CHAPTER - 1
REDEFINING DISABILITY
1. REDEFINING DISABILITY

Introduction:
Diversity is one of the salient features of creation, one cannot find two identical entities on earth. Every creature is unique with thousands of differences and diversities thus diversity and uniqueness are not contradictory but make creation more comprehensive and interdependent. As we find diversities in creation in the same way we find diversities in human society. Human society has thousands of diversities which facilitates human beings to lead a life with dignity. Every human being is unique by nature with various differences, strengths, limitations, potentials, abilities and disabilities. We have accepted human diversities but unfortunately we are indifferent to those with disabilities.

Disparity from person to person is a grim reality of human society. There is a long history of discrimination between the have-nots, lords and serfs, rich and poor, ruler and ruled, educated and uneducated, man and woman, tribal and non-tribal, white and black, oppressed and oppressor, touchable and untouchable, disabled and the so called non-disabled since ages. It is difficult to find a society with absolute equality, thus egalitarian society is a myth. Every society is stratified into different strata based on various factors like age, sex, religion, caste, creed, race, prestige, power, privilege, wealth and physical and mental abilities. Those who belong to the lower strata in the social ladder are marginalised and disadvantaged and belong to the most deprived segment of society. Since social stratification is a universal phenomenon, differences are found in all societies. Disability is one such form of social stratification, which leads to powerlessness, degradation, dehumanisation, disempowerment, marginalisation, ostracisation, social exclusion and vulnerability of Persons With Disabilities.

There are various forms of stratification but this research is concerned about disability. It is estimated that Persons With Disabilities constitute 10% of the total population of any developing country. It is often said that this is a sizable and invisible minority which is neglected and marginalised since ages. They are perceived as objects of charity and pity. They are viewed as a problem rather than as a priority. Potential barriers such as environmental, legal, cultural, institutional and societal; crippling negative attitudes, stigma, discrimination, seclusion, prejudice, ignorance and fear impoverishes and reduces them to lesser or sub-human beings. The apathy of the state and society further worsens the situation. Earlier approaches to disability and development were charity and relief oriented which isolated them and made them dependent. Legislation enacted for the development of this section has many gaps. Moreover they remain in the Gazette of India without effective implementation. A well known disabled activist rightly remarks that they are,"Unseen, unheard and unaccounted for in the developmental process".

This research makes a sincere and serious attempt to examine various facts and ground realities pertaining to disability and development with regard to India in the light of central issues which affect the lives of millions of Persons With Disability in this country and the globe.
1.1. BASIC CONCEPTS

It is important to understand the basic concepts of disability from various dimensions before going into minute details, since the concept of disability is subjective, psychological, social, contextual, cultural and sensitive. There are dozens of definitions, which describe disability in different ways but none of them provides a standard and comprehensive definition to the term. Each definition ranges from the very narrow to the very broad, from the medical to the social, from the cultural to the local, from one intended to integrate them into society to one for exclusion and segregation. This particular chapter focuses mainly on the medical perspective of disability on the potential grounds of psychosocial, sociological, socio-cultural, political, economic, religious and environmental dimensions of disability.

Various agencies and pioneers of the sector have attempted to provide a working definition to disability and related concepts. The International Classification of Impairment Disability and Handicap (ICIDH) is one such attempt made by World Health Organisation (WHO) in 1980 to provide a base to initiate discussions, deliberation, debate, thought process and a framework to re-coin a most appropriate, comprehensive, contextual and socio-cultural definition to disability and related concepts.

WHO defines impairment, disability and handicap and provides a base for distinguishing these terms in a scientific way since these terms have linear connections with each other. Thus it is important to proceed in an orderly manner to understand the basic concepts. WHO has a mandate to develop a global common language in the field of health. In 1980 WHO implemented an International Classification of the Consequences of Disorders (ICCD) and ICIDH. This classification has been widely used but at the same time criticised as being too medical and individual. The feedback was taken into account during the revision of the classification of the concepts in 1996 and 2001.

WHO’s classification of impairments, disabilities and handicaps define functional ability using impairment, disability and handicap as central concepts (WHO 1980 and revision 1996). The relationship between impairment, disability and handicap has been defined as follows:

- Impairment refers to organ level functions or structures.
- Disability refers to person level limitations in physical and psycho-cognitive activities.
- Handicap refers to social abilities or the relationship between the individual and society.

ICIDH classification of impairments, disabilities and handicaps and ICDH of WHO, Geneva, Division of Mental Health and Prevention of Substance Abuse, 1977; defines these terms and their relations in the following way:

- Impairment is an abnormality of psychological or physical functions or of appearance.
- Disability is an interference with the performance of an activity by an individual in relation to the immediate environment.
- Handicap is a societal disadvantage for a given individual that limits or prevents the performance of a social role or participation. The following case study will help us to understand these terms more clearly.

Basavalingappa resides in Parvaianah Palya village of Harohalli Hobli of Kanakapura Taluk of Bangalore Rural District. He is 35 years of age, a farmer by profession, married with two children. He has a good relationship with the community members. He is physically strong,
psychologically healthy, spiritually peaceful and socially content. This condition of Basavalingappa is called as health.

One dark night he goes to his fields to water the crops. Unfortunately he falls into a dry well due to which he suffers severe spinal cord injury, which results in the dysfunction of the lower body, this condition is termed as impairment.

He is admitted to a hospital in Bangalore, where he undergoes a surgical operation for correcting the spinal injury. He is admitted for three months with no improvement in the function of the lower body. He has no control over his bowel and bladder functions and is bedridden. This prevents him from walking, performing his daily routine activities, farming and caring for his family, this condition is called disability.

His family members do not love and respect him and desert him. And he is looked down upon by the community, he has to bear insults and ridicule from everyone. He is unable to fulfill his role as a husband, father, farmer and as a member of the community. This condition is called as handicap. This research attempts to examine these concepts in the light of various definitions provided by different agencies and individual pioneers:

A. Impairment: Following are the operational definitions provided by various agencies, which will help in re-framing the definition of the concept of impairment.
1. Impairment is any loss or abnormality of psychological or anatomical structure or function [WHO].
2. A significant loss or deficiency in physical or mental faculties would be known as impairment [North Carolina General Statute 122C-3 12a].
3. Impairment is long lasting or permanent and it could be a physical or mental problem or defect [Robert Levi].
4. As per functional limitations, impairment may be defined as a specific reduction in bodily functions that one described at the level of person [Einar Helander].

From the above mentioned definitions, it can be concluded that:
1. Impairment is a long lasting or permanent problem or defect.
2. It can be physical, mental, sensory, intellectual, or psychological in nature.
3. It can be congenital or acquired.
4. It is loss or abnormality of structure or function of Psychological or Physiological nature at organ level.
5. Impairment cannot be cured completely but its impact on an individual can be reduced through medical restorative services.

B. Disability: Since the concept of disability is subjective and psychological, societies have defined this term in their own way. Distinction is made between disabled and non-disabled on the basis of appearance, behaviour, functional limitation and restriction of activity. Significant profound deviations of physical and mental faculties from the fixed standard of an individual, resulting in appreciable and substantial difficulty in performing functions in a social adjustment, would be perceived as a disability. The following few operational definitions provided by various agencies and individuals will be helpful to understand, re-visit and re-define this concept:

1. REDEFINING DISABILITY
1. Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being [WHO].

2. A person who in his/her society is regarded as disabled because of a difference in appearance and/or behaviour [Einar Helander].

3. Disability is the loss or limitation of opportunities that prevent people who have impairments from taking part in the normal community life on an equal level with others due to physical and social barriers [V. Finkelstain & S. Ferench].

4. A disability means an inability to perform a normal bodily or mental process. It could either be complete inability to do something (such as walking) or it can be a partial inability to do something (such as one can lift weights but not heavy ones) [Disability discrimination Act of British Government-1995].

5. An individual is considered as disabled if his/her physical mental impairment substantially limits one or more major life activities [Americans with Disabilities Act [ADA]-1990].

6. Disability in relation to a person means a total or partial loss of a person's bodily or mental function or a total or partial loss of a part of the body [Disability Discrimination Act of Australia-1992].

7. A Person With Disability is an individual whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognised physical or mental impairment [International Labor Organisation [ILO].

8. Any person who is unable to ensure for himself/herself, wholly or partly, the necessities of a normal individual or social life including work, as a result of deficiency in his/her physical or mental capability [Planning Commission of India].

9. Long-term impairment leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community [Department For International Development [DFID].

10. "A physical or mental impairment which has a substantial and long term adverse effect on a person's ability to carry out normal day to day activities [Disability Discrimination Act UK-1995].

Considering the above-mentioned definitions, it can be said that:

1. Disability is a difference in appearance or behaviour of an individual.
2. Disability is any restrictions or lack of ability of an individual to perform an activity in a normal range.
3. Disability is a specific reduction in bodily functions that are described at the level of the person.
4. Disability is contextual, cultural, episodic and perceived.
5. Disability is social, psychological, subjective, permanent or temporary.
6. Disability is not just individual pathology but a societal problem.

C. Handicap: There has been some controversy also in the use of the word handicap which has been in use for a very long time. For some time it was believed that the word disabled would be preferable. Now it is preferred to use the phrase "Person With Disability". The term handicap was used previously in reference to Persons With Disabilities. Many people working on disability and rehabilitation feel that this is not a socially acceptable and politically correct language, since all people with disability are not handicapped. The word also has a negative connotation. Otherwise only a small proportion of the total Persons With Disability are handicapped, since they are dependent on others and need constant care. The term handicap was used in Europe during ancient times to indicate beggars who used to beg by

1. REDEFINING DISABILITY
holding their caps in the hands, that is how the term came into existence. Usually those beggars were Persons With Disabilities. Thus, this term continued to indicate them as Persons With Disabilities. Attempts have been made to re-define this term for the sake of conceptual clarity. A few such definitions are examined below:

1. A Handicap is a social disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual [WHO].

2. The term handicap means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between persons with a disability and the environment. The purpose of this term is to emphasise and focus on the shortcoming in the environment and in many organised activities in society [United Nations [UN] Standard Rules-1999].

3. A person is handicapped when he or she is denied the opportunities generally available to the community that are necessary for the fundamental elements of living, including family life, education, employment, housing, financial and personal security, participation in social and political groups, religious activity, intimate and sexual relationships, access to public facilities, freedom of movement and the general style of daily living [Captan. HJM. Desai].

4. Handicap refers to a situation when physical and social barriers put Persons With Disabilities at a disadvantage and hinder their ability to fully participate in society. A person with a disability is not "handicap" but is handicapped by attitudinal, physical, and other barriers that society fails to remove [North Carolina General Statute 122C-3 12a].

From the above mentioned definitions of the concept handicap can be summarised as follows:

It is not an individual who is handicapped, but the society which makes an individual so by creating potential barriers like physical, mental, economic, social, health, architectural, political, religious, legal, institutional and cultural. It is society as a whole which is responsible for the handicap in the situation of a Person With Disability. Negative attitudes, prejudices and discrimination of society make a person handicapped. A prolific English author named Tony attempts to explain who is disabled in the following way.

**Who is disabled?**

*If you fail to see "the person" but only the disability - then who is blind?*
*If you cannot hear the cry of your brother for justice - then who is deaf?*
*If you cannot communicate with your sister and separate her from you - then who is dumb?*
*If you cannot stand up for the rights of all - then who is crippled?*
*If your heart and mind do not reach others - then who is mentally handicapped?*

The Person is not handicap but your attitude towards disability may be the biggest handicap.

Tony

The ICIDH of WHO-1980 was largely criticised by different agencies, NGOs and activists as this classification focused only on the medical angle of disability which ignores the socio-cultural dimension of disability. This strong and constructive criticism compelled WHO to reclassify and redefine the terms by taking the socio-cultural dimensions of disability into consideration in 2001. The revised classification is as follows:

1. REDEFINING DISABILITY
International Classification of Functioning and Disability ICIDH-2: This builds on developments arising from the WHO’s ICIDH, 1980. ICIDH-2 endeavours to classify, in a very specific and systematic way, anything and everything a person, or a body, can do. It is an attempt to ‘codify human functioning’ (p.7). It does not classify people, or disabilities, but aims to identify and describe the full range of human functions and any ‘disturbance’ of those functions. In order to achieve the new approach to classification, the WHO’s Assessment, Classification and Epidemiological Group has developed a ‘code’ or a series of numbers and letters with specific meanings. When these codes are put together they provide a profile of an individual’s functioning capacity. In short, they describe what a person can and cannot do.

The aim of the new classification is to provide a common language for describing functional states associated with health in order to improve communication between health care providers, other public sectors, and Persons With Disabilities, and to facilitate proper comparison of data across countries, disciplines and services. It can be used as a tool for structuring research, collating data, developing social policy, or for clinical assessment and education. The re-classification identifies three ‘dimensions’ in which these functions of the body operate:

1. body function (physiological or psychological functions) and structure (anatomical parts) (b-body);
2. activities at the individual level (a - activity); and
3. participation in society (p - participation).

These dimensions replace the original ICIDH’s words, and associated concepts, of ‘impairment,’ ‘disability,’ and ‘handicap’. b, a and p, are conceived as having two poles; one end indicates problems, e.g. impairment, activity limitation or participation restriction, and the other end indicates non-problematic aspects and, as such, neutral or positive.

Functions i.e. what a person can do and how much they can participate in society are categorised and coded in detail. In fact, the ICIDH-2 attempts to identify everything that a body is capable of, both autonomic and deliberate. Each function is re-defined and given a three digit numerical code, for example specific mental functions of recognising and using signs and symbols and other components of language are coded as b175 accordingly.

Coordinated action of advancing on foot, step by step, in a manner in which at least one foot is always on the ground is coded a410. Involvement in appropriate residence for living alone, or with others, either with a family or with some other group, as a function of the availability and accessibility of housing resources and services is coded p510. The dimensions a, b and p may be affected by ‘Environmental factors’ (e), which may be physical, social, or attitudinal, and ‘Personal factors’, which relate to the personality and attributes of an individual. Environmental factors are similarly coded, for example, legislation, regulations and standards, together with associated administrative control and monitoring mechanisms that govern the delivery of education programs is coded as e675, (e for environmental factors). Any of these codes then may be used to describe a particular aspect of a person’s life what they can and cannot do in any given environment at any time. The codes are personalised, or ‘qualified’ by the addition of a number, which provides further information about the particular characteristic. The numbers denote the degree of problem [see the examples below]:

[1] xxx.0 No problem (none, absent, negligible...)

1. REDEFINING DISABILITY
b, a and p, and the environmental factors (e), are treated in the same way, so that having a problem may mean an impairment, limitation, restriction or barrier. In addition, if an activity can be performed, or participation facilitated by means of a carer or assistant, a ‘+’ sign is used instead of the decimal point eg. xxx+2.

The classification system provides a valuable, if complex, new way of looking at and discussing traditional notions of impairment, disability and handicap, and provides a means of making comparisons over diverse situations, and over time.

ICIDH-2 [2001] dimensions:
A. Impairment: A loss or abnormality of body structure or of a physiological or psychological function
B. Activity: The nature and extent of functioning at the level of the person. Activities may be limited in nature, duration and quality.
C. Participation: The extent of a person's involvement in life situations in relation to impairment, activities, health condition and contextual factors. Participation may be restricted in nature, duration and quality. Context includes the features, aspects, attributes of, or objects, structures, human-made organisation, service provision, and agencies in the physical social and attitudinal environment in which people live and conduct their lives.

There have been differences in opinions of using different terms to indicate Persons With Disability. Using positive terms is certainly good and shows the keen interest of the society in the development of Persons With Disability. Change of terminology does not alone bring change in the life of Persons With Disability. It needs lot of commitment, hard work, and positive attitude. There should be a sincere effort to translate the change of terminology into reality, which makes positive changes in the lives of Persons With Disability. The term handicap was in use for a long time. Now it is considered preferable to use the phrase Persons With Disability and differently abled people. There are some other phrases such as physically challenged, mentally challenged, the use of such expressions, however, may amount to euphemism and running away from realities. "Persons With Disabilities" and "disabled persons/people" are the internationally agreed terminologies and widely accepted by the disabled community. These terminologies recognise the existence and dignity of an individual before recognising the impairment of an individual. The disabled rights movement and organisations of Persons With Disabilities across the globe strongly feel that these two expressions are socially acceptable and politically correct. It is better to use the terminology which is socially acceptable and politically correct since the majority of the disabled community and disability sector have a strong agreement with these terminologies.

1. REDEFINING DISABILITY
1.2. RE-CLASSIFICATION

Different agencies and statutory bodies have classified disability into various categories, according to their convenience to provide schemes and programmes for Persons With Disabilities. Due to lack of a standard and uniform definition for each disability and lack of resources in developing countries, some of the genuine groups of disabilities that need rehabilitation facilities have been left out from classification. Depending upon the nature of impairment, anatomical, physiological, psychological structure or function, disability/impairment can be broadly re-classified into three major categories:

I. Physical disabilities/impairments
II. Sensory disabilities/impairments
III. Mental disabilities/impairments.

Persons With Disabilities Act of 1995 identifies seven forms of disabilities, which can be categorised within the above-mentioned three categories. The three categories can further be re-classified into five broader groups. Almost all forms of disability find place in this re-classification. The five major forms of disabilities are as follows:

A. Visual disabilities/impairments
B. Communication [speech and hearing] disabilities/impairments
C. Mental disabilities/impairments
D. Locomotor [mobility] disabilities/impairments
E. Multiple disabilities/impairments

It is important to discuss briefly about each category of disability/impairment with a view to understand and review the nature and the magnitude of the disability/impairment.

A. Visual disabilities/impairments:
Visual disability means a person who is affected by any of the following conditions;
(a). Total absence of sight.
(b). Visual acuity is not exceeding 6/60 or 20/200 (Snellen) in the better eye with the correcting lenses and other corrections.
(c). Limitation of the field of vision subtending on angle of degree 20 or worse.

(Rehabilitation Council of India Act [RCIA]-1992)

Different conditions that come under this category are:
1. Total blindness;
2. Night blindness;
3. Refractive errors;
4. Partial sight;
5. Low vision; [Significant loss of vision and significant usable vision]
6. Squint;
7. Cataract;

B. Communication disabilities/impairments:
Communication disability means a person who is affected by any of the following conditions:
(a) Deafness with hearing impairment of 70 decibels and above in the better ear
(b) Total loss of hearing in both ears. (RCIA-1992)
(c) Speech of a person is judged to be disordered if the person’s speech is not understood by the listener, draws attention to the manner in which he/she spoke than to
the meaning and was aesthetically unpleasant. (National Sample Survey Organisation [NSSO] 1991)

Various conditions that come under this category of disability are:
1. Hearing impairment;
2. Speech impairment due to Cerebral Palsy or Mental Retardation;
3. Cleft lip or Cleft palate;
4. Hard of hearing;

C. Mental disabilities/impairments:
The term mental Disability refers to a wide range of conditions which are related to brain or mind as a result of brain damage, brain infections, arrested or incomplete development of brain, mental disorders, chemical imbalance of neurons and other disturbances to mind or brain and cause disturbances in thinking, feeling, relating, motor, cognitive, memory, orientation, behaviour and other bodily or mental functions. [Robert Levi-1978]

Other conditions associated with mental disability are as follows:
1. **Mental Retardation:** It refers to significantly sub-average general intellectual functioning, resulting in or associated with concurrent impairment in adaptive behaviour manifested during the developmental period [Grossman-1983] or "Mental Retardation" means a condition of arrested or incomplete development of mind of a person which is specially characterised by sub-normality of intelligence. [Persons With Disabilities act [PDA]-1995]
2. **Mental Illness:** A mental disorder is an illness with psychological or behavioural manifestations associated with impaired functioning due to biological, social, psychological, genetic, physical or chemical disturbance. It is measured in terms of deviation from some normative concept. Each illness has characteristic signs and symptoms. [DSM-IV-Harold I Kaplan, Benjanub J Sadlock-1996]. More than two hundred mental illnesses have been classified into psychiatric, neurotic, functional and organic illness.
3. **Autism:** Autism means a condition of uneven skill development primarily affecting the communication and social abilities of a person, marked by repetitive and ritualistic behaviour. [National Trust Act [NTA]-1999].
4. **Learning disability (LD):** A group of neurological conditions (e.g. dyslexia, dysgraphia, dyscalculia) which affect a person's ability to receive, interpret, and use information. A person with a learning disability may have normal intelligence; however, there is a significant discrepancy in intelligence levels and his/her ability to learn and perform certain tasks. Individualised instruction assists the person in improving his/her learning and performance abilities. A learning disability is life long. [North Carolina General Statute 122C-3 12a]
5. **Attention deficit disorder (ADD):** A condition characterised by difficulty in paying attention, being easily distracted, and the inability to focus more than a few moments on mental tasks. People with attention deficit disorder may also be physically active and behave impulsively. [North Carolina General Statute 122C-3 12a]
6. **Attention deficit hyperactivity disorder (ADHD):** A condition characterised by
   1) difficulty in focusing one's attention and effort on tasks;
   2) difficulties in impulse control on delay of gratification; and
   3) increased activity unrelated to the current task or situation.
Most people with ADHD alone are not eligible for developmental disability services. [North Carolina General Statute 122C-3 12a]

D. Locomotor disabilities/impairment: Locomotor disability means a person’s inability to execute distinctive activities associated with moving, both himself and objects from place to place, and such inability being caused by affliction of either bones, joints, muscles or nerves. [RCIA-1992]

Various conditions, which come under locomotor disability, are as follows:

1. **Post Polio residual paralysis** [PPRP]: [A condition which results due to Poliomyelitis and causes weakness of muscle].
2. **Cerebral Palsy** [CP]: [Condition related to body positioning and movements]. "Cerebral Palsy" means a group of non-progressive conditions of a person characterised by abnormal motor control of posture resulting from brain injuries occurring in the pre-natal, peri natal or infant period of development [PDA-1995]
3. **Muscular Dystrophy** [MD]: A group of progressive conditions resulting in weakness of muscles and affecting the nerves. [PDA-1995]
4. **Spinal cord injury**: [Partial or total lesion to spinal cord by accident or trauma resulting in weakness of muscles and lack of control over bladder and bowel].
5. **Stroke**: [Rapidly developed clinical sign of a focal disturbance of cerebral function presumed to be of vascular origin and of more than 24 hour’s duration].
6. **Amputations**: [Amputation refers to removing the limb or part of the limb by surgery].
7. **Multiple Sclerosis** [MS]: An unpredictable, potentially disabling disease of the central nervous system caused by hardening of patches in the brain and spinal cord. Onset usually occurs between age 20 and 40, resulting in difficulties in walking, talking, sensing, seeing, and grasping. [North Carolina General Statute 122C-3 12a]
8. **Arthritis**: [Arthritis is the inflammatory condition of the joints, characterised by pain and swelling].
9. **Arthrogryposis or Multiple contractures**: [A condition resulting at birth. Curved, stiff joints and weak muscles, child looks like a wooden puppet].
10. **Neuromuscular disorders**
11. **Leprosy cured deformity**
12. **Brittle bone disease**
13. **Dwarfism or Gigantism**
14. **Congenital Disability**: A disability present at birth. (Club feet, bow legs, knock-knees, spina bifida, absence or malformation of limbs). [North Carolina General Statute 122C-3 12a]
15. **Spina bifida**: A condition, occurring during foetal development and characterised by incomplete enclosure of the spinal cord by the backbone which often limits motor activity to varying degrees. [North Carolina General Statute 122C-3 12a]

E. Multiple disabilities/impairments: Multiple disability means occurrence of more than one kind or a combination of two or more disabilities e.g. visual disability with locomotor disability or locomotor disability with mental disability or communication disability with locomotor disability etc.

The common conditions seen with multiple disabilities/impairments are as follows:

1. **Developmental disability** (DD): Developmental Disability refers to a severe, chronic disability of a person which is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the person attains age 22, unless the disability is caused by traumatic head injury and is manifested after
age 22; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: (a) self-care, (b) receptive (understanding) and expressive language, (c) learning, (d) mobility (ability to move), (e) self-direction (motivation), (f) the capacity for independent living, (g) economic self-sufficiency; reflects the person's need for a combination or sequence of special interdisciplinary services which are of a lifelong or extended duration and are individually planned and coordinated; or when applied to children from birth through four years of age, may be evidenced as a developmental delay. [North Carolina General Statute 122C-3 (12a)].

2. Cerebral palsy: CP associated with hearing or speech or vision or mental retardation can also be called as multiple disability.

Re-classification of disabilities is a difficult task, bringing different conditions under five broader categories may not include all conditions since the list is not exhaustive. There is scope for addition to this list in order to make it exhaustive. Depending on the magnitude, degree or severity, each disability can be further re-classified into four categories. They are as follows:

A. Mild: Magnitude or degree of disability ranges from 40 to 60% whose rehabilitation requirements are very minimal. They can manage mostly without assistive devises. According to WHO's review report on World programme of Action [WPA] concerning Persons With Disabilities of 1981, this group requires none or minimal specialised services and this little support helps them to mainstream into communities. They constitute 70% of the total disability population. There is a tendency to ignore this group with a notion that all Persons With Disabilities require specialised services and disability is a technical issue.

B. Moderate: Degree or severity of disability ranges from 60 to 80% and this group needs rehabilitation to a greater extent. They have to use aids and appliances to improve their mobility, communication and vision.

C. Severe: Degree of disability is ranging from 80% to 90% whose rehabilitation needs are so pressing that they have to use aids and appliances, specialised services, therapeutic interventions and other technical services to improve communication, mobility and vision.

D. Profound: Degree of disability is 90% and above. They need constant care and will have dependency to a larger extent. They constitute a small proportion of the disability population.

1. REDEFINING DISABILITY
1.3. CAUSATIVE FACTORS:

Disability is a result of complex phenomenon that occurs during the interrelated interactions between people and a combination of factors in a given society. The causative factors of disability are complex and more complicated since both direct and indirect factors are responsible for causing disability or impairment, thus making estimation of the causes for disability a difficult task. A wide range of factors are responsible for causing disability, some directly while others indirectly. Some factors are still unknown despite the advancements in medical sciences. Intensive study is being carried out to identify as many causes of disability as possible. It is difficult to make an exhaustive list of all the known causes which can cause impairment. A wide range of factors are associated with different conditions of disability. Thus it makes it a tough job to enlist and review the causative factors. This research makes an attempt to draw attention of the society to the common factors that can cause disability directly or indirectly. This list of causes is not exhaustive; there is scope for addition.

The known factors that cause disability can be broadly re-classified into four categories which are:

a. Pre natal factors
b. Natal and peri natal or Neonatal factors
c. Post natal factors
d. General Factors

There is a common understanding that bio-medical factors are majorly responsible for causing disability, which is not true. The structural factors such as acute poverty and socio-cultural factors play major role in causing disabilities in developing countries. The common factors which cause disability or impairment can also be re-grouped into the following:

A. Biological,
B. Physical/environmental,
C. Economic,
D. Religious and cultural,
E. Medical and
F. Political factors.

This section makes an attempt to re-examine and analyse the various factors that cause impairment. This research attempts to analyse and re-assess various dimensions of causative factors of impairments which are as follows:

A. Prenatal factors: The period before or after gestation; the period from conception to delivery or the period before the actual birth takes place is normally called as pre-natal or ante-natal period.

Various factors that could cause disability before the birth of the child or during the developmental period of the womb of the mother are listed below:

1. Heredity
2. Malnutrition: A malnourished woman is one who cannot feed herself and the growing child in the womb. This malnourishment may result in some kind of disability in the child.
3. Consanguinity: Marriages among blood or close relations may result in developing some kind of defects that may cause disability.
4. Rh incompatibility: If one of the partners has a positive blood group and the other has negative and the child gets the group that does not match the mother’s blood
group, it results in production of antibodies against the child, which may lead to
disability.

5. **Non-infectious diseases:** Serious illness like Jaundice, blood pressure, epilepsy and
other chronic illnesses during pregnancy can cause disability.

6. **Infectious diseases:** like Rubella, Tuberculosis, Leprosy, Typhoid and Sexually
Transmitted Diseases [STD] during pregnancy may lead to certain disabilities.

7. **Consumption** of drugs, Alcohol and smoking during pregnancy

8. **Exposure to radiation** during pregnancy and consumption of drugs without
prescription

9. **Frequent unsuccessful abortions**

10. **Marriage Age:** Early Marriage [before 18 years] and giving birth to the first child after
35 years may cause birth defects.

11. **Accidents:** Accidents, trauma, injury, burns, psychological stress and physical and
mental abuse of pregnant women may lead to disability.

12. **Genetic disorders:** Chromosomal and other genetic disorders can cause disability.

**B. Natal or peri-natal or neo-natal factors:** Period from the time of actual birth to three
weeks is termed as natal or prenatal or neonatal period. Factors that affect during child
birth are mentioned below:

1. **Premature birth:** The average gestation period of human beings is 282 days. If the
delivery takes place much before actual gestation period is over the child is prone to
be at a high risk. In the same way post matured delivery also affects the child.

2. **Low birth weight:** If the weight of the newborn baby is less than 2.5 kg.

3. **Prolonged labor:** Delivery after 30 hours of beginning of labor pain.

4. **Induced labor**

5. **Absence of birth cry:** If child does not cry immediately after birth, i.e. a maximum of 2
minutes after birth. The birth cry of a baby enables supply of oxygen to the brain.
Absence or delay in crying results in lack of oxygen to the brain which leads to brain
damage.

6. **Absence of bilateral movements**

7. **Colour of the baby:** If the colour is bluish or yellowish, which is an indication of infection
or existence of risk factors

8. **Abnormal presentation**

9. **Forceps delivery**

10. **Accidents during delivery**

11. **Infections e.g.** Jaundice and other illness

12. **Delivery by an untrained person**

**C. Post natal factors:** Three weeks after actual birth to a lifetime is termed as postnatal. The
factors which can affect after birth are mentioned below;

1. **Malnutrition:** Deficiency of vitamins, proteins and micronutrients cause some ailments.
Iodine, vitamins, minerals and salts deficiency can lead to certain illness, which may
result in certain disabilities.

2. **Accidents:** Road accidents, accidents while playing with sharp objects, at work place,
fire accidents, injury, trauma, snake bite and burns can cause disabilities.

3. **Serious illnesses:** like encephalitis, meningitis, Glaucoma, Gangrene, Cancer, Heart
disease, may also lead to disabilities.

4. **Infectious diseases:** like TB, Leprosy, whooping cough, measles, chicken pox can
cause disabilities.

5. **Alcoholism and Drug abuse**

1. **REDEFINING DISABILITY**
6. Functional Psychiatric disturbances
7. Mental torture and violence
8. Ageing process

D. General factors: A wide range of general factors that can cause disabilities or impairments are listed below:
1. Poverty is a major cause that can contribute to disability in different ways; [Poor are most likely to become disabled and disabled are most likely to be poor]
2. Poor personal and community hygiene
3. Poor health care facilities
4. Poor communication and transportation systems
5. Ignorance, evil customs and superstitious beliefs
6. Inappropriate, delayed or lack of medical interventions
7. Fluorosis
8. Lathyrism
9. Use of insecticides, pesticides and poisonous drugs
10. Environmental pollution like water, air, sound and soil
11. Wars, conflicts, emergencies, riots, ethnic and other violence
12. Natural calamities like flood, earthquake, cyclone, volcanoes and famine
13. Lack of political will
14. Lack of access to basic information, awareness and health education
15. Lack of basic infrastructure and facilities
16. Globalisation, liberalisation, privatization and structural adjustment programmes of the state
17. Human made disasters such as; riots, landmines, explosives, terrorist activities and conflicts.
These general factors have major influence on causing disability than direct factors that contribute to cause disability or worsen the situation of Persons With Disabilities.
1.4. PREVENTION

Various studies undertaken by different agencies and pioneers in the field of disability, medical science, rehabilitation and development reveal that the majority of disabilities can be prevented by taking preventive measures in different ways. Prevention of disabilities can be classified into three categories:

a. **Primary prevention** refers to avoidance of the occurrence of impairment by tackling the basic causes.

b. **Secondary prevention** refers to methods for limitation or reversing disability caused by impairments by treatment, surgery etc.

c. **Tertiary prevention** refers to measures to stop impairment from developing into disability and handicap by taking care of the environmental and external factors.

Some of the important and common preventive measures are listed below:

1. **Nutrition:** Providing nutritious food to pregnant women by using locally available and low cost food materials can prevent malnourishment. Effective use of Vitamin A tablets, iron tablets, iodized salt can prevent various conditions, which lead to disability. Creating awareness about the importance of breast feeding and the use of nutritious diet using locally available low cost food grains, vegetables, fruits and other materials prevents malnutrition of the child.

2. **Mother and child health care [MCH]:** Improving health care of pregnant women through regular medical examinations and awareness programmes, providing health education on mother and child care can prevent many conditions that lead to disability.

3. **Immunisation:** Immunisation programme for pregnant women and children against serious illness should be intensified and made effective so that all can make use of this programme.

4. **Healthcare system:** The rural community’s health care conditions should be improved by providing necessary training, drugs and equipments to Primary Healthcare providers [PHCs]. Vacancies of PHC staff can be filled and intensive visits to villages can be made.

5. Avoid frequent abortions especially by unqualified people.

6. Access to safe drinking water and sanitation for people in rural areas is very important, which plays an important role in the rural health system.

7. Personal and community hygiene should be improved through health education programmes.

8. The PHC staff should provide extensive and effective training to traditional birth attenders.

9. Consanguineous marriages should be avoided through awareness programme and the blood groups of couples should be examined.

10. Effective treatment for illness should be made available in PHCs and general hospitals at the block levels.

11. Environmental pollution should be prevented and measures for protection of the environment should be taken up.

12. Accidents on roads, workplace, at home and at play should be prevented by following various preventive measures like improving conditions of roads, restrictions on rash driving and drunken driving, use of guards and protective materials at factories and careful monitoring of children at play.

13. Poverty is a major cause, which contributes in many ways to disability. Effective implementation of poverty alleviation programmes by both union and state
Governments will help in improving the economic condition of poor people, which will further help preventing disabilities that are linked with poverty.

14. Activating the mass media communication to make concerted efforts to raise the level of awareness on health, disability and rehabilitation programmes. Production and transmission of Television programmes by the Government and voluntary agencies should be intensified and in turn expanded to all needy people.

15. Use of pesticides, insecticides, chemicals and poisonous elements should be avoided and extra attention should be paid during their use.

16. Education about health, nutrition and hygiene is a solution for a majority of problems. This can be provided to children by including it in the regular curriculum. Teachers and health staff have to play a major role to raise awareness among masses in this regard who are usually more or less apathetic about this. Mass media must play a vital role in raising the level of awareness of masses through education programmes rather than concentrating only on commercial programmes.

17. Promoting communal harmony and peace between communities, groups, sections, religions, castes, regions, linguistic people, countries and nations in order to secure peace and justice among people at large.

18. Effective implementation of a wide range of disability prevention programmes of the state and focus on preventive health care services.

19. Improving the basic infrastructure such as; roads, transport system, health care system, communication, sanitation, housing and community toilets.

“Prevention is better than cure” is an appropriate saying and if we don’t take measures towards prevention; rehabilitation will be a difficult task.

1. REDEFINING DISABILITY
1.5. EARLY DETECTION

Early identification is very important in order to provide effective and successful rehabilitation. It often helps to prevent certain impairments. If a certain illness is identified at a very early stage effective treatment can help to prevent leading to an impairment or disability. Secondary deformities or complications can also be prevented which helps in reducing the magnitude of disability and successful rehabilitation. If illness and impairment are not identified they may lead to secondary complications, which results in severe handicap. Following tips can be helpful in the process of early identification.

1. **Pre-post maturity:** If the delivery takes place much before or after the normal gestation period that is 282 days.
2. **Prolonged labour:** If the birth takes place much after labour pain has started.
3. **Birth cry:** If birth cry is delayed or absent. Normally the newborn baby has to cry immediately after birth that is within 2-3 minutes.
4. **Birth colour:** If the colour of newborn baby is bluish or yellowish.
5. **Birth weight:** If the weight of the newborn baby is much less than 2.5 Kgs.
6. Absence or delay or abnormality in reflexes
7. Abnormality in sucking breast milk
8. **Visual test through light and colourful objects:** If a 3 month old baby shows poor response or no response at all.
9. **Auditory test through different sounds:** If a 3 month old baby has a poor response or no response at all to sounds.
10. Abnormal Bilateral movements
11. **Abnormality in physical appearance:** If a newborn baby has red-watery eyes, absence of fingers, malformation of limbs and other organs.
12. **Infections:** If newborn baby has infections like jaundice, encephalitis and meningitis.
13. If a child gets Fits
14. **Muscle tone:** If child has light/floppy or hard muscles.
15. **Developmental milestones:** Observation of developmental milestone with regard to movements, language, social cognitive and other aspects are important in the early detection process of impairment. If development is slow or not normal then one can be alerted and immediately take the baby to the concerned specialist. The following table gives a picture about developmental milestones with regard to various aspects.

---

1. REDEFINING DISABILITY
Table 1.1. Developmental milestones of human beings:

<table>
<thead>
<tr>
<th>Age in months</th>
<th>Motor</th>
<th>Language &amp; speech</th>
<th>Cognitive</th>
<th>Social</th>
<th>Vision</th>
<th>Hearing</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3</td>
<td>neck control</td>
<td>vocalises sounds</td>
<td>Looks at face, distinguishes mother from others</td>
<td>coos, laughs, smiles back</td>
<td>associate head &amp; eye movements</td>
<td>sounds have very little meaning, response are mainly reflexive</td>
</tr>
<tr>
<td>3-6</td>
<td>roles, creeps, sits with support.</td>
<td>vocalises for pleasure/babbles</td>
<td>Social contact, social smile</td>
<td>understands meaning of no</td>
<td>follows objects, uses binocular vision</td>
<td>sensitive to different intonations</td>
</tr>
<tr>
<td>6-9</td>
<td>sits without support, crawls, stands with support</td>
<td>initiate speech sounds</td>
<td>Shows curiosity, rushes from unknown, plays social games</td>
<td>draws attention by vocalising sounds</td>
<td>appreciation of depth and distance</td>
<td>Listens attentively</td>
</tr>
<tr>
<td>9-12</td>
<td>Stands independently, walks holding moving objects (bear walking)</td>
<td>utters 3 words</td>
<td>Expresses anger, anxiety, sadness, pleasure and other emotions. Plays simple ball game.</td>
<td>follows simple instruction</td>
<td>perceives objects as being of constant shape &amp; size</td>
<td>Turns around towards sounds</td>
</tr>
<tr>
<td>12-18</td>
<td>Walks without support, runs well, starting and stopping with good control, throws ball.</td>
<td>few intelligible words.</td>
<td>Expresses wants/needs by pointing</td>
<td>plays with other children</td>
<td>Uses 20 recognizable words</td>
<td></td>
</tr>
<tr>
<td>18-24</td>
<td>Runs with good co-ordination, walks on stairs with railing, and jumps small heights.</td>
<td>tells body parts, phases of 2 to 3 words, vocabulary of 10 words</td>
<td>Shows body parts, points out objects in pictures</td>
<td>goes about home and yard</td>
<td>Joins rhymes</td>
<td></td>
</tr>
<tr>
<td>24-36</td>
<td>rides tricycle by using pedals</td>
<td>speaks simple sentences, vocabulary of 40-80 words, speaks complex sentences</td>
<td>Questions, names common objects, relates experiences</td>
<td>initiates own play activities, relates experiences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36-48</td>
<td>hops on one foot</td>
<td>talks to others, relates events of daily life, tells use of objects</td>
<td>Tells its name, tells the names of familiar objects, repeats two digit numbers, repeats six to seven syllables</td>
<td>plays cooperatively at kindergarten level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>48-60</td>
<td>Jumps forward, skips alternating feet.</td>
<td>defines words, tells simple story</td>
<td>Repeats 3 digit numbers, repeats 12-20 syllables, copy a square</td>
<td>cares for itself, goes to neighbourhood unattended, plays competitive games</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


1. REDEFINING DISABILITY
These tips will help in identifying the risk factors. If a child has one of these symptoms it does not mean that the child has impairment. It is important to refer the child to concerned professional for further investigation. Health education helps the mother to identify risk at very early stage which results in prevention of impairments and make rehabilitation process effective and successful. Teachers, Anganwadi workers, health workers and social workers have to play a vital role in this regard. Education about childcare and developmental milestones for adolescent girls through educational institutions and voluntary organisations can be provided. An attempt has been made here to understand, redefine, review, revisit and reclassify the concept and term disability and associated factors in brief. The magnitude of disability is very vast but the fact of the matter is that 90% of the total disabled population is deprived of any kind of rehabilitation facilities. It is important that the concept of disability is understood by each and everyone with all of its dimensions, angles, spheres, factors and sectors with a right perspective and attitude to liberate people with disability from darkness and other barriers.

Conclusion:
It is a tough task to re-define the concept of disability since it is contextual, social, psychological and culturally determined. This research examines a wide range of definitions suggested by various agencies and attempts to understand the basis and principles on which this term has been defined. What so ever the basis and principles on which this concept was defined may be, but a large number of states have left out a wide range of categories from the purview of disabilities, such as autism, learning disability, chronic diseases and other serious impairments which are understood by Persons With Disabilities themselves, family members and the community. The reasons for omitting a wide range of disabilities from the definition of disability may be due to a serious resource crunch, lack of political will, narrow understanding of disability, ignorance of social and environmental dimension of disability and focus on medically determined definitions. The core legislations of India concerning Persons With Disability recognise only seven categories of disabilities. They ignore genuine disabilities such as autism, learning disabilities, chronic diseases and other serious ailments which lead to socio economic disadvantages and denial of rights and opportunities. It is evident from the research that disability is contextual, cultural, social, psychological and subjective. Disability may be temporary, permanent, episodic or perceived. It is very important to consider all these factors while defining the concept of disability. The working definition adopted in this research is largely based on these factors and derived from the "Bangkok draft of UN convention on the rights of Persons With Disabilities 2004" which is as follows: "Disability is the loss or limitation of opportunities to take part in the life of the community on an equal level with others due to physical, social, attitudinal and cultural barriers encountered by persons having physical, sensory, psychological, developmental, learning, neurological or other impairments (including the presence in the body of an organism or agent causing malfunction or disease), which may be permanent, temporary, episodic or transitory in nature".

General perception vis-à-vis the ground realities: The group discussions, case studies and schedule administered in the field work clearly points out that the concept of disability has got social, political, cultural, economic, religious, environmental, medical and legal dimensions. Communities urge the state to include people with chronic diseases, age related impairments and temporary impairments due to accidents in order to extend social security schemes and concessions of the state. It is evident that any kind of long term impairment leading to socio economic disadvantages, denial of rights and limited opportunities to play an

1. REDEFINING DISABILITY
equal role at par with their fellow citizens in their respective communities is termed as
disability by the society.

They also include; persons with one eye, ear, absence of fingers, fracture, asthma, cancer,
age related impairments, cataract, epilepsy, learning disability, autism, depression and other
chronic diseases along with other five groups of disabilities/impairments which have been
discussed earlier. Majority of the respondents with and without disabilities strongly feel that
disability is the outcome of the interaction between a person with impairment and society
which include both natural and human made environment. Disability is purely a societal
phenomenon not an individual pathology. The concept of disability has various dimensions
such as body functioning including anatomy and physiology of an individual, societal
attitudes, institutional, environmental and other social barriers which hinder a person to
discharge his/her daily routine activities.

It is a difficult task to re-classify disabilities into various categories. Few disability activists
strongly feel that disabilities should not be categorised as it leads to fragmentation of
disability sector and weakening of the disability movement and bargaining power. Where as
the moderate disability sector thinkers feel that it is essential to classify disabilities in order to
plan appropriate programmes with a caution that categorization should limit only to the
programmes and during clinical assessments not for identity.

General perception vis-à-vis the research universe: What so ever the argument but the
communities and Persons With Disabilities strongly feel that classification should limit only to
programmes. 71% respondents with disabilities, their families and 56% of communities
strongly feel that classification of disability is certainly required for the state and development
agencies at the national, state, district and block level for planning interventions. But it is not
so important at village level since family and community are concerned only about key issues
of disability rather than classification and specific issues of each category. The direct and
indirect cost involved in disability affect not only the individual but also the family in many
ways thus the majority of the respondents with and without disabilities strongly feel that the
population which is affected by disability constitute more than 25% of our total population
which needs to be given due attention by the state and other domains of the society.

Impairment or disability is the result of a combination of factors and complex phenomenon.
Apart from biomedical factors, a wide range of socio, economic, political, cultural,
environmental factors are also responsible for causing disabilities. The structural factors such
as poverty, poor governance, and lack of basic infrastructure, ignorance, negligence, cultural
and other factors play major role in causing disabilities in developing countries. The fact of
the matter is that the effects of globalisation on developing countries, privatisation and
liberalisation policies also contribute significantly to causative factors of disabilities in third
world countries. Taking the various factors into account the major factors that are directly or
indirectly responsible for causing an impairment or disability can be grouped into biological,
medical, physical or environmental, economic, social, cultural and political. There is also an
increased level of awareness among disability sector particularly among Persons With
Disabilities at global level about the structural factors such as poverty, wars, human made
disasters and other related issues of system and governance.

The global scenario vis-à-vis the ground realities: The focused group discussions and
schedule administered for the research reveal that 63% of Persons With Disabilities are
victims of these structural factors. The research findings clearly show that 27% are affected
by polio, 19% due to malnutrition, 11% by accidents, 13% due to negligence and 21% are because of ignorance, lack of treatment and superstitions; which is mainly due to acute poverty, poor governance and apathy of the state. There is a great need to improve governance, infrastructure, and health care facilities and eradicate poverty to prevent preventable disabilities. The CBR programme implemented by a NGO impacted on Persons With Disabilities and communities to a large extent with regard to generating awareness on these causative factors. 96% of Persons With Disabilities and families are aware of common causes of disabilities and causes for their own disabilities. 100% of the communities strongly feel that they have enough knowledge on common factors of disabilities. 99% of Persons With Disabilities, families and 83% communities strongly feel that poverty had a greater impact on the lives of Persons With Disabilities and families.

Disabilities can be prevented to a large extent. Reducing the incidents of disabilities may help in focusing on existing Persons With Disabilities effectively. A group of disability activists particularly Persons With Disabilities strongly feel that prevention of disabilities is nothing but bringing to an end the growing strength of disability sector and identity. Where as the moderate school feels that it is very important to prevent preventable disabilities since there is a great need to focus on improving the quality of life of Persons With Disabilities in terms of equal opportunities, promotion and protection of human rights and facilitate the process of effective and meaningful inclusion. There is an increasing protest and outward rejection of the provision of Medical termination of pregnancy act of 1972 in India, which permits the parents to abort the foetus with disability legally. However the UN programme of action concerning Persons With Disabilities focuses on three key issues of disability sector namely prevention, rehabilitation and integration.

Global trends vis-à-vis the ground trends: The field work brings out the fact that 91% of disabilities were due to acute poverty, ignorance, lack of health care facilities, appropriate and timely treatment, malnutrition, negligence and other preventable factors which can be prevented without much difficulty. The awareness on causes and prevention of disability is very low among communities. 98% of community members, Persons With Disabilities and family members are aware of causative and preventive factors but 2% are still unaware. If this is the situation in a community where a CBR programme was implemented for ten years then how pathetic will the situation be in other communities where there have been no interventions at all? There is a great need to generate awareness among communities especially in schools. Mass media communications will have to play a very important role in generating awareness to prevent preventable disabilities. The health care system has a very important role in preventing preventable disabilities. Apart from media and health care system the education especially preschools or Anganvadis have a greater role in early detection which will help in prevention and effective rehabilitation process. 91% of respondents with and without disabilities strongly feel that effective implementation of all the poverty alleviation programmes of the state, good governance, effective implementation of preventive health care schemes of the state will be more effective in preventing preventable disabilities. Improving basic infrastructure in rural areas will be more helpful in prevention of childhood and other disabilities.

The ground realities clearly shows that the 57% respondents with and without disabilities strongly feel that in majority of the instances detection was late which lead to secondary complications which could have been prevented if the detection was early and timely. This fact further stresses the need for generating awareness and equipping the community and service providers with appropriate knowledge and skills for early detection of disabilities.

1. REDEFINING DISABILITY
78% of the respondents with and without disabilities strongly feel that there is a greater need to establish effective coordination, linkages and networking with health care system, ICDS, education, rural development, Panchayat Raj institutions and concerned departments and ministries of the state, voluntary sector [NGOs], private players and civil society in general in order to improve early detection process and enable effective and timely prevention of disabilities.

Source: