TIC project of Inclusion of Persons with Disabilities in MSF

Glossary of disability and inclusion-related terms

Note: The purpose of this document is to support mainstreaming of inclusion in our communications and speaking out through correct and consistent use of disability-related terms. The explanations gathered in the glossary are drawn from or based on the existing reference documents to ensure coherence of MSF communications with how the highlighted concepts are used in the broader field of disability inclusion. References are available at the end of the document. This glossary is a living document that will be developed and modified as the needs for communication on disability and inclusion evolve. Contact: Sanni Myllyaho, sanni.myllyaho@helsinki.msf.org.

Accessibility

Accessibility describes the degree to which an environment, service, or product allows access by as many people as possible, in particular people with disabilities. [1]

Activities of daily living

A term used to collectively describe fundamental skills required to independently care for oneself, such as dressing, showering, or eating. The ability to perform the activities of daily living is used as an indicator of a person's functional status.

Activity limitations

Activity is the execution of a task or action by an individual; activity limitations are difficulties an individual may have in executing activities. An activity limitation may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition. [1, 2]

Adaptability

The feature of certain building spaces and elements that can be altered to accommodate the needs of persons with different types and degrees of disability. [3]

Ambulant disabled person

A person with a disability who experiences difficulty walking and may depend on prostheses, orthoses, crutches or other walking aid to walk on the level or climb stairs. [3]

Ambulatory difficulty

Having serious difficulty walking or climbing stairs.

Assistive devices (also: assistive technology)

Any device designed, made or adapted to help a person perform a particular task. Products may be specially produced or generally available for people with a disability. [1]

Autism/Autistic Spectrum Disorder

Autism spectrum disorder (ADS) refers to a range of conditions characterised by some degree of impaired social behaviour, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively. ASDs begin in childhood and tend to persist into adolescence and adulthood. In most cases the conditions are apparent during the first five years of life. Individuals with ASD often present other co-occurring conditions, including epilepsy, depression, anxiety and attention deficit hyperactivity disorder (ADHD). The level of intellectual functioning in individuals with ASDs is extremely variable, extending from profound impairment to superior levels. [4]

Barriers

Factors in a person's environment that, through their absence or presence, limit functioning and create disability – for example, inaccessible physical environments, a lack of appropriate assistive technology, and negative attitudes towards disability. [1]

Barrier analysis

An approach that focuses on identifying and reducing or removing barriers to access to medical care faced by persons with disabilities and other vulnerable groups (depending on the context, e.g. women, the elderly, ethnic minorities, LGBTQI people). In the MSF approach, we distinguish between four main types of barriers to access for persons with disabilities: institutional (e.g. segregation, discriminating policies), physical (e.g. inaccessibility of health facilities), communication (e.g. information disseminated in formats that exclude people with sensory impairments), and attitudinal (e.g. stigma). Barrier analysis is among the key tools recommended and advanced by the TIC project of Inclusion of Persons with Disabilities to help mainstream inclusion in humanitarian action of MSF. [5]

Body functions

In the International Classification of Functioning, Disability and Health (ICF; if needed, see further explanation below), the physiological functions of body systems. Body refers to the human organism as a whole and this includes the brain. The ICF classifies body functions under several areas including mental functions, sensory functions and pain, voice and speech functions, and neuromusculoskeletal and movement-related functions. [1]

Body structures

The structural or anatomical parts of the body such as organs, limbs, and their components classified according to body systems. [1]

Braille

A system of writing for persons with visual impairments that uses letters, numbers, and punctuation marks made up of raised dot patterns. [1]

Capacity

A construct within the ICF that indicates the highest probable level of functioning that a person may achieve, measured in a uniform or standard environment: reflects the environmentally adjusted ability of the individual. [1]

Captions/captioning

Captions are text versions of the spoken word presented within multimedia. Captions allow the content of web audio and video to be accessible to those who do not have access to audio. Though captioning is primarily intended for the deaf and hard of hearing, it has also been found to help those who can hear, but are not fluent in the language, or anyone in noisy situations, when the audio quality is poor, or where sound is not allowed. Captions should not be mistaken for subtitles. Captions are in the same language as the audio, whereas subtitles usually provide a translation of the audio or other visual language. Because captions are primarily targeted to the deaf and hard-and-hearing, captions are usually closed (meaning they can be turned on and off), whereas subtitles, which are intended for everyone, are usually open (they cannot be turned off). The primary distinction is that captions are vital to ensure accessibility to the deaf and hard-of-hearing and as such, they provide a verbatim, textual equivalent of all necessary auditory information. Subtitles, on the other hand, can provide additional, clarifying information that may not be necessarily vital for accessibility. [6]

Caregiver

A person, generally a relative, a friend or a professional, who provides social or physical support to a person with a disability.

Charity approach to disability

An approach to disability that sees persons with disabilities as victims who inspire compassion, who are to be pitied, who need our help, sympathy and charity, and who need to be looked after. Through emphasising helplessness, it risks to undermine their autonomy, independence and rights. In MSF projects, we advocate for replacing it with the rights-based approach (see details below). [5]

Community-based rehabilitation (CBR)

A strategy within general community development for rehabilitation, equalization of opportunities, poverty reduction, and social inclusion of people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations, and communities, and the relevant governmental and nongovernmental health, education, vocational, social, and other services. [1]

Condition – primary

A person's main health condition that may be associated with impairment and disability. [1]

Condition – secondary

An additional health condition that arises from the increased susceptibility to a condition caused by the primary condition – though it may not occur in every individual with that primary condition. [1]

Condition – co-morbid

An additional health condition independent of and unrelated to the primary health condition. [1]

Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD was adopted by the United Nations General Assembly on 13th December 2006. It was borne out of a commitment undertaken by the United Nations to change attitudes and approaches to people with disabilities from being viewed as objects of charity, medical treatment and social protection towards being viewed as people with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent. The convention reaffirms that all people with disabilities must enjoy all human rights and fundamental freedoms, and sets out protections to ensure that such rights and freedoms are upheld. The Convention states that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. By providing this concept, the Convention places responsibility for the enabling of people squarely on societies and communities, and removes the notion that people are to be characterised by their disability. [7]

Deafblindness (also: dual sensory loss, multi-sensory impairment)

Deafblindness is a combination of sight and hearing loss that affects a person's ability to communicate, access information and get around. A deafblind person won't usually be totally deaf and totally blind, but both senses will be reduced enough to cause significant difficulties in everyday life. These problems can occur even if hearing loss and vision loss are mild, as the senses work together and one would usually help compensate for loss of the other. To help compensate for the combined vision and hearing impairment, especially the tactile sense becomes important. [8, 9]

Developmental disability

Developmental disabilities are a diverse group of chronic conditions due to an impairment in physical, learning, language, or behaviour areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime. Most developmental disabilities are thought to be caused by a complex mix of factors. These factors include genetics; parental health and behaviours during pregnancy; complications during birth; infections the mother

might have during pregnancy or the baby might have very early in life; and exposure of the mother or child to high levels of environmental toxins. [10]

Disabled people's organization (DPO)

Organizations or assemblies established to promote the human rights of disabled people, where most members as well as the governing body are persons with disabilities. [1]

Discrimination on the basis of disability

Any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation. [11]

Early detection

Discovery or diagnosis of an impairment at an early stage. Since many impairments that eventually lead to disabilities manifest themselves during the first years of life, early detection can also refer to a diagnosis made before the birth, immediately after birth or in early infancy.

Early intervention

Involves strategies which aim to intervene early in the life of a problem and provide individually tailored solutions. It typically focuses on populations at a higher risk of developing problems, or on families that are experiencing problems that have not yet become well established or entrenched. [1]

Enabling environment

Environments which support participation by removing barriers and providing enablers. [1]

Environmental factors

Physical, social, and attitudinal environment in which people live and conduct their lives – for example, products and technology, the natural environment, support and relationships, attitudes, and services, systems, and policies. [1]

Facilitators

Factors in a person's environment that, through their absence or presence, improve functioning and reduce disability – for example, an accessible environment, available assistive technology, inclusive attitudes, and legislation. Facilitators can prevent impairments or activity limitations from becoming participation restrictions, since the actual performance of an action is enhanced, despite the person's problem with capacity. [1]

Frail elderly

Older persons, usually over 75 years old, who have a health condition that may interfere with the ability to independently perform activities of daily living. [1]

Functioning

An umbrella term for body functions, body structures, activities, and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). [1]

Global burden of disease

A measurement of impact of disease combining years of life lost to premature mortality plus years of life lost to time lived in states of less than full health, measured by disability-adjusted life-years. [1]

Global developmental delay

Global developmental delay is an umbrella term used when children are significantly delayed in their cognitive and physical development. It can be diagnosed when a child is delayed in one or more milestones, categorised into motor skills, speech, cognitive skills, and social and emotional development. [12]

Human rights based approach to disability

An approach that sees persons with disabilities as right-holders, and disability as the social consequence of impairment. It focuses on identifying and removing barriers that block inclusion. It advocates equal opportunities and non-discrimination on the basis of disability. [5]

Impairment

An impairment is a problem in body function or structure. [2]

Inclusion

Inclusion is an approach to improve the terms on which individuals and groups take part in society – providing rights and improving ability, opportunity and dignity of those disadvantaged. [13]

Inclusion includes the principles of rights, empowerment and participation, non-discrimination and equality, diversity, dignity, support and accessibility. [14]

Inclusion in humanitarian action refers to actions taken to ensure the right to information, protection and assistance for all persons affected by a crisis, irrespective of age, sexual and gender identity, disability status, nationality, or ethnic, religious or social origin or identity. Inclusive action focuses on identifying and removing barriers so that those individuals and groups who are more vulnerable, marginalized and/or excluded can participate in decision-making and benefit from humanitarian action on an equal basis with others. [15]

Inclusive communication

It is an approach to language, content and information sharing that favours respectful and accurate representation, as well as access to and understanding of communication regardless of people's gender, age, race, ethnicity, sexual orientation, culture, background and needs. It applies to all groups and to all aspects of communications work, whether it is informing, advocating, engaging with communities, spreading key messages or supporting fundraising campaigns.

Independent living

Independent Living is a philosophy and a movement of people with disabilities who work for selfdetermination, equal opportunities and self-respect. It is based on the belief that persons with disabilities should have the same control over their lives as others. It advocates greater choice of any assistance needed in everyday life; access to housing, transport, health, social care, education, employment and other services and opportunities; participation in family, community and civic life. [3]

Intellectual disability

Intellectual disability is a term used when there are limits to a person's ability to learn at an expected level and function in daily life. [16]

International Classification of Functioning, Disability and Health (ICF)

The classification that provides a unified and standard language and framework for the description of health and health-related states. ICF is part of international classifications developed by the World Health Organization. [1]

Invisible disabilities

Invisible disabilities, or hidden disabilities, are chronic conditions that interfere with day-to-day functioning, but are not immediately apparent to others.

Learning disability

A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty understanding new or complex information, learning new skills, and coping independently. A learning disability can be mild, moderate or severe. Some people with a mild learning disability can talk easily and look after themselves but may need a bit longer than usual to learn new skills. Other people may not be able to communicate at all and have other disabilities as well. [17]

Medical approach to disability

An approach that considers disability as a strictly medical problem that needs to be addressed. It focuses on "cure" and "care". The issue of disability is limited to the individual: according to this approach, it is the person with a disability that has to be changed, not the society. [5]

Mental disability

Mental disability refers to an illness or a disorder of the mind that has significant psychological or behavioural manifestations, is associated with painful or distressing symptoms, and impairs an individual's level of functioning in certain areas of life. [3]

Mobility aid

Device designed to improve the mobility of people who experience difficulties walking and moving around. Examples include crutches, walking frames, wheelchairs or mobility scooters. For people who are blind or visually impaired, the white cane and a guide dog have a long history of use. Other aids can help with mobility or transfer within a building or where there are changes of level. [3]

Multiple disability

Multiple disability is the simultaneous occurrence of two or more significant impairments that affect learning or other important life functions.

Multi-Sensory Impairment (MSI) (also: deafblindness, dual-sensory impairment, dual sensory loss)

A term used to describe the loss of both sight and hearing. People with MSI may also have cognitive, medical or physical disabilities, and challenges which affect the other senses. [18]

Occupational therapy

Promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. [1]

Older person

An older person is defined by the United Nations as a person who is over 60 years of age. However, families and communities often use other socio-cultural referents to define age, including family status (grandparents), physical appearance, or age-related health conditions. [19]

Orthosis

An externally applied device used to support, align or immobilise an extremity, joint or body segment for a particular reason (e.g. due to an injury), to prevent or correct deformities, to reduce pain, or to improve function of the body.

Participation restrictions

Participation is involvement in a life situation. Participation restrictions are problems an individual may have in involvement in life situations. [1, 2]

Person-first language

The use of language that puts a person before a disability or a diagnosis, describing what a person "has" or "experiences" rather than stating what a person "is". It uses phrases such as "persons with disabilities" or "children with hearing impairment". It is intended to avoid stigmatisation and dehumanisation of people living with a disability or a chronic illness.

Persons with disabilities

Persons 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 in society on an equal basis with others. [10]

Physical disability

A physical disability is a limitation on a person's physical functioning, mobility, dexterity or stamina.

Physiotherapy

Physiotherapy helps to restore movement and function when someone is affected by injury, illness or disability. It can involve a number of different treatment and preventative approaches, including education and advice, movement and exercise, and manual therapy. Physiotherapy takes a holistic approach that involves the patient directly in their own care. [20]

Prosthesis

An artificial device designed to replace a missing body part, lost due to trauma, disease, or a congenital disorder.

Quality of life

An individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to environmental factors that affect them. [1]

Reasonable accommodation

Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. [10]

Screen reader

Screen readers are software programs that allow users who are blind or have a vision impairment to read the text that is displayed on the computer screen with a speech synthesizer or braille display. [21]

Sensory impairment

A sensory impairment is an impairment that affects one of the senses: sight, hearing, touch, smell, taste or spatial awareness. Common sensory impairments include sight and hearing loss.

Sign language

The system of manual signs for communication with and among people who are deaf, hard of hearing or deaf-blind. [3]

Sign languages, which have evolved over years in the different deaf communities across the world in a similar way that natural languages have, vary widely between countries and ethnic groups. In some countries, more than one sign language is in use, and countries with the same spoken language may still have different sign languages. The number of sign languages worldwide probably exceeds 300. There have been attempts to develop a single sign language for broader international use, but with limited success. In the International Sign, meaning has to be continuously negotiated, as signers combine signs from their national sign languages with signs understandable for a larger audience.

Speech and language disorders

A speech disorder affects the articulation of speech sounds, fluency or voice. People with speech disorders have difficulty with forming specific words or sounds correctly, with making words or sentences flow smoothly. They can also experience problems with pitch, volume, tone, and other qualities of the voice that affect communication. A language disorder is a communication disorder in which a person has difficulties in understanding, learning and using language. Language and speech disorders can exist together or by themselves. [3, 22, 23]

Speech and language therapy

Therapy aimed at restoring people's capacity to communicate effectively and to swallow safely and efficiently. [1]

Universal design

The design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed. [10]

Visual impairment (also: vision impairment, vision loss)

A decrease in the ability to see to a degree that causes problems not fixable by usual means, such as glasses.

Vocational rehabilitation and training

Programmes designed to restore or develop the capabilities of people with disabilities to secure, retain and advance in suitable employment – for example, job training, job counselling, and job placement services. [1]

Vulnerability

Vulnerability can be defined as the diminished capacity of an individual or group to anticipate, cope with, resist and recover from the impact of a natural or man-made hazard. The concept is relative and dynamic. Vulnerability is often associated with **poverty**, but it can also arise when people are isolated, insecure and defenceless in the face of risk, shock or stress. People differ in their exposure to risk as a result of their social group, gender, ethnic or other identity, age and other factors. [24]

Web accessibility

Web accessibility means that websites, tools, and technologies are designed and develop so that people with disabilities can use them, and more specifically, so that people can perceive, understand, navigate, interact and contribute to the Web. Web accessibility encompasses all disabilities that affect access to the Web, but also benefits people without disabilities, e.g. people using mobile phones and other devices with small screens, older people with changing abilities due to ageing, or people with situational limitations, such as being in an environment where they cannot use audio. [25]

References

[1] WHO and the World Bank, *World Report on Disability*, 2011.

[2] WHO, International Classification of Functioning, Disability and Health.

[3] Disabled People's Association, Singapore, <u>Glossary of Disability Terminology. The Essential Guide to Words</u> <u>and Phrases Acceptable to People with Disabilities</u>, 2015.

[4] WHO, Autism Spectrum Disorders, 2019.

[5] TIC project of Inclusion of Persons with Disabilities, introductory e-learning course <u>Inclusion of Persons with</u> <u>Disabilities at MSF, Chapter 3: Barriers and Approaches to Disability</u>.

[6] The National Center on Disability and Access to Education, <u>Web Captioning and Education</u>.

- [7] International Day of People With Disabilities, Key Terms.
- [8] National Health Service (NHS), *Deafblindness*.
- [9] The World Federation of the Deafblind, <u>What is Deafblindness?</u>
- [10] Centers for Disease Control and Prevention (CDC), Facts About Developmental Disabilities.
- [11] Convention on the Rights of Persons with Disabilities.
- [12] Mencap, Global Developmental Delay.
- [13] World Bank, Social Inclusion.
- [14] CBM, *The Future is Inclusive: How to Make International Development Disability-Inclusive*, 2014.
- [15] Humanitarian Advisory Group, <u>Inclusive Humanitarian Action: A study into Humanitarian Partnership</u> <u>Agreement (HPA) agency practice in the Nepal earthquake response</u>, 2016.
- [16] CDC, *Facts About Intellectual Disability*.
- [17] NHS, *Learning Disabilities*.
- [18] See Ability, Children and multi-sensory impairment.
- [19] UNHCR, Emergency Handbook. Older persons.
- [20] NHS, *Physiotherapy* and *Physiotherapy Techniques*.
- [21] American Foundation for the Blind, <u>Screen Readers</u>.
- [22] CDC, Language and Speech Disorders in Children.
- [23] Johns Hopkins Medicine, Voice Disorders.
- [24] International Federation of Red Cross and Red Crescent Societies (IFCR), What is vulnerability?
- [25] W3C Web Accessibility Initiative, Introduction to Web Accessibility.