Disability Concepts Booklet

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1. Introduction

This booklet on basic concepts of disability is part of a broad 2- years project (2011-2012) titled **"Enhancing Participation of Somalis with disabilities for Human Rights and Democracy in Somaliland and Puntland"** thankfully funded by the European Union (EU) through Handicap International. The implementing partners of the project are two national NGO namely the Disability Action Network (DAN) and Somaliland National Disability Forum (SNDF).

The booklet is intended to enhance the understanding of development actors on basic concepts of disability as well as viewing disability in the lenses of rights based approach. The ultimate aim of the booklet is to facilitate the disability mainstreaming in the context of Somaliland and its target users may include the Disabled People's Organizations, Development workers, Government Ministries and institutions, and other actors such as service providers. The booklet paves the way towards inclusive policies as well as accessible services for people with disabilities.

More than a billion people (15% of the world's population) live with some form of disability. They face stigma, discrimination, exclusion and sometimes death. PWD are deprived of fundamental rights: Life, liberty, health, education, privacy, family, employment. People with disabilities are often an overlooked group within development programmes and government policies (WHO, 2011).

The total population of Somaliland is estimated to be 3.5 Million persons, with 60% living in nomadic ways (MNP, 2007). In Somaliland, one of the challenges encountered include the lack of disability disaggregated data and statistics as no national census on disability has yet taken place. Based on international figures approximately **535,000** to **546,000** (15% of the population) persons with different impairments live in the Republic of Somaliland. Persons with disabilities that live in nomadic setting are in harsh living conditions, as movements are frequent in search for water sources and pasture.

The adoption and the entry into force of the Convention on the Rights of Persons with Disabilities and its Optional Protocol challenge such attitudes and mark a profound shift in existing approaches towards disability. In the Convention, the focus is no longer on a perceived "wrongness" of the person, with the impairment seen as a matter of deficiency or disease. On the contrary, the Convention views disability as the result of the failure of societies to be inclusive and to accommodate individual differences. Societies need to change, not the individual, and the Convention provides a road map for such change (UN, 2006)

Case Story1:

This is perhaps the most chocking story I have ever heard over the 15 years I was working in the disability field in Somaliland. In 2010, while facilitating a workshop in Awdal region to sensitize primary school teachers about the principles of education for all, one of the workshop participant teachers told the story during a plenary discussion. The story goes as follow:

“There was a family in a rural area near Borama town, in Somaliland. They were nomads. As the context dictates in Somaliland, animal herders have to follow the grassing and water and hence move often from one area to another as the climate changes. Nomads mostly load their mobile shelters on a camel, if they are lucky, and otherwise on a donkey. Mostly men are assigned to load the shelter on camels and then lead the convoy camels through an attached robe. Women generally follow the footsteps of men together with the children and goats.

This family therefore moved in search for a grazing land. The man has loaded the shelter on two-camels and started to move. His wife followed behind with 3 children, including one with impairment, aged around 7 years at the time, as well as the goats. She carried the child with impairment in her back. At 7 years, the child must have been heavy to be carried on his mother’s back for a long distance. So, the mother disappeared from the view of her husband several times, which obliged him to halt the walk and wait. At the end, he waited, became crazy and once the wife reached him, he murdered the child, threatening also the life of his wife. When the community informed the local police about the horrific murder of the child, the assassin just disappeared into a far away bush area. At the end, local traditional leaders said that he only killed his son and they felt disempowered to intervene in such an internal family affairs.” This man has never been prosecuted as far as I know. The workshop participant teachers seemed to be familiar with the story, and the discussion concluded that the father did not have any other choice, as the coping mechanisms of the child’s condition was inexistent.

2. Understanding Disability

The preferences of words on disability vary from place to place and from one culture to another; for instance, a word considered appropriate and acceptable in one culture may be totally unacceptable in other culture using the same language. In the USA, “handicapped” has been for long time unacceptable, but has been generally acceptable in the UK, although less acceptable now than it used to be in the past; while “handicapped” is often used in French. In the UK, some people prefer the word “disabled people” to mean that “disabled people by society” (Frayers, 2011). In the Somali culture, the common labeling words are “Laangadhe” and “Curyaan” for the physical impairments on lower limbs, which roughly mean “the crippled”. Other common words are “Gacan” for the person who has one amputated or paralyzed arm. “Cawar” is named for a person who lost the sight of one eye and “Indhoole” is to mean blind; “Dhegoole” for a person with complete hearing impairment. “Faruur” means the one with a cleft lip. Even a man with an impaired finger is called “Farloow”. All these words have negative connotations.

The United Nations Convention on the Rights of Persons with Disabilities (2006) has chosen the word ‘Persons with Disabilities’ as the preferred word.

“Human beings have remarkable gifts, capacities and potential, but no person has all gifts, and no person is perfect and without inadequacies. All of us have limitations as well as potential, inadequacies as well as capacities, faults and failures as well as gifts and successes: there are many things we cannot do. For example, even in early adult life many people have visual defects affecting reading and close work, and needing eye-glasses. As we grow older, more and more defects and limitations of body and mind appear”(Frayers, 2011, p. 18).

2.1. Disability Definitions

Before we move further, we need to set the scene for a common understanding on what we mean by disability. Our views and understanding of disability determines what we do and how we do it.

On one-hand there is the reality of individual impairments and on the other hand the reality of negative social responses and barriers to participation in social and economic life. In other words, we have to separate two issues: 1) Health/impairment and 2) discrimination/exclusion by the society.

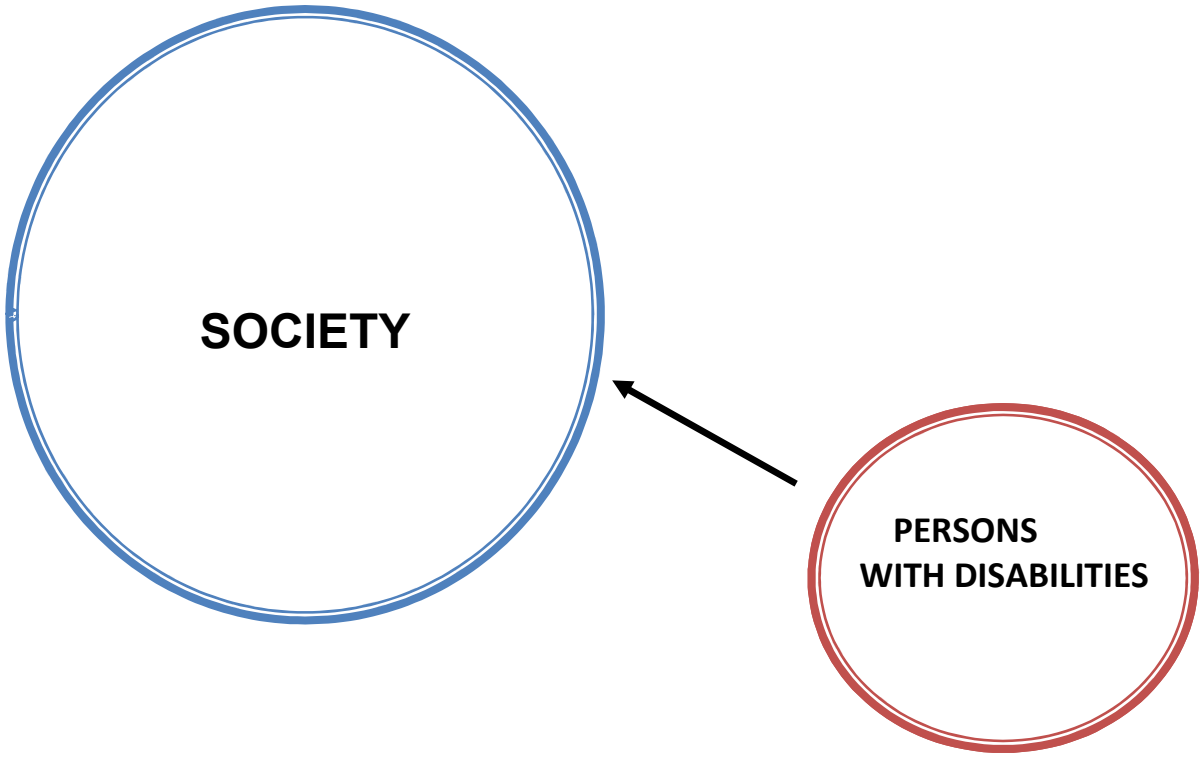
The two above-mentioned issues are clearly covered in the disability definition of the UN Convention on the Rights of Persons with Disabilities:

“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.” (UN Convention, 2006)”.

3. Disability Models

Human rights are the rights that everyone has by being a human being. Everyone is automatically entitled to enjoy the full range of human rights. Every human being has a right for instance to health, education and income generation. However the needs of people with disabilities have traditionally been treated as separate and specialized, which has excluded them from the mainstream society. The UN Convention on the Rights of Persons with Disabilities challenges this approach. The emphasis for inclusion is placed on society rather than on disabled people. PWD should be considered as people with the same needs as others. There are different ways disability has been approached in development. The first two models – medical and charity approaches – focus on barriers to participation being with the disabled individual. The third way – the social model – focuses on barriers being with society's view of PWD.

3.1. The Medical Model



(Adopted from Coe and Wapling, 2010)

Activities 'fix' the person with disability, who is 'sick', so they can join 'normal' society

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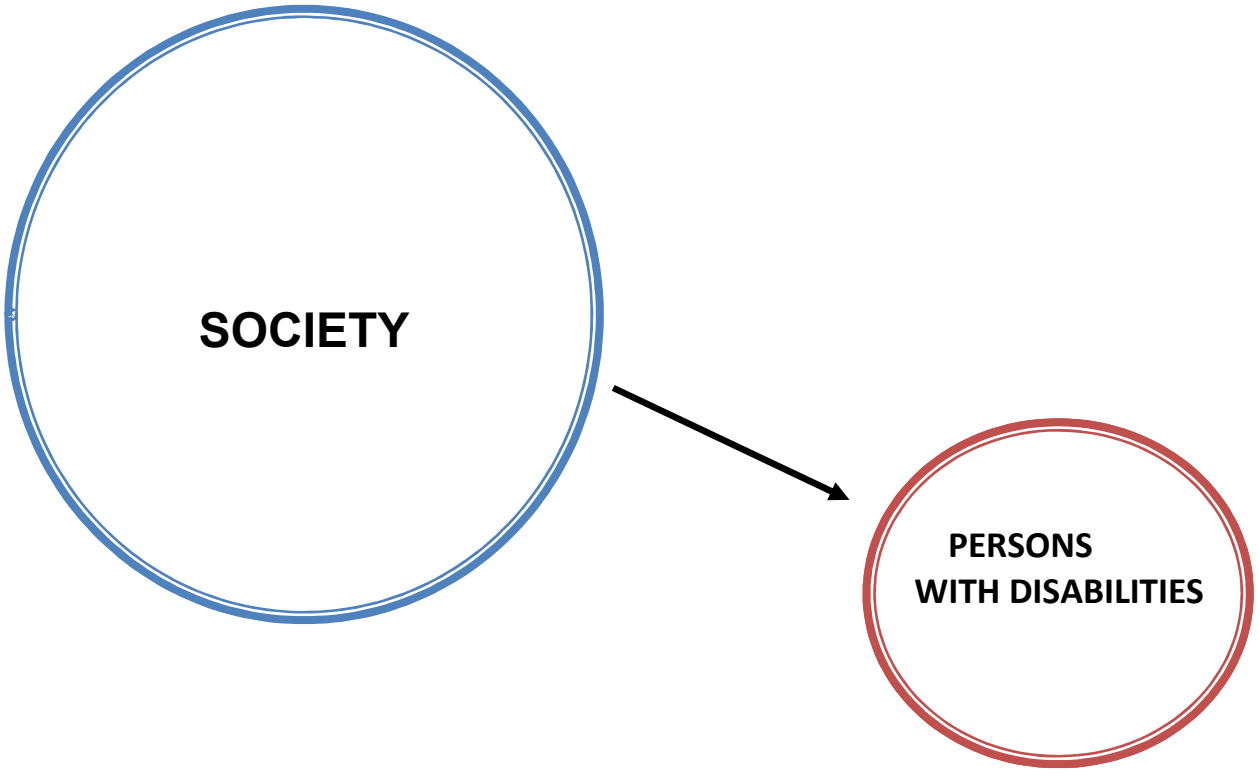
In the medical model, the disability is a problem in the person:

• A traditional understanding of disability
• Focuses on a person's impairment as the obstacle
• Seeks to 'cure' or 'improve' individuals to 'fit' them into society
• Defines the disabled person only as a patient with medical needs
• Segregates disabled people from the mainstream
• Offers only medical help, carried out by specialists
• Expensive, tends to benefit relatively few (Coe and Wapling, 2010)

3.2. The Charity Model



(Adopted from Coe and Wapling, 2010)

Activities 'help' the person with a disability who is 'helpless' and outside 'normal' society

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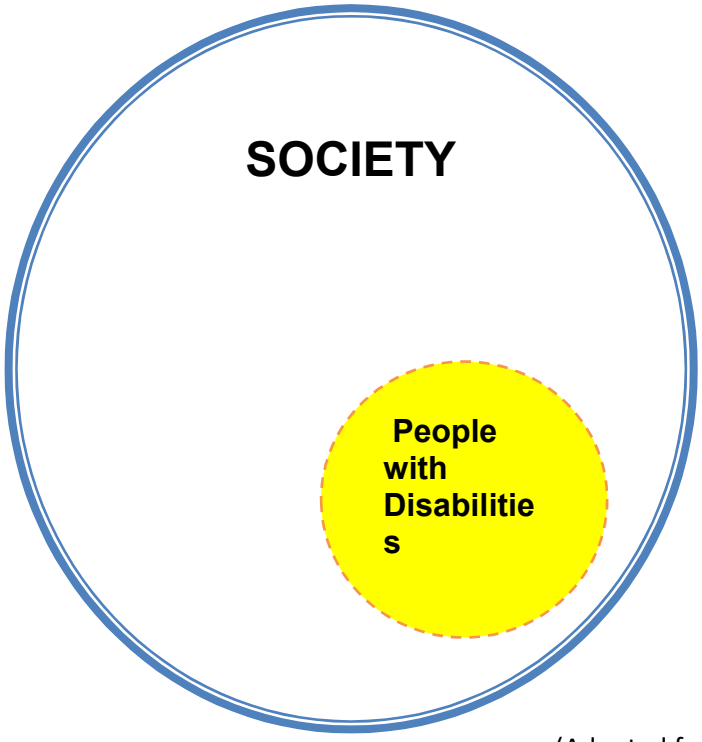
In the charity model, disability is a problem in the person:
• They are seen as 'unfortunate', 'dependent' or 'helpless'
• They are regarded as people who need pity and charity
• assumes people with impairments cannot contribute to society or support themselves
• Provides them largely with money or gifts, such as food or clothing
• Disabled people become long-term recipients of welfare and support

• Aid provided by specialist organizations not mainstream development
• PWD viewed and kept as separate group

3.3. The Social Model



(Adopted from Coe and Wapling, 2010)

Activities focus on inclusion – disabled people are part of society

The social model focuses on society, not people with disability, as the problem:
• Regards disabled people as part of society, rather than separate
• People are disabled by society denying their rights and opportunities
• Sees disability as the social consequences of impairment
• Disabled people's needs and rights are the same as non-disabled people's – e.g. love, education, employment, health etc.
• Activities focus on identifying and removing attitudinal, environmental and institutional barriers that block inclusion

3.4. Human Rights Model

The human rights model takes universal human rights as its basis. People with a disability are seen as holders of rights to access all within their society on an equal basis with others. The Rights Models focuses on **Duty bearers.** – "when something is defined as a right, it means that someone has a claim to have that right realized. The person or body who has the responsibility for ensuring the fulfillment of the right is known as a duty bearer. Duty bearers are primarily State actors and institutions at various levels of the governance structure, but also include non-state actors who are in a position to influence the rights of others. For instance, parents, teachers, the Government Ministries and Parliament are all duty bearers with obligations to ensure that people with disabilities are able to realize their right to education, health-care, income employment etc (Save the Children, 2009, p5).

Everyone is different, whether that difference relates to colour, gender, ethnicity, size, shape, or anything else. A disability is no different. It may limit a person's mobility or their ability to hear, see, taste, or smell. Regardless of its characteristics, disability neither subtracts nor adds to a person's humanity, value or rights. It is simply a feature of a person.

In Somaliland, the most prevalent disability model is perhaps the Charity Model. The two case stories below illustrate the practical experiences of persons with disabilities:

Case story 2

Mr Guuled (name changed) lives in Hargeisa, the capital of Somaliland. At an early age, he lost his sight due to an illness. Now, he lives with the support of his family and extended relatives. His main problem is not the impairment of his sight, but rather the attitudes of people towards his blindness.

"I mostly go to the market as someone, mostly a friend, a family member or a relative, help me go out. Often, the community shows a feeling of pity. Once, I went to one of Supermarkets in Hargeisa to purchase something. One customer took me as a beggar and approached me. Of course I did not see him, but I have felt someone who was trying to put something in my pocket. I asked him what he put in my pocket and the customer replied that he gave me some money. I felt anger, and requested him to take his money back."

Case story 3

Mr Kahin also explains a story that is almost similar to that Mr Guuleed encountered.

"Before, every time that someone took me as a beggar, I got angry. Now, I became familiar with such a behavior. There were times I avoided even to go out as I feared people would again treat me as a beggar. People do not intentionally want to harm me. They rather want to help me, but they are ignorant of how to best treat me. Few days ago, while I was riding my tricycle in the market, a woman gave me some money. She expressed a feeling of pity while giving me the money "Oh, Allah wanted him to be like this". She handed me some money. I just thanked her as I returned the money. I told her I had enough money with me. She did not believe I did not want to take her money." Explained Kahin, 35, who lives in Hargeisa and uses a wheelchair.

4. Disabling barriers that hinder participation

The various barriers that prevent PWD from participating in society on equal terms with non-disabled people can be grouped into four categories; here they are:

- Attitudinal
- Environmental
- Communication
- Institutional

4.1. Attitudinal Barriers

- **Attitudinal barriers –** People with a disability often report that negative attitudes are the most disabling barrier of all, including negative stereotyping of people with a disability, social stigma and other forms of discrimination. Often disability is associated with cultural beliefs about sin, evil and witchcraft. Some of the common negative assumptions about PWD are listed below by Coe and Wapling (2010). PWD are:

- Unable, or assumed to be unable, to do things
- Of low intelligence
- victims, or objects of pity
- burdens, either on society or on their families and carers
- In need of a 'cure'
- needing 'special' services or support
- Dependent and need help
- Exceptional

The non-disabled people often react with fear, pity, repulsion, or a sense of superiority toward PWD.

The story below shows how can people's attitudes influence negatively the targeted persons. Mr Guuleed (name changed) from Laasanod told the story, very artistically, in one of the workshops for human rights education of persons with disabilities, organized by DAN:

> "Once, a nomad man came to Laasanod town to sell his he-goat that was attached with a robe. A group of adolescents, who were sitting in an entry corner of the town, have seen the man and wanted to make fun with him. Mostly people from towns fool nomads. They decided to confuse the man. To fulfill their objective, they got divided into small groups of two persons each. The first two walked towards the nomad, and after greeting him, asked him: "where are you taking this dog to?" The man confidently replied, "It is not a dog, it is a he-goat that I am going to sell at the market". Then, the next two came to his way, greeted him and asked the same question. The nomad replied the same answer but he started to doubt gradually. Then the next two, then the next two and so on and so forth…at last the man believed them, and thought something must be wrong with him; he left his animal saying "I thought it was a he-goat"

The morale of Guled's story was to tell the PWD how negative attitudes can lead to people with disabilities believing themselves to be worthless.

4.2. Environmental Barriers

People with disabilities encounter these barriers in areas such as:

- Hospitals and clinics
- Public transport
- Schools and housing
- Shops and marketplaces
- Water pumps
- Roads/paths
- Offices and factories
- Places of worship
- Media and communications
- Public information systems

(Coe and Wapling, 2010)

The physical barriers in this category are obvious to most people– e.g. a hospital is inaccessible for wheelchair users because it has steps/stairs and narrow doorways.

Case Story 4

Farah is a young girl who lives in Hargeisa. She is a wheelchair user. She tells her story about physical barriers and how they hinder the participation of PWD in society.

"Once I happened to go to one of the Hawala (Remittance) institutions in Hargeisa. I wanted to collect some money sent to me. When I reached their premises with my tricycle, I realized it had stairs that are not possible to go through. As I had nobody around me, I had to wait outside. All the other customers were entering without any problems, and without realizing my presence at the entry area. I had to wait there for about 2 hours, after which one kind customer approached me and asked me why I was there. I told him about my problem. Then, he entered in the office and informed them about my issue. The staff sent me someone who helped me fill the forms outside. Then this staff member brought me the money. My case was managed in a special way. I was never happy about it. Now, several Hawala offices as well as some hotels have made accessible ramps thanks to the disability inclusion awareness campaigns".

4.3. Communication Barriers

Communication barriers are especially obstructing for those with sensory impairments – e.g. if sign language is not available for the persons with hearing impairments (e.g. HIV and AIDS messages). Students with hearing, visual or intellectual impairments are unlikely to access vital information unless their access needs have been met (Coe and Wapling, 2010)

This category includes written and spoken information such as:

- media,
- flyers,

- internet,
- Community meetings.
- Education system
- Public information systems such as drama and songs.

4.4. Institutional Barriers

The institutional barriers, sometimes called policy barriers, exclude or segregate people with disability from areas such as:
• Legal system
• Employment laws
• Electoral system
• Education policies
• Health service provisions
• Social services
• Masjids (Mosque, a translation refused by some)
• Humanitarian/Aid development programmes

(Coe and Wapling, 2010)

In the context of Somaliland, the institutional barriers represent a real obstacle. There is a national disability policy in place as well as sectoral policies such as education policy. There are at least two major hindrances against the effective implementation of these policies. A) Government resources are not allocated for their implementation; the excuse is that resources are scarce in this post-conflict context of Somaliland B) they tend to focus on individual model such as charity or medical model, placing the problem on the impairment. For instance, the Education policy on disability is title “Special Needs Education”. The focus is to create special schools and therefore the policy considers the educational needs of children with disabilities as a separate from the mainstream.

5. Mainstreaming disability

5.1. Poverty and Disability

Disability and poverty reinforce and perpetuate one another. People with a disability are among the poorest of the poor, while people living in poverty are more at risk than others of acquiring a disability. People with a disability have limited access to health care and education, have difficulty finding employment, face high levels of stigma and discrimination and are commonly denied their rights. These factors all contribute to economic vulnerability and social exclusion. In turn, poor households rarely have access to adequate food, shelter, hygiene and sanitation facilities, potable water and preventative health care services; characteristics known to exacerbate poverty and increase the risks of disability (CBM, 2012 p.10).

Disability is not mentioned in any of the 8 MDG goals, the 18 targets, or the 48 indicators. People with disabilities are also largely absent from international and national strategies and action plans for poverty reduction. The former President of the World Bank, James Wolfensohn stated in 2002: *'Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015'*.

5.2. Definition of disability mainstreaming:

Mainstreaming is a '*strategy for making disabled people's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic, and societal spheres so that disabled people benefit equally and inequality is not perpetuated'* (modified from the ECOSOC's gender mainstreaming definition).

"Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015…" (James Wolfensohn, President World Bank, 2002)

The essence of mainstreaming is to persuade the government and the organizations working in development in Somaliland to ensure that all development work benefits the whole community, and not only the majority.

It can be challenging for those responsible for implementing development programmes to give disability the attention it deserves, especially when faced with increasing demands to make their programmes inclusive to a whole range of marginalized groups - women, children, ethnic minorities as well as disabled people. There is also the problem that many development professionals see disability as a "specialist" issue, and will say that they lack the necessary expertise and experience.

HOW: Process of assessing effects on PWDs of any planned action (services, policies and programmes), in all areas and at all levels.

WHY: Strategy for making disabled people's concerns and experiences part of the design, implementation, monitoring and evaluation of policies and programmes in all areas.

The *advantages* of mainstreaming disability are:

- It enables people with a disability to participate in society;
- It helps attitudinal, institutional and environmental barriers;
- It is more cost-effective and capable of servicing many more people than charity approaches;
- It allows for people with a disability to be independent and make their own decisions for life.

AIM: The ultimate goal of mainstreaming is to achieve disability equality (adopted from UN ESCAP gender mainstreaming)

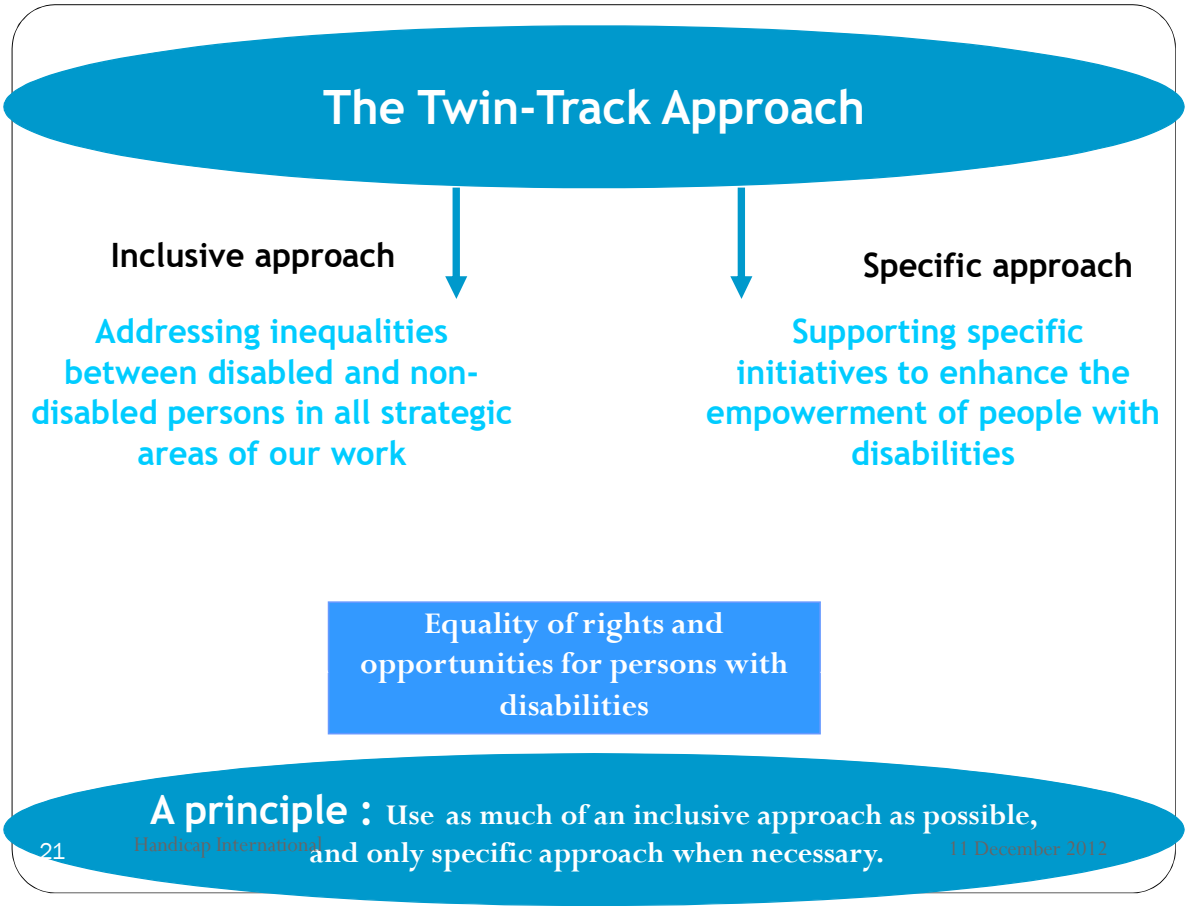
5.3. The Twin-Track Approach

The Twin-Track approach in disability is to working with cross-cutting issues such disability which combines mainstreaming with specific initiatives that empower the target group.

The twin track approach addresses disability across all areas of international development. It promotes concurrent action across two broad sets of initiatives. One set is through disability-specific activities that are targeted directly for people with a disability; the other is through the mainstreaming of disability into broader activities.

Disability specific interventions can include community based rehabilitation, setting up of Disabled People's Organizations (DPOs), mobility and adaptive devices such as wheelchairs, prosthetics and hearing aids etc.

The combination of disability specific interventions and mainstreaming has proven to be successful for a genuine inclusion and empowerment of persons with disabilities (CBM, 2012). The following diagram illustrates the Twin-Track approach.



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Glossary of key terms

Impairment – A long-term physical or mental limitation.

Disability – Social and environmental exclusion or limitation of a person as a result of societal attitudes towards impairment.

Mainstreaming/ inclusion – The process of integrating formerly segregated and/ or stigmatised issues and people into 'mainstream' society and development programmes – and out of the welfare department.

Disability-specific – Segregated (non-mainstream) efforts for working with persons with a disability.

Twin-track approach – An approach to working with cross-cutting issues such as gender and disability which combines mainstreaming with specific initiatives that empower the target group.

Cross-cutting issue – An issue which is important to be taken into consideration in all sectors and programmes, usually with a goal to including the needs of a particular marginalised group in society.

Medical model of disability – The medical model, also called *individual* or *charitable model*, views disabled people as patients who are incapable and in need of 'fixing'. Rehabilitation and/ or medical procedures are in this view the best way of dealing with disabled people for helping them to lead a 'normal' life. The problem of impairment and limitation is seen as an individual problem.

Social model of disability – The social model of disability, also called *rights-based model,* views disability as a problem brought about by society, which does not accept people with an impairment the way they are. A person with a disability enjoys the same rights as everyone else; however, attitudinal barriers, institutional barriers and environmental barriers keep a person from a dignified life. The social model puts emphasis on letting people with a disability decide what is best for themselves, instead of having non-disabled people take that decision for them.

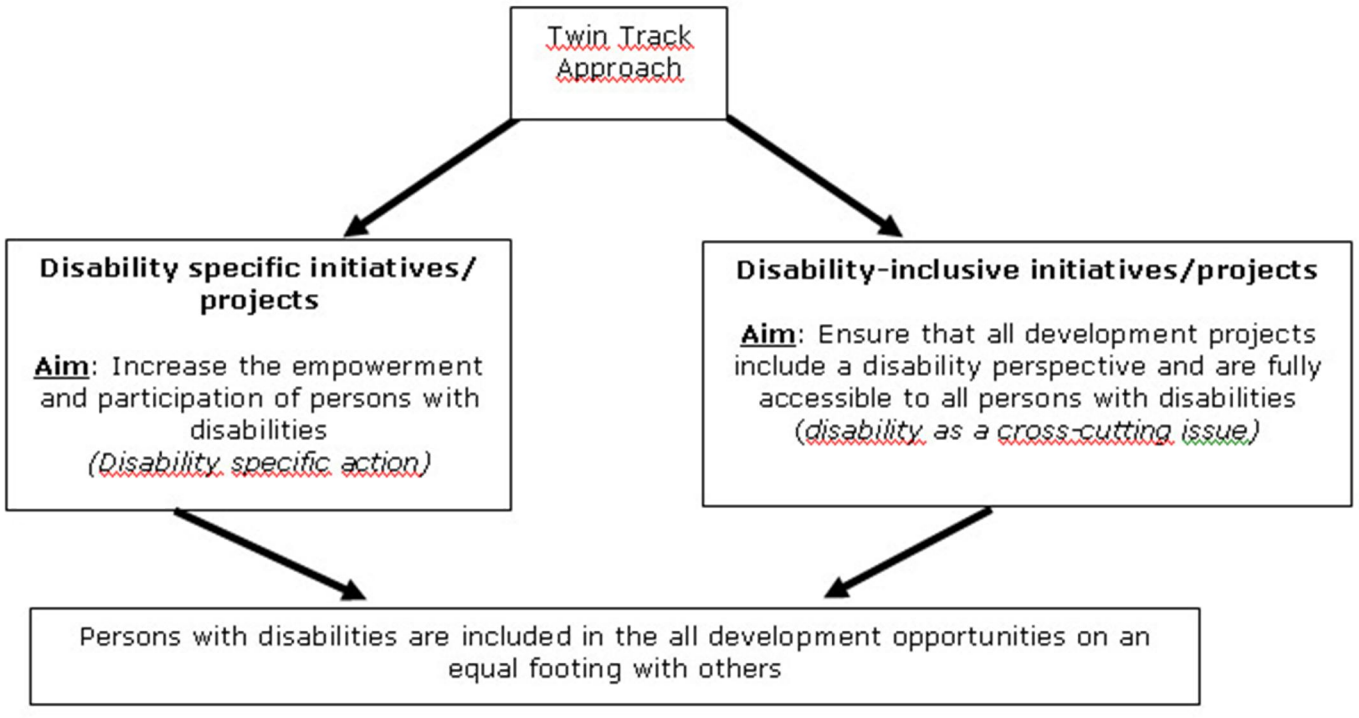
Development – A continuous process of change, involving multiple stakeholders and contexts.

Development industry – The ever-growing amount of international, bilateral, non-governmental, private and community-based organizations which concern themselves in one way or another with helping poor and marginalized people in so-called 'developing countries'.

Empowerment – **The process of attaining power to decide over one's life.**

The ideal approach within a development project is that persons with disabilities are fully included on an equal basis with others. This is what we call here 'including a disability perspective'; it is similar to the concept of 'disability mainstreaming' or 'treating disability as a cross cutting issue'.

However, in order for full inclusion and participation to be possible, it is often necessary to provide specific support to persons with disabilities in parallel, to ensure that they are empowered to participate on an equal basis with others. This combination of 'disability inclusion' with disability specific projects, or components of projects, which aim to empower persons with disabilities in particular, is called the 'twin track approach'; in practice it means:

- The inclusion of a disability perspective an all development projects
- At the same time, support, where appropriate, initiatives aimed directly at the empowerment of persons with disabilities.

The twin track approach is largely accepted by many international donors (for example the World Bank, DfID, the German Cooperation; the EC, the Finnish Cooperation) and NGOs. From a PCM perspective, using the twin track approach implies including the perspectives of persons with disabilities in all relevant development projects, while at the same time empowering persons with disabilities through disability specific projects, or components of projects.