Ability, disability, and difference in diversified CBL cases

Background

Ableism is an explicit or implicit preference for bodies and minds that function in (what is constructed as) typical ways based on ideas of normalcy, intelligence, desirability, excellence, productivity and fitness (among others). It results in discrimination and in social, economic, political and environmental structures that limit the life opportunities of persons with disabilities and negatively affects their health and the accessibility and quality of their health care.

No two disabilities and no two persons with disabilities are the same. Differences that are constructed as disabilities may include physical/mobility, mental/emotional, cognitive, developmental, learning, communicative or sensory experience(s). These differences may impact the ways in which people navigate sensory input, movement, thinking, remembering, learning, communicating, mental health, pain and social connection.

Disability communities emphasize that disability identities are often fluid and that individuals move in and out of these identities, both due to changes in an individual's mind or body that affect functioning and participation variably over time and due to changes in context that facilitate or pose barriers to functioning and participation. Disabilities may be present at birth, the result of an injury, or acquired over time; temporary, recurring, fluctuating and/or permanent. There are visible and invisible disabilities.

Figure 1 Workbook created by Dal Med students Marihan Farid, Abigale MacLellan, and R Zachary Ford. Available at https://t.co/E3FvAWrg01

For some persons, disability is a component of identity, intrinsic to membership in a community, and/or the expression of culture. For some persons, disability is a label that is practical necessity to access social services and adaptative supports. Some challenge the label of "disability" and think of themselves in terms of a range of natural variation. For example, intellectual and developmental differences may be understood as neurodiversity. Deafness may be understood as membership in deaf culture. Variations in sex characteristics may be understood as natural differences rather than disorders. As such, disability or difference may be supported with clinical diagnosis, with self-diagnosis, or with self-identification.

Not all disabilities are visible. People with invisible disabilities can face different kinds of ableism because they may not fit dominant society's idea of who is a disabled person. Within medicine, this can cause patients with invisible disabilities to experience medical invalidation and gaslighting, leading to clinician-associated medical trauma (Halverson et al. 2023; Witvliet 2023). Not believing people with invisible disabilities can intensify the ableism that they experience.
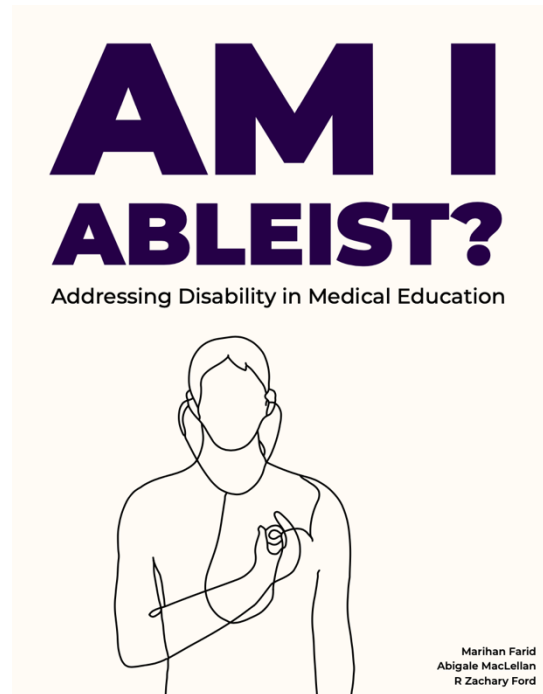
Disability, health, and healthcare

Despite disability being a common human experience, ableism creates barriers for persons with disabilities in many contexts. In healthcare, both access to care and quality of care received are inadequate for many persons with disabilities. A recent US survey reports that fewer than half of US doctors feel confident they can provide the same quality of care for disabled as they do for non-disabled patients (a requirement of the UN Convention on the Rights of Disabled Persons) (Iezzoni et al. 2021). A qualitative study of community practice in Ontario raises similar concerns (McColl et al. 2008). Common concerns include missed diagnoses and neglect of routine preventive care due to a focus on the person's disability and not on their presenting complaint or preventive health care needs. A long overdue movement in medical education and practice is to consider disability as an identity, from a human rights perspective, and to educate health care providers in disabilities competencies (Havercamp 2021).

In health care environments, ableism can be reflected in inaccessible assessment and treatment spaces, inflexible communication styles, negative attitudes towards disability (and especially about quality of life for disabled people), pathologization of particular ways of functioning, a lack of respect for patient autonomy, a lack of knowledge of how to adapt the physical exam with persons with disabilities, and a medicalized focus on disability.

At the height of the social dominance of ableism, medical, social welfare, and legal systems adopted eugenicist views, according to which it was a goal of health care to promote "normal" and "superior" intelligence, fitness, and moral standing at the population level, including by forced sterilization and discriminatory immigration policies (see the Western Canada Eugenics Archive at https://eugenicsarchive.ca). Although explicit eugenicist policies were discredited with the fall of Nazi Germany, devaluation of the lives of persons with disabilities is still common, as reflected (for example) in stigmatizing narratives and language in news reports of the murder of disabled persons (Buitan and Cresciani 2023).

Historically, many people with disabilities--whether psychosocial, mobility and sensory, or intellectual and developmental--were removed from families and communities and housed, or detained, in institutional settings. Since the late 20th century, there has been a movement towards "de-institutionalization," including shifting mental health care to community-based team settings and closing sheltered workshops while promising to support employers to employ persons with disabilities. This has been supported by human rights advocacy for respecting the human rights of persons with disabilities and adapting communities to be places where persons with disabilities can live a full range of life opportunities.

This de-institutionalization is incomplete, under-resourced, and subject to counter-veiling trends. An important Court Decision in Nova Scotia **in 2023** directs Nova Scotia to cease institutionalizing persons with intellectual disabilities, in violation of their human rights (https://truthsofinstitutionalization.ca). Funding for community-based mental health was not forthcoming as de-institutionalization progressed, and low-income housing supports were reduced, resulting in inadequate housing, homelessness, and a de facto shifting of persons with disabilities from health care institutions to carceral institutions, with racism having an intersectional effect on the consequences (Maynard 2017). In addition, it has taken time for medicine to define and start to teach competencies for providing health care to persons with disabilities in the community. The first competencies for persons with IDD in Canada were published in 2011 and the first for disability in general were published in the US in 2021.

Disability and human rights

The United Nations agreed to a Declaration of the Rights of Persons with Disabilities in 1975, but it was only in 2006 that a Convention was ratified committing member states "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." The UK passed specific legislation to protect the rights of persons with disabilities in 1970, the US in 1990, and **Canada in 2019** (the Accessible Canada Act). Several provinces have (NS) or are planning to (NB) pass similar legislation. As health care is within provincial jurisdiction, these provincial laws will be important for medical practice. Although some medical specialties have long advocated for inclusion, accessibility, and quality of care for patients with disabilities, satisfying the human right to equitable health care is unfinished business and likely to be a focus of medical practice improvement over the next few decades.

The Accessible Canada Act defines disability is "any *impairment*, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment—or a *functional* limitation—whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person's full and equal *participation* in society." Using a similar definition, Stats Canada reports that just over 1 in 5 Canadians live with a disability. People living with pain-related functional limitations constitute the largest group. This figure under-counts the true numbers; for example, it does not include people in institutional living situations, and Stats Canada data do not include on-research Indigenous persons.

Disability and intersectionality

Ableism intersects with other oppressive power structures, e.g. colonialism and imperialism, that continue to create disability through violence, war, toxic industries, and genocidal practices that disrupt family structures and spiritual practices, etc. (Puar, 2015; Meekosha, 2011; Senier, 2013). Intersectionality is reflected (for example) in Indigenous disability rates in Canada and in disability in refugee (newcomer) populations.

Ableism is a structural determinant of health; having a disability will in turn affect intermediary social determinants of health, such as income and housing. Having a disability doubles your likelihood of having income below the low-income threshold and living in housing need, for example (Stats Canada 2023), and if you have well-remunerated work, limits your ability to change employment due to reliance on benefits.

An important development in intersectional disabilities advocacy was the legal recognition of Jordan's Principle (AFN 2019). Jordan River Anderson was a young boy with complex care needs from Norway House Cree Nation in northern Manitoba. Due to jurisdictional wrangling over who would pay for his care, he lived his entire 5-year life in hospital instead of in his community and at home with his family. Championed by First Nation Child & Family Caring Society, Jordan's Principle states that First Nations children have a right to substantial equality and culturally appropriate care, safeguarding the best interests of the child (FNCFCS 2023). Effectively, this means that First Nations children (on or off reserve) can access the immediate medical, social, and educational supports and resources that they need via a national 24/7 phone centre (1-855-JP-CHILD; information at: https://www.sac-isc.gc.ca/eng/1568396296543/1582657596387#247).

This model has been adapted for Inuit children in Nunavik (https://nrbhss.ca/en/nrbhss/out-region-services/child-first-initiative). One of the significant learnings we can take from Jordan's Principle is how central and important people (and children specifically) with disabilities are to Indigenous communities; they are an integral part of the community.

How can physicians practice and advocate for care consistent with the human rights of persons with disabilities?

1. **Understanding the social model of disability and respecting the human rights of persons with disabilities.**

On the social model, disability arises from ableism—from the failure of the social and physical environment to enable and support the function and participation of people with different physical, sensory, mental, emotional, and functional capacities.

This social model of disability and the related framework of individual impairment or difference, function, and participation, arising in interaction with the social and built environment, is at the core of the WHO ICF (International Classification of Functioning, Disability and Health), a key tool for measuring barriers to persons with a variety of physical, sensory, emotional, and intellectual abilities achieving (the WHO's inclusive definition of) health (WHO 2002).

The social model contrasts with the medical model, which seeks to prevent disability by addressing the physical causes of individual impairment or difference.

The two models are not necessarily inconsistent. Medical practitioners prevent disability by timely and accurate diagnosis and treatment of potentially disabling conditions. But the medical model is incomplete: it doesn't consider the human rights of persons with existing disabilities. On the social model, health inequities experienced by disabled people and communities are due to the intersectional effects of ableism and other structural injustices linked to social determinants of health, socioeconomic status, race, Indigeneity, nationality, gender, sexuality, and age.

2. **Ask yourself: What does society consider normal and why?**

Developing self-awareness of how society is organized around the needs of "non-disabled" persons is an important element of developing disability competencies. Sometimes "temporarily able-bodied" or "differently abled" are used to raise awareness, but they should not be used routinely. They are generally found to be patronizing attempts to sugar-coat reality.

Disability advocates often point to the degree to which physical and social environments are designed to support the function of typical individuals. Consider, for example, the environmental and fiscal costs of generating and transporting electricity so that public spaces can be lit for the benefit of sighted people and audio amplified for the benefit of hearing people. If the built world were constructed for wheelchair users instead of people walking, having a condition that leads a person to use a wheelchair would not be something that interferes with activities of daily living. As the saying goes, one doesn't notice the wind when it's at your back.

3. **Advocate, including practicing social prescribing**

Through advocacy and interprofessional practice, physicians can play an important role in enabling people with disabilities to access income and other supports: completing disability assessment forms for

provincial or federal benefits like provincial income assistance programs or Canadian Pension Plan disability benefits; providing documentation of disability for educational or workplace accommodations; and confirming disability for short -term disability benefits through private insurers like Blue Cross or public benefits like federal Employment Insurance or income tax benefits. Knowing and using Jordan's Principle in the care of Indigenous children with disabilities is an important physician competency.

4. **Provide adaptive and inclusive care**

What inclusive care for patients experiencing disability looks like in any specific case will depend on the particular patient and their functional and participatory goals. It also involves how you set up your physical practice space, using universal design principles (https://www.undp.org/sites/g/files/zskgke326/files/migration/ua/Manual_UD-in-Healthcare_eng.pdf).

That said, some themes that arise in discussion of what "good" care—accessible, high quality care—looks like include:

- Taking a deeply patient-centred approach to care, including asking questions about preferences related to language, communication styles, examination techniques, and prior experiences with care;
- Recognizing the person's expertise regarding how their body or mind functions and working collaboratively to determine the best way to provide care for them;
- Focusing care on achieving functional and participatory goals as identified by the patient;
- Being aware of the ways in which ableism structures social environments as well as health care practice, working to disrupt the assumptions and structures that result from ableism, and advocating for change.

Inclusive care for patients with disabilities requires understanding the context and concepts related to disability; practicing respectful and patient-centred care that maintains the dignity and autonomy of persons with disabilities; understanding high quality comprehensive care for persons with disabilities as a legal requirement in addition to a moral responsibility; collaborating interprofessionally and advocating across systems for team-based care; adapting communication approaches and examination techniques in clinical assessment; and participation in coordinated care plans across the lifespan and during transitions (Havercamp 2021). Supported decision-making is a key approach to respecting patient autonomy for persons with relevant disabilities (https://supporteddecisions.org/).

Trauma-informed care should be a universal precaution and is particularly relevant in clinical care of persons with disabilities. Explaining what you are doing with patients before and during a physical examination and seeking consent builds trust within the relationship and provides the clinician with the information and patients with the control necessary to minimize negative clinical, such as pain flares. If patients need interpretation services, ensure that appropriate and skilled medical interpreters are booked before the appointment and that these services are secured for any external referrals as well.

Disability in case diversification

In Med 1 cases, we address ableist and stigmatizing language in cases where we identify it. In Med 2 cases, we integrate patients with disabilities as they seek medical care for conditions unrelated to their disabilities, and portray inclusive and accessible care provision, including physician advocacy and the different ways that patients understand their own difference and/or disability and manage changes in their abilities, function, and participation over time.

Language notes:

- There is variety in how people with disabilities understand themselves and their health. People who count as disabled by Stats Canada definitions might not identify as persons with disabilities or as needing supports or accommodations.
- People use wheelchairs as devices that enable mobility. They are not "confined" to them.
- Avoid language of "helping" people with disabilities, and don't say that people "suffer" from their disabilities. Reject the pity narrative.
- Physicians and other health care providers often need to sign off on applications for supports and services for programs that might have a different understanding of disability than a patient does. Health care providers should be prepared to navigate this and explain when they need to use particular language or terminology in order to facilitate access to resources rather than assuming that language is okay.
- Some persons with disabilities prefer "person first language". Disability rights activists pioneered advocating for this approach. Others talk about themselves as "disabled persons," to emphasize their identity and collective rights and interests, and to emphasize that their disabilities aren't things they have; rather, they are disabled by ableism.
- In a medical context, it is preferable to talk about people's specific conditions (whether psychiatric/psychosocial, intellectual and developmental, sensory, mobility, or related to another chronic health condition), and to use the language of having a disability or being disabled only in the context of self-ascribed identity, human rights and health equity.
- A number of important terms that factually describe disabilities (for example, "functional" limitations) are used in medicine as derogatory, stigmatizing, or gaslighting terms. Point out and challenge (where possible) the stigmatizing use of this language when you hear it.
- There is a persistent false belief, particularly in health care, that persons with disabilities experience a lower quality of life.
  - The so-called disability paradox is that people even with "serious disabilities" rate their quality of life as the same as people without disabilities. Research supports the hypothesis that this is mediated by the extent to which their environment enables activity and participation (Fellinghauer et al. 2012).
- In general, "Normal," "healthy," and "non-disabled" are NOT synonymous terms, and should be used with caution and awareness.
  - Many people with disabilities are healthy.
  - The term "healthy" is ambiguous (does it mean physically or emotionally fit or resilient, or does it mean the absence of diagnosed medical conditions?).
  - Don't use "normal" when you mean typical or average. Everyone is "normal" from their own perspective, and the implied opposite (abnormal) is stigmatizing. In many cases in medicine, there is a more specific and technical term that is better than "normal" (e.g. inside or outside reference ranges for lab test results; remarkable or unremarkable pathology results).

Citations and resources:

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