



Definitions of disability in Canadian disability policy

Why do we need a definition of disability?

If a government is to fulfill its obligations in a democracy, defining administrative categories of need and entitlement is one of the ways it discharges its duties toward citizens (Hedlund, 2009). The judicious definition of those eligible for certain considerations is the basis for distributive justice. It not only ensures that those in need receive their share; it also reassures the population as a whole that government is discharging its duties and its resources with all due deliberation and efficiency.

Administrative definitions of disability attempt to ensure that all those in legitimate need are deemed eligible, while those not eligible are prevented from exhausting the system's resources. Yet the very process of categorizing or classifying disability is seen by some as undermining the value of the individual, and contributing to labelling or stereotyping.

As the Government of Canada's 2003 report states in its title, defining disability is a complex issue (Office for Disability Issues, Human Resources Development Canada, 2003). In fact, it is a political minefield of perceived infractions of rights, preferences, identities and ideologies.

Historical definitions of disability

Over most of the 20th century, four definitions of disability held sway (McColl & Bickenbach, 1998). In each instance, disability was defined by various social authorities that controlled the destiny of people with disabilities.

1. Until the middle of the 20th century, the most common way of thinking about disability was the **Charitable** model. Disability was defined by religious authorities, who identified a sense of mission toward people they saw as the victims of misfortune and objects of pity. They determined that the appropriate response towards disabled people was one of charity and benevolence. While this definition on the surface sounds benign, it reduces disabled people to passive recipients of philanthropy, without agency to care for themselves or to control their own circumstances. They were literally at the mercy of well-meaning others.
2. By the middle of the 20th century, the development of the field of rehabilitation led to a situation where people with disabilities could realistically contemplate a life beyond disability. It was a different life than the one they had expected, but it was a life

nonetheless. The rehabilitation system had socialized them to strive for independence and to master their own personal care and daily activities. They were encouraged to take their place in society, even to the extent of contributing their labour in limited ways. This environment gave rise to the **Economic** model of disability. The labour market, specifically employers and businesses, defined people with disabilities according to their ability or inability to work, to be economically self-sufficient, and to represent an economic force in society. The worth of people with disabilities was defined by their productivity. In the absence of the ability to generate a reasonable income, the responsibility of society toward people with disabilities was to acknowledge their limitations and their need for financial supports, and to develop programs and systems to provide them with a subsistence living. This era gave rise to vocational rehabilitation, sheltered workshops and disability pensions, to name a few examples of expressions of the Economic definition. While this view of disability acknowledges the need of all people to have a productive outlet and to contribute to something beyond themselves, it stops short of truly honouring the contributions disabled people are capable of making to society. Instead it relegates them to the role of recipients of welfare, rather than contributors to society. It also tends to entirely disregard their needs and preferences as potential customers.

3. By the 1950s and 60s, post-war prosperity had led to a zeal for social reform and an affinity for the good life. Scientific developments seemed to promise unbridled progress and improvements to social status for many. The middle-class was growing as all aspired to the social ideal of full employment, home ownership, higher education and perhaps even a few luxuries. The **Sociological** model grew out of this milieu. The Justice system and powerful institutions within society were charged with upholding these social norms and the expectations of citizens. People with disabilities, particularly those with mental or emotional impairments, were seen as being outside of the mainstream of society, at the margins, a minority group (Imrie, 1997). This specification provided justification for them to be segregated from society – hospitalized, institutionalized, or even incarcerated.
4. By far the most prevalent definition of disability to evolve in the 20th century is the **Biomedical** model. As people became increasingly enamoured of developments in medical science, health professionals became powerful sources of authority in modern society. The biomedical definition of disability hinges on the idea that there is an impairment, a fault, a flaw in some tiny part of the person, and if only we could find it and correct it, then the person could be restored to health, happiness and function. This reductionistic approach situates disability in objective, organic findings, and it assumes that if the biological problem can be overcome, then all will be well. The appropriate response from society toward disabled people is to ensure that timely and compassionate diagnosis and treatment are available. Consistent with the previous definitions, the biomedical model situates disability inside the person, and defers to an external medical authority to decide what is needed to remediate the situation.

The preceding definitions prevailed at different times over the past 100 years. All reflect what was important in society at the time. Until the 1980s, and arguably even up to today, these models were all evident in images and portrayals of disability around us.

Modern definitions of disability

In the early 1980s, people with disabilities responded to the many social movements that were afoot in the previous two decades – the civil rights movement, the peace movement, the women’s movement. The disability movement became the “last civil rights movement” (Driedger, 1989). In response to the rallying cry, “Nothing about us without us”, people with disabilities insisted that they, and only they, were qualified to define the condition of disability. The following definitions of disability have arisen in the past 35 years, in keeping with the post-modern paradigm – experiential, context-dependent, relativistic, subjective (McColl, 2019).

5. The first modern definition of disability to challenge the medical model was the **Independent Living** approach to disability. The Independent Living movement arose in the United States to assert the right of self-determination for people with disabilities. The Independent Living movement thus defined people with disabilities as *consumers* (rather than patients or clients) – meaning rational decision-makers in control of the resources that shape their lives. Choice is at the heart of independent living – specifically, the same range of choices enjoyed by non-disabled people within a society. Key themes in Independent Living are housing, living situation, employment, personal support services, social opportunities and advocacy. Independent Living Centres arose in cities across North America, providing services “of, by and for people with disabilities”.
6. Disability activists in England offered another alternative definition of disability – the **Social** model of disability (Oliver, 1990). They viewed disability as entirely socially constructed by a society designed without their needs in mind. Disability did not exist in any objective reality of impairment or diagnosis, but rather in the barriers that society erected to inhibit the full participation of disabled people. This model proposed that the appropriate social response to disability, was the removal of all barriers that create inequities for people with disabilities. Hosking (2008) describes the Social model as the “mighty shove” needed to shift the dominant discourse away from the biomedical model to something more structural rather than individualized – away from individuals to society at large as the origin of disability.

The social model became so dominant in disability advocacy and activism around the turn of the 21st century that it was virtually hegemonic. To subscribe to any other definition of disability was heresy. But that sort of dominance cannot be sustained – it is a set-up for criticism, and sure enough, criticism of the social model began to emerge.

- The social model was utopian and unrealistic. The ideal of a barrier-free society was unattainable.
- It didn’t deal with the practical realities that people with disabilities faced today, tomorrow and the next day.

- It simply replaced the oppressive language of medicine with the equally alienating and esoteric language of sociology and political science.
 - It failed to deal with the heterogeneity of disability.
 - Disability research based on the social model categorically rejected the scientific paradigm, in favour of participatory and emancipatory research approaches. While these methods responded to the need for an alternative to traditional research methods, they situated disability studies entirely outside of mainstream science.
 - Finally, the most damning critique of the social model was that it failed to acknowledge the lived experience of disability and the individuality of disability. For example, for people who experience pain and its implications for daily life, no amount of social engineering is going to make that go away. Structural solutions were simply too remote to deal with intimate and personal issues.
7. A subset of the Social model is the **Human Rights** model. It focuses on the potential for an insensitive society to inflict discrimination on people with disabilities by virtue of society's failure to account for the needs of disabled people when establishing structures and programs within society. Discrimination can arise from deliberately excluding people with disabilities, but more often, it arises unintentionally – by failing to give a thought to how people with disabilities will interact with the physical, social and legal environment. The remedy, according to the human rights model, is to challenge prevailing structures where they lead to discrimination, and systematically alter laws and policies to ensure equity for people with disabilities. Discrimination against people with disabilities must be eliminated case by case, whether intentional or unintentional.
 8. Another corollary of the Social model of disability is the **Critical disability** approach (Pothier & Devlin, 2003). This approach characterizes disability as an issue of power, and a source of historical oppression. Disability arises when dominant forces in society exercise their privilege regardless of its implications for other. According to this approach, disability exists as a result of ableist assumptions about how people and societies should be and relate to one another. The critical disability approach rejects all attempts at objectivity or rational inquiry into disability, since these are expressions of the dominant normative discourse that privileges the status quo and silences the voices of disabled people.
 9. Another approach to conceptualizing disability is found in the **Capabilities** approach. The Capabilities approach was first proposed by Sen (1980) as a means of understanding inequality and disadvantage experienced by some individuals and groups in society. Capabilities are defined as opportunities to partake in certain activities or goals in life, by virtue of having the ability, resources, means, knowledge and external circumstances to do so. Nussbaum (2000) built on the Capabilities approach by specifying ten 'functionings' that are essential to human flourishing – life/survival, bodily health; bodily integrity; use of the senses, thought and imagination; emotions; practical reasoning; affiliation; relating to other species; play; and, control over one's environment. Rather

than a normative concept of ability, the Capabilities approach emphasizes freedom to live a life of one's choosing (Baylies, 2002; Burchardt, 2004; Riddle, 2010).

10. A model was proposed by Swain & French (2000) called the **Affirmation** model of disability. This model attempted to turn the tables on disability definitions. The authors maintained that all of the above models were still “tragedy” models, in that they focus on disability as a problem – as a source of oppression, discrimination, ignorance and disregard. The Affirmation model of disability focuses on the advantages experienced by people with disabilities. Some of the advantages they enumerate include: the ability to eschew class distinctions, freedom from society's expectations and requirements, empathy with other oppressed minorities. They point to expressions of disability pride in the arts scene – in dance, visual arts, poetry, comedy, and music – as manifestations of the Affirmation approach.
11. Finally, The **Biopsychosocial** model arose in an attempt to reconcile the critique of the social model, as being inadequately attentive to the lived experience of disability. Over time, as the social model failed to produce the changes it sought in social structures, critics pointed to its often alienating rhetoric, its utopian view of the world, and its denial of real personal challenges accompanying disability. The biopsychosocial model attempts to reconcile these issues by situating disability at the interface of a person with an impairment and a society that fails to adequately adapt for that impairment. It represents a swing of the pendulum away from an entirely structural perspective on disability, toward a perspective that also recognizes the individual experience. However, unlike the medical model, the biopsychosocial model offers no objective indicator of who does and does not have a disability (World Health Organization, 2001).

While it is tantalizing to think that a single definition of disability might lead to a policy environment that is coordinated and consistent, there is a growing consensus that this is not possible (Human Resources and Skills Development Canada, 2013; ODI, HRDC, 2003). The complexity of disability defies a single definition leading to a single set of eligibility criteria for all disability programs and services. There is acknowledgement that a broader definition of disability is often used when considering human rights or when discussing disability policy in the abstract, while a more targeted and restrictive definition is necessary when disbursing benefits or providing services (ODI, HRDC, 2003).

Qualities of a good definition of disability

What follows then is a set of criteria for assessing a “good” definition of disability. These emerge from a review of the literature.

1. There appears to be consensus on the necessity for an underlying health condition as the basis for defining a disability (Leonardi, Bickenbach, Bedirhan Ustun, Kostanjsek, & Chatterj, 2006; World Health Organization, 2001). Although no clear link can be established between any particular health condition and its manifestation as disability (Paetzold, 2005), it is clear that a health condition must be present.
2. There is also broad agreement that a disability is inherently an inability to perform some important function or role. While not a perfectly objective state, disability must be more

than a subjective experience of limitation, or a negative evaluation of quality of life (Leonardi et al., 2006). It must result in specific limitations or restrictions that have important consequences for the person's life.

3. There is no agreement about who is qualified to assess or measure disability. In many policy areas, medical or health professional authentication of disability status is required for eligibility for benefits. And yet, medical professionals are qualified only to testify to the underlying medical condition, and not to the disability itself (Corson-Rikert & Christmas, 2009).
4. A good definition of disability must align with current knowledge, practice and ideology about disability. And so, in the current climate, the only acceptable definition of disability is one that places at least equal emphasis on the role of society and on the role of the individual in creating a disability.
5. Depending on the aim of disability policy, the best definition may be context-free or context-dependent (Letizia, 2002; Paetzold, 2005; Scanlon, 2013). When considering policy aimed at **equity** or **access**, the definition of disability should be context-free; that is, the policy should address all types of disabilities, regardless of the particular manifestations in different situations. On the other hand, when considering policy aimed at providing **supports**, the definition of disability must be context-dependent. It must reflect the specific needs of those individuals who are tactically disadvantaged in participating in a particular life area by virtue of their disability.
6. Also depending on the area of policy, the definition of disability may need to acknowledge that people with disabilities:
 - have extraordinary expenses associated with daily living, such as drugs, supplies, equipment;
 - have fewer options for transportation, housing, recreation and many other aspects of life;
 - may need to schedule assistance or attendant care in order to participate;
 - may already be benefit recipients in another sector of government;
 - may experience “double jeopardy” associated with multiple vulnerabilities;
 - may need more time in order to fulfill the same degree of participation;
 - may need to avoid known “triggers” of exacerbation or complication;
 - may have fluctuating abilities to participate, depending on their underlying health condition;
 - may have uncertainty about future ability to participate.
7. Some areas of disability policy require a severity indicator, as a means of establishing eligibility (Scanlon, 2013). Severity of disability is usually related to the ability to be independent. It may be expressed in terms of frequency, intensity or interference. Severity is also sometimes interpreted in terms of the number of areas of life affected by disability. A disability is seldom classified as severe if it affects only one particular sector of life (vs affecting multiple areas of daily living).

8. In some instances, it may be reasonable to restrict consideration to those with a *permanent* disability, meaning to the end of one's lifespan, or a *prolonged* disability, usually meaning 12 months or more (sometime including cumulative episodes totalling 12 months or more). In other instances, it makes sense to include consideration for those whose disability is temporally specific. Particular challenges to disability definitions arise with:
 - Relapsing / remitting conditions, where the underlying health condition has a natural course of exacerbation and remission. In such circumstances, the person may be virtually disability-free during some periods, and experience greater or lesser degrees of impairment depending on the state of the illness. Examples of this would be: some cases of multiple sclerosis, mental illness, or chronic pain / fatigue syndromes. This category might also include conditions where treatments render the person temporarily disabled, such as chemotherapy or necessity of serial surgeries.
 - Recent onset conditions, where the ultimate disposition of the underlying health condition is unknown. It results in a verifiable disability at the time of assessment, but it may recover to a state where no disability remains. An example of this would be complicated musculoskeletal injuries, back, neck or head injuries, including concussion. Another example in this category might be cancer or HIV/AIDS, where the ultimate functional outcome cannot be anticipated.
 - conditions that arise in response to particular activities or conditions. When they do so, they can be legitimately disabling, but at other times, they may not be in evidence at all. Examples of these conditions might include migraine, back and neck pain.
9. Most authors agree that disability is a universal phenomenon, and as such, definitions of disability should not be age- or gender-specific, nor should they be jurisdiction-specific.

References

- Baylies, C. (2002). Disability and the notion of human development: Questions of rights and capabilities. *Disability & Society*, 17(7), 725-739. doi:10.1080/0968759022000039037
- Bickenbach, J. (1993). *Physical disability and social policy*. Toronto, ON: University of Toronto Press.
- Burchardt, T. (2004). Capabilities and disability: The capabilities framework and the social model of disability. *Disability & Society*, 19(7), 735-751. doi:10.1080/0968759042000284213
- Corson-Rikert, J., & Christmas, W. A. (2009). The medical excuse game revisited. *Journal of American College Health*, 57(5), 561-563.
- Driedger, D. (1989). *The last civil rights movement: Disabled people's international*. London, England: C Hurst & Co Publishers Ltd.
- Escorpizo, R., Reneman, M. F., Ekholm, J., Fritz, J., Krupa, T., . . . Chan, C. C. (2011). A conceptual definition of vocational rehabilitation based on the ICF: Building a shared global model. *Journal of Occupational Rehabilitation*, 21, 126-133.
- Hedlund, M. (2009). Understandings of the disability concept: A complex and diverse concept. In C. Marshall, E. Kendall, M. E. Banks & R. M. S. Gover (Eds.), *Disabilities: Insights from around the world* (Volume 1 ed., pp. 5-18). United States of America: Praeger Publishers.
- Hosking, D. (2008, September). *Critical Disability Theory*. Paper presented at the 4th Biennial Disability Conference at Lancaster University, United Kingdom.
- Human Resources and Skills Development Canada. (2013). *Federal disability reference guide*. (Guide No. ISSD-091-06-13E).
- Imrie, R. (1997). Rethinking the relationship between disability, rehabilitation, and society. *Disability and Rehabilitation*, 19(7), 263-271.
- Leonardi, M., Bickenbach, J., Bedirhan Ustun, T., Kostanjsek, N., & Chatterj, S. (2006). The definition of disability: What is in a name? *The Lancet*, 368(9543), 1219-1221.
- Letizia, J. M. (2002). The Supreme Court helps employers by narrowing the definition of disability. *Home Health Care Management and Practice*, 14(6), 484-485.
- McColl, M.A., James, A., Boyce, W., & Shortt, S. (2003). Evidence based policy-making about disability: Evaluating the evidence. In D. Pothier, & R. Devlin (Eds.), *Critical disability theory: Legal and policy dimensions*, (pp. 25-46). Vancouver: UBC Press
- McColl, M.A. (2019). *Appreciative disability studies*. Toronto ON: Captus Press/
- McColl, M. A., & Bickenbach, J. (1998). *Introduction to disability*. London, England: WB Saunders.
- Nussbaum, M. C. (2000). *Women and human development: The capabilities approach*. Cambridge, New York: Cambridge University Press
- Office for Disability Issues, Human Resources Development Canada. (2003). *Defining disability: A complex issue*. (No. RH37-4/3-2003EISBN: 0-662-35368-4). Gatineau, Quebec: Human Resources Development Canada.
- Oliver, M. (1990). *The politics of disablement*. Warminster, Wiltshire: MacMillan Education Ltd.
- Paetzold, R. (2005). Mental illness and reasonable accommodations at work: Definition of a mental disability under the ADA. *Law and Psychiatry*, 56(10), 1188-1190.

Riddle, C. A. (2010). Indexing, capabilities, and disability. *Journal of Social Philosophy*, 41(4), 527-537. doi:10.1111/j.1467-9833.2010.01514.x

Scanlon, D. (2013). Specific learning disability and its newest definition: Which is comprehensive? And which is insufficient? *Journal of Learning Disabilities*, 46(1), 26-33.

Sen, A. (1980). Equality of what? In S. McMurrin (Ed.), *Tanner lectures on human values*. Cambridge: Cambridge University Press.

Swain, J., & French, S. (2000). Towards an affirmation model of disability. *Disability & Society*, 15(4), 569-582. doi:10.1080/09687590050058189

United Nations (2006). *Convention on the rights of persons with disabilities*. No. Treaty Series 2515, 3.

World Health Organization (2001). *International classification of functioning, disability and health*. Geneva: WHO.