Unit 1: Understanding Disability

1.1 Historical perspectives of Disability - National and International & Models of Disability;

1.2 Concept, Meaning and Definition - Handicap, Impairment, Disability, activity limitation, habilitation and Rehabilitation;

1.3 Definition, categories (Benchmark Disabilities) & the legal provisions for PWDs in India;

1.4 An overview of Causes, Prevention, prevalence & demographic profile of disability: National and Global;

1.5 Concept, meaning and importance of Cross Disability Approach and interventions;

1.1 Historical perspectives of Disability - National and International & Models of Disability

Disability is not a new concept and not something that has emerged as a result of increasing numbers of people affected. Rather, disability is an ancient concept that has existed for as long as people have existed. Although disability has not changed, our views of the meaning of disability have changed over time-for the better.

Early Views of Disability

In the medieval era, disability was considered a punishment from God for one's sin or misbehavior or that of one's ancestors. Others over the centuries have viewed disability as the work of the devil. Disability was seen as a failure, deformity or defect of the individual. As a result of the myths about disability, people with disabilities were feared and often stigmatized, shunned, abused, or condemned. People with visible disabilities were even used for entertainment (e.g., court jesters or

oddities in circuses and freak shows). Children and adults with severe disability were kept at home, isolated and hidden from public view. They were often denied what others received, including education, care, employment, and a place in the family or in society. Disability was viewed as inability and those with disabilities were often viewed as a burden to their families and to society as a whole.

People with disabilities have been considered sick or unhealthy. Being healthy and having a disability have been perceived as a contradiction in terms. Disability was seen as an issue blamed on the individual with a disability. Quality of life of individuals with disability was often seen---and still is by some---to be poor by others who have very negative views about disability, even though only an individual can determine the quality of life of his or her own life.

Changing Views about Disability

By the 1800s disability began to be viewed as an issue that had individual health and public health implications, as well as social and policy implications. Disability was seen as a medical problem due to disease, trauma, or other health conditions. This generally led to the medical model of disability, which viewed disability as an issue of the person with a disability. The goal of medical management was cure of the disabling condition or modification of behaviors of the individual with a disability. The medical model viewed physicians as the experts who knew what was best for those with disabilities. Those with disabilities were not seen as capable of knowing what they needed in the way of health care and other services.

More recently, disability has been viewed as a result of environmental and societal factors that serve as barriers to the ability of persons with disabilities to participate fully in their communities or families or to obtain the care and services they need. Individuals with disability, their families, and advocacy groups have viewed disability as a consequence of an inaccessible environment and rejected the medical model in favor of other models, such as the social and biopsychosocial models of disability that address barriers to health care from different perspectives.

Events/Subjects (A)	*Themes/Concepts/Ideas (B)*	*Project/Intent (C)*
Hindu/Buddhist/ Islamic traditions — miracles, blessings, curses	Charitable treatment of deformed persons as part of religious practice.	To describe and explain social attitudes to disablement and disabled persons in present times.
	Deformity as result of past actions — *karma* (Miles 2001) (**blessing** or **curse**?) **Reverence** of persons with deformities/**Pity** shown to persons with deformities.	To understand theological contexts and the emergence of concepts of charity, institutionalisation/ segregation and social stigma.

Ancient and medieval culture and traditions	Social ostracism in the face of religious exclusion of disabled persons. Medical texts such as *Caraka Samhita* — disease as result of wrong actions in the past (Bhatt 1963). *Caraka Samhita* as instance of medical knowledge; evidence of moral model of Hindu practices; prescription of social behaviour? Manu's laws: **Legal precepts**? **Religious prescriptions**? King Ashoka's methods of vocational rehabilitation: Instance of royal administrative governance method? Instance of religious (Buddhist) influence on governance. Aurangzeb's need to hide his weak knee.	To explain current reactions to disability in India as a curse or as a shameful feature and study the history of this negative perception to one's disability being the result of individual fault.
Colonial intervention in the form of schools, hospitals and institutions	Beginning of formal care and rehabilitation of disabled people. Disruption of the old order of familial care; implementation of segregation of sick and ill persons; methods of modern medicine isolate the person with disease/ disability from community-based care (Arnold 1993; Bhatt 1963; Miles 1995).	India treated its disabled people as faulty and punished or cursed. Colonial modernity reinstated maligned people to charity, care and rehabilitation. Present attitudes as a result of traditional fatalistic attitude and superstitious mindset of Indians. India had a glorious past when disabled people were treated with respect; this was disrupted by British rule.

The Models of Disability

Models of Disability are tools for defining impairment and, ultimately, for providing a basis upon which government and society can devise strategies for meeting the needs of disabled people. They are often treated with scepticism as it is thought they do not reflect a real world, are often incomplete and encourage narrow thinking, and seldom offer detailed guidance for action. However, they are a useful framework in which to gain an understanding of disability issues, and also of the perspective held by those creating and applying the models.

For Models of Disability are essentially devised by people about other people. They provide an insight into the attitudes, conceptions and prejudices of the former and how they impact on the

latter. From this, Models reveal the ways in which our society provides or limits access to work, goods, services, economic influence and political power for people with disabilities.

Models are influenced by two fundamental philosophies. The first sees disabled people as dependent upon society. This can result in paternalism, segregation and discrimination. The second perceives disabled people as customers of what society has to offer. This leads to choice, empowerment, equality of human rights, and integration. As we examine the different Models in this and subsequent articles, we will see the degree to which each philosophy has been applied.

We should not see the Models as a series of exclusive options with one superior to or replacing previous sets. Their development and popularity provides us with a continuum on changing social attitudes to disability and where they are at a given time. Models change as society changes. Given this degree of understanding, our future objective should be to develop and operate a cluster of models, which will empower people with disabilities, giving them full and equal rights alongside their fellow citizens.

Biomedical Model of Health

The biomedical model of health is the most dominant in the western world and focuses on health purely in terms of biological factors. Contained within the biomedical model of health is a medical model of disability. In a similar vein, this focuses on disability purely in terms of the impairment that it gives the individual.

Medical Model of Disability

The medical model of disability is presented as viewing disability as a problem of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care provided in the form of individual treatment by professionals.

- In the medical model, management of the disability is aimed at a "cure," or the individual's adjustment and behavioral change that would lead to an "almost-cure" or effective cure.
- In the medical model, medical care is viewed as the main issue, and at the political level, the principal response is that of modifying or reforming health-care policy.

What it looks like: People in your community perceive you as “sick” because of your disability. Most services are focused on curing your disability or making you appear non-disabled, instead of making the environment more accessible. For example, wheelchairs may be provided, but the streets are not accessible.

Identity Model

Disability as an identity model is closely related to the social model of disability - yet with a fundamental difference in emphasis - is the identity model (or affirmation model) of disability.

This model shares the social model's understanding that the experience of disability is socially constructed, but differs to the extent that it 'claims disability as a positive identity'

Social Model of Disability

The social model of disability sees the issue of "disability" as a socially created problem and a matter of the full integration of individuals into society.

In this model, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment. Hence, the management of the problem requires social action and is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life.

The issue is both cultural and ideological, requiring individual, community, and large-scale social change. From this perspective, equal access for someone with an impairment/disability is a human rights issue of major concern.

Minority Model of Disability

The minority model of disability, also known as sociopolitical model of disability, adds to the social model, the idea that disability is imposed on top of impairment via negative attitudes and social barriers, in suggesting that people with disabilities constitute a entitative, (relating to or possessing material existence), social category that shares in common the experience of disability.

The minority model normalizes the experience of disability as a minority experience no more or less aberrant or deviant than other minority groups' experiences (sex, race, sexual orientation, etc.). Essentially, this is the assertion that people with disabilities are, in part, disabled not by what's going on with our bodies per se, but by the manner in which the able-bodied majority of society views us and either molds or does not mold itself to allow us to fit.

Expert or Professional Model of Disability

The expert or professional model of disability has provided a traditional response to disability issues and can be seen as an offshoot of the medical model.

Within its framework, professionals follow a process of identifying the impairment and its limitations (using the medical model), and taking the necessary action to improve the position of the disabled person. This has tended to produce a system in which an authoritarian, over-active service provider prescribes and acts for a passive client.

This relationship has been described as that of fixer (the professional) and fixee (the client), and clearly contains an inequality that limits collaboration. Although a professional may be caring, the imposition of solutions can be less than benevolent. If the decisions are made by the "expert", the client has no choice and is unable to exercise the basic human right of freedom over his or her own actions. In the extreme, it undermines the client’s dignity by removing the ability to participate in the simplest, everyday decisions affecting his or her life. E.g. when underwear needs to be changed or how vegetables are to be cooked.

Tragedy and/or Charity Model of Disability

The tragedy and/or charity model of disability depicts disabled people as victims of circumstance who are deserving of pity.

This, along with the medical model, are the models most used by non-disabled people to define and explain disability.

What it looks like: People in your community assume you will always need help and pity you. You are considered a burden requiring charitable resources for support.

Moral Model of Disability

The moral model of disability refers to the attitude that people are morally responsible for their own disability. For example, the disability may be seen as a result of bad actions of parents if congenital, or as a result of practicing witchcraft if not.

This attitude may also be viewed as a religious fundamentalist offshoot of the original animal roots of human beings when humans killed any baby that could not survive on its own in the wild. Echoes of this can be seen in the doctrine of karma in Indian religions.

Legitimacy Model of Disability

The legitimacy model of disability views disability as a value-based determination about which explanations for the atypical are legitimate for membership in the disability category. This viewpoint allows for multiple explanations and models to be considered as purposive and viable.

Empowering Model of Disability

The empowering model of disability allows for the person with a disability and his/her family to decide the course of their treatment and what services they wish to benefit from. This, in turn, turns the professional into a service provider whose role is to offer guidance and carry out the client's decisions. In other words, this model "empowers" the individual to pursue his/her own goals.

Social Adapted Model of Disability

The social adapted model of disability states although a person's disability poses some limitations in an able-bodied society, oftentimes the surrounding society and environment are more limiting than the disability itself.

Economic Model of Disability

The economic model of disability defines disability by a person's inability to participate in work.

It also assesses the degree to which impairment affects an individual's productivity and the economic consequences for the individual, employer and the state. Such consequences include loss of earnings for and payment for assistance by the individual; lower profit margins for the employer; and state welfare payments. This model is directly related to the charity/tragedy model.

Diversity Model of Disability

Disability as Human Variation, an alternative model intended to focus attention on how society's systems respond to variation introduced by disability (Scotch and Shriner 1997). Under this model, accessibility in the built environment, for example, is not solely achieved by anti-discrimination regulation requiring a 'universal solution; the diversity of disability must be acknowledged (Scotch and Shriner 1997). Shriner and Scotch (2001) further question the socio-political definition of disability, in which (all) barriers faced by people with disability are (built-environment) imposed and therefore removable, feeling that this common underlying ideology of disability rights activists and independent living movements insufficiently recognizes that impairment does have a bearing on accessibility outcomes.

Seeking to overcome the false dichotomy of ability/disability, Bickenbach et al. (1999) pursue the concept of universalism, proposing: While the social model is now universally accepted, it is argued that universalism as a model for theory development, research and advocacy serves disabled persons more effectively than a civil rights or minority group approach.

Religious Model of Disability

The moral/religious model of disability is the oldest model of disability and is found in a number of religious traditions, including the Judeo-Christian tradition (Pardeck & Murphy 2012:xvii). The religious model of disability is a pre-modern paradigm that views disability as an act of a god, usually a punishment for some sin committed by the disabled individual or their family. In that sense, disability is punitive and tragic in nature.

This model frames disability as something to be ashamed of and insinuates that disabled people or their families are guilty of some unknown action that caused their impairment. But that mentality only serves to stigmatize disability, and the claim that praying heals disability is based on purely anecdotal evidence.

Sometimes the presence of "evil spirits" is used to explain differences in behaviour, especially in conditions such as schizophrenia. Acts of exorcism or sacrifice may be performed to expel or placate the negative influence, or recourse made to persecution or even death of the individual who is "different".

In some cases, the disability stigmatises a whole family, lowering their status or even leading to total social exclusion. Or it can be interpreted as an individual's inability to conform within a family structure. Conversely, it can be seen as necessary affliction to be suffered before some future spiritual reward.

It is an extreme model, which can exist in any society where deprivation is linked to ignorance, fear and prejudice.

Market Model of Disability

The market model of disability is a minority rights and consumerist model of disability that recognizing people with disabilities and their Stakeholders as representing a large group of consumers, employees and voters. This model looks to personal identity to define disability and empowers people to chart their own destiny in everyday life, with a particular focus on economic empowerment.

By this model, based on US Census data, there are 1.2 billion people in the world who consider themselves to have a disability. An additional two billion people are considered Stakeholders in disability (family/friends/employers), and when combined to the number of people without disabilities, represents 53% of the population. This model states that, due to the size of the demographic, companies and governments will serve the desires, pushed by demand as the message becomes prevalent in the cultural mainstream.

Human Rights Based Model of Disability

From the mid 1980's countries such as Australia enacted legislation which embraced rights-based discourse rather than custodial discourse and seeks to address the issues of social justice and discrimination. The legislations embraced the shift from disability being seen as an individual medical problem to it instead being about community membership and fair access to social activities such as employment, education and recreation.

The emphasis in the 1980's shifted from dependence to independence as people with disabilities sought to have a political voice. Disability activism also helped to develop and pass legislation and entitlements became available to many people. However, while the rights-based model of disability has helped to develop additional entitlements, it has not changed the way in which the idea of disability is constructed. The stigma of 'bad genes' or 'abnormality' still goes unchallenged and the idea of community is still elusive.

What it looks like: A person with a disability is able to attend a school, go to work, participate in community activities alongside non-disabled people, perhaps using disability-related accommodations or modifications that make the environment more accessible to them.

Relational Model of Disability

In the late 1960s Nirje, a Swedish social theorist, formulated the principles of normalization emphasizing strong support of de-institutionalization, recognition of the diversity of the human condition, and belief that people with disability and 'normal' (ordinary) life, including access to the built environment, are not mutually exclusive.

This work represents part of an emerging grand idea of social inclusion for people with disability in the community and within the neighborhood (Nirje [1969] 1994). Following on in this continuum of Nordic interest in people - environment interaction, a new disability model developed around the end of 1990s - early2000s, and has subsequently been recognized as the (Nordic) Relational Model of Disability (Goodley 2011)

Affirmation Model of Disability

The affirmation model of disability is essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life experience of being impaired and disabled. This view has arisen in direct opposition to the dominant personal tragedy model of disability and impairment, and builds on the liberatory imperative of the social model.

Rooting their idea in the values of Disability Pride and perspectives emerging from the disability arts movement, Swain and French identified the affirmation model as a critique of the personal tragedy model corresponding to the social model as a critique of the medical model.

Spectrum Model of Disability

The spectrum model of disability refers to the range of visibility, audibility and sensibility under which mankind functions. The model asserts that disability does not necessarily mean reduced spectrum of operations.

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1.2 Concept, Meaning and Definition - Handicap, Impairment, Disability, activity limitation, habilitation and Rehabilitation

Education is a lifelong process involving many planned and unplanned experiences that enable children and adults alike to develop and learn through interaction with the society and culture in which they live. It involves experiences at all stages of life, from infancy through to old age. Education also involves adaptations to society and culture. With all the combinations of life events, adaptation will mean that each person is subject to a unique set of learning and problem-solving experiences that constitute an understanding of the world and the events that take place in it. However, if we limit our attendance to intentional learning and instruction of children across the time from preschool to tertiary education, this would involve learning from a curriculum that has been determined by the central or state education authority.
There are many children who, for some reason, are unable to take full advantage of the school curriculum as it is normally offered. For these children special arrangements must be made to ensure that they receive the opportunities and experiences, which will help them to learn and develop to the extent of their capabilities.
To help us to deal with the question of who these children may be, we need first to understand a few adjectives which you will, no doubt, encounter in your reading about children with special

needs. These adjectives are ‘impaired’, ‘disabled’ and ‘handicapped’. Over the years, these terms have often been used interchangably and at times carelessly. However, they have specific meanings and conceptual differences, which are important for us to know.

International Classification of Impairment, Disability and Handicap as given by World Health Organisation (WHO)

The World Health Organisation (WHO) has defined the terms ‘Impairment’, ‘Disability’ and ‘Handicap’ in 1980 through the publication of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which is a manual of classification relating to the consequences of diseases. The ICIDH proposes the concepts and definitions of Impairment, Disability and Handicap, and discusses the relation between these dimensions. It is based on a linear model (Figure 1) implying progression from disease, impairment and disability to handicap.

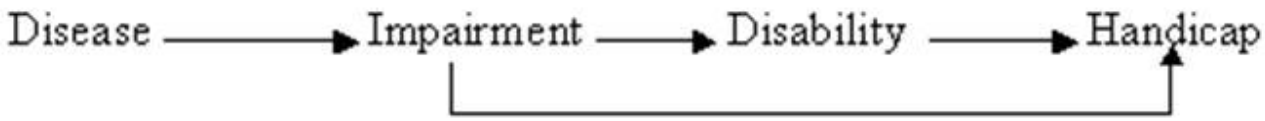

Figure 1: ICIDH Model (WHO 1980)

Definitions of Impairment, Disability, Handicap

Impairment: According to the ICIDH, impairment is any loss or abnormality of psychological, physiological or anatomical structure or functions, generally taken to be at organ level

Impairment is damage to tissue due to disease or trauma. A person who has poor or no vision due to damage to retina or optic nerve may be said to have a visual impairment.

Disability: Disability has been defined as any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being, generally taken to be at the level of the individual.

Disability denotes the consequences of impairment in terms of functional performance and activity by the individual. A person who has an optic nerve or retinal damage would have limitations in performing those tasks that requires the use of eyesight.

Handicap: The ICIDH defines Handicap as a disadvantage for an individual, resulting from an impairment or disability, which limits or prevents fulfillment of a role that is normal (depending on age, sex and social cultural factors) for that individual.

Condition	**Concerned with**	**Represents**
Impairment	Abnormalities of body structure, organs, appearance and system functioning	Disturbances at organ / tissue level
Disability	Limitations/loss of functional performance and activities	Disturbance at personal level

Handicap	Disadvantages resulting from impairment and disabilities	Situation specific limitations

In order to understand children with special needs we must know the different adjectives or terms by which they are often described. Impairment, Disability and Handicap are terms, which are frequently used interchangeably. However, there are conceptual differences among the terms.

The differences have been clearly outlined in the definitions of each of the terms by **WHO** in the **International Classification of Impairment, Disability and Handicaps.**
Impairment represents exteriorization of a pathological state and occurs at tissue level.
Disability refers to excesses or deficiencies of customarily expected activity, performance and behaviour, and is located at the level of the person.
Handicap reflects the consequences for the individual - cultural, social, economic and environmental - that stem from the presence of impairment and disability.

Activity limitation is a dimension of health/disability capturing long-standing limitation in performing usual activities (due to health problems). Indicators based on this concept can be used to evaluate the general health status, disability and related inequalities and health care needs at the population level.

Example of an operational definition used within the European Statistical System:

One question instrument – the Global Activity Limitation Instrument (GALI) - assessing the presence of long-standing activity limitation: “For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do? Would you say you have been …” severely limited / limited but not severely or / not limited at all? The question was developed by the Euro-REVES project. It is used in European Health Interview Survey (EHIS) (HS3 variable) and EU Statistics on Income and Living Conditions (EU-SILC) (PH030 variable).

Although they work side-by-side, rehabilitation and habilitation mean two different things:

Habilitation refers to a process aimed at helping disabled people attain, keep or improve skills and functioning for daily living; its services include physical, occupational, and speech-language therapy, various treatments related to pain management, and audiology and other services that are offered in both hospital and outpatient locations.

Rehabilitation refers to regaining skills, abilities, or knowledge that may have been lost or compromised as a result of acquiring a disability or due to a change in one’s disability or circumstances.

As defined in the CRPD, Habilitation and Rehabilitation “enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social, and vocational ability, and full inclusion and participation in all aspects of life.”

Without adequate habilitation and rehabilitation services, persons with disabilities may not be able to work, go to school, or participate in cultural, sports, or leisure activities. At the same time, barriers to other human rights can prevent persons with disabilities from claiming the right to habilitation and rehabilitation. Services may exist, but if there is not accessible transportation, many persons with disabilities will not receive the benefit of these services. If information about habilitation and rehabilitation services is not available in accessible formats, persons with certain disabilities may never know that they exist.

1.3 Definition, categories (Benchmark Disabilities) & the legal provisions for PWDs in India

The Ministry of Social Justice and empowerment of Person with Disability (Divyangjan) Department administers the following three Acts:-

· The Rights of Persons with Disabilities Act, 2016

· The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999

· Rehabilitation Council of India Act, 1992

The RPwD Act, 2016 was enacted on 28.12.2016 which came into force from 19.04.2017. The salient features of the Act are:-

i. Responsibility has been cast upon the appropriate governments to take effective measures to ensure that the persons with disabilities enjoy their rights equally with others.

ii. Disability has been defined based on an evolving and dynamic concept.

iii. The Act covers the following specified disabilities:-

1. Physical Disability

a. Locomotor Disability

i. Leprosy Cured Person

ii. Cerebral Palsy

iv. Muscular Dystrophy

v. Acid Attack Victims

b. Visual Impairment

c. Hearing Impairment

ii. Hard of Hearing

d. Speech and Language Disability

2. Intellectual Disability

a. Specific Learning Disabilities

b. Autism Spectrum Disorder

3. Mental Behaviour (Mental Illness)

4. Disability caused due to-

a. Chronic Neurological Conditions such as-

i. Multiple Sclerosis

ii. Parkinson’s Disease

b. Blood Disorder-

iii. Sickle Cell Disease

5. Multiple Disabilities

iv. Additional benefits have been provided for persons with benchmark disabilities and those with high support needs.

v. Every child with benchmark disability between the age group of 6 and 18 years shall have the right to free education.

vi. 5% reservation in seats in Government and Government aided higher educational institutions for persons with benchmark disabilities.

vii. Stress has been given to ensure accessibility in public buildings (both Government and private) in a prescribed time-frame.

viii. 4% reservation in Government jobs for certain persons or class of persons with benchmark disability.

ix. The Act provides for grant of guardianship by District Court or any authority designated by the State Government under which there will be joint decision – making between the guardian and the persons with disabilities.

x. Broad based Central & State Advisory Boards on Disability to be set up as policy making bodies.

xi. The Act provides for strengthening of the Office of Chief Commissioner of Persons with Disabilities and State Commissioners of Disabilities which will act as regulatory bodies and Grievance Redressal agencies and also monitor implementation of the Act. These Offices will be assisted by an Advisory Committee comprising of experts in various disabilities.

xii. Creation of National and State Fund to provide financial support to the persons with disabilities.

xiii. The Act provides for penalties for offences committed against persons with disabilities.

xiv. Designated special Courts to handle cases concerning violation of rights of PwDs.

There are innumerable types of disabilities that can affect a human being. Some of these conditions are more common than others. Some of the types of disabilities are recognized by the government in order to provide disability benefits to the needy ones. Often people wonder what are the disabling conditions that are more prevalent. Here is the list of 21 disabilities that have been identified under the RPWD Act 2016 of India.

1. Blindness

Blindness is defined as the state of being sightless. A blind individual is unable to see. In a strict sense the word blindness denotes the condition of total blackness of vision with the inability of a person to distinguish darkness from bright light in either eye.

2. Low-vision

Low-vision means a condition where a person has any of the following conditions, namely:

1. visual acuity not exceeding 6/18 or less than 20/60 upto 3/60 or upto 10/200 (Snellen) in the better eye with best possible corrections; or

2. limitation of the field of vision subtending an angle of less than 40 degree up to 10 degree.

3. Leprosy Cured Persons

Leprosy, also known as Hansen's disease (HD), is a chronic infectious disease caused by a bacteria called Mycobacterium leprae. The disease mainly affects the skin, the peripheral nerves, mucosal surfaces of the upper respiratory tract and the eyes. Leprosy is known to occur at all ages ranging from early infancy to very old age. About 95% of people who contact M. Leprea do not develop the disease.

4. Hearing Impairment

Hearing impairment is a partial or total inability to hear. It is a disability which is sub-divided in two categories of **deaf** and **hard of hearing**.

- "Deaf" means persons having 70 dB hearing loss in speech frequencies in both ears.
- "Hard of hearing" means person having 60 dB to 70 dB hearing loss in speech frequencies in both ears.

5. Locomotor Disability

Strictly speaking Locomotor Disability means problem in moving from one place to another — i.e. disability in legs. But, in general, it is taken as a disability related with bones, joints and muscles. It causes problems in person's movements (like walking, picking or holding things in hand etc.)

6. Dwarfism

Dwarfism is a growth disorder characterized by shorter than average body height.

7. Intellectual Disability

Intellectual disability, also known as general learning disability and mental retardation (MR), is a condition characterized by significant limitation both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior which covers a range of every day, social and practical skills.

8. Mental Illness

Mental illness or mental disorder refers to a substantial disorder of thinking, mood, perception, orientation or memory that grossly impairs judgment, behavior, capacity to recognize reality or ability to meet the ordinary demands of life. But it **does not include** retardation which is a condition of arrested or incomplete development of mind of a person, specially characterized by sub-normality of intelligence.

9. Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurological and developmental disorder which affects communication and behavior. Autism can be diagnosed at any age. But still it is called a "developmental disorder" because symptoms generally appear in the first two years of life. Autism affects affects the overall cognitive, emotional, social and physical health of the affected individual.

10. Cerebral Palsy

Cerebral Palsy (CP) is a disabling physical condition in which muscle coordination is impaired due to damage to the brain. It occurs at or before child birth. Cerebral Palsy is not a progressive condition; meaning it does not get worse with time. However, muscle disuse could increase the extent of disability over the period of time. At present there is no cure available for this condition. Thus, Cerebral Palsy is incurable and life-long condition, at present.

11. Muscular Dystrophy

Muscular Dystrophy (MD) is a group of neuromuscular genetic disorders that cause muscle weakness and overall loss of muscle mass. MD is a progressive condition; meaning that it gets worse with the passage of time.

12. Chronic Neurological Conditions

Examples of Chronic Neurological Conditions:

1. Alzheimer's disease and Dementia
2. Parkinson's disease
3. Dystonia
4. ALS (Lou Gehrig's disease)
5. Huntington's disease
6. Neuromuscular disease
7. Multiple sclerosis
8. Epilepsy
9. Stroke

13. Specific Learning Disabilities

Specific Learning Disabilities is a group of disabling conditions that hampers a person's ability to listen, think, speak, write, spell, or do mathematical calculations. One or more of these abilities may be hampered.

14. Multiple Sclerosis

In Multiple Sclerosis (MS), the immune system of body attacks the Central Nervous System, which includes brain and spinal cord. As a result of MS, the **myelin sheath** covering on neurons gets damaged. This exposes the nerve fiber and causes problems in the information flow through nerves. With time, MS can lead to the permanent damage to nerves.

15. Speech and Language Disability

A permanent disability arising out of conditions such as laryngectomy or aphasia affecting one or more components of speech and language due to organic or neurological causes.

16. Thalassemia

Thalassemia is a genetically inherited blood disorder which is characterized by the production of less or abnormal hemoglobin. As we know, hemoglobin is a protein found in Red Blood Cells. Hemoglobin is responsible for carrying oxygen around in the body. Thalassemia results in large numbers of red blood cells being destroyed, which leads to anemia. As a result of anemia, person affected with Thalassemia will have pale skin, fatigue and dark coloration of urine.

17. Hemophilia

Hemophilia is a blood disorder characterized by the lack of blood clotting proteins. In the absence of these proteins, bleeding goes on for a longer time than normal. Hemophilia almost always occurs

in males and they get it from their mothers. Females are rarely affected with hemophilia.

18. Sickle Cell Disease

Sickle Cell Disease is a group of blood disorders that causes red blood cells (RBCs) to become sickle-shaped, misshapen and break down. The oxygen-carrying capacity of such misshapen RBCs reduce significantly. It is a genetically transferred disease. Red Blood Cells contain a protein called hemoglobin. This is the protein that binds oxygen and carry it to all the parts of the body.

19. Multiple Disabilities including Deaf-blindness

Multiple Disabilities is the simultaneous occurrence of **two or more disabling conditions** that affect learning or other important life functions. These disabilities could be a combination of both motor and sensory nature.

20. Acid Attack Victims

An acid attack victim means a person disfigured due to violent assaults by throwing of acid or similar corrosive substance.

21. Parkinson's disease

Parkinson's disease (PD) is Central Nervous System disorder which affects movement. Parkinson's disease is characterized by tremors and stiffness. It is a progressive disease, which means that it worsens with time. There is no cure available at present.

Government of India uses the term **benchmark disability** quite often in the official communications regarding persons with disabilities. Often you come across question like **"are you a person with benchmark disability?".** For example, in the Rights of Persons with disabilities Act 2016 (RPWD Act 2016), this term is used at many places. Department of Personnel and Training (DoPT) also uses it often in their job vacancy ads where certain seats are reserved for the disabled people. Then you also find mention of this term in context of examinations like UPSC, Bank Services, NET Exams etc.

But most people do not understand what exactly is this benchmark disability. Well, here is the answer!

Benchmark disability refers to having at least 40% disability of any type recognized under the RPWD Act 2016.

So, to be in the category of having benchmark disability, a person has to have at least 40% disability as mentioned on her disability certificate or UDID Card.

1.4 An overview of Causes, Prevention, prevalence & demographic profile of disability: National and Global;

Prevalence of a condition or disability in determined by epidemiology.

Epidemiology is a science concerned with the study of factors that influence the occurrence and distribution of disease, defect, disability, or death in aggregation of individuals. Epidemiology involves making a determination or estimate of the number of cases of some condition in a population. In addition, it attempts to relate this estimate to other classification of population, such as age, sex, and social class.

A good epidemiologist depends upon the definition of the condition in question. If the condition is poorly or vaguely defined, there will be a problem with the estimates of its occurrence.

An epidemiologist uses two methods for estimating the occurrence of a condition in a population: the incidence rate and the prevalence rate.

Difference between Incidence and Prevalence

Incidence refers to the number of new cases in population during a specified period of time. Prevalence refers to the total number of cases in a population group during a specified period of time.

As per the Census 2011, the differently abled population in India is 26.8 million. In percentage terms, this stands at 2.21 %. There has been a marginal increase in the differently-abled population in India, with the figure rising from 21.9 million in 2001 to 26.8 million over the period of 10 years.

As per the Census 2011, there are 14.9 million men with disabilities as compared to 11.9 million women in the country. The total number of differently-abled people is over 18.0 million in the rural areas and just 8.1 million enumerated in the urban settings. The percentage of men with disabilities is 2.41 per cent as against 2.01 in women. Social groups wise analysis shows 2.45 per cent of the total disabled population belong to the Scheduled Castes (SC), 2.05 per cent to the Scheduled Tribes (ST) and 2.18 per cent to other than SC/ST.

About 15% of the world's population lives with some form of disability, of whom 2-4% experience significant difficulties in functioning. The global disability prevalence is higher than previous WHO estimates, which date from the 1970s and suggested a figure of around 10%. This global estimate for disability is on the rise due to population ageing and the rapid spread of chronic diseases, as well as improvements in the methodologies used to measure disability.

A few outstanding figures of disability around the world (according to the WHO's 2011 report):

· 253 million people are affected by some form of **blindness and visual impairment**. This represents **3.2%** of the world's population. That's twice Mexico's population*!

· 466 million people have a disabling **deafness and hearing loss**. This represents **6%** of the world's population, that is to say all of the inhabitants of the European Union!

· About 200 million people have an **intellectual disability** (IQ below 75). This represents **2.6%** of the world's population. It covers the number of inhabitants in Brazil!

· 75 million people need a **wheelchair** on a daily basis. This represents **1%** of the world's population. That's twice Canada's population!

These statistics may remain an evolutionary average, but one thing is certain: the number of people affected by any form of disability represents a significant part of the world population, from children to adults alike. It is also important to underline the fact that some people may have **multiple disabilities**. This explains why the total number of people with disabilities in the world isn't equal to the sum of people with disabilities per disability type. Indeed, the same person can be both deaf and blind.

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CAUSES

Risk factors for the disabilities:

Communicable diseases (Infectious diseases) such as lymphatic filariasis, tuberculosis, HIV/AIDS, and other sexually transmitted diseases; neurological consequences of some diseases such as encephalitis, meningitis, and childhood cluster diseases (such as measles, mumps, and poliomyelitis) contribute to disability.

Non communicable diseases (NCDs)–

· Chronic diseases such as diabetes, cardiovascular disease, arthritis and cancer cause the majority of long-term disabilities. The increase in NCDs observed in all parts of the world, will have a profound effect on disability.

· Lifestyle choices and personal behavior such as obesity, physical inactivity, tobacco use, alcohol consumption, illicit drugs that lead to non communicable diseases are also becoming major contributing factors;

· Air pollution, occupational disease, poor water supply, sanitation, and personal and domestic hygiene, malnutrition also contribute for disability.

Injuries due to road traffic accidents, occupational injury, violence, conflicts, falls and landmines have long been recognized as contributors to disability.

Mental health problems– mental health retardation and mental illness are the causes of mental disability. In more than 50% cases mental retardation has been reported to be caused by serious illness or head injury in the childhood and birth defects. Mental retardation was observed mostly at birth or at very early ages of life while the problem of mental illness is more of an old age problem.

Those with lower education levels, lower incomes, and those who are unemployed were also more likely to suffer a disability.

There is higher risk of disability at older ages.

PREVENTION OF DISABILITIES

- **Primary Prevention** – Action taken prior to the onset of the disease/disability, which will remove the possibility that a disease/disability will occur.
- **Secondary Prevention** – Action, which halts the progress of the disease/disability at its incipient stage and prevents complications. The specific interventions are early diagnosis and adequate treatment.
- **Tertiary Prevention** – All measures available to reduce or limit impairments and disabilities, and minimize suffering caused by existing disability. This phase is also called rehabilitation, which includes physical, psychosocial and vocational measures taken to restore the patient back to normal or near normal condition

It is extremely important that the women undertake adequate and effective preventive measures during their pregnancy and immediate postnatal period and also for their children especially during the early childhood period, in order to significantly reduce the incidence of impairment and disabilities in them. Therefore, in this chapter examples of easily understood primary preventive measures, for mother and child are summarized.

General preventive measure

1. Marriage between very close blood relations like uncle, niece, first cousin should be avoided for prevention of hereditary disorders.

2. Avoid pregnancies before the age of 18 years and after the age of 35 years.

3. Consult a doctor before planning the pregnancy;

    - If there is incidence of birth defects in your family.
    - If you have had difficulty in conceiving or have had a series of miscarriages, still births, twins, delivery by operation (Caesarean), obstructed

labour/prolonged labour(more than 12 hours) and/or severe bleeding in previous pregnancy .
- If you have RH - negative blood type.
- If you have diabetes.

Care during pregnancy

1. Avoid hard physical work such as carrying heavy loads, especially in fields, and other accident - prone activities such as walking on slippery ground or climbing stools and chairs.

2. Avoid unnecessary drugs and medications. Even the normally considered safe drugs which are sold commonly can potentially cause serious defects in an unborn child.

3. Avoid smoking, chewing tobacco, consuming alcohol and narcotics.

4. Avoid X - rays, and exposure to any kind of radiation.

5. Avoid exposure to illnesses like measles, mumps etc, especially during the first 3 months of pregnancy.

6. Avoid sexual contact with a person having venereal disease.

7. Take precautions against lead poisoning.

8. Avoid too much use of ‘Surma’ and ‘Kohl’.

9. Eat a well-balanced and nourishing diet supplemented with green leafy vegetables, proteins and vitamins.

10.All women of the child bearing age need 0.4mg of folic acid daily. It is also available in folic acid plus iron tablets which should be taken for at least 3 months during the third trimester when the risk of developing iron deficiency anemia is greatest.

11.Ensure weight gain of at last 10 kgs. Have regular medical checkups.

12.All pregnant women should be given tetanus injection.

13.Woman at ‘high - risk’, whose weight is < 38 Kg, height is less than 152 cm, weight gain during pregnancy <6 kg or who is severly anaemia c (Hb < 8mg), having frequent pregnancies, having a history of miscarriage/ abortion/premature deliveries, must get expert prenatal care so as to have a normal baby.

14.Must consult a doctor, in case of edema (swelling) of feet, persistent headache, fever, difficulty or pain in passing urine, bleeding from the vagina, and yellowness of eyes (jaundice)

Care at the time of birth

1. Delivery must be conducted by trained personnel, preferably in a hospital where all facilities are available.

2. If a baby does not cry immediately after birth, resuscitation measures should be undertaken at once.

3. Babies born prematurely and with a low birth weight (<2.5 Kg) may need Neonatal Intensive Care.

4. If the baby’s head appears to be abnormally small or large then a physician should be consulted, preferably a pediatrician. The approximate head size for a male child at birth is 35 cm

and for female child is 34.5 cm.

5. To protect a child from infections, breast - feeding must be started immediately after birth. First milk (colostrum) must be fed to the baby and should not be thrown away, as it has antibodies which are protective.

Early childhood care

1. Do not allow a child's temperature to rise above 101 degree F because of any reason. It can cause febrile seizures

2. If a child gets a fit take him to doctor immediately.

3. Every child should be immunized against infectious diseases as per the recommended schedule of immunization.

4. Do not allow a child to have too much contact with paint, newsprint ink, lead etc. as they are toxic.

5. Take precautions against head injury, and other accidents.

6. Ensure that the child gets a well-balanced diet and clean drinking water.

7. Introduce additional foods of good quality and in sufficient quantity when the child is 4 -6 months old.

8. Vitamin A deficiency and its consequences including night blindness can be easily prevented through the use of Vitamin A supplementation.

9. Protect a child from Meningitis and Encephalitis by providing a hygienic environment which is free of overcrowding.

10.Common salt must be iodized as a precaution against goiter and cretinism.

11.Do not allow a child to use hairpins, matchsticks and pencils, to remove wax from the ears.

12.Use ear protectors to reduce the exposure to high levels of noise, if children are living or working in a noisy environment.

13.Do not slap a child over the face as this may lead to injury of the eardrum and consequent hearing loss

1.5 Concept, meaning and importance of Cross Disability Approach and interventions;

CROSS DISABILITY APPROACH:- This historical fact changed with the emergence of DPI(Disabled people international) the slogan of DPI is "nothing about us without us".

DEFINITION:- it is an approach that does not distinguish between types of disability.

In other words – it is an approach which comprehensively takes in to account all different kinds of disabilities together and promote collective planning

In this approach focusing on particular subgroup should b avoided whenever possible because "distinction often leads the most vulnerable people to further stigmatization." This is about making

policy decision collectively and gives equal wattage across all disabilities for the disabled people themselves. This approach seeks co-operation and network on various categories of disabled.

Includes different disabled persons and with different abilities.

NEEDS OF CROSS DISABILITY:-

For fulfillment of right to equality there is very necessary to include all the persons in a same frame work unless they have different abilities.

· Better access to decision-making.

Without involvement of all disabled/differently able in a same context, it is not easy to access to making decision on their rights and needs.

Disabled people should be participated their own policies decision and program for themselves.

We cannot access the needs of disabled people because the disabled people know their needs very well. So, participation of disabled people is very necessary.

· Main need is equal opportunities.

· Equal Membership to the society and respect of the individual and equal right is necessary.

For respect of the equal right, there should be equal membership of the entire person (normal/disabled) to the society is needed.

· Need to be protected, need to be promoted and spread out.

BENEFITS OF CROSS DISABILITY APPROACH: - The cross-disability movement has rainbow approach to include all those who are given a disability label in fact some have named it the movement of the dis-labled.

It leads to-

o Independence: as we have discussed cross disability approach provide exposure to disabled to mix in society, the disabled learn to live independent, work independent for achieving equality level.

o Full citizenship: in past disabled person did not consider as a full citizen because they were not an active part of society due to disability, but cross disability approach provided opportunities in making decision and participation, they considered as full citizen.

o Total inclusion:

o Promote leader ship:

o Full enforcement and implementation of disability related laws.

o Program-to enhances the life and it reduces the poverty and unemployment.

o It ensures the right to live.

- Uniformity in the terminology of the disability.

- To educate the public and government policy makers regarding issues and affecting people with disability.