



NWT Disabilities Council

Disability Definition Update

Alannis McKee, 2018

Introduction

Currently, there is no universal language surrounding the definition of disability. Absence of universal language can be attributed to the nature of disability and the function of defining disability. Firstly, disability is a complex and dynamic phenomenon that encompasses a range of conditions of the body and mind that exist in different environmental contexts. Because of this complex nature of the experience of disability, developing language around a definition of disability that is fully inclusive is difficult. Additionally, different definitions of disability serve different functions. For example, definitions of disability that are tied to social benefits must be needs based in order to be rational (Degener, 2004). Comparatively, definitions of disability for purposes of anti-discrimination are more inclusive because equal treatment as a right is not a benefit that should be offered to only those in need but to all people that could potentially be affected by discrimination (Degener, 2004). Attempts to use the same definition of disability across a range of contexts results in definitions that are poorly targeted and of limited relevance. As such, definitions of disability must be aligned with the purpose of the definition (Bolderson et al., 2002).

This project is an analysis of the Northwest Territories Disabilities' Council (NWTDC) existing definition of disability and proposes an updated definition of disability with accompanying disability value statements. This project provides a new definition of disability for the NWTDC that better aligns with best practices the vision of the NWTDC. This is accomplished by research in global and national standards in defining disability, outlined in the methodology section. Subsequently, the existing NWTDC disability definition is presented and gaps are identified. Lastly, an updated definition of disability for the NWTDC is presented justified by research findings.

Methodology and Sources

Research for this project was completed through review of definitional standards from government, disability activist organizations, and multinational bodies through online searching and direct phone interviews. This began with a review of definitions of disabilities established by international organizations to determine best practices. Following this phase, national and territorial definitions from across Canada were reviewed to mold international standards to our unique Northern context. Lastly, published literature on defining disability was consulted to establish a theoretical grounding.

Below is a list of the reviewed material (Note: a full breakdown of specific information obtained from each of these sources is available in Appendix I; full reference information available in the References section):

International Sources:

- United Nations Convention on Rights of People with Disabilities (2006)
- World Health Organization, *International Classification System of Functioning, Disability and Health* (2001)
- Commonwealth Disability Discrimination Act (1992)
- UK Equality Act (2010)
- Australia Public Service Commission (2007)
- Germany Discrimination Law (2001)
- Ireland Equality Act (1998)
- Sweden Discrimination Act (1999)

National Sources:

- Economic and Social Development Canada, *Federal Disability Reference Guide* (2013)
- Council of Canadians with Disabilities (2018)
- Ontario Human Rights Commission (2018)

Territorial Sources:

- NWT Human Rights Act (2015)
- NWT Department of Health and Social Services, *NWT Disability Strategic Framework* (2017)

Literature Sources:

- *Definitions of Disability in Europe: A Comparative Analysis: Final Report* (Bolderson et al., 2002)
- *Defining Disability: Metaphysical Not Political* (Riddle, 2013)
- *EU Network of Experts on Disability Discrimination: Definition of Disability* (Degener, 2004)
- *Disability Rights and Wrongs* (Shakespeare, 2006)

Existing NWTDC Disability Definition

The NWTDC's existing definition of disability was developed in 2011, and reads as follows:

"We define disability as any limitation that someone experiences that causes difficulty in doing the usual activities of daily living. There are six areas to consider:

- Physical: Involves significant loss of mobility, agility, strength, flexibility or coordination such as Juvenile Arthritis, Cerebral Palsy, Polio, or MS.*
- Sensory: Involves the senses. Sensory disabilities include blindness or significant vision loss, deafness and significant hearing loss, the inability to speak, and the lack of balance from disorders such as vertigo or Meniere's Disease.*
- Intellectual: Affects the rate at which a person develops, learns and/or remembers. This disability is usually present from birth. People with intellectual disabilities may have Down's Syndrome, traumatic brain injury, fetal alcohol spectrum disorder (FASD), drug related birth defects and other unidentified disabilities.*
- Learning Disability: Affects the way that people with average or above average intelligence take in, process and express information. Learning disabilities are permeant, range from mild to severe, and encompass a group of disorders. Common learning disabilities include problems with memory, attention, reading, writing, arithmetic, reasoning, social, emotional maturity and coordination.*
- Cognitive: Usually a degenerative condition that affects the brain's ability to process information. It is not present from birth. Cognitive disabilities may include brain injuries or strokes.*
- Psychiatric: Affects persons suffering from mental illness. Some mental illnesses include mood and anxiety disorders, various psychoses and schizophrenia."*

Analysis of Existing NWTDC Definition

When the existing NWTDC definition of disability, as stated above, is analyzed against best practice standards, several gaps are evident. Below key gaps in the existing NWTDC are identified:

- The existing NWTDC definition of disability does not explicitly articulate a locus of causality for the experience of disability. Disability is defined as "any limitation that someone experiences", without attributing this "limitation" to an impairment (individual factors), the environment (social factors), or a combination of both of these. Without stating a locus of causality, the NWTDC definition of disability does not effectively situate itself within a **model** of disability. Models of disability include the **medical model** (i.e. individual, biological causality), **social model** (i.e. social, environmental causality), and

interactionist model (i.e. interaction of individual and social factors), among others.

- The existing NWTDC definition of disability does not address temporality. This means that the existing definition does not speak to the experience of disability across the lifespan, nor the experience of past, present, or future/anticipated disability.
- The existing NWTDC definition of disability does not address differing presentations of disability (e.g. visible/non-visible; episodic/temporary/permanent).
- The existing NWTDC definition of disability limits itself to activities of daily living.
- The existing NWTDC definition of disability does not address the dynamic nature of disability and the fluid boundaries between disability and non-disability. This is evident in the existing definition's use of six domains of disability (physical, sensory, intellectual, learning, cognitive, psychiatric). By embedding six domains of disability within the existing NWTDC definition, the NWTDC reinforced boundaries between disabilities 'types' that are problematic and often contested within the disability community.
- Does not address the dynamic nature of disability and the boundaries of disability; this is particularly evident in the use of 6 areas of disability (these should be avoided because boundaries are not unproblematic/uncontested); it is not easy to
- The existing NWTDC definition of disability does not effectively address the spectrum of lived experiences that coexist with disability. Specifically, there is no reference to the role that intersecting individual and social factors (e.g. race, gender, socioeconomic status etc.) that influence the impact of disability on the person. Without reference to these factors the NWTDC is unable to acknowledge complex life situations that cooccur with disability, such as homelessness, poverty, and trauma, among others.

Updated NWTDC Disability Definition and Value Statements

Below is the updated NWTDC definition of disability and accompanying disability value statements. The one-sentence definition will be what the NWTDC markets widely to the general public in short interaction media, such as posters or PSAs. The disability value statements will accompany the short definition when the NWTDC employs extended interaction media such as our brochures, websites, or funding grants.

Definition

Disability is a dynamic lived experience of restricted or limited participation in life that results from the interaction of an individual's bodily impairment and their physical and social environment.

NWTDC Disability Value Statements

- Disability is a **dynamic** experience that:
 - includes past, present, or future impairments,
 - can present apparently or non-apparently,
 - can present across the lifespan, and
 - can present permanently, temporarily, or episodically.
- Disability is a complex phenomenon that encompasses many conditions of the mind and body that exist in different physical and social environments. As such, the boundaries between disability and ability are fluid and subjective; for this reason, the NWTDC will rely on **self-identification** of disability.
- The NWTDC definition of disability is situated within the **interactionalist approach** to disability. This acknowledges that disability has bodily (individual) and environmental (social) dimensions that interact with each other.
- The impact that disability has on a person is influenced by the **intersection** of individual and social factors (e.g. age, gender identity, sexual orientation, culture, religious affiliation, race, and socioeconomic status, among others). For this reason, we acknowledge that the **spectrum of lived experience** of disability encompasses complex life circumstances, including, but not limited to: institutionalization, trauma, poverty, restricted housing options, and homelessness.

Rationale for Updated Definition and Value Statements

The updated definition of disability and disability value statements fill the gaps presented in our existing definition of disability. Below key features of the new definition of disability and disability value statements are highlighted.

- Relevant literature in disability studies tells us that definitions of disability must be responsive to the specific purpose they serve (Bolderson et al., 2002). The purpose of the NWTDC definition of disability was to make a definition of disability that was relevant to the widest range of people in the NWT. For this reason, our definition of disability identifies our organization's emphasis on **self-identification**. Self-identification of disability is critical because it is the least restrictive means of inclusion. Additionally, by emphasizing the importance of the individual's identification of their experience, our organization elevates the legitimacy of lived experience, rather than aligning ourselves with arbitrary medical or functional cut-offs of severity that are restrictive and reinforce problematic boundaries between disabled and non-disabled (Degener, 2004).
- The updated NWTDC definition of disability and disability value statements explicitly situate our organization in the progressive **interactionalist approach** to disability. This acknowledges the material consequences of corporeality while continuing to politicize disability by emphasizing the significant role that social and physical environmental factors play in limiting or restricting participation (Degener, 2004; Riddle, 2013; Shakespeare, 2006).
- The updated NWTDC definition of disability and disability value statements acknowledge the **dynamic** nature of disability in time (i.e. past/present/future impairment; across the lifespan; permanent/temporary/episodic) and in presentation (i.e. apparent/non-apparent).
- The updated NWTDC definition of disability and disability value statements addresses the new mandate of the NWTDC to address disability in complex life circumstances. This is accomplished by acknowledging that the impact of disability results from an **intersection** of social and individual factors, whereby impairment is just one aspect of the person. This is represented through the introduction of a **spectrum of lived experience**, which speaks to the range of impacts that disability can have on an individual.

Conclusion

Definitions of disability are important because they directly contribute to the social construction of disability. As such, the NWTDC definition of disability shapes not only who our organization become relevant to, but also influences how our communities come to conceptualize disability. The new definition of disability and disability value statements, presented in this summary report, enable the NWTDC to define disability in such a way as to include the most people and acknowledge the range of lived experiences that coexist with disability in the NWT.

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Appendix I

Summary of Researched Sources

United Nations Convention on Rights of People with Disabilities (2006)

- Disability is an evolving concept that results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation
- People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation

World Health Organization (2001)

- International Classification of Functioning, Disability and Health (ICF)
- Disability is the interaction between the individual (health condition) and contextual factors (environmental and personal factors)
- Bio-psycho-social model
- Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions
 - Impairment: A problem in body function or structure
 - Activity Limitations: Difficulties an individual may have in executing activities based on personal factors
 - Participation Restrictions: problems an individual may experience in participation in life situations, mainly referring to external factors

EU Network of Experts on Disability Discrimination: Definition of Disability (Degener, 2004)

- No universal language of disability across the EU
- Disability is difficult to define because it encompasses numerous conditions of the mind and body and the boundary between ability and disability is unclear
- Our definitions of disability are important because they contribute to the social construction of disability
- Disability discrimination laws need to define discrimination as well as disability; it makes no sense to define disability as the outcome of discrimination
- Definitions of disability-- in the context of discrimination-- should be cleared about any assumptions of ability or incapability
- Definitions of disability cannot be too narrow because this can obscure the cause of discrimination and purport the individual model of disability
- Definition of disability should:

- Relate to the impairment, chronic illness or malfunctions
- Not be based on certain severity of disability
- Should cover past, present, future or imputed impairments or chronic diseases and associates

Defining Disability: Metaphysical Not Political (Riddle, 2012)

- We need to address embodiment/impairment as a causal factor in the experience of disability
- The social model denies the causal relationship between impairment and disability
- Impairment has a social dimension to the extent that it is culturally defined

Definitions of disability in Europe: A comparative analysis: Final report (Bolderson et al., 2002)

- Definition of disability must be aligned with the purpose of the definition
- Different definitions of disability are relevant to specific policies and attempts to use the same definition across a range of policies can result in the use of definitions that are poorly targeted or have limited relevance

UK Equality Act (2010)

- You are disabled if you have a physical or mental impairment that has substantial and long term negative impact on your ability to do normal daily activities.
 - Long term means 12 months or more
 - Substantial means more than minor or trivial
 - Includes progressive and fluctuating conditions

Australian Government, Public Service Commission (2007)

- Persons are considered to have a disability if they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities.
- Domains identified: sensory, intellectual, physical, psychosocial (mental illness), head injury/stroke/acquired brain injury, and other.

Commonwealth Definition of Disability (1992)

- Disability, in relation to a person, means:
 - total or partial loss of the person's bodily or mental functions
 - total or partial loss of a part of the body
 - the presence in the body of organisms causing disease or illness
 - the presence in the body of organisms capable of causing disease or illness
 - the malfunction, malformation or disfigurement of a part of the person's body
 - a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction
 - a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour
 - and includes a disability that:
 - presently exists; or
 - previously existed but no longer exists; or
 - may exist in the future; or
 - is imputed to a person

Germany Discrimination Law (2001)

- Persons are disabled if their physical functions, mental capacities, or psychological health are highly likely to deviate for more than six months from the condition which is typical for the respective age and whose participation in the life of society is therefore restricted.

Sweden Discrimination Act (1992)

- Disability means every permanent physical, mental or intellectual limitation of a person's functional capacity that is a consequence of an injury or illness that existed at birth, arose thereafter or may be expected to arise.

Disability Rights and Wrongs (Shakespeare, 2006)

- Interactionalist Approach: "the experience of a disabled person results from the relationship between factors intrinsic to the individual, and the extrinsic factors arising from the wider context in which she finds herself" (i.e. intrinsic limitation of impairment and externally imposed social discrimination)

- Impairment forms a continuum, not the polar opposite to normality and labels are often arbitrary

Economic and Social Development Canada, Federal Disability Reference Guide (2013)

- Disability is a complex phenomenon, reflecting an interaction between features of a person's body and mind and features of the society in which they live. A disability can occur at any time in a person's life; some people are born with a disability, while others develop a disability later in life. It can be permanent, temporary or episodic. Disability can steadily worsen, remain the same, or improve. It can be very mild to very severe. It can be the cause, as well as the result, of disease, illness, injury, or substance abuse.

Council of Canadians with Disabilities

- Adopted the UN Definition

Ontario Human Rights Commission

- Disability is complex and evolving (i.e. present at birth/caused by accident/develop over time)
- Should be interpreted in broad terms
- Subjective component of disability exists that is based on one's perception of disability
- Non-evident disabilities (invisible or episodic or other disabilities only are apparent in a given situation) must be specifically addresses
- Mental health disabilities are included

NWT Human Rights Act

- Disability means any of the following conditions:
 - Any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness,
 - A condition of mental impairment or a developmental disability
 - A learning disability, or dysfunction in one or more of the processes involved in understanding or using symbols of a language
 - A mental disorder

NWT Disability Strategic Framework

- Adopted the WHO definition