provided information in a way that is overwhelming or with an unrealistic expectation of health literacy
...is reluctant to be examined	<ul style="list-style-type: none"> ▪ Consider how you are examining this patient. Have you asked for their consent, given them the option to decline, provided a space that is comfortable, have a chaperone present? ▪ Have you prioritized their autonomy throughout the exam? ▪ Have they been informed how and why you need to examine them this certain way?
...doesn't adhere to their medications	<ul style="list-style-type: none"> ▪ Maybe you could have clarified why they aren't taking their medications properly, or if they are having medication side effects ▪ Try confirming how and if they are able to pay for their medication ▪ Perhaps their pharmacy isn't accessible to them

And there are many more possible answers too!

Chapter 2

How Do You Think About Disability?

Pre-Chapter reflection questions:

- Did you have close relationships with anyone with a disability growing up?
- Did you have meaningful interactions with disabled individuals in a professional setting before starting your training?
- Do you remember ever seeing disability in popular media or books you've read?
- How did these opportunities influence your understanding of disability?

Understanding language and concepts regarding the meaning of disability in society play a key role in providing competent care to disabled patients. Scattered throughout this chapter are themes of disability justice that we hope to articulate while discussing models of disability that have been developed over the years¹⁹. Some models are created and endorsed by disabled people and disability scholars, while other models come from more insidious origins. Our aim is to provide you with the tools necessary to identify which models of disability are most familiar to you, and how you can start being intentional with how you define disability as you move through your training.

Medical Model

Medical education still primarily focuses on disability using the medical model. Medicalization of disability means identifying disability as an "intrinsic problem that needs to be fixed". A key aspect of this model promoted in medical education is a focus solely on the clinical manifestations of a disability that must be corrected. It is largely impossible to account for systemic discrimination or other extrinsic barriers affecting someone's disability experience with the medical model approach. For example, a way a physician might perpetuate this model and perpetuate further discrimination could be by always seeing someone's disability as their chief complaint when in many instances someone can be themselves healthy and have a disability. This means the physician wouldn't approach the patient's care in a holistic way that considers how factors other than their disability are contributing to their needs.

In addition to the medical model, there is also the intertwined **charity model** of disability—which poses themes that disability can be "fought" with fundraising (i.e., charity model)—closely connected to disability can then be cured and eradicated (i.e., medical model)²⁰.

To counter the dominant narrative of medical and charity models of disability, disability advocates developed the social model in the 1970s and later came the human rights model. The social model and the human rights model are some of the most common perspectives of disability in use today.

==== Social Model =====

According to the social model, disability is a social construct, caused by society's failure to provide adequate services to accommodate everyone¹². In this model, an inaccessible society is "disabling" the individual, and the person is not held responsible for their limitations. The creation of both the social and human rights models were crucial to begin to shift away from disability models that pathologize disabled people's bodies and minds, and instead place the focus on social conditions, oppression, and access¹³. The limitations of the social model, however, is that it does not reinforce disability as a natural aspect of human diversity and minimizes impairment related to disability if relevant. As a provider, if you use this model for someone who has mobility challenges, for example, it lets you consider how at a societal level inaccessible infrastructure excludes your patient (i.e., buildings without ramps, examination rooms that are inaccessible), but this model still makes you unable to appreciate if the patient themselves has an impairment that requires supports for their condition (such as access to approved funding to purchase a wheelchair).

==== Human Rights Model =====

The human rights model explains disability as a natural part of human diversity and it should not affect someone's access to societal privileges⁹. Despite advocating for equal access, the model has the limitation of arguing for equality without changing the unfair system. In medicine, using this model for disability equity would require modifying the original medical systems created by the non-disabled people who benefit the most from them, to allow for the equitable privilege for all patients at an individual and system level.

Thanks to the tireless work of disability advocates, progress about how society views disabled people has evolved; however, providers remain to hold a lot of power when it comes to understanding and labeling disabilities.

How did healthcare providers and scientists play a direct role in the societal understanding of disability and some of the older language and models used to describe disability?

Researchers were fond of labeling and categorizing different groups of people, and through the labeling and categorizing of others, a framework was created for measuring and controlling different groups of people⁸. Similarly, scientific research generated the evidence to support social management, which in turn became the basis for laws and policies. Then these laws and policies became the foundation for further laws, policies, and research defining and advancing our societal understanding of disability.

Research that supported these societal views was fuelled largely by classist, racist, sexist and ableist ideas of intelligence and capability that confirmed to non-disabled people their biases about disabilities they held in the first place⁹. While this extensive research was conducted, eugenics was popular, and eugenicists saw disability as an impediment to the emergence of a “fit” society²⁰. As a result of existing social injustices, eugenics focused on those in society who were struggling and labeled such individuals as disabled with the intention of eradicating them. Some eugenic attitudes about disabled people remain today.

Consider how you will navigate your own model of disability with decisions and interactions within the healthcare system. Think about your experiences with disability prior to starting training, your values surrounding disability, and how you tend to define how people participate in society. Do you define someone’s importance in their community by their productivity? By their kindness toward others? By their resource use? All of these ideas will be subconsciously incorporated into your future interactions with all your patients but particularly your disabled patients. Consider the value of people as they are, for who they are, with inherent worth outside of capitalistic ideas of productivity¹⁹. You may have to separate your personal beliefs and your professional beliefs in order to provide equitable care to all your patients.

You must recognize the need for humility when defining what it means to have a disability if you yourself do not have one. Consider the providers who have come before you using diagnoses and labels to further marginalize groups in the community¹⁷.

Many healthcare providers can also control people's access to social assistance, programs, and services through how they define and label someone's disability. In other words, we will be responsible for access to things including accessible housing, transportation, workplace accommodations, mobility aids, attendant care, technology, counseling, income, and even access to food²⁰. To make matters more complicated, a lot of times, resources that are available if any exist, aren't designed specifically for disabled people. Healthcare professionals have a responsibility to be advocates for the populations they serve. Think about the power you have as an advocate and how your perception of disability can affect the advocacy work you participate in.

Definitions

Mental age refers to the level of perceived cognitive development of an individual, and compares these traits to the intellectual function for people of the same chronological age. This concept can be dangerous in its implication that disabled people are inherently inferior or less capable, further reinforcing harmful stereotypes that are created by an oversimplification of individuals' complexities. Providing a mental age to a disabled adult also infantilizes them, as we discuss in [Chapter 2](#).

There is advocacy in how we use language to describe disability. The language surrounding disability is also incredibly important, as it can be a representation of the thoughts and ideas someone has about disability. Language is also influenced by the various models of disability someone holds. One example is person-first language (e.g., “person with a disability” instead of “disabled person”). Language of this type was coined with the rationale that people are first and foremost people and that their disabilities do not comprise their full identity.

A limitation of this language is that it separates disability from personhood while conveying the impression that people with disabilities are somehow unfortunate. Many disability advocates choose identity-first language (e.g., “disabled people”). This type of language ensures that disability is not seen as passive or an afterthought, but rather an important part of a person’s identity. You’ll notice throughout these chapters that we include person-first and identity-first vocabulary.

Different individuals may have a preference for different language based on their own disability self-concept. When speaking about disability, it is important to begin to be aware of the language you use, and how your language can be a vehicle for the thoughts and ideas you hold regarding disability. We acknowledge that different people may have different preferences regarding their descriptive language and there is no right way. As a provider, consider how you should reflect and use the language your patient uses as a way to build trust and relate to how your patient understands themselves and their disability. Consider the language you use about disability when speaking directly to a disabled person and when you are alone or with colleagues and less directly accountable. You may need to correct your language to represent the ideas about disability you want to have.

Post-Chapter reflection questions:

- How do you relate to someone who acquired a disability as compared to someone with a congenital disability?
- What are some language you've used to describe disability in the past?

Interactive Activity

Scan the QR code to answer on your phone!



What's wrong with the following sentences?

I am so sorry, but we believe it's likely your baby has Down Syndrome

...but they don't look disabled...

Your child has cerebral palsy; she will never be able to walk and will always be dependent on you for care

These people with an intellectual disability

Hey there buddy/sweetheart, I am going to explain the treatment plan to your caregiver... [while speaking to an adult with a disability]

I am so **sorry**, but we believe it's likely your baby has Down Syndrome

Consider the language we use, as students, as well as the language our preceptors use and how our words impact patients.

Be mindful of how your words affect your—and others'—perceptions of individuals.

We encourage you to reflect on if—and why— you have a certain bias of what disability might "look" like. It will help to refer to **Chapter 3**, where we will have a more in-depth conversation about invisible disabilities.

...but they don't look disabled...

Your child has cerebral palsy; she will **never** be able to walk and will **always** be dependent on you for care

As a future provider, you have so much responsibility to set the tone for expectations for this family's understanding of disability and their child's capabilities. Your words can help shape how the family thinks about this child's future. Think about how you use language like "always" and "never" as a provider (*this patient will never go to school, never communicate, etc.*) as you cannot

guarantee what is and isn't possible for this patient based on your own biases regarding a particular disability. Many disabilities exist on a wide spectrum and something as important as communication is not a binary action and can encompass a wide range of mechanisms.

Using this language instead of just person-first or identity-first language alone instills "otherness", that you are somehow different from a group of individuals. If you feel a sense of otherness, explore that feeling so you can work on it. You may want to refer to **Chapter 2 reflection questions** of how you relate to someone with an acquired disability (e.g., someone with a recently obtained spinal cord injury) versus someone with a congenital disability (e.g., someone born with a different number of chromosomes than you have) as a starting point.

These people with an intellectual disability

Hey there **buddy/sweetheart**, I am going to explain the treatment plan to your **caregiver**... [while speaking to an adult with a disability]

Notice infantilizing language when speaking to an adult with a disability. This can also bring out larger biases such as a lack of consideration of disabled people as sexual beings and denying individuals that aspect of their healthcare if thinking of an adult as child-like. This language also assumes the patient cannot consent, cannot participate in their treatment plan, and assumes a specific role of the support person.

Additionally, the concept of mental age is problematic. Despite a global move away from this term, it is still used in some settings with adults with intellectual disabilities. This conflicts with rights-based approaches and can reinforce harmful stereotypes. A study in Ireland found that while mental age is still used, it is considered problematic and inconsistent with best practices. It has negative connotations and oversimplifies abilities, leading to infantilization. For more insights, refer to the article "Mental Age and Intellectual Disability"¹⁹ and the video "Conversations with Ivanova: Mental Age Theory."²⁰

Chapter 3

Current Day Disability and Healthcare Considerations

Research shows that non-disabled people assume that the quality of life of people with disabilities is lower than they would report²¹. This has huge implications for how a clinician would counsel their patients with disabilities. If and when people with disabilities do report a lower quality of life it has less to do with the direct effect of their physical impairments but the effect of living in a society that is built for able-bodied individuals²¹.

Today, many people with disabilities continue to struggle in our healthcare system due to systemic barriers and biases. One particular way providers contribute to these barriers is by questioning a patient's capacity because they are disabled. It is always wrong to assume that someone is incapable of providing consent because they are disabled. As students, we learn that everyone should be assumed to have capacity until proven otherwise and do our best to provide the necessary support for consent to occur. However, using someone's disability status alone as a justification that they will be unable to consent is unethical. This is part of a larger theme of ensuring individuals are at the forefront of their care and their family members, partners, and support people are involved in the way the patient wants them to be.

We led a focus group with individuals with IDD (Intellectual or Developmental Disability) when beginning create this resource, and a participant mentioned "...when a doctor knows more, they can do more!" This was in relation to instead of relying on an assumption about disability—the more that healthcare providers understand someone's disability experience and learns about their own biases, the better

Think about the privilege you bring to the following statements:

- I will not be left to die in the hospital from completely treatable and curable conditions like pneumonia because of negative assumptions about my quality of life or a belief that I would be better off dead.
- I don't have to worry about not being provided a ventilator should I get really sick and be hospitalized from COVID-19 due to assumptions people have about my quality of life.
- I will not be denied life-saving organ transplants because of how my brain or body works when I would otherwise be eligible.

care that they can provide. The same can be said for the decision-making process: By asking the patient what they know, what they understand, who else they want as part of these decisions, and how they can be best supported.

An ethical discussion healthcare providers continue to have is how healthcare providers define quality of life.

Imagine that as a provider, a disabled patient is coming in and they are now diagnosed with a chronic illness on top of their existing disability.

- How was your assessment of a patient's quality of life before this additional diagnosis?
- How would your assessment be of a patient if you were asked by a colleague about their quality of life now?
- How much of your evidence was based on facts versus assumptions you made?

Non-disabled people often believe that people with disabilities have a lower quality of life due to their disability²¹. This belief is rooted in ableism, and we must consider that certain abilities do not mean less fulfillment in life. As a future healthcare provider participating in quality-of-life discussions, consider how you find meaning and value in your life, and how different that could look for other individuals. Continue to reflect on assumptions you might bring to how you define a healthy body and a healthy brain.

Discussions regarding quality of life contribute heavily to how healthcare providers decide who gets to live and die. MAID (Medical Assistance in Dying) for people with disabilities can be complicated by views of ableism. MAID is the administration of a substance to a person at their request that causes death or the provision or prescription of a substance for a person at their request so they can self-administer the substance and in doing so cause their death²². One of the criteria for

MAID is that the individual must have a serious and incurable illness, disease, or disability. This is defined as either an advanced state of irreversible decline in capability, illness, disease, or disability or a state of decline that causes enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable²². The belief that living with a disability is worse than dying is at the core of hesitations surrounding MAID and its delivery for individuals living with a disability. This would equate disabled people to those who are terminally ill with imminent death and of course, many disabled people live long, healthy lives. This issue is further complicated for individuals who require care by caregivers because the person's life worth is now tied to the "workload" placed on the caregiver.

Can you, as a healthcare provider, determine if an individual has a "poor quality of life"? Is quality of life subjective or objective?

In a similar light, disabled people may be pressured to sign a "Do Not Resuscitate" order by healthcare providers. These healthcare providers might be arriving at this conversation with the patient or their family trying to "help", but also will bring their conscious and subconscious ideas about disability and quality of life. This can further be complicated by the ideas of quality-of-life family members and substitute decision-makers hold. As the provider, and as a "gate-keeper" of these interventions or lack thereof, it's crucial to identify your biases and reflect on them so you arrive at these conversations best able to support your specific patient in the way they want²³.

We've discussed the power a healthcare provider brings to an interaction at an individual level when it comes to reduced resource access, this extends even to more direct medical access to things like preventative healthcare. People with disabilities receive less preventative care²⁴. For example, the DisAbled Women's Network of Canada published a report in 2013, highlighting the various barriers to breast cancer screening specific for women with disabilities²⁵. Despite a publicly funded healthcare system, we fail to meet the healthcare needs of our disabled patients. According to a national study, disabled adults (aged 20-64) have three times more unmet healthcare needs than nondisabled adults²⁶. Several studies in Canada have noted the decreased access to screening programs for physically and intellectually disabled individuals^{26,27}. Specifically, disabled women have a lack of access to sexual health care across the country²⁸. We ask you to reflect on this in relation to the parallels of reproductive control across history discussed in **Chapter 1**.

Intersectionality

Intersectionality is a metaphor for understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves and create obstacles that often are not understood among conventional ways of thinking.

Some people who are defined by society as being disabled do not view themselves as disabled at all. For example, many Deaf and Hard of Hearing people connect with individuals outside of hearing groups and feel that having hearing would isolate them from their Deaf community.


Many individuals in the Deaf community continue to be labeled by healthcare providers as needing cochlear implants, while people will often express feelings of regret post-surgery²⁹. Additionally, a recent introduction of a newborn hearing screening program in Nova Scotia and around the country has huge implications for the Deaf community and has been opposed by many because parents often feel pressured by their providers to consent to cochlear implants for their children^{29,30,31}. Ethics surrounding cochlear implants for newborns and Deaf culture are complex, but as students, it is crucial for us to appreciate and acknowledge Disability Pride.

Disability Pride

Disability pride views disability identity as valuable, enriching, and positive. Disability pride is thought to be a way to promote and protect self-esteem against stigma as it is based on acceptance in a disabled person's full self. This rejection of assimilation into stigmatizing majority culture and instead a disabled person choosing to identify with other disabled individuals while emphasizing intersectional experiences within disability communities³². Celebrating disability pride as a non-disabled person in part means promoting advocacy at an individual and community level. For future healthcare professionals, to promote disability pride could be to support activism in disability communities.

Conversely, people with invisible disabilities have more control over when and how they are defined as disabled by society.

Individuals with invisible disabilities are individuals you might not assume to be disabled when first meeting them. Because of this, individuals could have more choice over the disclosure of their disability. However, this doesn't mean that a person with an invisible disability experiences less ableism, it might just be that it is different than someone with a visible disability. Having an invisible disability can make it challenging to receive accommodations, and like visible disabilities, accommodations are heavily influenced by medical evidence provided by a physician. These are just a few of the countless considerations of current healthcare issues facing various disability communities.

Scan the QR code to answer on your phone! 

Interactive Questions

- How do you define disability?
- How has your understanding of disability in education changed?
- How comfortable would you feel generally as a student, interacting with patients without disabilities?

completely uncomfortable completely comfortable

| | | | | | | | | |
0 1 2 3 4 5 6 7 8 9 10

- How much do you trust your training to provide competent care to disabled people in the future?

my training will not make me competent my training will make me completely competent

| | | | | | | | | |
0 1 2 3 4 5 6 7 8 9 10



Interactive Activity

Read each statement and check the boxes that best represents your current understanding or ability. Use this as a tool to reflect on areas for growth and learning.

- I am aware of my own biases and am taking steps to address them.
- I can identify at least three common stereotypes about people with disabilities.
- I am aware of how to make my practice more accessible to people with disabilities.
- I recognize that different people have different preferences for communication.
- I understand the difference between medical and non-medical models of disability.

We hope that these chapters have begun to provide you with some context to begin to develop your own frameworks for when you enter the healthcare profession. Continue to be humble and seek out learning opportunities from those within disability communities. We have included some further reading materials at the end of this book to act as a starting point for more of your own research. We hope you will take the time to provide feedback on our chapters and if there are considerations to be made for us to improve for future learners.

Reviewers

Sue Robins (she/her) is a healthcare activist, speaker, and author of the books *Ducks in a Row: Health Care Reimagined* and *Bird's Eye View: Stories of a Life Lived in Health Care*. Sue has also written for The New York Times, Canadian Medical Association Journal, and The Globe and Mail. Sue can be found at www.suerobins.com and on Twitter @suerobinsyvr.

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Shawn Jennings, MD (he/him) is a Dalhousie Medical School graduate who spent 20 years as a successful family doctor. Shawn suffered a brainstem stroke, forcing retirement from medicine; however, now as a disability advocate and writer, Shawn is the past president of the Canadian Association of Physicians with Disabilities and a published novelist.

Donna Lee (she/her) is an educator and consultant who has worked with people with intellectual disabilities and those that support them for over 30 years. She has facilitated training with self advocacy groups and organizations providing disability services across the country in areas such as disability rights, self-advocacy, person directed support practices, and supported decision making. Donna has a graduate degree in Disability Studies from York University, taught Disability Issues at Toronto Metropolitan University for several years, and is currently faculty with Nova Scotia Community College's Disability Supports and Services program.

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How did this book come to be?

During our first year of medical school, we noticed ableist themes perpetuated in the curriculum. We began looking for resources addressing ableism within medical education, but our search came up empty. So we decided to design and create the resource ourselves. Over the next year, this became the basis for the project, creating a resource to teach medical students how to begin addressing ableism. We partnered with the Regional Residential Services Society (RRSS), affiliated with Dalhousie University. RRSS provided guidance with our project design, introduced us to RRSS members with lived experience, and helped create a focus group with disabled members to guide our process. We sought expertise from disability advocates across Canada as we started researching and writing. After drafting our manuscript, we reached out to experts in medical and disability communities to ensure that experience was the forefront of this resource. The end product is this! We are so grateful to all those involved in the process. We hope you enjoyed, and hopefully even learned something!

Follow us on Instagram [@AmIAbleist!](#)

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Additional resources

History of Institutionalization in Canada:

- Interview with Leilani Muir describing her experiences as mentioned in **Chapter 1** <https://youtu.be/F5Lp9Ga3HY4>
- Truths of Institutionalization: Past and Present. <https://truthsofinstitutionalization.ca/>
Six interactive modules outlining the historical timeline to current day of institutionalization of people with disabilities in Canada with political and social context.
- Invisible Institutions Podcast <https://invisibleinstitutions.com/>
A documentary podcast exploring past and present institutions in Canada for disabled individuals.

Disability Ethics:

- Ashley Treatment: Permanent Infantilizing vs Improving Quality of Life
A 6 year old, Ashley X with severe developmental disabilities in Seattle was physically shortened, and sterilized to make it easier for her parents to care for her.
Harnacke, Caroline. "The Ashley Treatment: Improving Quality of Life or Infringing Dignity and Rights?" *Bioethics.* 30;3(2016):141-50
- Tracey Latimer: Mercy or Murder. A 12 year old with severe Cerebral Palsy in Saskatchewan was murdered by her father in the 1990s to relieve her suffering.
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- The Eve Decision: Canadian Institute for Inclusion and Citizenship
More than a decade after sterilization laws were repealed in BC and Alberta, in 1986, a PEI mother went to court for the right to have her disabled daughter sterilized. The case was lost, but won on appeal and went to the Supreme Court of Canada where it was ruled that Eve could not be sterilized without her consent, setting Canada-wide precedent allowing guardians to have their disabled children sterilized.

Current-day Resources:

- For further reading on the Social Model of disability: <https://youtu.be/9s3NZaLhcc4>
- Bird's Eye View: Stories of a Life Lived in Health Care by Sue Robins
A book of stories of lived experience with the Canadian healthcare system for both herself as a patient, and as a parent of a disabled child. It is targeted toward medical professionals and has heavily inspired our journey to creating medical student specific resources.
- My Leaky Body: Tales from the Gurney by Julie Devaney
A medical memoir and an award winning novel about a woman's experience with ulcerative colitis exploring themes of invisible disability and ableism in healthcare in Canada.
- "Mental age" and intellectual disability
Psychologists' perspectives on the use of the term 'mental age' as it relates to adults with an intellectual disability:
<https://onlinelibrary.wiley.com/doi/full/10.1111/jppi.12498>
<https://youtu.be/8OWHxQ70F8>
- Locked In Locked Out by Dr. Shawn Jennings
A Dalhousie Medicine graduate working 20 years as a busy family physician until he suffered a brainstem stroke leaving him unable to move, speak, smile or feed himself. He wrote a book about his disability experience going from physician to patient.
- Gault MA, Raha SS, Newell C. Perception of disability as a barrier for Canadian medical students. *Can Fam Physician.* 2020;66(3):169-71
Reflect about ableism toward colleagues with disabilities as well. We reference this article about perception of disability as a barrier for Canadian medical students
- Surrey Place has a "Decision Making in Health Care of Adults with Intellectual and Developmental Disabilities" document as well as a variety of primary care focused disability specific guidelines. <https://ddprimarycare.surreyplace.ca/>