



Block

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PERSONS WITH DISABILITIES

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BLOCK 4 PERSONS WITH DISABILITIES

The previous Block of this Course dealt with the various types of mental disorders, such as cognitive disorders, mood disorders, neurotic disorders, personality disorders etc. In this Block, “Persons with Disabilities” you will be oriented to various types of disabilities. You will study disabilities like sensory impairments, mental retardation, mental illness, locomotor disabilities and multiple disabilities. This Block consists of five Units.

Unit 15 is on “*Orientation to Disability*”. The Unit defines disability and differentiates disability from impairment and handicap. It explains the various causes of disability like hereditary factors which include chromosomal anomalies, defective genes etc. and environmental factors like poor nutrition, chronic disease, radiations etc. It also explains that both heredity and environment interact to cause disability. There are some important acts and legislations of Government of India on disability. The Unit describes these acts in detail like RCI Act 1992, PWD Act, 1995 and The National Trust Act, 1999. In the end of this Unit, we will study how to create a disabled friendly society, wherein we would focus on the various needs and problems of children with disabilities. We would also highlight some important points to remember when dealing with persons with disabilities.

Unit 16 focusses on “*Persons with Sensory Impairments*”. As the name suggests, the Unit acquaints you with the knowledge on sensory impairments like hearing disability, visual disability and deaf blindness. The Unit begins with the concepts and definition of sensory disability. Further, it explains various methods of identification and assessment of sensory disability. The Unit describes the various causes of sensory impairments. In the end of this Unit, various interventions for sensory impairments are discussed; for example, sensory training, orientation and mobility training for visually impaired persons.

Unit 17 is entitled “*Persons with Mental Retardation*”. The Unit begins with the definitional aspects of mental retardation, and then proceeds to explaining the various classifications in detail. The Unit further describes the various causes of mental retardation. The identification and diagnosis of mental retardation has also been focused upon. Children with mental retardation manifest some specific physical, cognitive and behavioural characteristics; the Unit enumerates these characteristics as well. The later part of the Unit deals with the prevention and intervention for mental retardation. It includes genetic counselling, prenatal care and postnatal care. Further, the Unit highlights the specific role of community members like teachers and parents.

Unit 18 is on “*Mental Illness and Psychosocial Rehabilitation*”. The Unit defines mental illness and its positive and negative symptoms. The disability arising due to severe mental illness is known as psychiatric disability. The Unit explains the clinical characteristics and key areas of psychiatric disability. Further, the Unit explains the psychosocial rehabilitation of persons who are impaired, disabled or handicapped by the mental disorder. It describes the aim, goals, values and guiding principles of psychosocial rehabilitation. The Unit acquaints you with the knowledge of historical perspectives of psychosocial rehabilitation. It explains the present scenario and magnitude of the problem. Strategies of management in psychosocial rehabilitation including pharmacotherapy and psychosocial management are well explained in this Unit. The Unit also deals with the legal

aspects, advocacy and community participation. In the end of this Unit, the role of the counsellor and family therapist is explained.

Unit 19 is entitled “*Persons with Locomotor Disability and Multiple Disabilities*”. The Unit begins with the definition of locomotor disability and various causes that may lead to locomotor disability. It also explains the other conditions that lead to locomotor disability, for example, spinal cord injury, polio, cerebral palsy, epilepsy, cerebrovascular accidents, arthritis, muscular dystrophy, amputation, club foot and leprosy. The Unit further deals with the prevention of locomotor disability, which includes primary level, secondary level and tertiary level of preventions. Further, the Unit explains various types of problems faced by the locomotor disabled. As you go through the Unit, you will be able to understand the process of rehabilitation of locomotor disabled persons. It includes assistive devices, orthodontics, prosthetics, walking aids etc. In the end of this Unit, we study about multiple disabilities in which we learn about the causes, examples and prevention of multiple disabilities.



UNIT 15 ORIENTATION TO DISABILITY

Structure

- 15.1 Introduction
- 15.2 Definitions of Disability
- 15.3 Distinction between Disability, Impairment and Handicap
- 15.4 Causes of Disability
- 15.5 Legislations and Acts in India
- 15.6 How to Create a Disabled Friendly Society
 - 15.6.1 Needs and Problems of Children with Disabilities
 - 15.6.2 Points to Remember while Dealing with the Persons with Disabilities
 - 15.6.3 Role of Society
- 15.7 Let Us Sum Up
- 15.8 Glossary
- 15.9 Answers to Check Your Progress Exercises
- 15.10 Unit End Questions
- 15.11 Further Readings and References

15.1 INTRODUCTION

Majority of us know of some one who has some kind of disability or, also, might be ourselves suffering from some kind of impairment or disability. Disability is a common term these days. Till recent past the words 'disability', 'impairment' and 'handicap' were used interchangeably. Most of the persons with disability till date lead a segregated and secluded life due to our social misgivings and are deprived of their rights to a larger extent. This Unit would differentiate among these three terms. These terms have different meanings and are used in different contexts.

The estimated disabled population in the world as well as in India is quite high. According to the Census of India, 2001 their number is 22 million. However, according to the Disability Manual, 2005 brought out by the National Human Rights Commission, Delhi the actual number of Indians with temporary and permanent disability could be as high as 50 million. With the rising number of persons with disabilities, it is pertinent for a counsellor and family therapist to understand the needs, requirements and characteristics of persons with disabilities. The information contained in this Unit will give a deeper understanding about the persons with disabilities. In this Unit, we would have a general overview about it and the other Units of this Block would discuss in detail about the specific disability concerns.

Objectives

After studying this Unit, you will be able to:

- Differentiate the meaning of the terms disability, impairment and handicap;

- List the factors that cause disability;
- Identify various types of disabilities;
- Understand the misconceptions associated with disability; and
- Contribute to the development of a disabled friendly society.

15.2 DEFINITIONS OF DISABILITY

The concept of disability differs from person to person and from survey to survey depending on the base on which it is collected. In the simplest words, disability refers to any limitation experienced by the disabled in comparison to the able persons of similar age, sex and culture.

The Persons with Disabilities Act, 1995 defines “disability” in terms of blindness, low vision, leprosy-cured, hearing impairment, locomotor disability, mental retardation and mental illness. According to the Act, “person with disability” means a person suffering from not less than forty percent of any disability as certified by a medical authority.

The International Classification of Functioning (ICF), Disability and Health, produced by the World Health Organisation (WHO), distinguishes between body functions (physiological or psychological, for example, vision) and body structures (anatomical parts, for example, the eye and related structures). Impairment in bodily structure or function is defined as involving an anomaly, defect, loss or other significant deviation from certain generally accepted population standards, which may fluctuate over time. *Activity* is defined as the execution of a task or fact or action by the bodily structure or function.

Medical Definition of Disability

Medically, disability is perceived as a medical clinical problem, thereby identifying people with disabilities as ill, different from their non-disabled peers and unable to take charge of their own lives. Medical definition does not take note of the imperfections and deficiencies in the basic social structures and processes that fail to accommodate the differences on account of disabilities. World Health Organisation (WHO) defines the relationship between impairment, disability and handicap. The term *impairment* refers to damage or loss related to organ level functions or structures; *disability* refers to person-level limitation in physical and psycho-cognitive activities; and *handicap* refers to social abilities or relation between the individual and society. The ICF further states that the medical model views disability as a problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals.

Social Definition of Disability

The Disability Manual, (NHRC, 2005) focusses on the shift from individual pathology to a social construct in accordance with the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993. The Standard Rules have defined disability from a perspective that emphasises social conditions which disable a group of individuals by ignoring their needs of accessing opportunities in a manner conducive to their circumstances (Disability Manual, 2005).

The definition of disability should have human rights perspective. UN convention on the Rights of Persons with Disabilities in 2009 promoted the human rights perspective for persons with disabilities. Definition of disability takes into account the social conditions which disable a group of individuals by ignoring their needs of accessing opportunities in a manner different from others. Disability can be defined as the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activities (Disability Manual, 2005).

Check Your Progress Exercise 1

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. Define disability according to the human rights perspective.

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15.3 DISTINCTION BETWEEN DISABILITY, IMPAIRMENT AND HANDICAP

The World Health Organisation (WHO) has made distinctions between the definitions of impairment, disability and handicap. The definitions given are as follows:

An *impairment* is any loss or abnormality of psychological, physiological or anatomical structure or function.

A *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.

A *handicap* is a disadvantage for a given individual, resulting from impairment or disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex, social and cultural factors) for that individual.

For example, suppose a person at the age of 15 years meets with an accident and loses his right arm. This results in an impairment. Now, this person is not able to write and use his right arm for functioning as he would use it earlier. This results in a disability. This person when not able to perform his role as a student, for instance, take notes in the class or write an examination, experiences a handicap.

Check Your Progress Exercise 2

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Fill in the blanks:

- i) refers to organ level abnormality or dysfunction.
- ii) refers to person level limitation in physical and psycho-cognitive activities.
- iii) is considered as a loss or limitation of opportunities to take part in community life on an equal level with others.

15.4 CAUSES OF DISABILITY

Disability could be a result of heredity, environmental factors and the interplay between these two groups.

1. Heredity

Genetic components or heredity of an individual is one of the important causes of disability. For instance, mental retardation is said to run in families and is associated with hereditary endowments. Chromosomal anomalies, defective genes, inheritance of fragile genetic components etc. lead to various disabilities among humans. For example, 21st Trisomy. You have read about it in detail in Course MCFT-001.

2. Environment

Environmental components play an important role in deformities which occur in children. It starts from the moment of conception in the womb. Factors like poor health status and nutritional intake of the mother as well as smoking, alcohol consumption and exposure to radiation harm the foetus during pregnancy. Even at the time of birth, the birth process may also lead to deformity in the infant. Later jaundice, chronic health diseases, poor diet or nutrition intake (e.g. protein energy malnutrition), accidents, etc. lead to disability among children.

3. Heredity and Environment Interplay

Both heredity and environment interact to cause disability. Heredity paves the path and environment reinforces disability among the children.

Disability is caused by various factors which could be hereditary or non-hereditary. World Health Organization (WHO) prepared a list of reasons of disability which covers the following areas:

- Non-contagious somatic illnesses,
- Injuries/wounds,
- Malnutrition,
- Functional psychiatric disorders,
- Chronic alcoholism and drug abuse,

- Congenital diseases, and
- Contagious diseases.

In broad terms the causes of disability can be described as follows:

- Violation of human rights, torture, ill treatment or amputation,
- Natural disasters or earthquakes,
- Irreversible diseases,
- Old age,
- Environmental pollution,
- Cardiovascular disease,
- Neuromuscular diseases,
- Traffic accidents,
- Industrial accidents,
- Diseases like poliomyelitis,
- Wars,
- Mal-nutrition: Nutritional deficiency like lack of iodine leads to slow growth, learning difficulties, intellectual disabilities, mental defects, deafness and dumbness.
 - Vitamin A deficiency leads to blindness.
 - Vitamin B Complex deficiency leads to beri-beri (inflammation or degeneration of the nerves, digestive system and heart), pellagra (central nervous system, gastro-intestinal disorders, skin inflammation) and anaemia.
 - Vitamin D deficiency leads to rickets (soft and deformed bones).
 - Iron deficiency leads to anaemia (impedes learning and activity).
 - Calcium deficiency leads to osteoporosis (fragile bones).
- Chagas' disease – *Trypanosoma cruzi* parasite is carried in the blood and is spread by blood transfusions. This disease prevents the person from leading a normal life and is also a cause of death,
- Down's syndrome (Mongolism),
- Dwarfism (Achondroplasia),
- Insufficient care and cruelty towards children and women,
- Under development caused by lack of public hygiene, degradation of the environment, poor food and housing, indigence, inadequate education and health information, illiteracy,
- Hunger,

- Lack of adequate health system,
- Use of certain pesticides, hormones, antibiotics or other additives,
- Dumping of toxic and dangerous products and wastes,
- Extreme poverty,
- Apartheid,
- Deliberately inflicted forms of punishment like mutilations, and
- Crime, for example, for begging children are amputated.

Check Your Progress Exercise 3

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. Which are the major areas covered under the list of reasons of disability by WHO?

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15.5 LEGISLATIONS AND ACTS IN INDIA

The year 1981 was declared as the International Year of Disabled Persons with the theme as, “Full Participation and Equality”. On 3rd December, 1982, the World Program Action Concern was adopted by United Nations to enhance full participation of disabled persons in social life and national development. The decade 1993-2002 was declared as Pacific Decade of Disabled Persons and in 1999, the decade was further extended to 2003-2012 as Asian Pacific Decade of Disabled Persons and called Biwako Millennium Framework with the theme “towards an inclusive, barrier-free and rights based society”.

Government of India like other countries agreed to implement the Biwako Millennium Framework for Action towards an inclusive barrier-free and rights based society for persons with disabilities in the Asia and the Pacific.

In the recent past, the welfare of the disabled has gained much importance. Government of India has enacted various Acts and initiated various schemes and measures for the welfare of the disabled. The Government of India has enacted three major legislations for overall development and mainstreaming of persons with disabilities, that are:

- i) The RCI Act, 1992, which regulates the training policies and programmes in the field of rehabilitation of persons with disabilities,
- ii) The Persons with Disabilities (Equal Opportunities, Protection of Rights, and Full Participation) Act, 1995, which aims to protect and promote the educational, economic and social rights of persons with disabilities, and to promote and ensure equality and full participation of persons with disabilities, and

- iii) The National Trust Act, 1999 which enables and empowers people with autism, cerebral palsy, mental retardation and multiple disabilities.

All these legislations have come into force for overall growth of persons with disabilities. The Persons with Disabilities Act, 1995 (PWD Act, 1995) is one of the major Acts enacted for the welfare of the persons with disabilities. This Act covers “Disability” in the following areas:

- i) Blindness,
- ii) Low vision,
- iii) Leprosy-cured,
- iv) Hearing impairment,
- v) Locomotor disability,
- vi) Mental retardation, and
- vii) Mental illness.

These would be discussed in detail in the other Units of this Block. Recently, Government of India signed the Convention on the Rights of Persons with Disabilities and Optional Protocol for promotion of rights of the persons with disabilities.

According to this convention, we are now committed to promoting a Rights-based society for the persons with disabilities, as matter of right of the disabled people rather than the society doing any kind of favour or an act of sympathy for them.

Check Your Progress Exercise 4

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. List the disabilities covered under the PWD Act.

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15.6 HOW TO CREATE A DISABLED FRIENDLY SOCIETY

Now, let us discuss how we can create a disabled friendly society. A society which is friendly and welcoming to the persons with disabilities needs to understand their needs and problems before being able to be caring and inclusive.

15.6.1 Needs and Problems of Children with Disabilities

Needs and problems of children with disabilities are varied. The specific problems of people with the disabilities would be discussed in the other Units of this Block. Here, we would discuss in general the problems faced by children and people with disabilities. These are:

- **Acceptance of one's condition or problem:** The persons with disability and their family have to accept the disability or disabling condition. For instance a hard of hearing child has to accept wearing hearing aid, child with low vision has to wear thick spectacles, etc. and sit in the first row in the class. Also, the other non-disabled children need to accept their classmate's condition.
- **Acceptance by the society:** People and children with disability like any other person or child need to be accepted by others in the society. They have a need of sense of belongingness, acceptance and love of their near and dear ones. They need to be accepted as they are.
- **Educational facilities:** Children with disabilities should be provided education and appropriate measures should be taken for their education.
- **Vocational opportunities:** Children and persons with disabilities should be provided occupational and vocational rehabilitation and opportunities. As per the abilities of the children with disabilities they should be given vocational training.
- **Assistive aids and assistive devices:** The children with disabilities should be given assistive aids, equipments and devices for facilitating them to meet their learning, developmental and adjustment needs. Examples of such aids are hearing aids for the hearing impaired, braille and talking books for the blind, large print for low vision, etc.
- **Barrier free environment:** The physical environment of the children and persons with disabilities should be barrier free. Provision of ramps in the school and other public places is a step towards developing a barrier free environment.
- **Guidance, counselling and family therapy:** Parents and/or caregivers of children with disabilities need timely guidance, counselling and family therapy to meet the developmental needs of their children. Also, need for counselling and family therapy is felt by persons and children with disabilities. Various social and emotional needs of these persons and their families may be met with the help of the counsellor and family therapist. The other normal siblings of the children with disabilities may also have certain problems and need to be guided to face situations and their siblings. Counselling and family therapy helps to channelise the parents and children/persons with disabilities to use their emotional energy in useful productive ways as well as build resilience and acceptance of each other. For example, a child with disability may be jealous of his normal siblings and *vice-versa*.

Table 15.1: Myths related to the persons with disabilities

S.No.	Myth	Fact
1.	Disabled child cannot attend regular classroom.	With assistive aids and devices, some modifications in the infrastructural arrangement in the school building and provision of trained sensitised teachers towards the needs of the disabled, the disabled child can attend regular classroom.

2.	The schools may or may not admit children with disabilities.	According to the provisions made under Indian legislation, the schools do not have choice to give admission or not to, the differently abled but they have to admit the child with disability.
3.	Causes of disabilities are known.	Causes of most of the disabilities are known but not for all the disabilities.
4.	Treatment of disability is unknown.	How to care and look after, what remedial measures to be undertaken are mostly known about the different disabilities.
5.	Disability and handicap mean the same.	Disability and handicap are two different terms. Disability is caused by one's inability to do something while handicap is the social restriction imposed on the person.
6.	Sympathy for the person with disability is good.	No, empathy for the person with disability is good.
7.	They are not useful and productive members of the society. They are not capable of performing well in their education or profession.	Many disabled persons have become renowned persons in their professions. Many disabled persons have invented things of immense use and importance.
8.	Disability is caused due to God's wrath on the person.	It is a superstitious belief. Research shows that undertaking preventive measures can avoid many disabilities.
9.	Disabled cannot lead a married life.	Mildly disabled persons can lead a healthy married life.
10.	People having severe epilepsy, cerebral palsy can be cured with marriage.	Epilepsy and cerebral palsy cannot be cured with marriage.
11.	Disabled persons like the company of other disabled persons.	They feel comfortable in the company of people who accept them as they are. This myth resulted from the fact that in older days disabled persons were kept separately.
12.	Disabled people especially blind have sixth sense.	In fact, the lack of a sense makes other senses more focused and sensitised.
13.	Disabled people should be protected against failure.	Overprotection of the disabled people should be avoided. They should be given opportunity of both failure and success like other normal human beings.

15.6.2 Points to Remember while Dealing with the Persons with Disabilities

One should remember the following points while dealing with the person with disability:

- Do not discriminate against persons with disabilities. They are human beings like anyone else with different abilities and needs.
- To remove misconceptions about transmission or spread of disability, general public should be educated and sensitised towards the concept of disability.
- It is necessary for the masses to have acceptance of the disabled which will help to eradicate handicappedness among the disabled so that social change in favour of the person with disabilities is brought about.
- Indigenous material, that is material available in the local area should be used to lessen the effect of disability.
- Do not stigmatise and sympathise with the disabled. Rather, sensitise, empathise, make aware, spread information and educate the common person towards the needs and abilities of the persons with disabilities.
- The requisite additions and modifications should be made in the public utility services, like buildings, transport system, etc. to make them user friendly for the disabled.
- To help the persons with disabilities develop a well organised social support system of family, neighbourhood and the workplace.
- Services leading to treatment and rehabilitation of the disabled are a must and their availability and use should be promoted.
- Innovations leading to development of services and materials for the disabled should be encouraged.

15.6.3 Role of Society

Society has an important role to play in the development of its inhabitants. Child is born in the society and dies in the society. It is the society that decides what is “average”, “normal”, “deviation”, “exceptional” and “different”. The social norms of the society regulate the overall development of the individuals. So, it becomes the duty of the society to provide optimum environment to the differently abled. The boundaries of the medical and social disability need not become a handicap for the person if the society so desires.

Parents, teachers and caregivers of the persons with disabilities need to keep an appropriate balance between over protection to over stimulation. Care needs to be taken that enough opportunities are provided to the differently abled child to develop independence and self esteem. Social participation of the differently abled gets slackened and stunted in many activities due to the cultural and social handicap these individuals face. People think they need to be sympathised with and looked down upon always, but, instead they should be provided empathy of the society and opportunities to grow into an independent person. Self-dependence would lead to self-decisions which would enhance their self-esteem and help them to develop a good self-concept. This helps the differently abled to become productive and useful members of the society.

Check Your Progress Exercise 5

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. State True or False.

- i) Causes of disabilities are known.
- ii) Sympathy for the persons with disability is good.
- iii) Only blind persons have sixth sense.
- iv) Epilepsy and cerebral palsy cannot be cured with marriage.

15.7 LET US SUM UP

The census 2001 shows that there are about 21 million persons (2.1 per cent of the population) in the country having one or another form of disability. Under these circumstances the Government of India has enacted three major legislations for overall development and mainstreaming of persons with disabilities, that are, (i) the RCI Act (1992), which regulates the training policies and programmes in the field of rehabilitation of persons with disabilities, (ii) the Persons with Disabilities Act (1995), which aims to safeguard the rights and ensure provision of requisite facilities to persons with disabilities and (iii) the National Trust Act (1999) to enable and empower people with autism, cerebral palsy, mental retardation and multiple disabilities. One needs to understand the causes of disability, needs and problems of children with disabilities to facilitate their inclusion in the mainstream society in all aspects. A society cannot declare itself modern and equitable, unless it makes sincere efforts to achieve equality in extending opportunities for all its less privileged citizens including the persons with disabilities.

15.8 GLOSSARY

Disability	: Restriction or lack of ability to perform an activity in the manner considered normal among human beings.
FAS	: Foetal Alcohol Syndrome.
ICF	: International Classification of Functioning.
Impairment	: Any loss or abnormality of psychological, physiological or anatomical structure or function.
WHO	: World Health Organisation.

15.9 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check Your Progress Exercise 1

- According to human rights perspective, disability can be defined as disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activities.

Check Your Progress Exercise 2

1.
 - i) impairment
 - ii) disability
 - iii) handicap

Check Your Progress Exercise 3

- 1) Following are the major areas covered under the list of reasons of disability by WHO:
 - i) Non-contagious somatic illnesses,
 - ii) Injuries/wounds,
 - iii) Malnutrition,
 - iv) Functional psychiatric disorders,
 - v) Chronic alcoholism and drug abuse,
 - vi) Congenital diseases, and
 - vii) Contagious diseases.

Check Your Progress Exercise 4

1. Following are the disabilities covered under PWD Act:
 - i) Blindness,
 - ii) Low vision,
 - iii) Leprosy-cured,
 - iv) Hearing impairment,
 - v) Locomotor disability,
 - vi) Mental retardation, and
 - vii) Mental illness

Check Your Progress Exercise 5

1.
 - i) False
 - ii) False
 - iii) False
 - iv) True

15.10 UNIT END QUESTIONS

1. How will you differentiate between disability and handicap? Explain with examples.
2. Describe the legislations and acts related to disability.
3. How will you create a disabled friendly society? Illustrate with the help of examples.

15.11 FURTHER READINGS AND REFERENCES

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UNIT 16 PERSONS WITH SENSORY IMPAIRMENTS

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16.1 INTRODUCTION

This Unit will provide you a broad overview of the concept and definition of sensory impairment and its rehabilitation and mainstreaming needs. The concept, identification and assessment, support services and various other related aspects of sensory disability have been explained in very objective terms. Besides above, this Unit deals with the identification based on common characteristics, and aids and appliances meant for the persons with sensory impairment. Here the types of sensory impairments such as hearing impairment, visual impairment including blindness and low vision and multi-sensory impairment as deaf blindness have been discussed in detail. The Unit is designed to cover various dimensions with a view to enable you to help and deal with the persons having sensory disability. These include management of the different aspects of rehabilitation.

After studying this Unit, you will be able to:

- Explain the concept and meaning of sensory impairment;
- Identify and assess the children and persons with sensory impairments; and
- Plan specific intervention with regard to the children and persons with sensory impairments.

16.2 CONCEPTS AND DEFINITIONS

Sensory impairment refers to difficulty either in seeing or hearing. There are different levels of difficulty; for instance, some people may not be able to hear at all while others will be able to hear partly and might use hearing aids. In the same way, a person could be totally blind or able to see partly. The following Section will help us in developing a clear understanding about the different types of sensory impairments, which include the following:

16.2.1 Hearing Impairment

The importance of hearing is known to everybody. You cannot imagine the agony faced by a persons, who has a problem in hearing or hearing impairment. Some important concepts related to hearing impairment are discussed below:

Hearing : Hearing is a process of detection, discrimination, recognition and comprehension of sounds.

Hearing impairment : Hearing impairment may be defined as any deviation or change for the worse in either auditory structure or auditory function. This may involve any defect in the hearing process due to hereditary or environmental factors. Owing to this impairment the child cannot use her or his hearing for ordinary purpose.

Hearing disability : Hearing disability is defined as the auditory problem experienced and complained by the individual. When the impairment reduces the child's functional potential and restricts her or his level of performance, it becomes a hearing disability.

The Persons with Disabilities Act, 1995, recognises having impairment as a disability, defining it as a loss of sixty decibels or more in the better ear in the

conversational range of frequencies.

Hearing handicap : Hearing handicap is the disadvantage for an individual resulting from the impairment or disability, which limits or prevents the fulfillment of a normal role depending on age, sex, and social and cultural

factors for the individual. The restriction imposed upon, or acquired by the individual affects the efficiency of her or his day-to-day life. For example:

1. A defect in the eardrum is impairment. It distorts the process of sound vibration and restricts the normal process of transfer of the message to the middle ear.
2. This distortion creates a disability in hearing as the normal process of hearing sounds cannot be performed.
3. The result is the loss of quality of life.

16.2.2 Visual Impairment

Vision is the most important sense required to observe and learn from what is happening in one's environment. Any type of impairment in vision not only creates problems in the learning process rather it disturbs whole development of the individual. Visual disability ultimately hampers the development of the child or person, especially her or his learning.

Broadly, visual impairment can be divided into two types. These are:

1. **Low vision:** Low vision means markedly reduced functional vision in the individual. Low vision may demand large print materials and magnifiers for reading. Recent technological advancement has facilitated better learning opportunities for low vision children. A person with low vision is one who has impairment of visual functioning even after treatment; for example an operation and/or standard refractive correction with glasses or lenses. The Persons with Disabilities Act, 1995, recognises low vision as a category of disability and defines it as follows:

“Person with low vision” means a person with impairment of visual functioning even after treatment of standard refraction.

2. **Blindness:** “Blindness” refers to a condition where a person suffers from total absence of sight or extremely limited field of vision or visual acuity not exceeding 6/600 or 20/200 in the better eye even with corrective lenses or limitations of the field of vision subtending an angle of 20 degree or worse.

16.2.3 Deaf Blindness

Deaf blindness is a dual sensory loss involving visual as well as auditory sense. According to the U.S. Federal law governing special education (Individuals with Disabilities Education Act – IDEA), the term “children with deaf blindness” means children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities. (PL101 – 476, 20 USC, Chapter 33, Section 1422 [2])

Check Your Progress Exercise 1

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Fill in the blanks:

- i) Sensory impairment refers to difficulty either in or hearing.
- ii) is a process of detection, discrimination, recognition and comprehension of sounds.
- iii) Persons with low vision mean a person with impairment of even after treatment of standard refraction.
- iv) Deaf blindness is a sensory loss.

16.3 IDENTIFICATION AND ASSESSMENT

There are different methods for identification and assessment of all types of sensory impairments. The identification can be done through common features or symptoms and through formal clinical methods.

16.3.1 Hearing Impairment

The child with hearing impairment can be identified with the help of the following methods:

During childhood it can be identified through the following symptoms or features:

- History of high risk factors,
- Absence of normal response to various sounds,
- Language development not seen even after one to two years of age,
- Attention on the lips of the speaker,
- Liquid discharge from ears, and
- Constant itch in the child's ear.

Hearing impairment at classroom level can be identified through:

- Lack of linguistic skills, normal for one's age,
- Difficulty in comprehension,
- Specific problem in reading and speaking,
- Slow mastering of language skills, and
- Asking for repetition frequently.

Assessment: Assessment of hearing impairment can be done to know the degree and type of hearing loss. This can be done in two ways. It is illustrated through following Fig. 16.1.

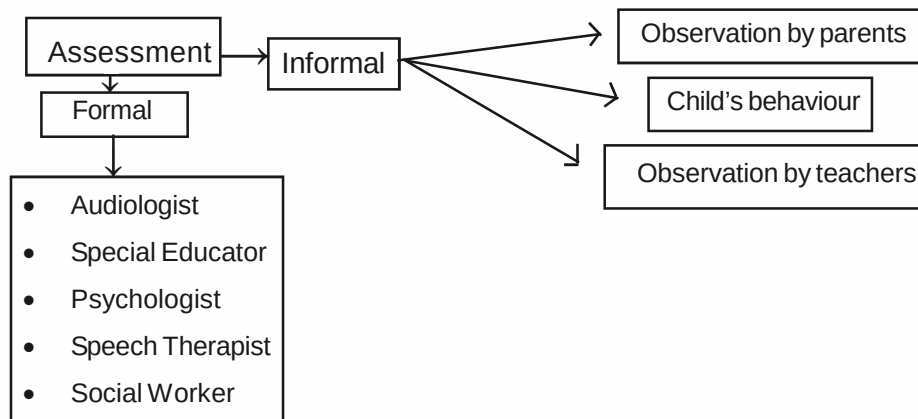


Fig 16.1 : Assessment of hearing impairment

The child showing one or more than one of the above mentioned signs and symptoms should be referred to an audiologist. The audiologist assesses the hearing loss using various audiological equipment like pure tone audiometer, speech audiometer, play audiometer, sound field audiometer, impedance audiometer, Brain Evoked Response Audiometry (BERA), etc. It is now possible to assess degree and type of hearing loss at an early age of the child.

Screening Audiological Tests for Infants and Children

There are a number of screening audiological tests depending upon the age of children. Let us discuss some of these tests:

1. Birth to Six Months

Infants with congenital or neonatal hearing loss can be identified using objective physiological tests such as the Auditory Brainstem Response (ABR) evaluations, or the Oto Acoustic Emission (OAE) before 3 months of age, and an intervention programme started soon thereafter. Both these tests are accurate, non-invasive and do not require any observable response from the infant. For the purpose of screening, both the methods are extremely effective.

- i) Auditory Brainstem Response (ABR):** In order to process sounds, electrical impulses are transmitted through nerves from our ears to the brainstem at the base of the brain. An auditory brainstem response (ABR) is a physiological measure of the brainstem's response to sound. It tests the integrity of the hearing system from the ear to the brainstem. The test is performed by fixing four to five electrodes on the infant's head, after which a variety of sounds is presented to the infant through earphones. As the hearing nerve fires, the sound stimulus travels up to the brain. This electrical activity generated by the nerve can be recorded by the electrodes and is represented as waveforms on a computer screen. The audiologist can then present different loudness levels of each sound and determine the softest levels at which the infant can hear. For infant screening purposes, only one sound is used to test the hearing, commonly referred to as a "click". The click is a grouping of several sounds to test a wider area of the hearing organ at one time. The click is typically presented at a loud level and a soft one. If a healthy response is recorded, then the infant has "passed" the hearing screen.
- ii) Automated Auditory Brainstem Response (AABR):** The automated auditory brainstem response (AABR) is another objective means of evaluating hearing. It is mainly used in many newborn-screening programmes. The

instrument is automated and provides a pass-fail report; no test interpretation by an audiologist is required.

- iii) **Otoacoustic Emission Test (OAE):** The otoacoustic emission test (OAE) measures an acoustic response that is produced by the inner ear (cochlea), in response to a sound stimulus. The test is performed by placing a small probe that contains a microphone and speaker into the infant's ear. As the infant rests quietly, sounds are generated in the probe and responses that come back from the cochlea are recorded. Once the cochlea processes the sound, neural impulses are sent to the brainstem. In addition, there is a second and separate sound that does not travel up the nerve, but comes back out into the infant's ear canal. This "byproduct" is the otoacoustic emission. The emission is then recorded with the microphone probe and represented pictorially on a computer screen. The audiologist can determine which sounds yielded a response or emission and the strength of those responses. If there is an emission present for those sounds that are critical to speech comprehension, then the infant has "passed" the hearing screen.

Both ABR and OAE tests have advantages and disadvantages when used for screening. The OAE is easy and cost effective. However, the false-positive rate (that is, an infant fails a hearing test but actually has normal hearing) may be higher for an OAE than for an ABR. The two tests, however, rely on different mechanisms of hearing for the screening. For in-depth testing and a complete hearing evaluation of infants, these tests work best together as a complement to each other.

2. Six Months to Two Years

Conditioned Oriented Response (COR) or Visual Reinforcement Audiometry (VRA): Children as young as six to 12 months of age can be screened using conditioned oriented responses or visual reinforcement audiometry. These are the behavioural tests measuring responses of the child to speech and frequency-specific stimuli presented through speakers. Both the techniques condition the child to associate speech or frequency-specific sound with a reinforcement stimulus, such as a lighted toy. However, these tests do not give ear-specific results.

3. Two Years to Four Years

Play audiometry is a behavioural test aimed at measuring the auditory thresholds in response to speech and frequency-specific stimuli presented through earphones or bone vibrator. The child is conditioned to put a peg in a pegboard or drop a block in a box when stimulus tone is heard. It gives ear-specific results and assesses auditory perception of the child. However, attention span of the child may limit the amount of information obtained.

4. Four Years to Adolescence

Conventional Pure Tone Audiometry is a behavioural test measuring auditory thresholds in response to speech and frequency-specific stimuli presented through earphones or bone vibrator. The child is instructed to raise her or his hand when stimulus is heard. It gives ear-specific results and depends on the level of understanding and cooperation of the child.

16.3.2 Visual Impairment

When prevention of disability is not possible, cure becomes the objective. When cure is not possible, rehabilitation becomes the goal. Identification and assessment help a great deal in facilitating rehabilitation of the blind and those with low vision. The assessment of disability and identification of children or persons with visual disability may be based on the common features, informal methods such as direct observation and formal procedures with the help of some assessment tools. The details in this respect are given below:

Common features: Visual impairment may be identified with the help of common features as mentioned below:

Blindness

- Child tilts her or his head to locate the light source,
- Pain and irritation in the eyes,
- Bumps into objects in the environment,
- Unable to write from the blackboard, takes help from peers to copy from the blackboard,
- Poor performance in the class,
- Unable to read in poor lighting conditions,
- Unable to see during night,
- Depends too much on oral information,
- Rubs eyes excessively,
- Watery eyes,
- Eyelids are often red,
- Holds objects and the book too close to eyes,
- Squints or blinks when looking at something,
- Blinks more frequently, and
- Regular headaches.

Low Vision

- Confident movement in school environment,
- Visual orientation to the new stimuli,
- Light gazing,
- Avoidance response to shadows,
- Interested in visual games,
- Avoidance of large obstacles,
- Unusual head tilt,
- Flickering,

- Distracted by movement in the environment,
- Startled response to suddenly approaching objects,
- The child experiences difficulty in reading small prints,
- The child experiences difficulty in identifying small details in pictures or illustrations,
- The child frequently complains of dizziness after reading a passage or completion of assignments involving vision, and
- The child frequently complains of headache, infection in eye; the child uses one eye more than the other.

Informal Methods of Assessment

There are some informal methods to identify visual impairment. These are simple methods and activities that parents and teachers can use in the classroom for assessing visual problems of the child, if any.

Direct Observation

- Light perception of difference between sunlight and dim light,
- Light perception of difference between good light and poor light in a class,
- Tracking of light,
- Detecting hand movement,
- Distance of detecting hand movement,
- Finger counting: Fingers raised one at a time,
- Finger counting: Fingers spread apart,
- Finger counting (General): Fingers closed together,
- Finger counting inside the classroom with good lighting condition,
- Finger counting inside the classroom with poor lighting condition,
- Visual background,
- Colour detection,
- Visual closure,
- Form constancy,
- Eye-hand coordination,
- Eye-foot coordination,
- Print size preference without magnifiers,
- Print size preference with magnifiers,
- Time taken to read a passage in mother tongue or English,
- Ability to write, and
- Writing speed.

Formal Methods of Assessment

The assessment of visual problems requires teamwork of educational, medical and other personnel such as volunteers and health workers. The teamwork consists of vision screening of all children, continuous classroom observation for behavioural and physical symptoms, and extending referral services for identified children for comprehensive eye examinations. An adequate programme of identification requires carrying out of each step in a carefully planned systematic manner.

Some children may be handicapped due to the restriction of the field of vision. The *field of vision* is the entire area which can be seen while the eye remains fixed upon one point in straight line. When the widest angle of the central field is restricted to 20 degrees or less in the better eye with correction, the person is considered *legally blind*, even though she or he is usually able to read ink print materials.

Assessment Tools

These are commonly used tests to measure the extent of visual functioning and are discussed in brief in this sub section.

Snellen test and visual field tests: These tests are used to measure visual acuity and visual field.

Muscles Balance Tests: For testing muscle balance, special instruments are used. The most common tests are:

- **Maddox Rod Test:** This test is used to determine the postural position of the eyes when fusion is disrupted. This test yields excellent measurement of heterophoria and can also be used to detect heterophoria. The procedure calls for the presentation of a different image to each eye at the same time.
- **Allied Muscle Balance Test:** This test consists of a procedure in which the child wears specialised lenses while using a projector to place a red dot within a rectangle projected on a screen. This test may be difficult to teach to some children, and it requires fine motor control and eye-hand coordination.
- **Tests for Distant Vision:** The tests for distant vision will detect the child with hyperopia or far-sightedness. The hyperopic child usually sees quite well at a distance but must accommodate for near-vision task.
- **Plus Lens Test:** It is a more adequate test to detect hyperopia. The child's vision is checked on the Snellen chart or on one of the binocular instruments while he is wearing plus lenses mounted in a small, inexpensive frame. If the child can see the 20 feet line at 20 feet from the chart with both eyes while wearing these lenses, she or he should be referred.
- **Near Vision Testing:** Near visual acuity should be determined for children with low vision. Near vision information is of special importance for children with pathological defects where only distance visual acuity may be inadequate. Near vision is determined with one of several reading cards, which have either symbols, numerals or letters printed on them. The reading distance for low vision children and illumination should be recorded.

16.3.3 Deaf Blindness

All the methods applied for identification of hearing and visual disability that we have discussed earlier may be used in combination for identification of deaf blindness in the individual.

Check Your Progress Exercise 2

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. List the various common features based on which the persons having sensory impairment can be identified.

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2. What are the assessment tools used to measure visual functioning?

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16.4 CAUSES AND TYPES

There are many causes which directly or indirectly contribute to the development of sensory disability. Some causes are dominating contributors and some are supportive in the development. Let us now take a look at the causes and types of hearing loss, visual impairment and deaf blindness.

16.4.1 Hearing Impairment

The ear is the sense organ of hearing. It is mainly divided into three parts:

- a) Outer ear,
- b) Middle ear, and
- c) Inner ear.

The sound waves from the environment including speech enter the outer ear, strike on the eardrum, and make the tiny three bones in the middle ear vibrate. This results in the transfer of mechanical energy in the middle ear and then into electrical energy in the inner ear. Frequency and intensity analysis of sounds takes place in the inner ear. The electrical energy from the inner ear is carried to hearing area in the brain through auditory nerve and other complex auditory pathways for processing and interpretation of the meaning of the sounds.

The hearing loss can occur due to damage at any stage or in different parts of ear. The causes of hearing disability can occur at any time during the developmental period that is before birth, during birth or after birth. The causes before birth may

concern family history of childhood deafness, consanguineous marriages, illness during pregnancy, history of mother suffering from rubella during pregnancy and poor physical condition of the mother. The possible causes during birth are premature delivery, lack of oxygen during birth, absence of birth cry and low birth weight. The causes after birth are deformities of ear, nose, face and throat; infectious diseases (mumps, measles, meningitis, viral fever etc); injury to ear, exposure to loud sound and neglected ear discharge. Children with the above factors may be considered as high-risk children and their hearing assessment should be done as early as possible.

Higher the level of hearing sensitivity, greater the severity of hearing loss. Hearing loss may be mild, moderate, moderately severe, severe or profound:

- **Mild hearing loss (26 to 40 dB HL):** A child with mild hearing loss will have trouble hearing and understanding soft speech in a noisy background.
- **Moderate hearing loss (41 to 55 dB HL):** A child with moderate hearing loss will have difficulty in hearing conversational speech.
- **Moderately severe hearing loss (56 to 70 dB HL):** A child with moderately severe hearing loss will have difficulty in hearing conversational speech even at close distances.
- **Severe hearing loss (71 to 90 dB HL):** A child with severe hearing loss may only hear loud environmental sounds.
- **Profound hearing loss (91 dB HL and above):** A child with profound hearing loss may only hear very loud environmental sounds.

The types of hearing loss are as follows:

- i) **Conductive hearing loss:** Hearing loss due to any problem in the outer ear and/or middle ear can lead to conductive hearing loss.
- ii) **Sensory neural hearing loss:** Hearing loss due to any problem in the inner ear and/or auditory nerve is termed as sensory-neural hearing loss.
- iii) **Mixed hearing loss:** Hearing loss due to any problem in the outer and / or middle ear including inner ear is termed as mixed hearing loss.
- iv) **Central hearing loss:** The hearing loss due to defects in central auditory processing is termed as central hearing loss. The child can hear the sound but has problem in understanding and interpreting the speech and language.
- v) **Functional hearing loss:** This is hearing loss when there is no anatomical and physiological abnormality in the auditory system but the child has problem in hearing due to malingering or psychological problems.

16.4.2 Visual Impairment

VISION 2020 has identified many causes of avoidable blindness, among which five conditions have been identified for immediate priorities on the basis of the burden of blindness they represent and the feasibility and affordability of interventions to prevent and treat them. These are cataract, trachoma, onchocerciasis, childhood blindness, and refractive errors and low vision. Other disorders, such as glaucoma and diabetic retinopathy, at present do not meet all these criteria, but are likely in the future. Let us discuss some of the common causative conditions:

- **Cataract:** It refers to a clouding of the crystalline lens of the eye and stands out as the first priority amongst the major causes of blindness. Today, an estimated 20 million people are blind from this condition. Cataracts are not generally amenable to prevention but currently available surgery can restore near normal vision in a large proportion of those who suffer from this condition.
- **Trachoma:** Trachoma remains the most common preventable cause of blindness in the world. Trachoma is common in areas of the world that are socio-economically deprived of basic needs in housing, health, water and sanitation including India.
- **Childhood blindness:** Childhood blindness is caused mainly by vitamin A deficiency, measles, conjunctivitis in the newborn, congenital cataract and retinopathy of prematurity (ROP).

Other causes of childhood blindness that are congenital, or genetically determined, do not generally lend themselves easily to preventive strategies at present.

Childhood blindness is considered as a priority area, because of the number of years of blindness that ensues. Its developmental implications are tremendous.

16.4.3 Deaf Blindness

To know more about deaf blindness let us understand the four groupings of individuals who are deafblind.

1. **Congenitally deafblind:** Individuals who are born with vision and hearing losses.
2. **Congenitally deaf, adventitiously blind:** Individuals who are born with deafness and later acquire blindness.
3. **Congenitally blind, adventitiously deaf:** Individuals who are born with blindness and later acquire deafness.
4. **Adventitiously deafblind or acquired deafblind:** Individuals who are born with hearing and vision senses but later lose both the senses in varying degrees and at different times.

Check Your Progress Exercise 3

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. List the types of hearing loss.

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2. What are the major causes of avoidable blindness identified by VISION 2020?

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16.5 INTERVENTION

Intervention is a major and important aspect of rehabilitation process. It is a team approach, in which the role of parents, family members and community people are equally important. Let us now take a focussed look at intervention in the case of sensory impairment.

16.5.1 Hearing Impairment

Approximately 1 of every 1,000 children is born deaf. Many more are born with less severe degrees of hearing impairment, while others develop hearing impairment during childhood. Reduced hearing acuity during infancy and early childhood interferes with the development of speech and verbal language skills. Although less well documented, significantly reduced auditory input also adversely affects the developing auditory nervous system and can have harmful effects on social, emotional, cognitive and academic development, as well as on a person's vocational, and economic potential. Moreover, delayed identification and management of severe to profound hearing impairment may impede the child's ability to adapt to life in a hearing world or in the deaf community.

The family members who have just come to know that their child has a hearing loss typically have no prior experience or information about what this means for their child and family. Since more than 90 per cent of the parents with a child who is deaf or hard of hearing are themselves able to hear, the news often comes as a complete surprise. Although parents react to the identification of their child's hearing loss in many different ways, they often need support as they adjust to this new and unexpected information. Parents want information about their child's hearing abilities, how to communicate clearly, and how they can enhance their child's development. Early intervention services provide families with support and information that promote the family's abilities to support their child's growth and development, keeping in mind the special needs of the child. The intervention in the case of hearing disability consists of language and speech therapy, behaviour therapy, family counselling and fitting of hearing aid and ear mould.

The most important period for language and speech development is generally regarded as the first 3 years of life and, although there are several methods of identifying hearing impairment during the first year, the average age of identification in the United States remains close to 3 years and even higher in India. Lesser degrees of hearing loss may go undetected even longer. The result is that for many hearing-impaired infants and young children, much of the crucial period for language and speech learning is lost. There is general agreement that hearing impairment should be recognised as early in life as possible, so that the remediation process

can take full advantage of the plasticity of the developing sensory systems and so that the child can enjoy normal social development.

During the past 30 years, infant hearing screening has been attempted with a number of different test methods, including cardiac response audiometry, respiration audiometry, alteration of sucking patterns, movement or startle in response to acoustic stimuli, auditory brain stem response (ABR) audiometry has been the method of choice. More recently, attention has turned to the measurement of evoked otoacoustic emissions (EOAE), which show promise as a fast, inexpensive, non-invasive test of cochlear function.

Each method is effective in its own way, but technical or interpretative limitations have impeded its widespread application. Moreover, these approaches vary in their sensitivity, specificity and predictive value in identifying hearing impairment.

16.5.2 Visual Impairment

Following are some of the interventions for visually impaired persons.

1. Sensory Training

Many people believe that persons with visual impairment have God given abilities in using their senses but it is not true. The abilities of the senses will not develop unless they are specifically trained. As sighted persons tend to rely mostly on the vision, the other senses are not used to the optimum level whereas a visually impaired person is compelled to use other senses. Therefore, proper training in the use of the remaining senses becomes vital. The ability to use the senses enhances the orientation and mobility skills of the child too as concepts like landmark, clue, etc., that we use in the mobility training help the child to understand the environment better. Therefore, systematic development of the abilities to use the senses becomes an integral part of the training to the visually impaired child.

2. Orientation and Mobility

There are visually disabled individuals who are extremely capable of moving independently without any physical assistance in a known environment. Such individuals have a complete control over things in the environment and their judgement about the distance, direction, etc. of these objects and the relation to self may be remarkable. Visually disabled children are trained by teachers and mobility instructors to have safe, secure and graceful mobility skills. Persons with these abilities are able to move unassisted in known environment. Though this is commendable, the visually disabled individual must be encouraged to use a mobility device as it provides independence even in an unknown environment. The skills also differ between visually disabled person from birth and the one who has acquired blindness later in life.

To improve the mobility, visually impaired persons use the following:

- **Sighted guide travel:** We also come across visually disabled individuals who prefer to travel with the help of a sighted companion. Specific sighted guide techniques are necessary both for the guide and for the visually disabled individual. This technique has both merits and limitations. The visually disabled individual can feel safe and walk gracefully in the company of the sighted guide. On the other hand, if the sighted guide is the only helper in travel, the visually disabled individual will be developing dependence which is not conducive for her or his overall development.

- **Long cane technique:** The long cane which is popularly known as the 'white cane' is widely used by visually disabled individuals. The cane can help in finding surfaces of different textures, stairs, etc. Visually disabled person should use certain clues and landmarks while using long cane for independent travel.

3. Daily Living Skills

Daily living skills may be treated as basic survival skills. These are the abilities which enable the visually impaired children to carry on their daily routine without assistance or with minimum assistance. Development of these abilities instills confidence in the children for their mainstreaming with non-disabled children. It is often misunderstood that loss of sight means darkness and incapacity in life. Research studies strongly indicate that it is not true. Daily living skills develop in an individual only by practice and therefore, adequate practice should be given to the child.

Now, the main question that arises here is, "What is to be done for developing daily living skills?"

In daily life, the individual comes across a wide range of events. Combing the hair may be a minor activity compared to preparation of a complete meal but both are important in their own ways. How to teach such activities to the unseeing person is a vital and formidable task. Alternative strategies have to be worked out if the usual techniques fail. Besides, the strategies and instructional procedures, criteria for performance assessment are also needed. Therefore, diagnosis of areas, development of strategies, and evaluation of performance of daily living skills are equally important. There are no special daily living skills for visually impaired children. Whatever skills are expected of a sighted person, the same are also expected of a visually impaired person. Therefore, considering skills of sighted children as reference, may help in planning better strategies for teaching daily living skills to visually disabled children. The six-stage strategy in teaching daily living skills may be as follows:

- i) Observation of the daily living skills exhibited by sighted children at various grade levels,
- ii) Diagnosing the difficulties faced by visually disabled children in acquiring those skills in a natural manner,
- iii) Designing pre-requisite skills after necessary diagnosis of difficulties encountered by visually disabled children,
- iv) Teaching those readiness skills which lead to the learning of daily living skills,
- v) Preparing evaluation criteria to measure the level of acquisition of daily living skills, and
- vi) Evaluating the performance of the children in daily living and suggesting appropriate remedial measures.

Daily living skills in an individual are vital ingredients for proper social development. The skills should be in accordance with the norms of any society. The absence of sight in the visually disabled person imposes a restriction on acquiring information

of the world in a natural way. This area needs to be strengthened in the overall curriculum of visually impaired children in schools and in rehabilitation programmes. Teaching these skills to visually disabled children may be difficult but not impossible.

16.5.3 Deaf Blindness

As the popular sayings state ‘early intervention is the best prevention’ or ‘prevention is better than cure’.

It is vital for medical professionals to be sensitive to their role as the medical care provider on the team promoting rehabilitative therapies for children with disabilities. Medical professionals can help in creating an environment in which the physician, family and other service providers work together in a caring, collegial, and compassionate atmosphere that ensures that early intervention services are of high quality, accessible, continuous, comprehensive and culturally competent.

Some of the early interventions that can be used for persons with both visual and hearing impairments are discussed below:

- **Pharmacotherapy:** Physicians can recommend the appropriate medicine to the child after considering the condition of the child.
- **Therapeutics:** Physicians can play a vital role in guiding the therapists like physiotherapist, occupational therapist and/or speech therapist. They can suggest the therapist about the condition of the child, the prognosis, risks for associated disabilities and the effect of continuing drugs thereby affecting therapy decisions.
- **Clinical assessment:** Families of children with multiple disabilities need support in the area of clinical assessments from doctors. Complete and appropriate information in a simple manner about the child’s exact condition is a need for all family members. Appropriate diagnosis for sensory conditions, epilepsy, degenerative disorders, surgeries, biochemical reactions and so on is extremely important for families to cope with the every day needs of children with multiple disabilities. Often after a thorough check up and diagnosis, families have little idea on what to expect from their child in the future or their role in the child’s medical intervention. Interpreting the diagnosis in a simple and straight manner will help the parents to prepare as per the child’s medical needs.
- **Genetic counselling and family counselling:** This is a specialised area for medical professionals and more so in the area of multiple disabilities. Most causes for disabilities are related to genetic factors. A genetic test, analysis and counselling at the appropriate time will reduce the occurrence of children with multiple disabilities and impede the spread of the disability further.

16.6 LET US SUM UP

Sensory impairment refers to difficulty either in seeing or hearing. There are different levels of disability — some people may not be able to hear at all while others will be able to hear partly and might use hearing aids. In the same way a person could be totally blind or able to see partly. Sensory disability includes hearing disability, visual disability and deaf blindness.

When the impairment reduces the child's functional potential and restricts her or his level of performance, it becomes a disability. Hearing disability is defined as the auditory problem experienced and complained by the individual. Visual disability is of two types that is blindness and low vision. Blindness acuity refers to a condition where a person suffers from total absence of sight or extremely limited field of vision or visual acuity not exceeding 6/600 or 20/200 in the better eye even with corrective lenses or limitations of the field of vision subtending an angle of 20 degree or worse. Low vision means markedly reduced functional vision in the individual. Low vision may demand large print materials and magnifiers for reading. Recent technological advancement has facilitated better learning opportunities for low vision children. A person with low vision is one who has impairment of visual functioning even after treatment, for example an operation and / or standard refractive correction with glasses or lenses.

Assessment of hearing impaired child can be done by direct observation of behaviour and formal assessment with the help of audiologist, psychologist and speech therapist. On the basis of the degree of impairment, the hearing loss may be classified as mild hearing loss, moderate hearing loss, moderately severe hearing loss, severe hearing loss and profound hearing loss. The assessment and identification of children or persons with visual disability may be based on the common features, informal methods such as direct observation and formal procedures with the help of some assessment tools.

The causes of hearing disability can occur at any time of the developmental period that is before birth, during birth or after birth. The causes before birth may concern family history of childhood deafness, consanguineous marriages, illness during pregnancy, history of mother suffering from rubella during pregnancy and poor physical condition of the mother. VISION 2020 has identified many causes of avoidable blindness, among which five conditions have been identified for immediate priorities. The choice of these conditions is based on the burden of blindness they represent and the feasibility and affordability of interventions to prevent and treat them. These are: cataract, trachoma, onchocerciasis, childhood blindness, refractive errors and low vision. The intervention in the case hearing disability consists of language and speech therapy, behaviour therapy, family counselling and fitting of hearing aid and ear mould. For visual disability sensory training, orientation and mobility and training in daily living skills are important.

The intervention for deaf blindness includes, pharmacotherapy, therapeutics, clinical assessment, and genetic and family counselling are very important.

16.7 GLOSSARY

Central hearing loss	: Hearing loss due to defects in central auditory processing.
Field of vision	: The entire area which can be seen while the eye remains fixed upon one point in straight line.
Mixed hearing loss	: Hearing loss due to any problem in the outer and / or middle ear including inner ear.
Sensori-neural hearing loss	: Hearing loss due to any problem in the inner ear and / or auditory nerve.

16.8 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check your Progress Exercise 1

1. i) seeing
- ii) Hearing
- iii) Visual functioning
- iv) dual

Check Your Progress Exercise 2

1. Visual impairment may be identified with the help of common features as mentioned below:

Blindness

- Child tilting her or his head to locate the light source,
- Pain and irritation in the eyes,
- Bumping into objects in the environment,
- Unable to write from the blackboard, takes help from peers to copy from the blackboard,
- Poor performance in the class,
- Unable to read in poor lighting conditions,
- Unable to see during night,
- Depending too much on oral information,
- Rubs eyes excessively,
- Watery eyes,
- Eyelids are often red,
- Holds objects and the book too close to eyes,
- Squints or blinks when looking at something,
- Blinks more frequently, and
- Regular headaches.

Low Vision

- Confident movement in school environment,
- Visual orientation to the new stimuli,
- Light gazing,
- Avoidance response to shadows,

Persons with Disabilities

- Interested in visual games,
 - Avoidance of large obstacles,
 - Unusual head tilt,
 - Hand flickering,
 - Distracted by movement in the environment,
 - Startled response to suddenly approaching objects,
 - The child experiences difficulty in reading small prints,
 - The child experiences difficulty in identifying small details in pictures or illustrations,
 - The child frequently complains of dizziness after reading a passage or completion of assignments involving vision, and
 - The child frequently complains of headache, infection in eye; the child uses one eye more than the other.
2. Following are the assessment tools used to measure visual functioning:
- i) Maddox rod test,
 - ii) Allied muscle balance test,
 - iii) Tests of hyperopia,
 - iv) Plus lens test, and
 - v) Near vision testing.

Check Your Progress Exercise 3

1. Following are the five types of hearing loss:
- i) Conductive hearing loss,
 - ii) Sensory neural hearing loss,
 - iii) Mixed hearing loss,
 - iv) Central hearing loss, and
 - v) Functional hearing loss.
2. Following are the five causes of avoidable blindness identified by VISION 2020:
- i) Cataract,
 - ii) Trachoma,
 - iii) Onchocerciasis,
 - iv) Childhood blindness, and
 - v) Refractive errors and low vision

16.9 UNIT END QUESTIONS

1. What are the symptoms and features indicative of hearing impairment in a child?
2. What are the identification processes for deaf blindness?
3. What are the interventions needed for visually impaired persons?

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UNIT 17 PERSONS WITH MENTAL RETARDATION

Structure

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- 17.2 Definitions and Classifications
- 17.3 Causes of Mental Retardation
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 - 17.3.3 Perinatal Causes
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17.1 INTRODUCTION

Mental retardation is a commonly heard word which refers to a person having below average intelligence. At all times, in all societies there have been persons mental retardation. Mental deficiency was a term which was earlier used. *Mental retardation* means that the person has limited mental functioning like understanding, following instructions, memory, recall, communicative abilities, and social skills. Such persons may be dependent on others and/or may be less capable to take care of themselves. Because of so many limitations, a child with mental retardation is slow in learning social skills and intellectual work. Such children may take longer time than a normal child to speak, walk, take care of themselves, be toilet trained, learn alphabets and concepts like numbers, time, money and much more. Such children would learn the skill but need much more practice and time than an average child. In this Unit, we will learn more about it.

After studying this Unit, you will be able to:

- Define mental retardation;
- Delineate the causes of mental retardation;
- Describe characteristics of persons with mental retardation; and
- Analyse the role of community in prevention, intervention and care of persons with mental retardation.

17.2 DEFINITIONS AND CLASSIFICATIONS

Mental retardation has been included in the Persons with Disabilities (PWD) Act (1995). According to the PWD Act (1995), mental retardation refers to a condition of arrested or incomplete development of mind of a person, which is specially characterised by sub normality of intelligence. Any mental disorder other than the mental retardation is mental illness.

The National Sample Survey Organisation (NSSO) in 2002 categorised mental disability into mental retardation and mentally ill persons. Persons with mental retardation were defined as those persons who have difficulty in understanding instruction, who do not carry out activities like others of their age group or exhibited behaviors like talking to self, laughing, crying and scaring, without reasons. Further for a person to be identified as having mental retardation it was stipulated that the above conditions must be either present since birth or childhood, or before the age of 18 years. Typically these persons are late in talking, sitting, standing or walking. On the other hand mentally ill persons may have difficulty in understanding instruction, or carrying out their activities like others of their age group and may exhibit abnormal behaviours like talking to self, laughing or crying, without reasons, but they do not possess these above conditions since birth or childhood and before 18 years of age. Moreover, they are not late in talking, sitting, standing or walking. The PWD Act recognises mental retardation and mental illness as two different types of disabilities. We will discuss about mental illness in the next Unit.

In this Unit, let us focus on mental retardation. Persons with mental retardation manifest subnormal cognitive, language, motor and social abilities. Thus, broadly speaking mental retardation may be referred to as a disability characterised by significant limitations in both intelligence and adaptive behaviour. This disability originates before 18 years of age.

World Health Organisation (WHO) classified disabilities through International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 2001. The document; referred to as the ICIDH – 2 and International Classification of Functioning, Disability and Health (ICF) gave the definition for mental retardation. This definition includes “any person who is unable to ensure himself or herself, wholly or partly, the necessities of a normal individual or social life including work, as a result of deficiency in his or her physical or mental capability”. It is a condition usually characterised by abnormal brain development in the womb that does not correspond with normal physical growth. The person’s learning ability,

reasoning power and judgement, all develop at a slower pace. Accidents, poisoning, or illness after birth can be a cause for mental retardation. Many of the persons with mental retardation can work with the non-disabled people with additional support and appropriate adaptations. They can be effectively integrated into the social structure. Mental retardation can be divided into the following four categories:

- Mild mental retardation (IQ : 50 - 70),
- Moderate mental retardation (IQ : 35-49),
- Severe mental retardation (IQ : 20-34), and
- Profound mental retardation (IQ : under 20).

The definition of mental retardation is given in the tenth revision of the International Classification of Diseases (ICD-10). It characterises mental retardation as a condition resulting from a failure of the mind to develop completely. It suggests that cognitive, language, motor, social, and other adaptive behaviour skills should be used to determine the level of intellectual impairment. The levels of mental retardation specified in ICD – 10 (Biasini, *et al.*, 2007) are:

- F70 - Mild mental retardation (IQ 50-69)
- F71 - Moderate mental retardation (IQ 35-49)
- F72 - Severe mental retardation (IQ 20-34)
- F73 - Profound mental retardation (IQ below 20)
- F78 - Other mental retardation
- F79 - Unspecified mental retardation

Other mental retardation, F78, should be used when associated physical or sensory impairments make it difficult to determine the degree of impairment.

Unspecified mental retardation, F79, should be used when there is evidence of mental retardation but not enough information to establish a level of functioning. (Biasini, *et al.*, 2007).

Wikipedia describes mental retardation as a generalised disorder, characterised by significantly impaired cognitive functioning and deficits in two or more adaptive behaviours that appears before adulthood. Historically it has been defined as an Intelligence Quotient score below 70. Now, however, the definition includes a component related to mental functioning as well as one relating to individuals' functional skills in their environment.

American Association on Mental Retardation (AAMR), that has in 2007 changed its name to American Association on Intellectual and Developmental Disabilities (AAIDD), now prefers to use the term “intellectual disability” rather than “mental retardation”. It defines intellectual disability as “a disability characterised by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behaviour, which covers a range of everyday social and practical skills. This disability originates before the age of 18”.

The ‘Text Revision’ of the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM - IV TR) divides mental retardation into mild, moderate, severe and profound categories on the basis of intelligence quotient (IQ) derived from intelligence tests.

The categories of mental retardation described under DSM-IV TR are given below:

Category	Range of IQ
i) Mild mental retardation	- 50-55 to approximately 70
ii) Moderate mental retardation	- 35-40 to 50-55
iii) Severe mental retardation	- 20-25 to 35-40
iv) Profound mental retardation	- Below 20 or 25

The diagnosis on DSM-IV TR is entered on Axis II and for some problems like autism, bipolar disorder, and schizophrenia, the diagnosis is entered on Axis I.

With “intelligence quotient” or “IQ” being referred to so frequently, let us take a look at what the term means.

Alfred Binet (1973) introduced the concept of mental age. According to him, majority of children of a particular age are of normal intelligence and have mental level approximating that age. Thus, their *mental age* approximates their chronological age. From Binet’s work the phrase “intelligence quotient” or “IQ”, entered the vocabulary. The IQ is the ratio of “mental age” to chronological age. William Stern (1976) suggested multiplying this ratio by hundred so as to avoid fractions. Intelligence quotient (IQ) is hence calculated as follows:

$$IQ = \frac{MA}{CA} \times 100$$

where IQ is Intelligence Quotient

MA is Mental Age

CA is Chronological Age

Therefore, if the mental age of a person is the same as his or her chronological age, the IQ of the person would be 100.

Educational classifications of mental retardation (e.g. Biasini, *et al.*, 2007) tend to classify children with mental retardation into three groups. These are:

- **Educable:** Children who can learn simple academic skills but not progress above fourth grade level.
- **Trainable:** Children could learn to take care of their daily needs but very few academic skills.
- **Untrainable:** Children who were dependent and considered in need of long term care at home or residential setting.

According to Elkind and Weiner (1978), persons with mental retardation are generally classified in four categories. These are given in Table 17.1:

Level of mental retardation	IQ Range	Categorisation	Characteristics of the persons
Mild	55-69	Educable	These people may lag behind somewhat in their early development, but they are seldom identified as retarded until they enter elementary school. These children are also called <i>slow learners</i> at school.
Moderate	40-54	Trainable	These people lag behind noticeably in developing communication and motor skills during the preschool years and usually cannot master useful academic skills.
Severe	25-39	Untrainable or Custodial	These people usually cannot take care of themselves and require institutionalisation, usually early in life. They may learn basic self-care skills as feeding and dressing. They need total nursing care themselves.
Profound	Below 25	Dependent throughout life	They may not be able to feed themselves, control their bowels movements or walk.

Table 17.1: Classification of persons with mental retardation according to educational retardation

Luckasson *et al* (1992) emphasised on the level of the support needed by the person with mental retardation. Intensity of support or level of support is measured as intermittent, limited, intensive and pervasive, which may be described as follows:

- *Intermittent support* refers to support that is needed but not necessarily present at all times;
- *Limited support* refers to support to be provided on a regular basis for a short period of time;
- *Extensive support* refers to ongoing and regular involvement of support to the person; and

- *Pervasive support* refers to support that is constant and of high-intensity. It involves more staff members and is provided across environments.

These terms are related to mild, moderate, severe and profound categories of mental retardation, and emphasise the necessary support for the individuals (Kirk *et al*, 2006).

Check Your Progress Exercise 1

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. How has “mental retardation” been defined in the Persons with Disabilities Act (1995) of our country?

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17.3 CAUSES OF MENTAL RETARDATION

Mental retardation could be caused due to various factors. It could be a result of injury, disease, brain abnormality, genetic disorder, malnutrition, etc. At times, the cause of mental retardation is unknown. The various known reasons for mental retardation are discussed below.

17.3.1 Genetic Factors

Mental retardation could be caused by genetic factors that the child inherits from the parents in the form of chromosomes and genes. In a normal human being, there are 46 chromosomes or twenty-three pairs of chromosomes, of which twenty-two pairs are called *autosomes* or *non-sex chromosomes* and the twenty third pair consists of *sex chromosomes*. Chromosomes are made of genetic material called *genes*. Each gene within these pairs of chromosomes has a duplicate gene on the matching chromosome (details of this you have read in Course MCFT-001, Unit – 2). Deformities may occur during the formation of ovum or sperm. The error occurs when the process of meiosis takes place. The resultant mental retardation conditions are:

1. **Down Syndrome:** Down syndrome is also called mongolism. The person has an extra or deviant chromosome. Down syndrome individual has 21st chromosome genetic disorder. Down syndrome is named after the physician who first described it. This is of three types:
 - i) **Trisomy 21:** In this, there is an extra 21st chromosome. Instead of having a pair of 21st chromosome, the person has a triplet of 21st chromosome causing a condition called trisomy.

- ii) **Mosaicism (Mosaic type):** In this the person shows trisomy 21st only in a portion of the analysis of blood or skin cells and the rest shows normal 46 chromosomes. So, some parts of the body have faulty development while the other body parts have normal development.
 - iii) **Translocation:** In this, extra chromosomal material, that is, whole or part of chromosome is attached to another chromosome. In simple words, all or part of the extra chromosome of the twenty-first pair becomes attached to another chromosome pair.
2. **Phenylketonuria (PKU) :** It involves the inability of the body to convert an amino acid – phenylalanine found in protein foods to tyrosine due to lack of the enzyme needed for the purpose. The accumulation of phenylalanine leads to abnormal brain development and may result in severe mental retardation. A special low protein diet helps to reduce and improve this condition.
 3. **Tay–Sachs disease:** It happens when both mother and father are carriers of this disease. It results in progressive brain damage and eventually death of the person.
 4. **Cri-du-chat syndrome or Prader-Willi syndrome:** It is an autosomal abnormality and is caused due to deletion of 4th – 5th chromosomes.
 5. **Fragile X Syndrome:** It happens from a mutation on the long arm of the X chromosome, and it affects about twice as many males as females – about once in four thousand (Kirk *et al*, 2006). Fragile X syndrome is the most common form of inherited mental retardation.

Other reasons for mental retardation could be:

- Trisomy 13-15
- Trisomy-18
- Klinefelter syndrome
- Turner syndrome
- Triple X syndrome

You would recollect reading about some of these factors in Unit-2 of Course MCFT-001.

17.3.2 Prenatal Causes

The mal-development of the embryo or foetus resulting in mental retardation occurs due to the following factors during pregnancy:

- German measles (Rubella) in the first trimester (first three months) of pregnancy,
- Toxemia,
- Syphilis,
- Influenza,
- Encephalitis,

- Incompatibility between the Rh factor and blood group of the mother's blood and that of the foetus.
- Consumption of alcohol during pregnancy leads to foetal alcohol syndrome(FAS).
- Smoking (nicotine), coffee (caffeine), tea (tannins) have a harmful effect on foetus,
- Heavy metals like lead, cadmium, mercury affect the prenatal development of human brain,
- Drugs both medicinal and non-medicinal like cocaine, opium, smack etc. have a harmful effect on the growing foetus,
- Radiation like X-rays, etc. are quite harmful to the foetus, and
- Oxygen deprivation to the foetus or embryo leads to depletion of brain cells and therefore, mental retardation.

17.3.3 Perinatal Causes

The perinatal causes are the factors that result in mental retardation during the birth process. These are given below:

- During the birth process, lack of oxygen (called *anoxia*) to the central nervous system results in mental retardation,
- Use of forceps during birth may fracture the skull and cause brain damage, and
- Neonatal jaundice.

17.3.4 Postnatal Causes

Postnatal causes are also known as after birth factors that can lead to mental retardation. These are listed below:

- Illness like meningitis, encephalitis, whooping cough or measles,
- Asphyxia under anesthesia or from drowning or cardiac arrest may lead to permanent brain damage,
- Malnutrition and lack of protein during early childhood years has an adverse effect on intellectual functioning, and
- Niemann - Pick disease is a disorder of lipid metabolism during early infancy which may cause mental retardation.

17.3.5 Other Conditions

There are some other conditions also that may cause mental retardation, these are:

- **Cranial anomalies:** In this, there are alterations to the size and shape of the head. It is of three types:
 - a) *Macrocephalus* : In this, there is an abnormal increase in the size and weight of the brain.

- b) *Microcephalus* : In this, there is a decrease in the size and weight of the brain.
 - c) *Hydrocephalus* : In this, a rare disorder, there is an abnormal amount of cerebro-spinal fluid within the cranium causing its enlargement and damage to brain tissue.
- Head injury,
 - Stroke,
 - Iodine deficiency,
 - Severe sensory deprivation,
 - Severe atypical parent-child interactions, and
 - Psycho-social disadvantage like poor diet, poor health practices, poor housing, and use of such language which is not common in the community.

Check Your Progress Exercise 2

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Fill in the Blanks:

- i) In, the presence of an extra 21st chromosome leads to mental retardation.
- ii) The inherited inability of the body to convert phenylalanine leads to
- iii) Lack of oxygen at the time of birth is called.....

17.4 TESTS FOR DIAGNOSIS

Mental retardation is diagnosed mainly through assessment of :

- **Intelligence Quotient (IQ) of the child:** In this, the child's ability to think, learn and solve problems is tested on various intelligence tests.
- **Social adaptability of the child:** In this, an assessment is made of the child's ability to master the social skills that are necessary for independent living, including the child's learning of daily living skills such as dressing, toileting, feeding, etc; communication ability such as to understand what is told, to follow the instructions and give appropriate reply; and social skills necessary to mix with others in social groups like parents, family, teachers, peers and community.

One can diagnose mental retardation through use of the following tools.

Intelligence or Cognitive Developmental Assessment Tools:

Some of the commonly used intelligence or cognitive development assessment tools are given below:

- Bayley Scales of Infant Development (BSID) – Second Edition
- The Differential Ability Scales (DAS)

- Wechsler Preschool and Primary Scale of Intelligence – Revised (WPPSI-R)
- Wechsler Intelligence Scale for Children – Revised (WISC – R)
- Performance Intelligence Test Battery by Dr. C.M. Bhatia
- Indian adaptation of Wechsler Intelligence Scale for Children by A. J. Malin
- General Mental Ability Test by R.P. Srivastava and Kiran Saxena
- Seguin Form Board Test adapted by J. Bharat Raj and S.K Goyal for Indian Children.
- Stanford – Binet Intelligence Scale – Fourth Edition.
- McCarthy Scales of Children’s Abilities
- Draw A Man Test – Good Enough
- Draw A Man Test – Pramila Phatak
- Raven’s Progressive Matrices (RPM)
 - The Standard Progressive Matrices (SPM)
 - The Coloured Progressive Matrices (CPM)
 - The Advanced Progressive Matrices (APM)

Adaptive Behaviour Assessment:

To assess adaptive behaviour, the following scales are commonly used:

- Vineland Adaptive Behaviour Scales (VABS)
- The American Association on Mental Retardation (AAMR) Adaptive Behaviour Scale (ABS)

Achievement Tests:

Following achievement tests are also used to assess mental retardation:

- Woodcock-Johnson Psycho-Educational Battery – Revised.
- The Wide Range Achievement Test – Revised (WRAT-R).

Other Tests:

Some other test and scales that are useful in assessing mental retardation are given below:

- Peabody Picture Vocabulary Test – Revised (PPVT – R)
- Columbia Mental Maturity Scale
- Leiter International Performance Scale

Other Techniques to Assess Mental Retardation

In addition to standardised scales, tests and batteries there are some other techniques, which are useful for assessment of mental retardation. These are:

- Interviews
- Observations
- Informal assessment

Check Your Progress Exercise 3

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

- 1) What are the two key aspects that are assessed for diagnosing mental retardation in a child?

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- 2) Name two intelligence tests developed in India.

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- 3) Name two adaptive behaviour assessment scales.

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17.5 CHARACTERISTICS OF CHILDREN WITH MENTAL RETARDATION

Some of the characteristics of children with mental retardation have been grouped under physical characteristics, cognitive characteristics and behavioural characteristics in this section.

17.5.1 Physical Characteristics

Let us take a look at the physical characteristics commonly found among children with mental retardation. These characteristics include physical features, somatic development and motor abilities. Head circumference of children with mental retardation is often less than the normal children, which can be seen in the case of microcephalus. However, if the child has hydrocephalus, the head circumference is larger than normal as the head is filled with fluid. Children suffering from Down syndrome tend to have short and stout stature, thick fingers or club fingers and toes, moon shaped eyes, small nose, wide spacing between eyes, mouth usually open and fissures in the tongue, and saliva coming out of mouth.

Children with mental retardation generally have a clumsy gait and may also give blank looks. They may have hoarse or broken voice. The growth and development of these children follows the same developmental pattern as of normal children but their abilities are quite delayed, depending upon their mental age. Motor activities like walking on one line, jumping, hopping, etc. develop according to the mental or intellectual functioning of the child.

17.5.2 Cognitive Characteristics

Let us now consider the cognitive or mental or intellectual characteristics of children with mental retardation. These children cannot concentrate for long time and are unable to keep their attention on anything for long time. It is a major task to keep them occupied in one activity for a significant duration; say 15 to 20 minutes. Poor memorisation and forgetfulness is common among such children. They have very short term memory and rehearsing is poor among such children. They may have speech and language problems. As the level of retardation goes higher, language problem becomes severe. The capability of information processing, organising, classification, generalisation among these children is less developed as compared to a non-disabled child. In severe cases, the higher order of cognitive functioning is less developed. Higher mental abilities like decision making, analysis, synthesis, problem solving, cause and effect relationship, etc. are not present among these children.

The academic performance of these children is less than their normal peers. Understanding of concrete objects is present, but abstract thinking is not seen. They can follow verbal instruction which are repeated frequently, but they cannot memorise the instructions.

17.5.3 Behavioural Characteristics

The behavioral and personality characteristics of persons with mental retardation are different from their normal peers. They display difference in social and emotional behaviours which at times, results in social and emotional problems. Their self motivation level is low and they avoid leading and initiating any activity. They have low self-confidence. They cannot face challenges and easily give up. They have problems in social gathering and avoid situations which involve gathering of many people. They have low self-esteem and self concept. Their social interaction is limited. They may exhibit self injurious behaviours. They tend to engage in repetitive behavioral activities. Creativity among these children is low. They generally, prefer to play with children of lower age group than their age mates.

Check Your Progress Exercise 4

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. What are the physical characteristics of children with Down syndrome?

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17.6 ASSOCIATED DISORDERS

McLaren and Bryson (1987) said that a variety of disorders are associated with mental retardation like epilepsy, cerebral palsy, vision and hearing impairments, speech or language problems and behaviour problems. Baird and Sadovnick (1985) stated that the number of associated disorders appears to increase with the level of severity of mental retardation. We will discuss some of these disorders in detail in the next Unit.

Check Your Progress Exercise 5

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

- 1 State any four associated problems which persons with severe mental retardation may suffer from.

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17.7 PREVENTION

Some of the measures discussed below could help in preventing mental retardation to a large extent.

17.7.1 Genetic Counselling

Avoid late pregnancy as far as possible. One should go for genetic counselling as genetic factors make a significant contribution to mental retardation. Pre-natal assessment would prepare the new parents about the coming problems. We have discussed these tests and procedures in Unit 2 of Course MCFT-001. Consanguineous marriage should be avoided.

17.7.2 Prenatal Care

During pregnancy proper care of mother is important. Vaccination for German measles or rubella at least three months before conceiving is advisable. Proper nutrition and health care of the mother is necessary. Expectant mothers should avoid alcohol, smoking, drugs and irradiation as these are very harmful to the foetus as well as for their own health. Good nutritious diet needs to be given to the pregnant woman including dietary supplements like iron and calcium tablets. Proper medical care is equally important.

17.7.3 Postnatal Care

Proper medical facility at the time of birth should be present. Preferably, delivery of child should be done at hospitals or nursing homes or under the supervision of trained medical personnel. Immediate treatment of new born baby for jaundice should be given. Proper schedule of immunisation during childhood should be followed strictly. Care should be taken to prevent occurrence of head injuries and accidents. Food of good nutritive value should be given to young children. A nurturant and stimulating physical, social and mental environment should be provided to the child.

Check Your Progress Exercise 6

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. Write a short note on prenatal care.

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17.8 INTERVENTION

Appropriate interventions for the child with mental retardation are important for the child's optimum development, including social adjustment, psychological well-being and educational growth. Intervention has to be need based, that means depending on the needs and requirements of a particular child. Intervention can be given in a group of similar children with similar needs and problems like same IQ, social skills, adaptive behaviour etc. It has to be given in the least restrictive environment to the child. Professional trained educators and sensitised parents can teach and help the child with mental retardation. The child should be provided opportunities to interact with non-disabled peers and community members.

● Intervention for Infant

Counselling, family therapy, parent training, language services, assistive technology, intervention for sensory organs, nutrition counselling, occupational therapy and physiotherapy may be provided to the infant who is suffering from mental retardation. It could be home based or institution based.

- **Intervention for Preschool and School Child**

The services for preschool and school going child are mostly centre based. Individualised Education Plan (IEP) should be used even for children in the same classroom. Both parents and teachers coordinate with each other to maximise their child's learning and achievement. The intervention services mentioned for infant can also be used here.

- **Social Intervention**

Participation with non-disabled peers in social functions and family ceremonies like birthday party, sports, marriage, etc. benefit in teaching appropriate social skills to the child with mental retardation. Parent support group meetings of children with mental retardation should be frequently held so that parents and/or caregivers get the opportunity to express their feelings, share experiences and learn from others' experiences.

- **Education for Children with Mild and Moderate Mental Retardation**

During early elementary school, emphasis is more on providing the children with readiness skills and development of abilities that are prerequisites for later learning. Hallahan and Kauffman (1991), said that these include such activities as the ability to:

1. Sit still,
2. Obey teacher,
3. Discriminate auditory and visual stimuli,
4. Follow directions,
5. Develop language,
6. Increase gross and fine motor coordination,
7. Develop self help skills, and
8. Interact with peers in a group situation.

- **Education for Children with Severe and Profound Mental Retardation**

Educational programmes for children with severe and profound mental retardation according to Hallahan and Kauffman (1991) should include the following:

1. Age appropriate curriculum and materials,
2. Functional activities,
3. Community based instruction,
4. Integrated therapy among a variety of professionals such as speech, physical and occupational therapists,
5. Interaction with non-disabled students, and
6. Family involvement.

Check Your Progress Exercise 7

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Outline school-level intervention strategies for the children with mild mental retardation.

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2. Write a short note on social intervention.

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17.9 ROLE OF COMMUNITY MEMBERS

Environment affects learning of all children – whether normal or those with mental retardation. Role of the community members hence become important. Community members dealing with a child with disability need to be more compassionate, patient and skillful in meeting the challenges of the child. Teachers and parents influence the child the most.

• Teachers

Special educators play a significant role for children with mental retardation. Many children go to normal schools and attend special classes. All schools follow, or should follow, an Individualised Education Programme 'IEP' to teach the child according to the child's unique abilities, needs and requirements. A well organised and structured classroom environment should be provided. Teachers need to motivate the child to learn. Tools, equipment and materials present in the classroom should be child friendly. Teachers can help the child learn things using concrete experiences and simple verbatim. Teachers should also involve children in group activities. Parents of these children should be taken into confidence and both parents and teachers should work together for the child's optimum growth. Both parents and teachers should follow the same educational plan at a given time. Repetition and reinforcement are two important methods of teaching a child with mental retardation.

• Parents

Parents need to overcome their shock and grief quickly to take care of their child with the disability. They should learn more about their child. Parents should consult counsellors and family therapist to help them to deal with this situation and develop

resilience to help their children realise their potential. They should encourage and motivate their child to do things rather than making the child dependent on themselves. They should include their child in family functions and celebrations. Parents should be in constant touch with the teachers. They should follow the same educational plan as of teachers. Repetition, reinforcement along with motivation, encouragement, providing opportunities to act and do are important teaching methods for the parents of the child who suffers from mental retardation. Parents should also participate in parent support groups to share their experiences, feelings and concern with others having similar difficulties. The stress among parents is high on discovery of the problem and also when the child reaches adolescence and adulthood. Rehabilitation through educational and vocational training should be done.

Check Your Progress Exercise 8

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. Write a short note on the role of parents in taking care of children with mental retardation.

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17.10 LET US SUM UP

- Mental retardation commonly means a person having below average intelligence. A person with mental retardation has limited mental or cognitive functioning, communication skills and social skills.
- Mental retardation is one of the disabilities mentioned in the Persons with Disabilities Act, 1995 (PWD Act, 1995) of India. According to the Act, mental retardation is a condition of arrested or incomplete development of mind of a person which is specially characterised by subnormality of intelligence.
- General categories of mental retardation are:
 - i) Mild retardation with IQ 50-70
 - ii) Moderate retardation with IQ 35-49
 - iii) Severe retardation with IQ 20-34
 - iv) Profound retardation with IQ under 20
- Mental retardation can be caused due to genetic factors, prenatal, perinatal and postnatal causes.

- Mental retardation can be diagnosed using intelligence tests and social adaptive ability tests on the child.
- A child with mental retardation lags behind the normal child in all the developmental domains and milestones like to sit, stand, walk, toilet training, speech etc.
- Children with mental retardation may suffer from other problems like epilepsy, cerebral palsy, vision and hearing impairments as well.
- Mental retardation in a child can be prevented by avoiding late pregnancy, adequate care and treatment during pregnancy, proper immunisation, avoiding head injuries etc.
- Interventions by educators, family counsellors, parent training and assistive technology are used to benefit children with mental retardation.
- Role of community members, teachers and parents is significant for the optimum development of a child with mental retardation.

17.11 GLOSSARY

Anoxia	: Lack of oxygen at the time of birth
CA	: Chronological Age
IEP	: Individualised Education Plan
IQ	: Intelligence Quotient
MA	: Mental Age
Mental retardation	: A condition of arrested or incomplete development of mind of a person which is specially characterised by sub normality of intelligence.
PKU	: Phenylketonuria
PWD Act	: Persons with Disabilities Act.

17.12 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check Your Progress Exercise 1

1. PWD Act (1995) defines mental retardation as a condition of arrested or incomplete development of mind of a person, which is specially characterised by subnormality of intelligence.

Check Your Progress Exercise 2

1. i) Down syndrome
ii) Phenylketonuria (PKU)
iii) anoxia

Check Your Progress Exercise 3

1.
 - i) Intelligence Quotient (IQ) of the child
 - ii) Social adaptability of the child
2. Following are two intelligence tests developed in India:
 - i) Performance Intelligence Test Battery by Dr. C.M. Bhatia
 - ii) General Mental Ability Test by R.P. Srivastava and Kiran Saxena
3. Following are two adaptive behaviour assessment scales:
 - i) Vineland Adaptive Behaviour Scales (UABS)
 - ii) The American Association on Mental Retardation (AAMR) Adaptive Behaviour Scale (ABS).

Check Your Progress Exercise 4

1. The physical characteristics of children with Down syndrome are:
 - i) Short and stout stature,
 - ii) Thick fingers or club fingers and toes,
 - iii) Moon shaped eyes,
 - iv) Small nose,
 - v) Wide spacing between eyes,
 - vi) Mouth is usually open and fissures in the tongue, and
 - vii) Saliva comes out of mouth.

Check Your Progress Exercise 5

1. Following are the associated problems which persons with severe mental retardation may suffer from (any four):
 - i) Epilepsy
 - ii) Cerebral palsy
 - iii) Speech and language problems
 - iv) Behavioural problems
 - v) Visual impairment
 - vi) Hearing impairment

Check Your Progress Exercise 6

1. During pregnancy proper care of mother is important. One should be vaccinated for German measles or rubella at least three months before conceiving. Proper nutrition and health care management of the mother is necessary. Expectant women should avoid alcohol, smoking, drugs and irradiation as these are very harmful to the foetus as well as for their own health. Good nutritious diet needs to be given to the pregnant woman including

dietary supplements like iron and calcium tablets. Proper medical care is equally important.

Check Your Progress Exercise 7

1. School-level intervention strategies for children with mild mental retardation include encouraging the child to:
 - i) Sit still,
 - ii) Obey teacher,
 - iii) Discriminate auditory and visual stimuli,
 - iv) Follow directions,
 - v) Develop language,
 - vi) Increase gross and fine motor coordination,
 - vii) Develop self help skills, and
 - viii) Interact with peers in a group situation.
2. Participation with non-disabled peers in social functions and family ceremonies like birthday party, sports, marriage, etc. benefit in teaching appropriate social skills to the child with mental retardation. Parent support group meetings should be frequently held so that parents and/or caregivers of the children with mental retardation get the opportunity to express their feelings, share experiences and learn from others' experiences.

Check Your Progress Exercise 8

1. Parents need to overcome their shock and grief quickly to take care of their child suffering from mental retardation. They should learn more about their child. Parents should consult counsellors and family therapist to help them to deal with this situation and develop resilience to help their children realise their potential. They should encourage and motivate their child to do things rather than making the child dependent on themselves. They should include their child in family functions and celebrations. Parents should be in constant touch with the teachers. They should follow the same educational plan as of teachers.

17.13 UNIT END QUESTIONS

1. How can you assess the child for mental retardation?
2. How can one prevent mental retardation?
3. What is the role of intervention in the life of a child with mental retardation?

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UNIT 18 MENTAL ILLNESS AND PSYCHOSOCIAL REHABILITATION

Structure

- 18.1 Introduction
- 18.2 Mental Illness and Disability
 - 18.2.1 Clinical Characteristics of Psychiatric Disability
 - 18.2.2 Prominent Severe Mental Illnesses
- 18.3 Psychosocial Rehabilitation
- 18.4 Historical Perspective
- 18.5 Magnitude of the Problem
- 18.6 Present Scenario
- 18.7 Strategies of Management in Psychosocial Rehabilitation
- 18.8 Legal Aspects, Advocacy and Community Participation
- 18.9 Role of Counsellor and Family Therapist
- 18.10 Let Us Sum Up
- 18.11 Glossary
- 18.12 Answers to Check Your Progress Exercises
- 18.13 Unit End Questions
- 18.14 Further Readings and References

18.1 INTRODUCTION

Mental illness is not a new term in the world of disability. It is seen that a person who is suffering from a severe mental illness is often unable to perform even daily routine activities. To overcome this condition, psychosocial rehabilitation is a good option along with the medicines. Psychosocial rehabilitation is a process to restore social functioning and wellbeing of a person who is suffering from mental illness.

We will learn about mental illness and the disability caused due to this, in this Unit. Further, we will study about psychosocial rehabilitation. We will get acquainted with the historical perspectives of services provided for mental illness and also study the magnitude of the problem. Proper strategies are required to manage the psychosocial rehabilitation in the area of mental illness. We will discuss these strategies in this Unit. Community participation is necessary for the success of psychosocial rehabilitation. We will learn how the family and the community can help the persons with mental illness. To conclude the Unit, we will discuss the role of the counsellor and family therapist in dealing with mental illness.

Objectives

After studying this Unit, you will be able to:

- Know about disability arising out of mental illness and its features;
- Learn what is psychosocial rehabilitation;
- Gain knowledge about historical aspect and magnitude of the problem;
- Explain existing provision of services for the mentally ill person; and
- Understand strategies of psychosocial rehabilitation of persons with mental illness.

18.2 MENTAL ILLNESS AND DISABILITY

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 has included “mental illness” in its ambit of definition of “disability”. According to the Act, “mental illness” means mental disorder other than mental retardation.

Mental illness is a term that describes a wide range of mental and emotional conditions. Mental illnesses causing disability are prolonged and chronic in nature. Now they are known as severe mental illnesses. Severe mental illnesses, which require psychosocial rehabilitation, include chronic schizophrenia, long standing bipolar illness, persisting depression, delusional disorders and dementias.

Disability arising out of severe mental illness is also known as *psychiatric disability*. This disability is defined as a substantial limitation in a major life activity (Lieberman, 1993). World Health Organisation (WHO) defines this disability as an inability to participate or perform at a socially desirable level in such activities as self care, social relationship, work and situationally appropriate behaviour.

18.2.1 Clinical Characteristics of Psychiatric Disability

Depending on age, gender, education, profession, income, sociocultural background, diagnosis, and other factors, severely mentally ill persons vary greatly in many respects. They do, however, have a number of features in common. These common features, usually seen among persons with severe mental illness, are categorised into three groups of handicapping factors namely intrinsic, extrinsic and secondary factors (Wing, 1978, 1981).

- **Intrinsic factors:** Intrinsic or primary factors consist of continuing psychiatric symptoms that are part of the illness itself, that is, thought disorder, delusions and psychomotor retardation. One to two thirds of discharged chronic schizophrenic patients are significantly disabled by psychiatric symptoms.
- **Extrinsic factors:** Extrinsic factors include premorbid handicaps such as lack of social or vocational skills and intellectual or physical disabilities. A number of researches have concluded that 20 to 50 per cent of severely mentally ill persons have no friends and only a minority has any significant community involvement. Those who are married and employed or who have an active social life are much less likely to join the ranks of a person with severe mental illness. Even when they do enter this category, they tend to function at a higher level than those who are single, unemployed or socially isolated.

- **Secondary factors :** Secondary factors represent maladaptive reactions to the illness rather than being part of the illness itself, and include loss of self esteem, low self-confidence, helplessness and passivity.

18.2.2 Prominent Severe Mental Illnesses

Two major severe mental illnesses namely chronic schizophrenia and bipolar affective disorder are primarily more prominently covered under the psychosocial rehabilitation of severely mentally ill.

- **Chronic Schizophrenia**

Clinical characteristics of prolonged schizophrenic illness or chronic schizophrenia are as follows:

- Chronic deteriorating course and
- Disorganised behaviour like, violence, inappropriate affect, self neglect, wandering and thought disorder.

From the management point of view, symptoms of schizophrenia are categorised into two groups; these are, positive symptoms and negative symptoms. *Positive symptoms* signify an excess or distortion of normal functions, whereas *negative symptoms* reflect a diminution or loss of normal functions (DMS-IV; APA 1994).

Negative symptoms are more difficult to treat and are more disabling than positive symptoms. The main features of positive and negative symptoms are listed in Table 18.1.

Table 18.1 : Features of positive and negative symptoms

Positive Symptoms	Negative Symptoms
Include distortion and exaggeration of: - Thinking and ideas (delusions), - Perception and sensation (hallucinations & illusions), - Language and communication (disorganized & bizarre speech), and - Behaviour self control (grossly disorganised).	Include losses or deficit in: - The range and intensity of emotional expression, - The fluency and productivity of thought and speech (alogia), and - The initiative of goal directed behavior (avolition).

- **Bipolar Affective Disorder**

Bipolar affective personality disorder (BAPD) often occurs in the form of episodes with intervening periods of normalcy and improvement. Further, cyclic episodes of mania and depression intermittently affect the victim. Phase of mania is characterised by elation-euphoria, overactivity, grandiosity, decreased need of sleep and interfering behaviour. During the phase of depression, one suffers depressed mood, psychomotor retardation, hopelessness, lack of energy, and decreased appetite and sleep.

During intervening periods some of the features seen are mild symptoms, irritability, mood fluctuations and psychosocial dysfunction.

A typical “chronically (currently, the term in use is severely) mentally ill” person might be expected to have (Bachrach, 1988):

- i) Diagnosis of schizophrenia or major affective psychosis;
- ii) At least two admissions in the last year or six months; and
- iii) Significant problems of functioning in at least two of the following areas:
 - Basic literacy,
 - Self care,
 - Financial support (including money management),
 - Housing (poor quality or unstable),
 - Lack of social support,
 - Lack of occupation or employment, and
 - Difficulties with close relationships.

In addition, they are likely to show:

- Poor compliance with prescribed medication,
- Some degree of drug or alcohol abuse,
- Difficulties in sustaining follow up and after care,
- Frequent crisis and re-admissions, and
- Significant history of self harm, self neglect or harm to others .

Social Security Administration of America identified four key areas of psychiatric disability (Liberman,1993). These are listed below:

1. Activities of daily living (for example, grooming, hygiene, maintaining a household, managing finances);
2. Social functioning (for example, with family, friends, community and in the workplace);
3. Concentration, pace and task persistence (ability to function for 6 to 8 hours without supervision); and
4. The ability to tolerate competitive work.

Check Your Progress Exercise 1

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Fill in the blanks:

- i) occurs in the form of episodes with intervening periods of normalcy and improvement.

- ii) is characterised by elation-euphoria, over activity, grandiosity, decreased need of sleep and interfering behaviour.
- iii) During periods of bipolar affective disorder, some of the features seen are mild symptoms, irritability, mood fluctuations, and psychosocial dysfunction.

2. What are the key areas of psychiatric disability?

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Let us now take a look at the crucial aspect of psychosocial rehabilitation in the case of mental illness.

18.3 PSYCHOSOCIAL REHABILITATION

Psychosocial rehabilitation is a process that facilitates the opportunity for the individuals who are impaired, disabled, or handicapped by a mental disorder to reach their optimal level of independent functioning (Rangnathan, 1999).

Psychosocial rehabilitation aims to provide the optimal level of functioning of individuals and societies, and minimisation of disabilities and handicaps, stressing individual's choices on how to live successfully in the community (Rangnathan, 1999).

Goals, Values and Principles of Psychosocial Rehabilitation: Mental health experts and organisations have outlined goals, values, and principles of psychosocial rehabilitation (Anthony *et. al.* 1983, Anthony *et. al.* 1990, Cnaan *et. al.* 1988, 1989, 1990 and IAPSRs, 1996). The goals, values and guiding principles identified, may be summarised as follows:

1. Goals

- i) **Recovery from mental illness** : It is a basic prerequisite of psychosocial rehabilitation in terms of symptom management. Compliance with medication plays an important role with the support of family and treating psychiatrist. Noncompliance of medication retards the process of psychosocial rehabilitation.
- ii) **Integration in the family and community** : It is a prominent goal to be achieved with all the efforts of psychosocial rehabilitation. Integration of person with severe mental illness in the family and community is the key determinant in the success of psychosocial rehabilitation.
- iii) **Better quality of life** : It needs to be ensured at par with members of the family and community through psychosocial rehabilitation services being rendered to the persons with severe mental illness.

2. Values

A rehabilitation professional actively involved in psychosocial rehabilitation follows certain values which facilitate achievement of goals in integrating the person with

severe mental illness in the family and in ensuring her or his better quality of life. These values are:

- i) Self determination,
- ii) Dignity and worth of every individual,
- iii) Capacity of every individual to learn and grow, and
- iv) Culture sensitivity.

3. Guiding Principles

Following are the important guiding principles of psychosocial rehabilitation:

- i) **Individualisation of services:** Psychosocial rehabilitation services should be planned to suit individual needs of the person suffering from severe mental illness according to his or her demographic characteristics (like age, gender, education, locale, socioeconomic status and cultural background), nature of illness and functional level in day to day work. Individual programme planning of psychosocial rehabilitation services for two persons with same diagnosis may differ in their individual rehabilitation needs of psychosocial rehabilitation services.
- ii) **Maximum involvement and due importance to be given to preferences and choices of person with severe mental illness:** In order to ensure maximum involvement, due importance should be given to choices and preferences of person with severe mental illness. Anything cannot be imposed on her or him in the name of psychosocial rehabilitation services.
- iii) **Normalised and community based services:** Scope for community based psychosocial rehabilitation services is wider, as this is known to be the door step service delivery with an intention to reach the unreached. Such services are not only in demand; rather, are known to be the need of the day, especially for greater reach in the rural areas for wider coverage of severely mentally ill population.
- iv) **Strength focus:** Severity of mental illness is likely to cause many losses. What has been lost due to severe mental illness should not be the primary concern. Remaining positive potentials in terms of cognition, emotion, motor activity level and social interaction of person with severe mental illness should be the focus of overall rehabilitation process.
- v) **Situational assessment:** Remaining positive potential has a situational dimension. Psychosocial milieu of the person (like family setup, work place, person's social living conditions etc.) may also need to be thoroughly understood to ensure favourable situational support.
- vi) **Treatment, rehabilitation, and integration through holistic approach:** Treatment, rehabilitation and integration into the community are linked; being integral part of each other. They should not be dealt with in isolation. Psychosocial rehabilitation for the management of severe mental illness should be a holistic approach.

- vii) **Ongoing, accessible, and coordinated services:** Psychosocial rehabilitation services should be coordinated in such a manner that they are not disrupted in between. They should be available with easy access as per the requirements of the persons with severe mental illness as continued care.
- viii) **Training of skills and vocational focus:** Severe mental illness undermines the individual's behaviour, performance, cognition and social interaction. Certain skill deficits are apparent in the major categories of severe mental illnesses. They are the focus of intervention in psychosocial rehabilitation. There is continuum of skill training in the process of rehabilitation, that is activities of daily living skills, social skills and lastly followed by vocational skills. Through acquisition of these skills vocational focus should be kept in mind to place the person in a remunerative job. This generates a feeling in the individual that she or he is also a productive member of the society.
- ix) **Environmental modification support:** At times modification in the environment facilitates the process of rehabilitation. Provision of support to such environmental modification should be available so that the same is flexibly used.
- x) **Partnership with the family:** The person with severe mental illness in the family is not the only sufferer; rather, the whole family is greatly affected due to severity of illness. This adds to the burden of caring on regular basis. Hence, the family needs to be involved as part of the process of psychosocial rehabilitation.
- xi) **Evaluative assessment with outcome oriented focus:** Evaluation of progress to ascertain the outcome of efforts of rehabilitation is necessary. Usually progress is disrupted due to relapse, which also makes evaluative assessment of outcome essential.

Check Your Progress Exercise 2

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. What are the goals of psychosocial rehabilitation?

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2. List the guiding principles of psychosocial rehabilitation.

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18.4 HISTORICAL PERSPECTIVE

Curative efforts have usually remained the focus of country's mental health services in the post independence era, although scanty efforts have been made in another priority area of psychosocial rehabilitation of severely mentally ill.

Early mental health services were centered around the mental hospitals of the country, which have gone through various (nearly 4 to 5) phases of development (Sharma & Chadda, 1996). Clinical management of cases was primary concern of these hospitals. Experiences are suggestive of the fact that a person suffering from mental illness is not brought to the mental hospitals until and unless her or his problems become dramatic and unmanageable. Thus, admission to a mental hospital was considered to be forced choice as a last resort. Due to stigma attached to mental illnesses prior to this admission, family used to make all possible efforts to manage the problem of mentally ill member with the help of local faith healers and doctors. Further, stigma plays significant role to the extent that in majority of mental hospitals it was observed that clients continued to stay even after recovery due to unacceptance by their families. This resulted in reduced availability of active treatment beds (Sharma & Chaddha, 1996).

An analysis of psychosocial characteristics of indoor cases under treatment in a leading psychiatric hospital of the country indicated that 60 per cent beds (269 out of total 450) were occupied by long stay clients suffering from chronic mental illness for more than two years. This analysis further concluded that nearly 54 per cent of total hospital strength required only opportunities for social learning and rehabilitation programmes (Gupta et al. 1996). Thus, out of nearly 20,000 beds available in 37 state run hospitals of the country, 50 per cent remain occupied by long stay clients (Gopinath, 2002). This shows that clinical management of clients, was major concern of mental hospitals. Apart from clinical management of clients some hospitals introduced activities to involve them in work related to recreation oriented activities, ward cleanliness, assisting as helper in kitchen in the name of rehabilitation (Gopinath, 2002). Hence, psychosocial rehabilitation is said to be non-existent (Gopinath, 2002) or still in infancy stage in India (Gopinath & Rao, 1994).

History of psychosocial rehabilitation can be traced back to community mental health movement (1950s) in the West, which strongly emphasised de-institutionalisation of clients in late 1950s and 1960s. It was done to promote community based management and encourage after care programmes, to facilitate clients to function optimally in the community.

Some positive efforts of this nature were also reported at that time in India which is not known only as anticipating factor of the present day existing psychosocial rehabilitation services of the country, rather said to be a landmark in this direction. In 1950s Professor Vidya Sagar involved family members in the treatment of mentally ill persons in 900 bedded hospital (Sharda Menon, 1996; Kapur, 2000). This helped in :

- i) Reducing hostility of the clients against their families,
- ii) Making day to day improvement distinctly visible to the relatives and
- iii) Reducing stigma (Kapur, 2000) attached to mental illness during those days.

Efforts of Dr. Vidyasagar, a psychiatrist from Rohtak, were able to prove that treatment of mental illness using drugs only is inadequate. Other psychosocial approaches, are also needed to manage. These approaches will enable a person who is suffering from chronic mental illness, to function optimally and to live in the community successfully. Final phase of development of mental hospitals in the country as reported by Sharma & Chaddha (1996) was seen in the post independence era (1974 onwards). By this time emphasis of Government of India (GOI) shifted from mental hospitals to creation of psychiatric departments in general hospitals and medical schools.

The growth and development of these general hospitals' psychiatric units (GHPU) brought a significant change in the mental health services of the country. This was referred to as a major revolution in the whole approach to psychiatric treatment (Wing, 1978). There was a greater acceptability of these units as a method of mental health delivery system. This also facilitated to a greater extent training of mental health professionals and research work. Thus, even during this phase of development of mental health services psychosocial rehabilitation was not focused sufficiently. However, a number of advantages of GHPU over traditional mental hospitals were able to prepare a foreground for the development of psychosocial rehabilitation services of the country. Some of the stated advantages of these services are listed below:

- a) General hospital psychiatric units (GHPU) are situated right in the community hence, they are easily accessible and approachable,
- b) Family and relatives can visit the client and a relative or family member can stay with patient,
- c) Stigma of mental hospitals nonexistent,
- d) No legal restrictions of admission or treatment, and
- e) Availability of other medical facilities in the same set up.

Reduced stigma, easy accessibility of experts and the clinics, and the provision to stay with disturbed client were some of the encouraging advantages that promoted psychosocial rehabilitation of the people in the family and community.

Another important landmark after emergence of GHPU was the community psychiatry movement in India, which began in early seventies. Main objectives of this movement were to incorporate mental health care into primary health care system. This programme was certainly able to take treatment into the community and this also brought into focus the need for psychosocial rehabilitation of the clients living in the community.

Subsequently, a well formulated National Mental Health Programme (GOI, 1982) could not be implemented at that time due to number of reasons (Srinivasamurthy, 1989). According to Gopinath & Rao (1994), at the governmental level, policy makers have not been able to devote serious attention to the development of rehabilitation services for the chronic mentally ill primarily due to economic constraints. However, mental health professionals, themselves, have to some extent, been complacent.

18.5 MAGNITUDE OF THE PROBLEM

Marked increase in the number of persons suffering from chronic mental illness has drawn the attention of professionals and State to cater to the needs of this population. “Our forgotten millions” is the apt remark (Agarwal, 1998), which signifies that we have paid inadequate attention to people suffering from mental illness. Professionals feel that this population has remained a neglected lot and now active action oriented efforts are needed to manage and rehabilitate this neglected population (Kulhara, 1997).

According to Kulhara (1997), nearly 3,00,000 and 1,05,000 cases of schizophrenia are added in a year in rural and urban population of the country, respectively. Out of these 40 to 60 per cent cases go through the phase of chronicity and suffer impairments and disabilities. These figures suggest that roughly 1,50,000 or more people suffering from schizophrenia are added every year to country pool of disabled schizophrenic population. A meta analysis of 13 epidemiological studies reported a prevalence rate of 2.7 per cent for schizophrenic and 12.3 per cent for affective disorder (Reddy and Chandrashekhar, 1999) which signifies urgent need to develop rehabilitation services for people suffering from chronic mental illness. Some earlier studies reported prevalence of schizophrenia from 2 to 3 per 1000 all over the world. Indian researchers have also reported prevalence rate ranging from 0.9 to 4.3 per 1000 (Sethi et al, 1967; 1972; Dube, 1970; Elnagar, 1971; Nandi et al. 1975). Rajkumar (1995) noted incidence of schizophrenia as 3 per 10,000 in urban areas. Above figures give an estimate that there will be approximately 2 million persons suffering from schizophrenia in the country at any given point of time.

Another disabling condition, affective disorders are now conceptualised as chronic illnesses and the earlier notion of a better prognosis is being replaced with the acceptance of the fact that very few patients of affective disorders have a single episode and majority have a chronic course (Stephens, 1978).

Overall reported prevalence and incidence figures suggest immediate need for psychosocial rehabilitation both in urban and rural areas with a nationwide service network to help people in the community suffering from chronic mental illness.

Check Your Progress Exercise 3

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. State ‘True’ or ‘False’ :

- i) Dr. Vidyasagar proved that treatment of mental illness using drugs only is inadequate.
- ii) Dr. Vidyasagar restricted family involvement in the treatment of mentally ill persons.
- iii) The general hospitals’ psychiatric units are easily accessible and approachable.
- iv) Affective disorders are now conceptualised as chronic illness.

18.6 PRESENT SCENARIO

Looking into the three areas, that are service, availability of manpower and research, it is evident that this significant area of mental health service, that is psychosocial rehabilitation has just been touched upon and many priority areas are still unexplored, in the Indian context.

In the Western countries, extensive efforts have been made to integrate persons suffering from chronic psychiatric illness into the mainstream of society. This includes drug compliance or medicinal management training, training in activities of daily living, social skill training and vocational rehabilitation. Another important development in the West is community mental health movement in the 1950s, which is usually known to be the origin of rehabilitation in psychiatry. Prior to 1950s care of chronically mentally ill was primarily institution based and custodial in approach. Much has been written about the long term deleterious effects of such care (Wing and Brown, 1970). This led to the “de-institutionalisation” of patients in the late 1950s and early 1960s. There was a growing realisation that people with major mental illness should be helped to maintain themselves in community and pharmacotherapy alone is inadequate for their management. A comprehensive system of care, encompassing a variety of therapeutic approaches is needed to enable chronically mentally ill persons to function optimally in the community.

In India, psychosocial rehabilitation is still a new area of mental health services. This has also remained a neglected area of Indian researchers. This is due to availability of only a few rehabilitation centres (like daycare centres, halfway homes etc.) in the country and greater reliance on medical model of treatment.

In a traditional Indian setup, unlike most of the Western societies, approximately 90 to 95 per cent of all chronically mentally ill are looked after by the family (Agarwal, 1998). India still lingers on to be an orthodox and traditional country in terms of family structure, ties and cohesiveness. Almost all our patients of chronic mental illness still live in family set up. Very few are in institutions for custodial care. Therefore, family is primarily the coping agency and significant adults in the family (for example, parents and spouse) are the primary caregivers. It has been shown that Indian families are accepting, less critical and hostile, and more involved than the families of patients of chronic mental illness in the West. However, despite this there is strong evidence that the presence of chronic mentally ill patient causes or results in considerable amount of burden to the family. The burden of care of patients of chronic mental illness is mainly felt in the areas of family finance (for example, the cost of treatment, cost of transport, follow-up visits, loss of earning, and loss of earnings of the caregiver due to the task of looking after patient), routine family activities and family leisure.

With increasing urbanisation, life style is undergoing rapid change. The nuclear family system and shrinking social networks combined with increasing financial strain is making it more difficult to care for an ill relative. Studies have documented that distress and burden of caring for an ill relative are high (Gopinath and Chaturvedi, 1992; Sam *et al.*, 1998) and disruptive of daily routine (Rao *et al.*, 1998). This is true for both rural and urban families (Mubarak Ali and Bhatti, 1988 ; Singh *et. al.* 2010; Chadda *et. al.*, 2007).

Aftercare services in the form of daycare centres, halfway homes or rehabilitation programmes are almost nonexistent in India, though an initiation in the field has taken place in some cities like Bangalore, Delhi, Ranchi and Madras (Pai & Kapoor, 1983; Gopinath & Rao, 1994).

In India, formulation of precise functional definition and quantification of psychiatric disability is still in the process. Some of the facts regarding the status of chronically mentally ill in India are as follows (Agarwal, 1998) :

- Roughly 0.5 to 15 per cent population will have certain disability, due to chronic mental illness,
- Barring a few thousand all others are living in the community,
- They are occupationally impaired. Their family and personal life is in shambles,
- Most of these patients are either maltreated or untreated,
- There are roughly 35,000 psychiatrists and most of them are concentrated in large towns or in big institutions. Most non-governmental psychiatrists are working single-handed, ignoring multi-disciplinary approach,
- Almost all major towns have one to two psychiatrists yet many cities remain uncovered,
- Only few hundred non-medical mental health professionals are available which includes clinical psychologists, psychiatric social workers and psychiatric nurses,
- There are roughly 35,000 hospital beds most of which are poorly managed and are often occupied by chronically ill,
- Treatment being completely voluntary, most patients seek treatment on outpatient basis and discontinue treatment when active symptoms are controlled or when they do not get adequate response or due to disabling side effects of drugs,
- Most psychiatrists depend on pharmacotherapy. Attempts at psychoeducation and rehabilitation are generally limited to occasional verbal advice,
- Many become homeless or live in their own house but uncared and their properties are misappropriated by their relatives,
- However, there are few centres of excellence doing commendable work in developing research data and models for treatment, and
- Most of these groups are active in few cities of India.

Factors which contribute to the prolonged (severe or chronic) nature of mental illness in the Indian context are worth considering, as they are closely related to the current practice of psychosocial rehabilitation in India. Let us discuss some of these factors:

1. **Misconception and stigma:** Misconception about mental illness and related stigma usually leads to delay in diagnosis and inadequate treatment. Although attitudes of the people have changed but still larger population of the country both in urban and rural areas are not aware of the importance of early

identification, diagnosis and treatment. Religio-philosophical thinking of people adds to the problem and makes it more severe and thus, delay in early treatment results in severity or chronicity of illness.

2. **Limited facilities of clinical care:** Considering the larger population of the country, treatment facilities still seem to be inadequate, especially in the rural areas, as most of these clinical services are available in the cities.
3. **Cost of treatment:** Many a times it has been observed that drug compliance is poor among the persons with severe mental illness of lower middle and lower socio-economic groups. Drug compliance is a significant part of psychosocial management. Due to economical reasons a good number of cases are unable to comply with the prescribed medication, which has to be taken regularly that also in most of the cases on long term basis or lifelong.
4. **Medicine's side effects:** Medication causes side effects and due to these effects treatment is discontinued when the side effect is severe or when most of symptoms are managed. Whereas, prescribed continued medication is very necessary to avoid relapse.
5. **Negative symptoms:** Negative symptoms are difficult to treat and their persistence also contributes to severity or chronicity of these illnesses.

Some other associated problems responsible for severity/chronicity are physical illnesses in addition to mental health problems, unemployment and poverty, no shelter and lack of family and social support.

Check Your Progress Exercise 4

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. List the factors which contribute to the prolonged mental illness in Indian context.

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18.7 STRATEGIES OF MANAGEMENT IN PSYCHOSOCIAL REHABILITATION

In this section, we will discuss some strategies which are important in the management in psychosocial rehabilitation.

1. Pharmacotherapy

Last few decades have very clearly demonstrated the effectiveness of pharmacological treatment for both affective disorders and schizophrenia.

Two points, which have been emphasised in most of the clinical reports are:

- i) Early and prompt drug treatment can reduce chronicity, and
- ii) Continuous treatment (drug compliance) is required for most relapsing clients and the treatment may be required lifelong.

2. Psychosocial Management

The psychosocial management includes following strategies:

- i) **Developing and applying measures to assess the effectiveness of medication:** When drugs are used to treat symptoms or psychopathology, the primary criterion for their success is behaviour change in the patient. Psychologists among the professionals (of mental health treatment team) are supposed to assess such behavioural changes. Intervention to increase medication compliance using behaviour management techniques, particularly with discharged client has been noted to be useful. Behavioural techniques are used to reduce the unpleasant side effects of medications as well.
- ii) **Intervention with cognitive techniques directly to remedy cognitive and behavioural deficits:** Mental health professionals especially psychologists can use self instructional training to help patients with schizophrenia to function more appropriately in social situations, or to examine treatment related cognitions to increase medication compliance. To combat hopelessness and to disrupt negative self fulfilling prophecies use of cognitive intervention also helps, which increases clients' expectations of success. Psychosocial intervention enhances the efficacy of treatment.
- iii) **Developing and applying measures to assess both the stress experienced by individuals and availability of the internal and external resources available to cope with the stress:** Intervening to reduce stress in the lives of vulnerable individuals, also reduces the risk of mental illness and thus also prevents re-hospitalisation. This is done by teaching stress management (for example, to identify stressors, manage stress, and solve problems), environmental management skills, and the social skills necessary to build their social networks. Although vulnerable individuals are thought to have lower thresholds for stress, social support has been shown to buffer stress and reduces vulnerability to both physical and mental illness. Clients and family members need to know and recognise the early signs of impending illness and develop strategies to reduce its likelihood, with the help of mental health professionals.
- iv) **Intervening to correct the deficits observed through functional assessment:** Behavioural and skills training approaches can increase the client's role functioning and help them develop support systems in the environment (Wallace *et al.*, 1980).

Advocacy is said to be very important in this approach (Anthony and Libermen, 1986). Negative attitudes of community towards persons with mental illness unfortunately are often also shared by mental health professionals (Lefley, 1989). To promote positive attitudes towards persons with chronic mental illness, involvement of mental health professionals in community education, professional education and in the administration of programmes concerned with chronically mentally ill persons has been reported to be beneficial.

- v) **Intervention to provide information about the nature, etiology, and treatment of mental illness to the family members (Psychoeducation):** Family members' skills which help them to become more effective caregivers and cope more effectively with the bizarre behaviours of the ill patients (Fallon *et al.*, 1985) depend on information passed to them by a mental health professional. By reducing the amount of *expressed emotion* (defined as critical comments directed towards the patient and over involvement in the patient's affairs) in the family environment, caregivers reduce the risk of client's relapse (Leff, Kuipers, Berkowitz, Eberlein-Vreis and Sturgeon, 1982). Finally, consistent professional support to the patients and their family members by teaching them skills for coping with stress and for expanding their social networks (Anderson *et al.*, 1986; Fallon *et al.*, 1985) facilitates the rehabilitation process and reduces the burden of caregiving. Family therapy helps the family to cope with the grief, guilt and anger of having a mentally ill family member and deal with any other problems that may make caregiving more difficult.

The Role of Psychosocial Rehabilitation in the Management of Chronically Mentally Ill Person: There cannot be a better explanation of the course of successful management than a client's account describing importance of psychosocial rehabilitation which distinctly illustrates role of drug compliance, family support and socio-cultural factors. According to a client's account (First person's account, 1996; Schizophrenia Bulletin 22, 1, 183 & 85):

"Overcoming schizophrenia was not easy. Taking my medications faithfully is the most important element in keeping me out of the hospital.....

.....A loving and close relationship with my parents has also helped me to overcome my illness.....

.....one factor that enabled me to get beyond the social effects of my illness, was religion.

A group of recovered clients identified helpful factors in overcoming the disabling effects of their chronic mental illness (Lee *et al.*, 1993). These are listed in Table 18.2.

Table 18.2 Helpful factors in overcoming the disabling effects of chronic mental illness

S.No.	Rank order of identified helpful factors	Percent (%)
1.	Psychotropic medication	71
2.	Cognitive coping efforts	42
3.	Social support and guidance	28
4.	Better organisation of occupation and time	28
5.	Work	13
6.	Stress reduction	10
7.	Efforts of self improvement	9
8.	Positive life events	8

Psychosocial rehabilitation is the cardinal feature in the management of chronic mental illness. Major concern is “how can we help people (who may not get better) despite their disability?” which conveys that “by all means try and treat people but if they do not respond then how can we help them make the best adaptation possible, given the fact that they have difficulties in functioning which are in the current state of knowledge, essentially untreatable?”

18.8 LEGAL ASPECTS, ADVOCACY AND COMMUNITY PARTICIPATION

In this section, we will discuss the legal aspects of rehabilitation and importance of advocacy and community participation. Legal aspects of rehabilitation relate to quantification of disability arising out of mental illness.

This enables the victim of severe mental illness to avail concessions, facilities and benefits made available by the government. Psychiatric disability has already been included in Person with Disabilities Act (1995). To assess degree of disability, ‘Indian Disability Assessment scale’ (IDEA:GOI, 2004) is now being used in most of the mental health service centres and psychiatry departments of the hospitals. A disability of 40 per cent and above entitles a person to avail the benefits.

Although family care is the best care for rehabilitation; a range of supported service options have been developed but they are available in cities only with limited numbers.

Halfway Homes

A person with severe mental illness goes to these homes during working hours where counseling services, skill training projects and facilities for vocational training are available. As per one’s rehabilitation needs services are provided under supervision. Residents are encouraged to participate in these activities. In the evening persons with mental illness come back to their families.

Long Term Group Residences

Cases with long term severe disability are provided support and supervision. These are known to be long stay clinical units. Basically in cases for whom expectations are low and benefits of rehabilitation are minimal these units are setup usually in hospitals.

Stigma about mental illness is still prevalent in the community which requires generation of awareness to change attitudes of people. This kind of change will promote early detection and early intervention which prevents severity or chronicity of mental illness. Many cases go untreated or right treatment at appropriate place is not availed which retards the treatment process and further process of rehabilitation.

18.9 ROLE OF COUNSELLOR AND FAMILY THERAPIST

Let us discuss the importance of role of counsellor and family therapist in psychosocial rehabilitation and learn about the different types of roles the counsellor and family therapist plays in psychosocial rehabilitation. These roles are as follows:

1. **Listen to the person carefully:** Allow the person with severe mental illness to express her or his emotions, feelings, and opinions and listen carefully and try to ascertain role of hope in her or his life and resources available with her or him that is, personal resources (like cognitive: attention, intelligence, memory; her or his emotion and activity level), and familial resources (like family support, financial status of the family to support treatment and rehabilitation).
2. **Psychoeducation:** Explain the facts about the illness to victim and her or his family members. Many a times person with severe mental illness may not be able to comprehend; then educating family members about the nature, etiology, course of treatment and prognosis to family members becomes vital. Cost of treatment and need of continued care need to be explained to family.

Expressed emotions in the family are reported to be many a times reason of relapse. Family members should be informed to avoid any direct critical comments to the affected family members or any negative comment about her or his illness.

Clearly state the importance of compliance to medication, its side effects and negative consequences of noncompliance to medication.

3. **Allow freedom to choose:** Provide information to the person with severe mental illness and her or his family about various treatment options available for her or his condition and allow them to choose.
4. **Maintain confidentiality:** Information gathered from the person with severe mental illness should be used for treatment and rehabilitation purposes exclusively and should not be shared with anyone.
5. **Provide desired information:** Families want to know about availability of service facilities, concessions, facilities and benefits available to the severely mentally ill as per provisions of the government.
6. **Respect the person with severe mental illness and her or his human rights:** All such persons are human beings and services provided to them should be in conformity with basic human rights. Physical punishments, unnecessary restraint, confining them in solitary cells are unethical. The tragic Yerwadi incident (2001) where 25 inmates of a treatment centre were burnt alive as they were chained led to passing legislation for regular inspection of hospitals to ensure that human rights of persons with severe mental illness in these hospitals are not violated.
7. **Conduct counselling and family therapy sessions to resolve specific issues:** Sometimes specific issues which emerge during the rehabilitation process like family support, interpersonal processes in the family, marital relations etc. should be addressed and resolved. Accordingly, counsellors or family therapists need to conduct counselling sessions with the person with mental illness and her or his family members to resolve such issues.

Check Your Progress Exercise 5

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. What are the strategies of management in psychosocial rehabilitation?

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2. Outline the role of counsellor and family therapist in psychosocial rehabilitation.

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18.10 LET US SUM UP

Major mental illnesses including schizophrenia and bipolar affective disorder are severe in nature. Their prolonged duration, if not treated properly in the initial stage are likely to cause disability. To manage this disability, psychosocial rehabilitation is important. Strategies applicable in this process are ensuring compliance to medication, psychoeducation to the person with severe mental illness and her or his family, remediation of cognitive and behavioural deficits, skill training (activities of daily living, social and vocational) and integration into the family and society. There are related issues like confidentiality of information, conformity to human rights, which should be kept in mind while extending counselling services.

18.11 GLOSSARY

Expressed emotion	: Critical comments directed towards the patients and over involvement in the patient's affairs.
GOI	: Government of India.
GHPU	: General Hospital's Psychiatric Unit
Intrinsic factors	: Primary factors
Psychiatric disability	: Disability arising out of severe mental illness
Psychosocial rehabilitation	: Process that facilitates the opportunity for disabled or handicapped by a mental disorder to reach their optimal level of independent functioning.

18.12 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Check Your Progress Exercise 1

- 1)
 - i) Bipolar affective disorder
 - ii) Phase of mania
 - iii) intervening
- 2) Following are the four key areas of psychiatric disability:
 - i) Activities of daily living skills (for example, grooming, hygiene, maintaining a household, managing finances),
 - ii) Social functioning (for example with family, friends, community, and in the workplace),
 - iii) Concentration, pace and task persistence (ability to function for 6 to 8 hours without supervision), and
 - iv) The ability to tolerate competitive work.

Check Your Progress Exercise 2

1. The major goals of psychosocial rehabilitation are given below:
 - i) Recovery from mental illness,
 - ii) Integration in the family and community; and
 - iii) Better quality of life.
2. Following are the guiding principles of psychosocial rehabilitation:
 - i) Individualisation of services,
 - ii) Maximum involvement and due importance to be given to preferences and choices of person with severe mental illness,
 - iii) Normalised and community based services,
 - iv) Strength focus,
 - v) Situational assessment,
 - vi) Treatment, rehabilitation and integration through holistic approach,
 - vii) Ongoing, accessible and coordinated services,
 - viii) Training of skills and vocational focus,
 - ix) Environmental modification support,
 - x) Partnership with the family, and
 - xi) Evaluation assessment with outcome oriented focus.

Check Your Progress Exercise 3

- i) True
- ii) False
- iii) True
- iv) True

Check Your Progress Exercise 4

1. Following are the factors which contribute to the prolonged mental illness in Indian context:
 - i) Misconception and stigma,
 - ii) Limited facilities of clinical care,
 - iii) Cost of treatment,
 - iv) Medicine's side effects, and
 - v) Negative symptoms.

Check Your Progress Exercise 5

1. Following are the main strategies of management in psychosocial rehabilitation:
 - i) Developing and applying measures to assess the effectiveness of medication,
 - ii) Intervention with cognitive techniques directly to remedy cognitive and behavioural deficits,
 - iii) Developing and applying measures to assess both the stress experienced by the individual and availability of internal and external resources to cope with stress,
 - iv) Intervening to correct the deficits observed through functional assessment, and
 - v) Intervention to provide information about the nature, etiology, and treatment of mental illness to the family members.
2. The role of counsellor and family therapist in psychosocial rehabilitation involves the following:
 - i) Listening to the person carefully,
 - ii) Psychoeducation,
 - iii) Allowing freedom to choose,
 - iv) Maintaining confidentiality,
 - v) Providing desired information,
 - vi) Respecting the person with severe mental illness and her or his human rights, and
 - vii) Conducting counselling and family therapy sessions to resolve specific issue.

18.13 UNIT END QUESTIONS

1. Name two major mental illnesses causing disability and list their clinical characteristics.
2. What is psychosocial rehabilitation?
3. List strategies used in the management of psychiatric disability.
4. Describe the role of counsellor and family therapist in psychosocial rehabilitation of persons with severe mental illness.

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UNIT 19 PERSONS WITH LOCOMOTOR DISABILITY AND MULTIPLE DISABILITIES

Structure

- 19.1 Introduction
- 19.2 Definition of Locomotor Disability
- 19.3 Causes of Locomotor Disability
- 19.4 Other Conditions that Lead to Disability
 - 19.4.1 Spinal Cord Injury
 - 19.4.2 Poliomyelitis
 - 19.4.3 Cerebral Palsy
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19.1 INTRODUCTION

An individual due to bodily impairment is unable to execute activities associated with moving both her or his body and objects in the surroundings from one place

to another and from one position to another. This condition is known as locomotor disability. And, if an individual has impairment as a result of involvement of two or more bodily functions such as deaf and dumb; deaf and blind; cerebral palsy and mental retardation; etc, it is known as multiple disability.

In this Unit, we would study about the causes and characteristics of locomotor disability and multiple disabilities.

Objectives

After studying this Unit, you will be able to:

- Define locomotor disability;
- Describe the causes of locomotor disability and multiple disabilities;
- Illustrate various types of locomotor disability and multiple disabilities; and
- Discuss the screening and intervention for them.

19.2 DEFINITION OF LOCOMOTOR DISABILITY

Locomotor disability is defined as an individual's inability to execute distinctive activities associated with moving both oneself and objects from one place to another. This inability could be a result of musculoskeletal and/or nervous system.

Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, defines *locomotor disability* as “the disability of the bones, joints or muscles leading to substantial restriction of the movement of the limbs or any form of cerebral palsy”.

World Health Organisation (WHO) (1980) defined “locomotor disabilities” as an individual's inability to execute distinctive activities associated with moving, both himself and objects from place to place.

National Sample Survey Organisation (NSSO) (1991) defined locomotor disability as “the loss or lack of normal ability of an individual to move both herself or himself and/or objects from one place to another”. It may occur due to 1) paralysis of the limb or body; 2) deformity in the limb(s); 3) loss of limb(s); 4) dysfunction of joints of the limb(s); and 5) deformity in the body other than limb (for example, deformity in the spine or in the neck or dwarfing or stunting).

Check Your Progress Exercise 1

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1) What do you understand by the term locomotor disability?

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19.3 CAUSES OF LOCOMOTOR DISABILITY

The various causes of locomotor disability are as follows:

1. **Neuromuscular impairments:** Neuromuscular impairment is a result of the involvement of the muscles and the nerves in the body.
2. **Musculoskeletal impairments:** Musculoskeletal impairment is a result of the involvement of the muscles and the bones of the body.
3. **Congenital and developmental causes:** Congenital and developmental causes have an impact on the development of foetus inside the mother's womb. The various deformities that arise due to this cause are: cerebral palsy; congenital tulips equinox virus (club foot or CTEV); congenital dislocation of hip; phocomelias (means very short or flipper like limbs caused by the intake of drug thalidomide during pregnancy) and, menigocele or menigo-myelocele (an anomaly in which instead of nerves a sac is present at the back of the brain containing cerebrospinal fluid).
4. **Acquired causes :** Acquired cause occurs due to external infections caused by bacteria and virus that infect the body through the routes of air, water, food, blood, saliva and semen. It could lead to tuberculosis of spine and other joints; chronic osteomyelitis, septic arthritis, acute poliomyelitis; gulling bare syndrome, leprosy, encephalitis; and AIDS.
5. **Traumatic causes :** Traffic accidents, domestic accidents, fall from height or slip on the floor/road; bullet injury, war, riots, violence, sport injury, natural calamities like earthquake, floods, etc. may lead to traumatic causes.
6. **Vascular Causes :** Vascular causes of locomotor disability are accidents which affect cerebrovascular region, amputations caused due to peripheral vascular disease and Perth's disease.
7. **Neoplastic causes :** Neoplastic causes which lead to disability are brain tumours, spinal tumours and osteosarcoma.
8. **Metabolic causes :** Metabolic causes like rickets, diabetic neuropathy, Vitamin B-12 deficiency, and gout also lead to locomotor disability.
9. **Degenerative causes :** Degenerative causes refer to causes that begin at birth and the condition deteriorates with the increase in age. These causes could be motor neuron disease, Parkinson's disease, multiple sclerosis, osteoarthritis and spondylosis.
10. **Other miscellaneous causes :** Locomotor disability may also be caused by muscular dystrophy; lathyrism which is caused by eating Kesari dal that looks similar to Arhar dal; rheumatoid arthritis and iatrogenic i.e. causes that are unknown.

Check Your Progress Exercise 2

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1) What is neuromuscular impairment?

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19.4 OTHER CONDITIONS THAT LEAD TO DISABILITY

In the above Section we have discussed about the various causes of disability. There are some more conditions which also lead to locomotor disability. We would discuss these in this section.

19.4.1 Spinal Cord Injury

Injury to the spinal cord is one of the major reasons that lead to locomotor disability. Spinal cord injury is caused by traffic accidents, activity during sports and recreation, fall from heights, penetrating wounds like bullet injuries, diseases like bone tuberculosis, injury due to heavy weight lifting, etc.

From spinal cord, nerves go to all parts of the body. The person with spinal cord injury would show the following signs and symptoms:

- Change in the tone of the limbs of which nerves are affected in the spinal cord injury,
- Loss of sensation,
- Loss of sexual function,
- Loss of urinary and faecal control,
- Inability to use the affected limbs, and
- Development of pressure sores on the weight bearing parts of the body like buttocks, heels, hips, back etc.

The injury to the spinal cord could be partial injury or complete injury. Injury to spinal cord can also lead to paralysis of the body limbs. If the paralysis involves the lower limbs then it is called *paraplegia*. If the paralysis involves all the four limbs then it is called *quadriplegia*. And, if the paralysis is only half of the body then it is called *hemiplegia*.

19.4.2 Poliomyelitis

Polio is a condition resulting as a consequence of a viral infection in the body. It occurs in young children and the infection starts with a cold, fever and diarrhoea.

Polio is caused by various strains of virus namely, *Leon*, *Lansing* and *Brunshilde* of which *Lansing* is the most virulent. It spreads through stool of the infected child who does not show apparent signs of polio but is a carrier of the virus.

Deformities in Polio:

- *Scoliosis*: In this condition the spine curves laterally. As a result it decreases the space in the upper or the thoracic cavity as a result of which the space for the heart and the lungs decreases.
- *Over extended knee joint*: This condition is called *genu recurvatum*. It is caused because the weight of the body is borne by the weak leg and as a result the knee of this weak leg gets bent backwards.
- *Knee flexion contracture*: In this condition the knee gets fixed in a bent position if not corrected.
- *High arched foot*: It is also called *pes cavus*. It is caused when the bones of the mid foot get bent. As the middle of the foot bends it gives the appearance of the foot having a high arch.

Signs and Symptoms of Polio

The various signs and symptoms of polio are:

- It results in paralysis of the lower limbs and the limbs become flacid, very loose and not stiff.
- The affected limbs become thin and also do not grow.
- The muscles of the affected limb become weak.
- Deformities and contractures may result due to paralysis of the limbs and deformities of the limbs may also occur due to disuse of the limb or inappropriate position in which the limb is held etc.
- Deformities that are seen in polio are scoliosis, over extended knee joint, knee flexion, contracture, high arched foot etc.

19.4.3 Cerebral Palsy

Cerebral Palsy is a neuromotor disorder of movement which is non-progressive and changes in its presentation. It is caused as a result of trauma to the developing brain during the growth years.

Causes of Cerebral Palsy

Cerebral palsy can be caused during any period of time from prenatal period, during birth or after the birth of the baby. Damage to the brain can occur during difficult labour process or due to trauma to the brain during premature delivery or due to use of forceps during the birth process. The foetus may also get infected and if poor brain development takes place during pregnancy it can also cause cerebral palsy. Cerebral palsy can be caused due to failure of the brain to develop normally because of various reasons like genetic disorders, chromosomal abnormalities or due to faulty blood supply to the brain. Infections like meningitis, encephalitis, neonatal jaundice, accidents and trauma to the brain, severe malnutrition, are other factors that may lead to cerebral palsy in children.

Thus, the brain can be neurologically damaged during the prenatal development, during the birth process and even after the birth of the baby.

Risk Factors During Pregnancy

There are various factors during pregnancy which make the growing foetus susceptible to cerebral palsy. These are:

- Mother suffering from hyperthyroidism, asthma, hypertension etc.,
- Pregnant woman being exposed to infections like rubella, typhoid, measles, chickenpox etc.,
- Pregnant woman does not get adequate nutrition,
- Pregnant woman consumes drugs, alcohol,
- Pregnant woman suffering from seizures,
- Overexposure of the pregnant woman to radiation;
- Rh incompatibility among the parenting couple, and
- Expectant mother facing stress and trauma.

Risk Factors During the Birth Process

The risk factors during birth process are:

- Baby is delivered prematurely,
- Labour process is prolonged and infant undergoes trauma,
- Difficult delivery due to breech or transverse positioning of infant,
- Child is born with the umbilical cord around the neck making breathing difficult causing anoxia,
- Delayed birth cry,
- Newborn is low birth weight due to under-nutrition,
- Neonate suffers convulsions, and
- Accidental injury to the neonate's head due to forcep delivery.

Risk Factors After Birth

The various risk factors that may cause cerebral palsy after the birth of the child are:

- Child suffers from infections such as meningitis and encephalitis in the early years of life,
- Child suffers from seizures due to abnormal brain activity,
- Brain receiving insufficient blood supply due to breathing difficulty (asphyxia),
- There is bleeding in the interior surfaces of the brain,
- Presence of tumors in the brain,
- Presence of excessive fluid in the brain (hydrocephalus),

- Trauma caused to the brain by accidents and injuries, and
- Jaundice just after birth of the newborn.

Screening

The newborn child can be screened for presence of cerebral palsy by complimentary neuromotor examination which is different from the basic neuromotor examination. It involves repeated assessments as well as immediate therapy. Such an examination can help identify babies with transient patterns of abnormality and also with persistent patterns of abnormality. This helps to assess the condition of cerebral palsy in the growing child.

In cerebral palsy some of the infantile reflexes that are present in infants for some period after birth, persist long after the ages when they should have been integrated within the nervous system. Some of these reflexes that persist are moro reflex, palmer reflex, tonic reflex, planter grasp etc. Children with cerebral palsy have weak muscles of the trunk, head, shoulder, and pelvic girdle.

Clinical types of movement disorders in cerebral palsy are:

Spasticity – Spasticity is a type of muscle hypertonia featured as an abnormal and increased response to rapid stretch, and movement occurs in disorganized fashion. It implies increased tone in the limbs but decreased tone in neck and trunk region. Spasticity is mainly in the anti-gravity muscles, that is, extending the arm produces more resistance than flexing it.

Dystonia – Dystonia is the production of one type of muscle activity when another was intended or would have been functionally appropriate.

Rigidity – Rigidity implies resistance to passive movements throughout the entire range of movement and pressure.

Choreo athetosis – Choreo athetosis implies when the individual assumes abnormal postures of the limbs, trunk, or head involving either slow, writhing movements or rapid, dance like changes. All postures are assumed involuntarily.

Ataxia – Ataxia implies when the child presents a poor balance with a wide-based, unsteady gait and inaccuracy of reaching with swinging, and large amplitude movements.

Intervention

The role of early intervention is important for the management of the child with cerebral palsy. The earliest care can begin at the neonatal unit along with the neurodevelopmental intervention. Neurodevelopmental intervention would include:

- Facilitation of normal motoric patterns through staging appropriate motor experiences,
- Facilitation of self smoothing and modulated tone changes by slow, rhythmic handling,
- To develop normal oral feeding,
- Positioning for non-nutritive sucking,

- Oral-facial-tactile stimulation, and
- Promoting parent–child bonding.

Proper intervention would also involve appropriate and need based feeding and positioning of the young child so as to avoid complications. The care givers should be trained to use appropriate handling techniques of lifting, carrying and providing sitting position for the child. Train the growing child to communicate using all possible methods and modes to communicate and also provide age based stimulation lest the child is under stimulated and mental retardation sets in.

Parents must encourage the child to learn to be independent in taking care of the daily needs of feeding, clothing, mobility, communication etc. An individual with cerebral palsy requires intake of adequate nutrition, and stimulating environment to be in a positive state of wellbeing.

Early physical therapy is one of the important aspects of early intervention. The following modalities are used during physical therapy treatment of cerebral palsy:

- Giving warmth leads to muscle relaxation. This can be done by applying warm soaks to spastic muscles before beginning the exercise regime.
- Cold applications can have the effect of reducing the muscle spindle activity.
- The occurrence of deformity and activity of muscles can be reduced by helping the child to do relaxed passive movements
- Exercises to stimulate opening of hand, developing hand grasp, and pincer grasp can be done with the child.

19.4.4 Epilepsy

Epilepsy is a condition where there is uncontrolled episode of excessive electrical activity in the brain leading to changes in behaviour, consciousness and movement. Various types of epileptic seizures can be classified as follows:

- **Partial seizures**

These are rare and are present only in certain part of the body. They can be simple or complex. There is no loss of consciousness in simple form of epilepsy and the complex form is characterized by loss of consciousness during the epileptic episode.

- **Grand mal**

During grand mal there is loss of consciousness, presence of convulsions, and generalised and uncontrolled body movements. The individual usually falls down during the episode and also may froth and urinate during the seizure. The seizure lasts for about 2-3 minutes and the individual feels exhausted after the episode and falls asleep after it is over. The individual loses orientation and does not remember what happened during the episode.

- **Petit mal**

Petit mal type of seizure is characterized by loss of consciousness lasting for about 3-15 seconds. During the seizure the person may stop all activity, appear to be staring into space, seem like day dreaming, blinking eyes rapidly. The individual may seem to lose muscular control.

- **Psychomotor epilepsy**

Psychomotor epilepsy lasts for usually 2-5 minutes and there are uncontrolled body movements, inappropriate actions as chewing, unaccountable violent physical outbursts. It may also be accompanied with abdominal pains, headaches and buzzing in the ears.

- Unclassified seizures

Causes

Epilepsy can be caused due to:

- Organic lesions as tumors in the brain
- Head injuries
- Fever
- Infections as meningitis
- Hereditary disorders as Batten's disease

Steps to be taken during the episode of seizures

The following steps should be taken during the episode of epilepsy:

- The caregiver should remain calm.
- Ease the individual to the floor.
- Loosen clothing, keep airflow around the affected individual, prevent choking on saliva or biting the tongue.
- Do not insert any object between the teeth and remove objects from the vicinity to avoid accidents and injuries.

Remediation

The medical management of seizures includes drugs and surgery. Depending on the type of the epileptic fit drugs can be prescribed by the trained doctors.

19.4.5 Cerebrovascular Accidents

Cerebrovascular accidents are also commonly known as stroke. It results due to presence of blood clot in the brain thus inhibiting blood supply to the nerves, thereby preventing the nerve from functioning in the normal fashion. If the treatment does not begin within 24 hours of the stroke attack, the individual loses the ability to talk, walk, use the upper limbs, control bowel activity or may also lose the ability to recognise faces and situations, ability to hear and vision also. The risk factors include high blood pressure, high blood cholesterol, diabetes, obesity, smoking, and family history of stroke.

19.4.6 Arthritis

Arthritis refers to inflammation of the body joints due to auto immune causes, infections, wear and tear, old age, etc.

Arthritis in adults is of different types such as osteoarthritis, rheumatoid arthritis, septic arthritis and gouty arthritis.

Juvenile arthritis is a condition that can be identified by the presence of pain and swelling in the joints of a child below 18 years of age and it mainly affects

children in the age range of 5 to 10 years. It results in pain, stiffness and swelling in the joints.

Signs of the Disease

Persons affected by this condition suffer from the following:

- The joints are usually stiff in the morning and gradually loosen as the day progresses. This condition is referred to as morning stiffness.
- There is presence of joint pain in the knees, ankles, wrists, neck, fingers, toes, elbows and shoulders, hips and bones of the back.
- Development of contractures due to inadequate exercise and body positioning.

Types of Juvenile Arthritis

a. Systemic

Children with this condition show high “spiking” fever once or twice a day, visibly enlarged lymph nodes, large spleens, rapidly changing flat pink rash and generalized malaise and fatigue. Such attacks may last for months and appear and disappear months or years later. Laboratory tests during the episode of illness may show the child to be anaemic, having high WBC counts and sedimentation rates, non-specific indications of severe inflammation.

b. Polyarticular

In addition to the rash, fever and anaemia the child also has severely involved joints. Most frequently involved joints include knees, ankles, and wrists, neck, elbow, fingers and shoulders. Later in the course, the hip joint also gets involved, and also the jaw gets affected resulting in a receding chin due to interference in the growth of the jaw bone. Such children are small for their age since the disease interferes with the growth and sexual maturation of the individual. The joints also lose their range of motion, then develop contractures and also subluxations.

c. Pauciarticular

This affects four or fewer joints. It mostly affects the knees, elbows, wrists and ankles. Usually only one side of the body is affected.

Management

Management of arthritis includes drugs as analgesics, corticosteroids, anti rheumatic drugs, biologic drugs, natural remedies and topical arthritis products and surgery in extreme cases.

19.4.7 Muscular Dystrophy

Muscular Dystrophy is a condition where the body muscle fiber is replaced by fat cells and the muscles gradually atrophy. Thus as the individual grows older the muscles waste away and there is progressive loss of muscle power in the body. It usually affects the male population and is also passed through the male progeny.

Early signs

The signs of this debilitating condition are:

- The well developed calf muscles of the young child feel rubbery as compared to the calf muscles of the normal child. The child also walks on tiptoes.

- The child shows Gower's sign — the child gets up by climbing on his own body.
- The child falls often when walking and cannot run.
- The feet of the child are affected initially, then the front of thighs, hips, belly, shoulders, and elbow. Later in the course of the condition the face, hands, and the neck muscles get affected.
- On reaching the teenage years, the children become wheel chair bound.
- The affected child develops lateral curvature of the spine due to weak muscles of the back.
- The muscles of the heart and the respiratory system get affected in the course of time.
- The affected individual suffers from pneumonia and heart failure as complications.

19.4.8 Amputations

It is the loss or absence of whole or part of a limb. Amputations can be congenital, due to accidents and also due to surgery to prevent spread of gangrene in the body.

19.4.9 Club foot

It is a condition where the foot or both the feet are turned towards the inner side i.e. towards the midline of the body.

Causes

This condition is caused due to congenital reasons, effect of drugs or due to idiopathic reasons.

Types

It can be unilateral or bilateral. In case only one foot is affected the affected foot is smaller and the calf muscles are also weak and thinner than the non-affected leg.

Treatment

The corrective treatment includes the PONSSETI method where the foot is repeatedly stretched and plastered every week so that the tissues relax and the foot is brought to the normal position slowly and with the course of time.

19.4.10 Leprosy

Leprosy or Hansen's disease is caused by bacteria called *mycobacterium lepre* that affects the mucous membrane, skin and the nerves of the peripheral nervous system.

Signs

Early signs include light coloured patches that have lost sensation of pain. This can be tested by scratching or pinching the affected area. Later lesions occur in that area that are either macules (skin blemishes) or as plaques (scaly patches). Deformity may also occur in the face and limb due to these lesions. In the hands the ulnar

nerve supplying the ring finger and the little finger is affected thus resulting in clawing of these fingers. If all the nerves of the hand are affected it gives rise to a total claw hand accompanied by wrist drop. If the nerves of the lower limb are affected foot drop occurs and also dorsiflexion and planter flexion.

Causative factors

Bacterial infection can spread through nasal discharge from the infected person and also the active leprosy patient is a potential source of infection for the population in the vicinity. The bacteria thrive in hot humid climate and can also spread through droplet infection from the sputum, skin lesions and mosquitos and mites.

Management

Management of leprosy involves administration of drugs, treatment of deformities with administration and use of splints, physical therapy and corrective surgery.

19.4.11 AIDS (Acquired Immuno Deficiency Syndrome)

The human immunodeficiency syndrome spreads through the means of human blood, semen, saliva and vaginal secretions.

Symptoms

Signs of infection in women include repeated yeast infections (vaginal candidiasis), pelvic inflammatory disease, growth and presence of precancerous cells in the cervical tissue, genital ulcers, genital warts and severe mucosal herpes infections. People may also develop flu like symptoms and at times they may also not show any signs of infection. With years the signs may show as swollen lymph nodes in the neck, underarm, groin area. There might be recurrent bout of fever including “night sweats” and also rapid weight loss with no apparent reason. The person might also feel tired constantly and white spots or unusual blemishes may appear in the mouth.

Complications in AIDS

The AIDS Virus does not directly attack the nervous system but the reduced vitality of the immune system leads to inflammation and damage to the brain and spinal cord. Neurological complications associated with AIDS include Vacuolar Myelopathy where symptoms include weak and stiff legs, unsteady walking and in the last stages the patient requires a wheel chair. Stroke and progressive multifocal leucoencephalopathy are other conditions that can be associated with AIDS. Both conditions are characterized by paralysis of the limbs.

Prevention

It includes practising safe sexual behaviour with preferably one partner, and use of contraceptives. Also avoid use of intravenous needles and take care of the genuineness of the blood units taken during medical emergencies.

19.4.12 Diabetic Neuropathy

This condition arises due to long term state of diabetes where one of the symptoms includes wasting of the muscles of the hands and feet. Peripheral neuropathy leads to muscle weakness and loss of reflexes, especially at the ankle leading to changes in the way a person walks. Deformities as hammertoes, and the collapse

of the midfoot may occur. Due to numbness in the regions, sores and blisters may occur that go unnoticed and through which infection sets in the skin and the bones leading to amputations in the future if not treated promptly.

19.4.13 Gout

The arthritis caused by gout results when deposits of uric acid crystals in the joint fluid and joint lining occur. Inflammation results causing pain and redness in the joint tissues.

Gouty arthritis is typically an extremely painful attack with a rapid onset of joint inflammation. The joint inflammation is precipitated by deposits of uric acid crystals in the joint fluid (synovial fluid) and joint lining (synovial lining). Intense joint inflammation occurs as white blood cells engulf the uric acid crystals and chemical messengers of inflammation are released, causing pain, heat, and redness of the joint tissues.

Check Your Progress Exercise 3

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Define the terms grand mal, hemiplegia and muscular dystrophy.

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2. Discuss how AIDS can be a source of locomotor disability.

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19.5 PREVENTION OF LOCOMOTOR DISABILITY

The prevention of locomotor disability can be taken care of at three levels: primary, secondary and tertiary.

Primary level of prevention: This approach stresses on the prevention of occurrence of the disease or condition. It includes taking steps to ensure that the disability condition does not occur. This can be done by propagating the message of attaining and maintaining general health conditions by giving information about adequate nutrition, taking safety measures to prevent accidents at home, at workplace etc. It also includes propagating the positive effects of following a

healthy lifestyle, making certain behavioural changes, maintaining proper hygiene and sanitation. It also includes making people aware and appreciating the need for proper immunization and also following rules and regulations when working in hazardous environments.

Secondary level of prevention: This refers to the early steps taken to control the disease and the disability when it has occurred. It aims at halting or slowing down the progress of the debilitating condition and also preventing the complications bound to arise if the condition is allowed to progress. For example deformities due to paraplegia can be prevented by taking care of positioning the affected individual in the bed and when doing different activities. Also occurrence of pressure sores can be prevented if care is taken in case of traumatic paraplegia.

Tertiary level of prevention: This involves proper rehabilitation of the affected individual when the disability has occurred.

Check Your Progress Exercise 4

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. People working in factories at times do not follow rules. Comment.

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19.6 PROBLEMS FACED BY THE LOCOMOTOR DISABLED PERSON

The locomotor disabled persons suffer from the following conditions:

Motor weakness: The body is weak and there is less strength in the muscles of the limbs and the joints leading to motor weakness.

Motor weakness refers to either complete or partial weakness. Complete weakness results in paralysis and partial weakness leads to severe pains etc. Both of these kinds of weakness result in deficiencies in areas of daily living. It requires rehabilitation intervention in maintaining the range of movement of joints of the affected limb, to regain or improve the muscle power in the weak muscles.

Paralysis: Paralysis is a loss of sensation in the affected limb so that the limb does not experience any sensation and also cannot make both voluntary and involuntary movements.

Spasticity: Spasticity is defined as a state of increased muscle tone proportional to the velocity of stretch applied. Spastic muscles have varying degree of weakness and incoordination. Thus repetitive activities requiring rhythmic contraction and relaxation are impaired. Long term spasticity leads to contracture and deformities.

It is important to control spasticity so as to improve muscle coordination, balance, strength, range of motion of joints for appropriate training for activities of daily living, walking and vocational rehabilitation. It can be controlled with the help of range of motion exercises, hydrotherapy, maintenance of appropriate posture and removal of any irritating focus below the level of lesion.

Sensory loss: Due to injury to the spinal cord, the nerves that are responsible for bringing about transmission of sensory information get damaged and thus the individual loses the ability to feel pain or discomfort.

Pressure ulcers: Due to long contact of the skin with the surface of bed where the immobile person lies, he or she may develop pressure sores at the area of contact that might begin to bleed and also get infected. They are areas of necrosis resulting due to prolonged excessive pressure on the soft tissues. They occur due to immobility, motor weakness, loss of sensation, excessive perspiration, urinary and faecal soiling, rough and crinkly bed sheet and lack of care. The common sites where bed sores occur are the sacrum, back of the heels, and the trochanter.

Deformities and contractures: Due to weak muscle control and inappropriate posture the individual's body takes up a postural position that is non painful and in the process leads to permanent deformity and contractures. Deformity is defined as an abnormal position, which is not passively corrected, and is assumed by the part of the body due to some disease or injury. Factors that lead to deformity include habitual faulty posture, muscle weakness, muscle imbalance, gravity, faulty walking pattern, limb length discrepancy etc. Contracture refers to a permanent shortening of the muscle that causes deformity with or without pain. It can be avoided with frequent changes in position and range of motion exercises.

Loss of limbs or other body parts: This can result due to accidents, skin lesions and infections, accidents, warfare, affect of drugs during prenatal period, etc.

Urinary and faecal incontinence: This can occur due to loss of sensation to the brain about the need to urinate and also can be due to loss of muscular control in the affected organs. Bladder and bowel dysfunction due to impaired neural control is commonly called "neurogenic" bladder and bowel. Long term complications of these include chronic prostatitis, stricture urethra, hydronephrosis and chronic renal failure.

Check Your Progress Exercise 5

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. Name three problems that may be faced by persons with locomotor disability.

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19.7 MULTIPLE DISABILITIES

Multiple disabilities have been defined as the combination of more than one disability in a person. It includes children who have two or more of the following conditions:

- Varying degrees of mental retardation
- Cerebral palsy
- Autism
- Blindness or low vision
- Deafness or hearing loss
- Physical disability as polio, paralysis, delayed motor development
- Neurological impairment
- Communication disorders

The combination of disabilities may vary from child to child and the degree of severity may also vary.

The age of onset of the condition can be since birth till teen years. Children may be born with one disabling condition but may also acquire the second or the third disabling condition in the following years.

Also a combination of disabilities may interact over time and in turn lead to developmental arrest and secondary complications which in turn may lead to physical or mental disorders such as deformities or contractures and psychiatric disorders.

19.7.1 Causes of Multiple Disabilities

Causes of multiple disabilities can be grouped under headings of pre-, peri- and postnatal as in case of single disabling conditions but with the result of interaction of the condition and the environmental factors may lead to a multiple disabling conditions. For example, the condition of Hydrocephaly can occur alone but it may be complicated by the effects of prematurity or birth asphyxia and have a precursor condition of spina bifida.

Examples of Multiple Disabilities

Conditions such as congenital Rubella, other infections due to viral teratogens, progressive neurological disorders such as mucopolysaccharidoses, rare metabolic disorders as Hurler syndrome, Duchenne and other muscular dystrophies, primary orthopedic problems such as arthrogryphosis multiplex congenital, primary muscle aplasia, lower motor neuron diseases and motor neuropathy, congenital amputations, defective limb bud rotation syndrome are examples of cases leading to multiple disabilities.

The categories of individuals with multiple disabilities can vary as deaf-blind, blind-mentally retarded, blind-cerebral palsy etc.

Each group varies with the needs, limitations and capabilities and also individuals belonging to one category can also differ in their individual needs. The deficits can be seen in the following areas:

- Self help skills: Such as dressing, feeding, bowel movements, and bladder control.
- Communication behaviour: These include speech difficulties, understanding and expression of language.
- Physical and motor behaviour: Such as maintaining posture, balance, mastery of gross and fine motor skills, mobility etc.
- Social skills: Such as participating in group activities requiring interpersonal interaction, exhibiting appropriate social and emotional behaviour.
- Presence of inappropriate behaviours and emotional disturbances: These may include aggression, withdrawal, shyness, suicidal tendencies, ritualistic behaviour, self injurious behaviour etc.

19.7.2 Prevention

The causes of multiple disabilities are numerous and are a result of interaction of causal factors in varying degrees and intensities. Thus prevention is important though not controllable. However prevention would include taking steps towards preventing the occurrence of disability at the critical stages when it is most likely to manifest during the development of the individual in the mother's womb.

At the prenatal stage the following precautions should be taken by the pregnant mother:

- i. She should abstain from alcohol intake and exposure to smoking both active and passive.
- ii. She should avoid situations that might lead to accidents and injuries to the unborn child.
- iii. Regular checkup at the maternity clinic and undertaking various screening procedures on the medical advice should be taken care of.
- iv. The expectant mother should be vaccinated for infections such as rubella, chicken pox etc.
- v. Vitamin supplementations of Folic acid, iodine, Vit K and iron should be given to the expectant mother.
- vi. Conditions as blood pressure, diabetes, thyroid problems should be kept under check for the pregnant mother.

Steps to be taken at the time of delivery:

- i. Steps should be taken to ensure that delivery occurs in a clean and hygienic environment under specialized supervision.
- ii. Complications during delivery such as breech and assisted delivery should be handled with utmost care and expertise.

For the neonate the following points should be kept in mind:

- i. The newborn should be fed and kept warm immediately after birth.
- ii. Cases of neonatal jaundice should be immediately taken under medical supervision.

- iii. Check newborn for early signs of epileptic fits and intervention should start at the earliest.
- iv. Conditions of neural defects, macrocephaly, microcephaly should be identified and prognostic steps should be taken immediately.
- v. The Apgar score of the neonate should be considered and steps should be taken to control deficient condition.

During the post natal stage the growing child should be provided with adequate nutrition, given timely vaccine to avoid nutritional deficiencies and infections. Also avoid over exposure to pollutants and irradiation. Accidents and injuries to the head of the children should be avoided and in case of occurrence immediate medical intervention should be provided.

19.7.3 Intervention

Steps to be taken to minimize the effects of the disabling condition include the following:

- Providing adequate nutrition to the growing child so that the immune system works to its full potential to fight secondary illness and infections and maintain growth and strength of the body and the brain.
- Provide for occupational and physiotherapy if the need arises
- Teaching of appropriate body movements of the body to avoid deformities and contractures
- Teaching adaptive behaviour to blind and deaf children to be more in control of their environment
- Provision of need based medication and early intervention and also giving importance to the need for stimulation of the mind and the body from early age.
- Provision for surgery if the case needs as in case of hydrocephaly.

Check Your Progress Exercise 6

Note: a) Read the following question carefully and answer in the space provided below.

b) Check your answer with that provided at the end of this Unit.

1. What are the precautions a pregnant woman can take to avoid disability in her child?

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19.8 REHABILITATION

Rehabilitation refers to the restoration of the physically disabled persons to their maximum possible physical, educational, economic independence and social

integration. The process of rehabilitation takes into account the level of recovery possible with each case of disability. Thus there are patients who can fully recover as in cases of neuropraxis, surgically repaired nerve injuries, Guillain Barre syndrome etc. In certain cases the patient exhibits permanent but stable disability as in amputations, post polio residual paralysis, nonprogressive paraplegia, hemiplegia etc. There are also patients with unstable disabilities such as rheumatoid arthritis, osteoarthritis etc.

The process of rehabilitation should include the following:

- Prevention of disability,
- To reduce or eliminate the disability to the maximum, and
- To train the affected individual to achieve independent living with whatever residual abilities one has.

Assistive Devices

Assistive devices are any devices that can help persons with disabilities in doing activities of daily living; they are items that can directly enable people with disabilities to participate in the activities of daily life. People may take help of assistive devices on their own or with help of other people.

Orthotics

This includes the provision of splints and appliances that improve the function and appearance of a disabled person. An orthosis can be said to be an appliance that is added to the patient, to enable better use of the body part to which it is fitted.

Functions of orthotics

The main function and aim for which orthoses are prescribed are to prevent and correct any deformity arising out of the disability. It also provides relief from pain as it limits motion and weight bearing. It also leads to immobilization and protection of weak, painful or healing musculo-skeletal segments. It also leads to improvement in the function of the specific limb.

Prosthetics

Prosthetics refer to any artificial substitute for lost part of the body. They can be external or internal. External prosthesis is used for upper and lower limbs and can also be further classified into endoskeletal limbs or conventional limbs or temporary pylon prosthesis.

Functions of prosthetics

Rehabilitation by the use of prosthetics aims at achieving maximum function out of the remaining stump of the lost or missing limb.

The points to keep in mind when choosing the appropriate prosthetic is to take care of the following:

- The level of amputation
- Type of socket
- Material of socket
- Type of joint to be used i.e., hip, knee, or elbow mechanism, ankle/foot or hand/terminal appliance

Cosmetics

It is the preservation, restoring or bestowing of bodily beauty. In terms of prosthetics it implies creation of life like limbs mimicking the real limb.

Walking Aids

Walking aids are used to increase the mobility of a patient. This is done when some of the weight of the body can be supported by the upper limbs. Examples of walking aids include parallel bars, walking frames, crutches and sticks etc. Selection of the walking aid depends upon the stability of the patient, the strength of the upper and the lower limbs, presence of degree of coordination of movement of the upper and lower limbs and the degree of relief from weight bearing equipment that is required.

Types of walking aids include crutches, frames, sticks and parallel bars.

Rehabilitation using walking aids requires time. The patient needs to regain strength after a prolonged illness. This can be gained by taking adequate diet and well planned progressive course of exercise. The patient also needs to become free of the fear of falling.

Architectural barriers

Patients with locomotor impairments are not in a position to walk through narrow entrances, lanes on elevated platforms, etc. So it is necessary to provide special ramps, remodeling of entrances, widening of doors, construction of slopes instead of stairs, and creation of plain, flat floors without raised obstacles in the house and public places also.

Psycho-social rehabilitation

Illness and injury lead to anxiety and frustration. Care should be taken to boost the morale of the disabled person and feeling of empowerment should be inculcated. The people surrounding them should be supportive, helpful and not indulging in pity for the disabled. The response to the incapacity depends upon the patient's personality, education, social and economic situation. Care should be taken to include these factors when planning for the individual's rehabilitation goals.

Specific psychological problems of persons with disabilities include depression, anxiety, feeling of insecurity, and inability, loneliness, behavioural disorders, affective disorders, personality disorders, suicidal tendencies, dependence, low self esteem, irritability, impaired psychomotor coordination and hysteria.

Check Your Progress Exercise 7

Note: a) Read the following questions carefully and answer in the space provided below.

b) Check your answers with those provided at the end of this Unit.

1. Enumerate the types of walking aids.

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2. Name some of the psychological problems of persons with multiple disabilities.

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19.9 LET US SUM UP

Locomotor disability is a condition that affects the mobility and body movements of the affected individual. It can be acquired at birth, be present congenitally, or occur due to accidents and traumas during the course of the life span. Its early diagnosis is thus necessary and important to check its further progress. It requires a team of different professionals to work towards intervention and rehabilitation of the affected person.

The case becomes more complicated when the condition of multiple disabilities occurs that leads to complex issues in prevention, complications, intervention and rehabilitation. A single disabling condition is much easier to check and control than a case of multiple disabilities as each limiting condition plays a role in compounding the disability in itself and also limits the development and use of other faculties for the growth and development of the affected individual.

19.10 GLOSSARY

AIDS	: Acquired Immuno Deficiency Syndrome
Hemiplegia	: Paralysis of half of the body.
Locomotor disability	: An individual's inability to execute distinctive activities associated with moving both oneself and objects from one place to another.
Musculoskeletal impairment	: A result of the involvement of the muscles and bones of the body.
Multiple Disabilities	: Combination of more than one disability in a person.
Neuromuscular impairment	: A result of the involvement of the muscles and nerves in the body.
Paraplegia	: Paralysis of two lower limbs.
Quadriplegia	: Paralysis of all the four limbs.

19.11 ANSWERS TO CHECK YOUR PROGRESS EXERCISES

Answer to Check Your Progress Exercise 1

1. Locomotor disability can be defined as an individual's inability to execute distinctive activities associated with moving both oneself and/or objects from one place to another because of any musculoskeletal and/or nervous system malfunction.

Check Your Progress Exercise 2

1. Neuromuscular condition that leads to locomotor disability is an impairment as a result of the involvement of the muscles and the nerves in the body.

Check Your Progress Exercise 3

1. Grand mal is a type of epileptic seizure wherein there is loss of consciousness and presence of convulsion and generalised and uncontrolled body movements. The individual usually falls down during the episode and may also froth and urinate during the seizure. The seizure lasts for about 2 to 3 minutes and the individual feels exhausted after the episode and falls asleep after it is over. The individual loses orientation and does not remember what happened during the episode.

Hemiplegia is a type of spinal cord injury in which paralysis of half of the body takes place.

Muscular dystrophy is a condition where the body muscle fiber is replaced by fat cells and the muscles gradually atrophy. As the person grows older fat cells and the muscles waste away and there is progressive loss of muscle power in the body.

2. Neurological complications which are associated with AIDS lead to weak and stiff legs, unsteady walking and in the last stages the patient requires a wheel chair. This condition classifies AIDS as a source of locomotor disability.

Check Your Progress Exercise 4

1. It is true that at times people working in a factory do not follow rules and regulations. This makes them prone to hazardous conditions and accidents which may lead them to live a disabled life in future especially like locomotor disability.

Check Your Progress Exercise 5

1. Pressure ulcers, deformities and contractures, and loss of limbs or other body parts.

Check Your Progress Exercise 6

1. The pregnant women should take utmost care of herself to look after her child. She should avoid alcohol, smoking both active and passive, radiations, drugs and medicines without a prescription from the doctor. She should go for regular health check-ups at maternity clinics and strictly follow the advice of the doctor. She should take vaccination for rubella, chicken pox, etc. She should take vitamin K, iodine, iron, etc. Conditions like diabetes, thyroid, blood pressure, etc. should be kept under control.

Check Your Progress Exercise 7

1. Types of walking aids are crutches, frames, sticks and parallel bars.
2. Some of the common psychological problems of persons with multiple disabilities are depression, anxiety, feeling of insecurity, inability, loneliness, behavioural and emotional disorders.

19.12 UNIT END QUESTIONS

1. Discuss the complications faced by the locomotor disabled persons if proper care is not taken.
2. What is the role of assistive devices in the rehabilitation of the locomotor disabled?
3. Elaborate why is psycho-social rehabilitation of the locomotor disabled important?
4. How do deformities and contractures occur in a cerebral palsied child?
5. Discuss the role of a multidisciplinary team in the care of a person with disabilities.

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