UNDERSTANDING DISABILITY

The understanding of disability has undergone a profound change over the past decades, in society as a whole and in terms of national and international development initiatives. Persons with disabilities have played, and continue to play, a major role in forging this change.

What is disability?

There are variations in the way disability is defined or explained, such as in the International Classification of Functioning Disability and Health (ICF) (WHO, 2001), the UN Convention on the Rights of Persons with Disabilities (UN CRPD) (UN, 2006) and national instruments.

The current conception of disability described by the ICF and the UN CRPD is as follows:

ICF 2001: The outcome of an interaction between health conditions and impairments and the physical, human-built, attitudinal, and social environment.

United Nations Human Rights Council Resolution 7/9, "Human rights of persons with disabilities", 2008 states "...disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others".

The UN CRPD (2006) adopts a social model of disability, and describes disability as including 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. The UN CRPD (UN, 2006) does not define disability. Rather, it attempts to explain disability by outlining some of the long-term impairments that some people may have, which in interaction with various barriers may pose a hindrance to their full and effective participation resulting in a disability. The distinguishing feature in the UN CRPD explanation of disability is the use of the phrase 'long term' to describe the nature of the impairment. Unlike the ICF Classification, UN CRPD does not recognize 'interaction with health condition' as one of the necessary aspects in the definition of disability.

Disability is diverse and might affect one or more of the following aspects of a person to varying degrees:

- Vision
- Movement
- Mental capability: thinking, remembering, learning
- Communicating, speech
- Hearing
- Mental health
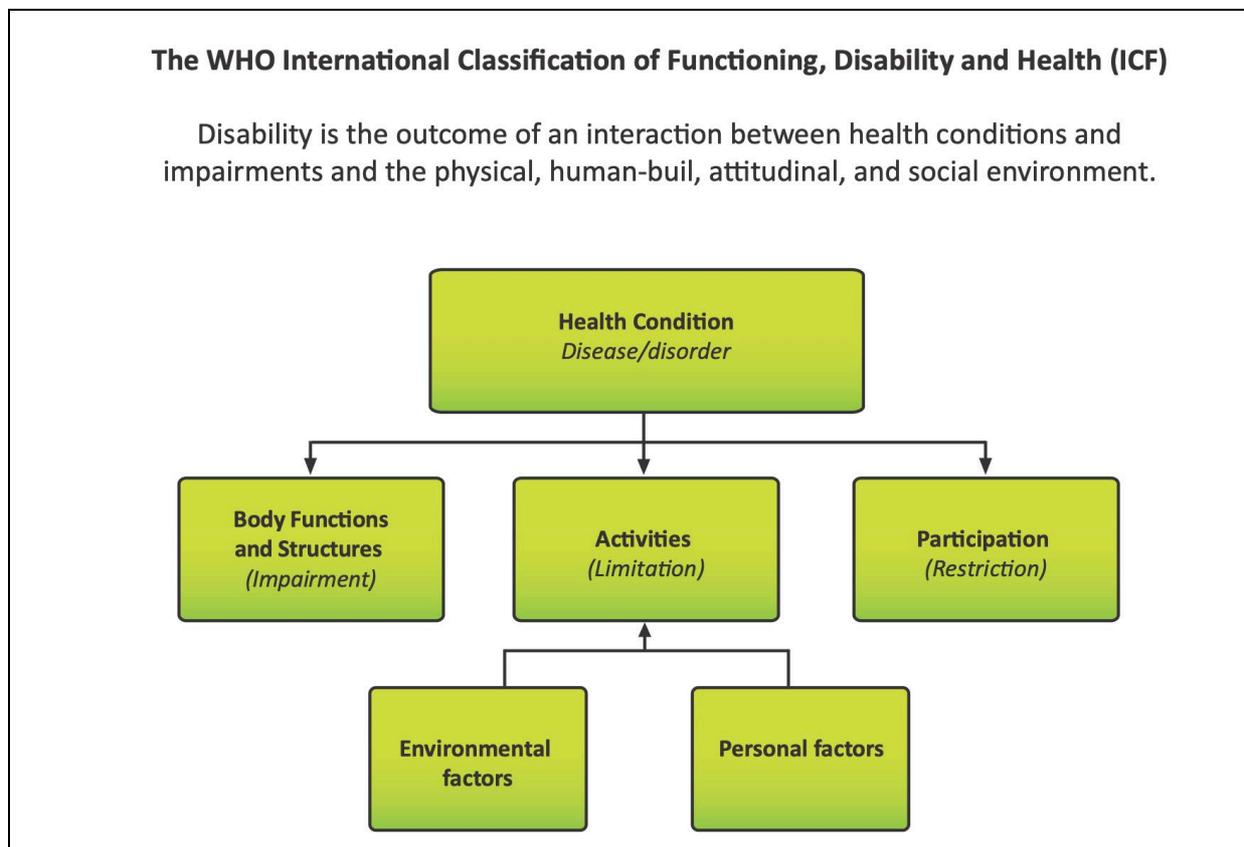- Skin
- Social relationships.

The International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) is the World Health Organization's (WHO's) framework for health and disability. It is the conceptual basis for the definition, measurement and policy formulations for health and disability.

ICF is concerned with the *health experience* of any individual who has had an impairment or health disorder. ICF classifies health and wellbeing, describing the situation of each person within the range of health and health related areas as well as within the context of environmental and personal factors. The ICF looks at how an individual functions in three areas, namely:

- *body functions and structures*
- *activities* (tasks or actions carried out by an individual)
- *participation* (involvement of the individual in society, or in daily living).

The WHO International Classification of Functioning, Disability and Health (ICF)

Disability is the outcome of an interaction between health conditions and impairments and the physical, human-buil, attitudinal, and social environment.

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                        ┌─────────────────────┐
                        │   Health Condition  │
                        │    Disease/disorder │
                        └─────────────────────┘
         ┌─────────────────────┼─────────────────────┐
┌──────────────────┐  ┌──────────────────┐  ┌──────────────────┐
│  Body Functions  │  │    Activities    │  │  Participation   │
│  and Structures  │  │   (Limitation)   │  │  (Restriction)   │
│   (Impairment)   │  │                  │  │                  │
└──────────────────┘  └──────────────────┘  └──────────────────┘
                  ┌───────────┴───────────┐
         ┌──────────────────┐  ┌──────────────────┐
         │   Environmental  │  │ Personal factors │
         │     factors      │  │                  │
         └──────────────────┘  └──────────────────┘
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Activities and *participation* describe what a person with a health disorder does do or can do. This does not depend on the individual alone but also on the social, physical and attitudinal environment in which the individual lives.

As a result of a health disorder, changes may occur in the *body functions and structures*, or in *activities* and *participation*. The following terms are used to describe any changes that may occur.

Impairments: are problems in body function or structure such as a change or a loss.

Activity limitations: are difficulties an individual may have in carrying out activities.

Participation restrictions: are problems an individual may experience in participating in family or society.

Two other terms are used in the ICF to describe the state of health and wellbeing: **functioning** and **disability**.

Functioning is an umbrella term encompassing all body functions and structures, activities and participation.

Disability is an umbrella term for impairments, activity limitations or participation restrictions.

The ICF promotes the viewpoint that disability is part of the diversity of the human race and identifies the components of health - functioning, activity, and participation and their status – whether impaired, limited or restricted.

The Washington Group on Disability Statistics

The Washington Group on Disability Statistics was constituted to address the need for cross-nationally comparable population based measures of disability. It is not possible to collect all information on persons with disabilities in a census. However, important information on selected aspects can be obtained.

Equalization of opportunities was agreed upon and selected as the purpose for the development of an internationally comparable general disability measure. One reason this purpose was chosen was because it was feasible to collect the proposed information using a small set of six census-like questions.

The questions identify the population with functional limitations that have the potential to limit independent participation in society. The intended use of this data would compare levels of participation in employment, education, or family life for those with disability versus those without disability to see if persons with disability have achieved social inclusion. In addition the data could be used to monitor prevalence trends for persons with limitations in the particular basic activity domains. The recommended 'short set' of questions developed by the Washington Group are below.

Proposed Washington Group Short Measurement Set on Disability

Introductory phrase: The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

Core Questions to which answer options are:

a. No-no difficulty   b. Yes–some difficulty   c. Yes – a lot of difficulty d. Cannot do at all

1. Do you have difficulty seeing, even if wearing glasses?

2. Do you have difficulty hearing, even if using a hearing aid?

3. Do you have difficulty walking or climbing steps?

4. Do you have difficulty remembering or concentrating?

5. Do you have difficulty (with self-care such as) washing all over or dressing?

6. Because of a physical, mental or emotional health condition, do you have difficulty communicating, (for example understanding others or others understanding you)?

Types of disabilities

Disability covers a wide range of conditions: for example: a child born with albinism; a soldier who loses his sight as a result of a gunshot; a young woman with chronic depression; or an older man with an intellectual disability, provide an example of the diversity. Disability can be visible or invisible; static, episodic, or degenerating; painful or inconsequential. It may be cognitive, developmental, intellectual, mental, physical, sensory (affecting sight or sense of hearing) or a combination of these that affects a person's daily life activities.

An impairment can be congenital – a disability that a person is born with such as hydrocephalus, cerebral palsy, Down's syndrome, a club foot, or bowed legs, extra fingers or toes, or syndactly of toes or fingers (webbed), cleft lip or palate, spina bifida, deafblindness, or leg length discrepancy. It can also be acquired – an impairment that is acquired for example as a result of a sickness, or injury, or drug and alcohol abuse. This category includes poliomyelitis, paralysis (paraplegia, quadriplegia, hemiplegia), TB spine, leg length discrepancy as a result of a fracture or break to the bone, or a psychosocial disability such as bipolar disorder.

Scale and diversity of disability

The World Health Organization/World bank (2011) estimates that persons with disabilities represent approximately 15% of any population. However, many countries official estimates are well below this figure. Disability is under-reported in most countries for a number of different reasons. Factors include:

- The general Census does not collect disability specific information.
- Data collectors are often inexperienced and lack the expertise to assess and document disability related conditions or diseases.

- Family members with disabilities may be hidden and not counted in a census.
- Information on family members with disabilities may not be presented during a census.
- People do not admit to their disability on a census form.

Nearly half the WHO 15% figure is composed of people over 60 years and those with long-term and chronic diseases, such as cancer and heart disease. The World Report on Disability found that lower-income countries have a higher prevalence of disability and that disability is more common among older people and households that are poor.

Models of disability

The way that disability has been viewed has changed over time through various perspectives - often called 'models'. The word models here refers to different interpretations of what disability means, and what it means to have a disability. The models of disability are:

A) The Traditional model

In the Traditional model, disability is perceived as a result of a curse – a natural consequence of an evil that the person with a disability or one of the family members might have done. Persons with disabilities are perceived not to be part of the human race. In this model, persons with disabilities are treated with pity, fear and patronising attitudes. The impairment is focused on, rather than the needs of the person, who is seen as a tragic victim.
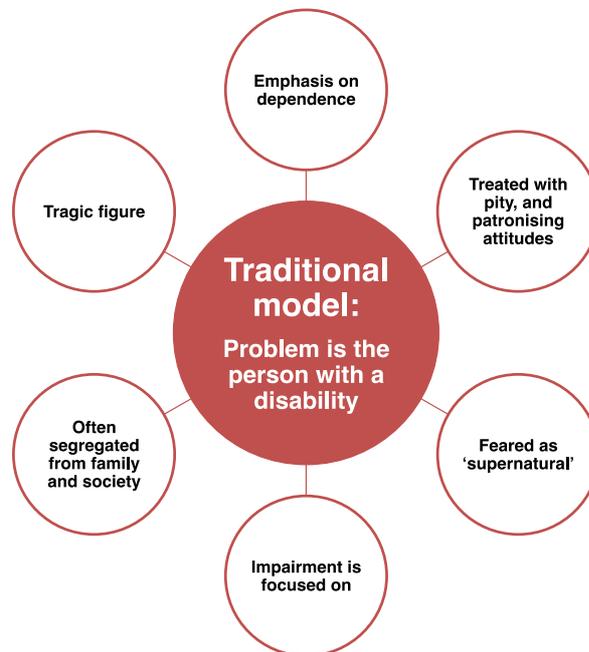
Dependence on the part of the person with a disability is emphasised.

B) The Charity model

In the Charity model disability is seen as a defect in the anatomical structure and function such as the loss or lack of function of a limb or part thereof. This makes them unable to participate in society and to fend for themselves. Persons with disabilities are seen as tragic. They are pitied and treated as objects of charity and welfare to be cared for by others, unable to help themselves or be independent. Their needs are seen in terms of being 'special'.
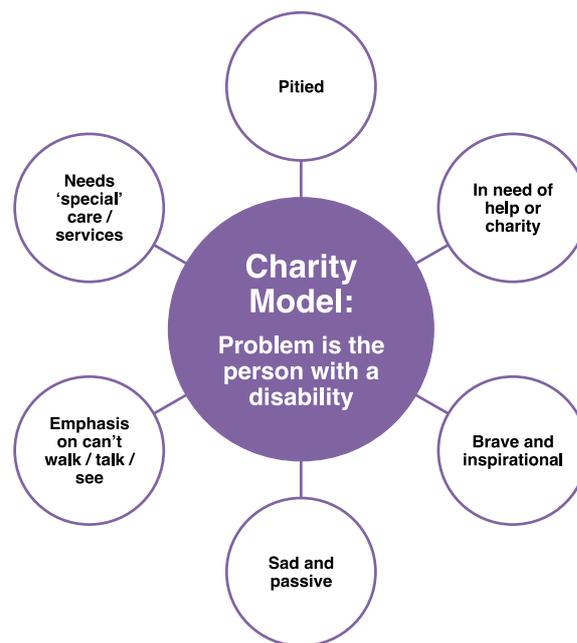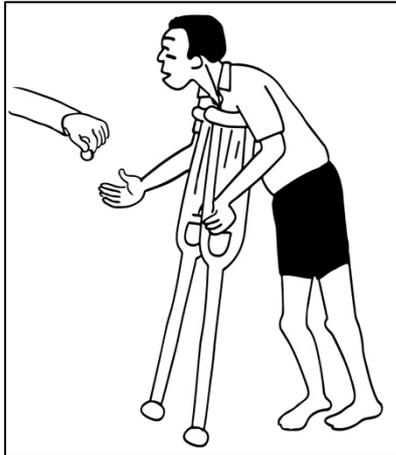
A focus is on providing special services, special schools etc. because they are different from 'normal' people. Within the Charity model some persons with disabilities commonly perceive themselves as powerless, useless, non-contributing individuals. Persons with disabilities who do achieve success are seen as 'brave' or 'inspirational' because there are low expectations of them.

C) The Medical model

As science and medicine developed, disability was commonly viewed in biological or medical terms. The Medical model looks at disability as a deviation from the normal, caused by an underlying disease or other health condition. The Medical model focuses on the impairment that requires fixing by a medical professional for the individual to be a 'normal' member of society. Their needs are seen as 'special'.
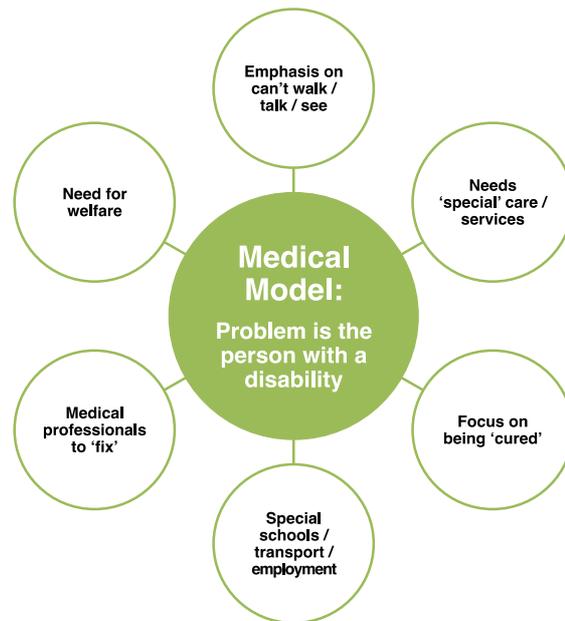
Disability is viewed as a 'problem' that belongs to the disabled individual: the person with a disability should ensure that they do not inconvenience anyone else. In practical terms, the Medical model would see an issue of a wheelchair user accessing public transport as an issue with the compatibility of the wheelchair to access the transport and not the way the transport system was organized.

D) The Social model

In the 1960s and 1970s the movement of persons with disabilities grew in strength and the movement argued that disability is not "located" in an individual body at all, but is created by the way society is organized in relation to individual difference – firstly through stigma and discrimination, and secondly through indifference to the accommodations that persons with disabilities may need to participate fully in society.
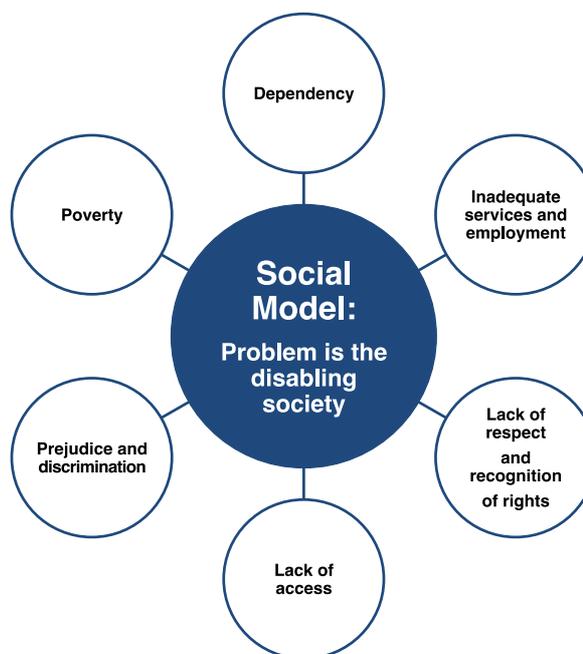

In the example above, the Social model of disability would see the design of transport as the disabling barrier for the wheelchair user – not the wheelchair.

The Social model considers that it is society that disables people, by designing everything to meet the needs of the majority of people who are not disabled. There is a recognition within the Social model that there is a great deal that society can do to reduce and remove disabling barriers, and that this is the responsibility of society, rather than of the person with a disability. The Social model is more inclusive in approach. Pro-active thought is given to how persons with disabilities can participate in activities on an equal footing with non-disabled people. Certain adjustments are made, even where this involves time or money, to ensure that persons with disabilities are not excluded.

E) The Rights-based model

This model is closely related to the Social Model. The Rights-based model takes universal human rights as a starting point. Persons with disabilities are seen to have a right to access all aspects of life within their society on an equal basis with others. Consequently, society has the responsibility to change to ensure that all people have equal possibilities for participation. Persons with disabilities are often denied their basic human rights such as the right to health, education, participation in social and political processes, and to employment.
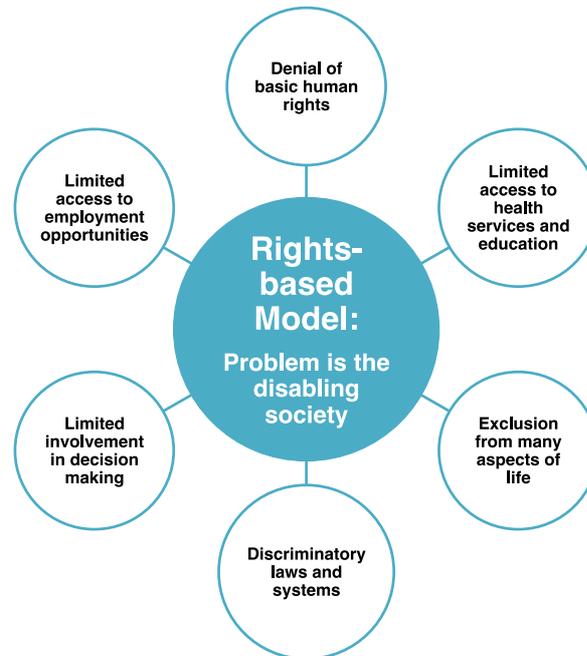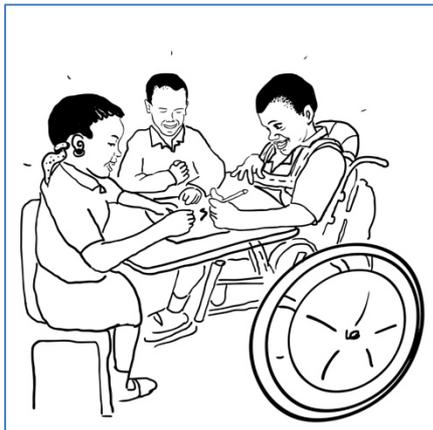
Laws and policies therefore need to ensure that these society-created barriers are removed. The two main elements of the Rights-based approach are empowerment (the participation of persons with disabilities as active stakeholders) and accountability (the duty of public institutions and structures to implement these rights and to justify the quality and quantity of their implementation).

The models do not manifest in a continuum – with one model succeeding or replacing another. There are elements of all models of disability in most countries. It should also be emphasized that the rights-based model does not reject medical treatment, but incorporates the positive aspects of the medical model. It promotes that medical interventions be provided in line with a rights-based approach that puts persons with disabilities at the heart of decisions that affect their lives.

The rights-based model also does not reject all charitable acts such as support of persons with disabilities to access assistive devices or training. The model recognizes that in the absence of a fair society, people with disabilities need support while the barriers they face in society still exist and while they are unfairly marginalized and stigmatized, and stopped from achieving their potential. It recognizes that acts of charity or support should always be provided in a way that gives respect and dignity to the person receiving it and should be considered not as charity, which often has negative connotations, but as good citizenship in the light of the equalities that exist that make it necessary. Such good citizenship has had a positive impact on the lives of many persons with disabilities while society has, and continues, to deny them their rights. The rights-based model contains the positive aspects of all the other models.

CBID and the models of disability

As the models of disability have developed and evolved, so too, has the concept of Community Based Rehabilitation (CBR) / Community Based Inclusive Development (CBID). When first conceived, CBR had a strong focus on health and rehabilitation and on issues of physical impairment. CBR/CBID is now a bottom-up, multi-sectoral strategy that extends beyond rehabilitation and health. It is a strategy for disability-inclusive development grounded in activities designed to empower persons with disabilities to take an active role in all features of community life in order to participate fully – on an equal basis with others.

Children and disability

Children with disabilities are frequently marginalized and excluded from society. They are less likely to attend school, access medical services, or have their voices heard. They are also at a higher risk of physical abuse, and often excluded from receiving proper nutrition or humanitarian assistance in emergencies.

Facing daily discrimination in the form of negative attitudes, and a lack of adequate policies and legislation, children with disabilities are prevented from realizing their rights. Frequently children with disabilities are either neglected or over-protected. They are often hidden because their parents are ashamed. Parents are often discriminated against and don't know how to care for their children with disabilities, particularly in the context of families who are already struggling with poverty and survival, and working with them to find solutions is critical.

Importance of early identification

Early childhood is defined as the period from prenatal development to eight years of age. For children with disabilities, it represents a critical time to ensure their access to interventions that can help them reach their full potential. Early childhood development (ECD) is a generic term that refers to a child's cognitive, social, emotional and physical development. Child development is a process through which children progress from dependency on caregivers in all areas of functioning during infancy, towards growing independence at primary school age, through adolescence and into adulthood. Skills develop in different areas through what are called milestones which involve mastering certain simple skills before moving onto more complex ones.

When children do not attain the milestones in the usual way for their age, they are said to have developmental delay. Developmental delays are measured using assessment methods and may be mild, moderate or severe.

Developmental delays can be caused by different factors including poor health habits during pregnancy, poor birthing methods, inadequate stimulation, malnutrition, or chronic ill health. Developmental delay may not be permanent, but when it is identified it can provide a basis to identify children who may experience a disability.

For this reason, early detection and identification through CBID initiatives is important so that children can be referred to specialists who can plan interventions in collaboration with family members aimed at addressing delays and creating the best environment for the child's development. Examples of interventions might include specialized medical, habilitation and/or rehabilitation services (e.g. therapy and assistive devices); family support (e.g. training and counselling); or social and psychological support. On an economic level, children with disabilities who receive good care and developmental opportunities during early childhood are more likely to become healthy and contributing adults.

Census on disability

Although advocacy can influence the questions asked in a census, and help improve the data, a census is always likely to be limited in its reporting of disability because the focus is to gather information on the entire population.

Unlike surveys, census tend to focus on collecting data that would reflect changes in overall population trends from one period to the other as opposed to collecting detailed information on specific variables such as on persons with disability. Ideally, countries should conduct specific disability surveys to more accurately establish the percentage of the population with disabilities and the types of disabilities.

A survey can be a more effective way to gather information on disability as it can ask more focused questions. These are asked of a sub-section of the population and the results can give an indication of the situation for the whole population.

Actions to take to help change attitudes towards persons with disabilities	
National and Regional	• *Develop guidelines, policies and laws which promote the full inclusion of persons with disabilities.* • *Ensure enforcement of laws which protect the rights of persons with disabilities to facilitate their greater inclusion and visibility.* • *Use and promote appropriate terminology when referring to or addressing persons with disabilities.* • *Plan and run disability awareness and inclusion training for staff from public, civil society and private sectors.* • *Promote positive images and case studies of persons with disabilities.* • *Avoid using negative images of persons with disabilities in materials such as depicting them as weak or pitiful.* • *Recruit persons with disabilities in all sectors.* • *Promote the appointment of persons with disabilities to decision making roles.* • *Promote and support the full integration of persons with disabilities in all sectors.*

District	• Recruit persons with disabilities in all sectors, including district committees and other decision-making bodies. • Advocate for policies, and bye laws which promote the full inclusion of persons with disabilities. • Lobby and advocate for enforcement of laws which protect the rights of persons with disabilities to facilitate their greater inclusion and visibility. • Promote and support the full integration of persons with disabilities in all sectors. • Use and promote appropriate terminology when referring to or addressing persons with disabilities. • Plan and run disability awareness and inclusion training. • Promote positive images and stories of persons with disabilities. • Mainstream disability issues in district development plans.

Community	• Empower persons with disabilities to be role models and present positive images of disability to educate and raise awareness of their challenges and capabilities. • Identify persons with disabilities in the community and promote their inclusion in all aspects of community life. • Use and promote appropriate terminology when referring to or addressing persons with disabilities. • Identify and remove the barriers that prevent persons with disabilities visibility and inclusion in community life. • Promote positive images and stories of persons with disabilities. • Discourage use of myths, beliefs and cultural practices that undermine the rights of persons with disabilities. • Recruit persons with disabilities to village and community committees and other decision-making bodies.

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