B.ED. SPL. EDUCATION

ASSESSMENT AND IDENTIFICATION OF NEEDS

SES MR-01

MADHYA PRADESH BHOJ (OPEN) UNIVERSITY

ASSESSMENT AND IDENTIFICATION OF NEEDS

B.Ed. Spl. Ed

(SES MR 01)

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Further information on the Madhya Pradesh Bhoj (Open) University Special Education courses may be obtained from the University's office of the Department of Special Education at Raja Bhoj Marg (Kolar Raod) Bhopal - 462016. Tel: (0755) 2492095. Fax: (0755)-2424640.
email: bedsede@gmail.com website : http://www.bhojvirtualuniversity.com

Bachelor of Special Education

B.Ed. Spl. Ed.

A Collaborative Programme of

Madhya Pradesh Bhoj (Open) University
&

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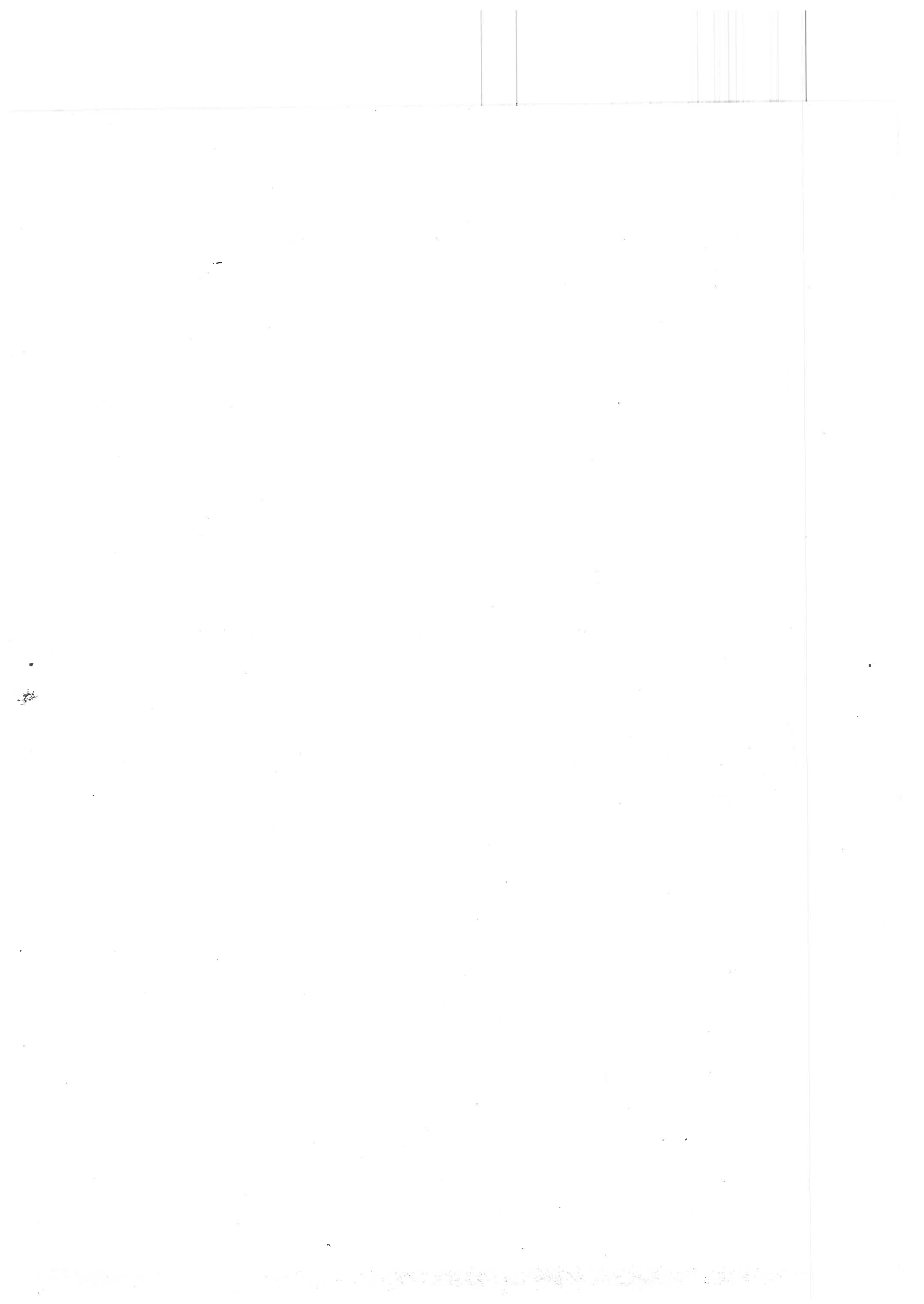
MADHYA PRADESH BHOJ (OPEN) UNIVERSITY

RAJA BHOJ MARG (Kolar Road), Bhopal (M.P.) - 462 016
Ph. 0755-2492095, Fax 0755-2424640
Email: bedsede@gmail.com
www.bhojvirtualuniversity.com



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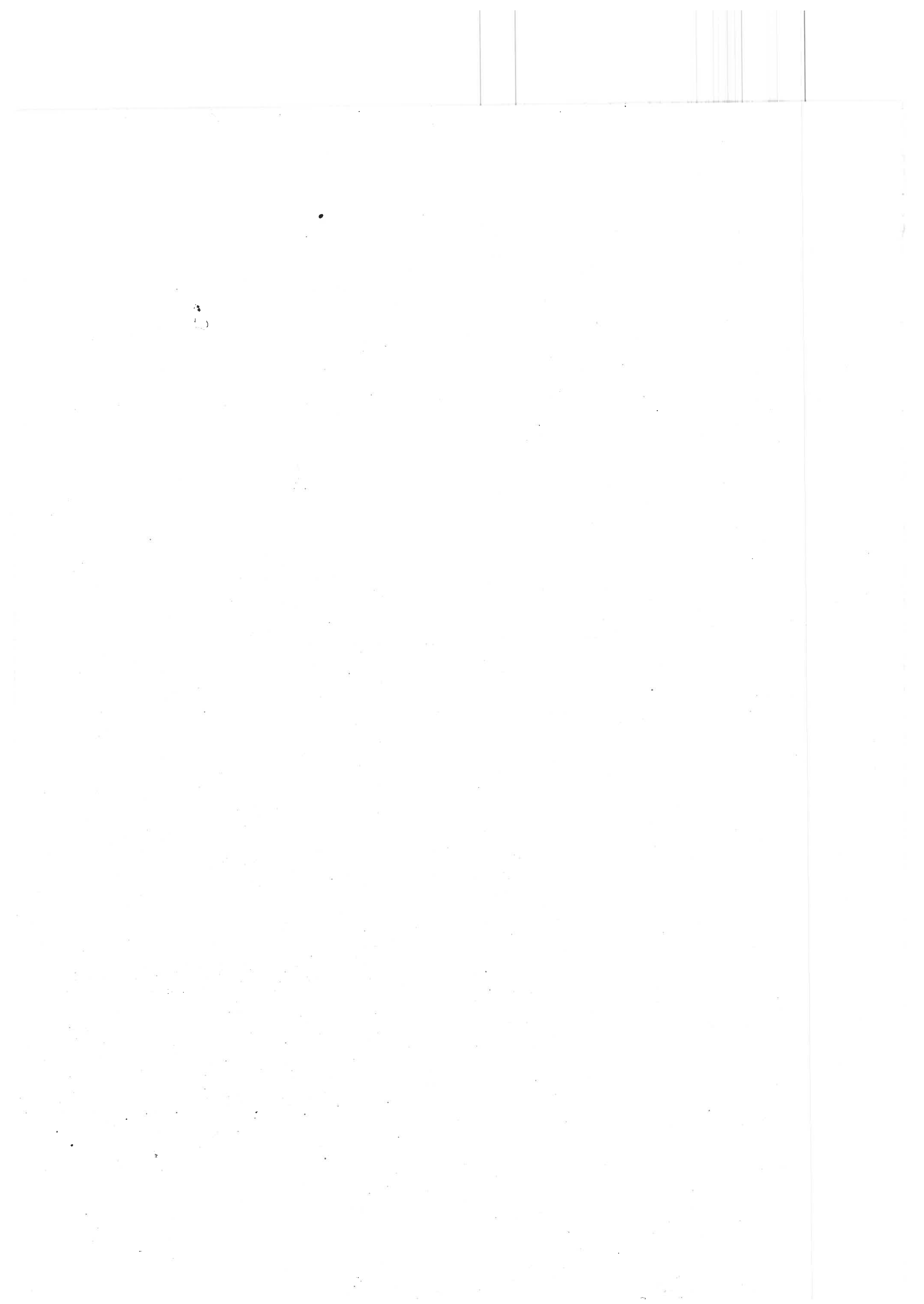


SES MR – 01
ASSESSMENT AND IDENTIFICATION OF NEEDS

BLOCK

1

INTELLECTUAL DISABILITY - NATURE AND NEEDS

BLOCK 1 : INTELLECTUAL DISABILITY - NATURE AND NEEDS

INTRODUCTION

So, you have chosen to specialize in teaching children with mental retardation! Well, it is a challenging task requiring a lot of commitment and creativity. Wish you all the best!

Through this block, we have planned to provide you information on nature and needs of persons with mental retardation. You might have observed that a person with mental retardation doe snot always have a conspicuous sign or feature.

Many-a-time, they look like you and me. Only when you start to interact you realize there is a difference! This aspect of mental retardation often is responsible for misconceptions about them, calling them as `mad' or such other derogatory terms.

Therefore, the block focuses on basic concepts on mental retardation. The block has three units.

Unit-1 deals with definitions as they have evolved through the years as perceptions changed, thus relating to historic perspectives. You will find the contents of the unit gradually taking you to present day's legal definition and its implication. The unit also narrates incidence and prevalence of mental retardation.

In Unit-2, you will find classification of mental retardation from medical, psychological and educational angle. Depending on the classification and degree of retardation, the characteristics vary which is also described in the unit. It is important to know how to screen and identify person with mental retardation at various stages of life ranging from infancy to adulthood, the details of which you will find covered in Unit-2.

The Unit-3 provides you information on causes and prevention of mental retardation.

Each unit has in-built self-check and activities. Though comprehensive the units are not exhaustive. It is recommended that you may refer to the suggested readings for additional information.

OBJECTIVES

On completion of the block, you will be able to:

- ; Relate definitions of mental retardation to the historic perspectives.

- ; Define mental retardation as per current usage.
- ; Narrate incidence and prevalence of mental retardation.
- ; Classify and describe characteristics of mental retardation.
- ; Screen and identify persons with mental retardation.
- Explain causes and prevention of mental retardation.

UNIT 1: HISTORICAL PERSPECTIVE OF INTELLECTUAL DISABILITY (ID)

STRUCTURE

1.1 Introduction

1.2 Objectives

1.3 Mental retardation: Concept
- 1.3.1 History of mental retardation
- 1.3.2 Changing trends

1.4 Definition – International perspective
- 1.4.1 Historic development of definition
- 1.4.2 Understanding intellectual functioning
- 1.4.3 Definitions of AAMD/AAMR
- 1.4.4 Definition of DSM4, ICD (WHO)

1.5 Definition: Indian perspective
- 1.5.1 Definition in India (P.D. Act)
- 1.5.2 Certification procedures

1.6 Incidence and prevalence
- 1.6.1 What is incidence and prevalence?
- 1.6.2 International data
- 1.6.3 Estimates in India
- 1.6.4 Difficulties in obtaining accurate data

1.7 Unit Summary: Things to remember

1.8 Check your progress

1.9 Assignment/Activity

1.10 Points for Discussion/clarification
- 1.10.1 Points for discussion
- 1.10.2 Points for clarification

1.11 Reference/Further Readings

1.1 INTRODUCTION

Mental retardation is one of the conditions, found most difficult to define, since many a time the persons affected may not have a conspicuous symptom. They are either identified and/or diagnosed incorrectly. Historically, the persons affected by mental retardation have experienced varied treatments ranging from abandoning them (in early years) to providing them (present day) equal opportunities like non-disabled persons. The definitions have undergone changes based on the trend of the day.

In this present unit, we will see how historically the concept of mental retardation has undergone changes influencing the definitions. The various definitions also will be discussed.

1.2 OBJECTIVES

After studying this unit, you will be able to:

- Narrate the historic perspective of mental retardation.
- Understand definition as they evolved.
- Define mental retardation as per AAMD/AAMR through years.
- Define mental retardation as per DSM IV, ICD 10 and as used in India.
- Compare the definitions and explain.
- Demonstrate your awareness on incidence and prevalence of mental retardation.

1.3 MENTAL RETARDATION: CONCEPT

Awareness on mental retardation is increasing rapidly in recent years. Yet, we have to go a long way in educating the public on right attitudes, available service facilities and correcting their misconceptions. Ignorance is one major reason for inappropriate understanding of mental retardation.

Who are persons with mental retardation? Can people with mental retardaton lead their lives independently? How many people in a given population are retarded?

These may be the basic questions coming to your mind. Let us try and find answers to these questions.

1.3.1 History of mental retardation

Centuries ago, the persons with mental retardation were considered subhuman. In many occasions, they were killed at birth by drowning or they were abandoned in the woods. The birth of such a child is considered a bad omen to the community and were got rid of in some manner. It is documented that they were also used as objects of entertainment in King's Courts. Some of the old scriptures like `Patanjali' in India has evidence that persons with mental retardation existed in early centuries.

As years passed by `the right to live' received recognition and importance. However, they were considered as a menace to the society (Neisworth and Smith, 1976) requiring segregation from the community and requiring close custodial supervision. Thus came up the institutional care. The persons with mental retardation were segregated from family and community and put in institution for 24 hour total care.

In later years, pity and charity on them developed. Their basic needs were fulfilled and were expected to live on charity. This was predominantly the developments in western countries.

In India, if you see through the history (see box 1) you will find that the mentally retarded persons were part of the society, which continues even today. The families take the major responsibility of these persons in our country.

1.3.2 Changing trends

During the 18th Century, many individuals with mental retardation were provided shelter in institutions. Following the American and French revolution in 1800s, education and training of children with disabilities including mental retardation gained focus. The concept of , `they can also be trained to lead lives with minimal support' was established. A number of ideas and assumptions regarding their training evolved during this period (See Box 2).

Box-1: History of Mental Retardation

- As early as the Ramayana period (probably around 5000 BC) we have a reference to mental retardation. Queen Kaikayi's maid Mantara was dull witted and thus easily duped. The concept of mental problems was mentioned first in the Atharva Veda.
- A much older system of philosophy the Sankya, contains a statement on different types of intellectual disabilities.
- The Garba Upanishad (around 1000 BC), a treatise on embryology, suggests that babies with defects are "born to those parents whose minds are distressed".
- Differential diagnosis among various sorts of odd behaviour has always been hard, but a more readily recognizable "childish mind" model for mental retardation appeared in a riddle of the Upanishads compiled perhaps in 500 BC.
- A careful study of the ancient Indian literature reveals that there have been a few references to persons with mental retardation. In the Mythology of Patanjali, we read that Patanjali had to teach Goudapathaga, who was a dull headed persons.
- The Patanjali Yoga Suthras deal with yoga as a therapy. A careful reading of these Sutras reveal that persons with mental retardation have also been taken into consideration for this therapy.
- The great physician Charaka has given various causes for mental retardation and discusses the different types and classification.
- Clear reference to persons with mental retardation can be traced in the Sangam literature (200 BC – 200 AD) by Erayanar and Avvaiyar and more recently by Thiruvalluvar.
- In the 4th century BC, Kautilya banned the use of terms insulting persons with disabilities. He employed many people with disabilities in his spy network.
- King Amarsakti had three sons, Vasusakti, Ugrasakti and Anekasakti, who were "greater fools" or "supreme block-heads". This folly caused their father's courtier Vishnu Sharma to devise the world's first special education text Panchatantra, around the 1st Century BC. Basham remarks "Never was a school text book better written".
- Ancient Hindu, Buddhist and Sanskrit texts treat idiocy like other birth handicaps, arising through sin in an earlier incarnation. According to Manu, the Law Giver, that as a consequence of a remnant of the guilt of former crimes, as persons are idiots, dumb, blind, deaf and deformed, all despised by the virtuous.
- The Buddhist Mantalsi Jatakar recounts an early attempt to teach "the profound dullards" by activity methods and practical curriculum, but he did not succeed. Later some teachers did persevere so that the unfit rather than being weeded out

Source: NIMH Notes on "Curriculum and Teaching" Prepared for DSE (MR).

Box-2: Major ideas influencing Special Education in the United States

Initiator	Dates	Nationality	Major Idea
Jean Marc Gaspard Itard	1775-1838	French	Single-subject research can be used to develop training methods for those who are mentally retarded.
Thomas Hopkins Gallaudet	1787-1851	American	Children who are deaf can learn to communicate by spelling and gesturing with their fingers.
Samuel Gridley Howe	1801-1876	American	Children with disabilities can learn and should have an organized education, nor just compassionate care.
Louis Braille	1809-1852	French	Children who are blind can learn through an alternative system of communicating based on a code of raised dots.
Edward Seguin	1812-1880	French	Children who are mentally retarded can learn if taught through specific sensory-motor exercises.
Francis Galton	1822-1911	English	Genius tends to run in families, and its origin can be determined.
Alexander Graham Bell	1847-1922	American	Children who have a hearing disability can learn to speak, and can use their limited hearing if it is amplified.
Alfred Binet	1857-1911	French	Intelligence can be measured, and it can be improved through education.
Maria Montessori	1870-1952	Italian	Children can learn at very early ages, using concrete experiences designed around special instructional materials.
Lewis Terman	1877-1956	American	Intelligence tests can be used to identify gifted children, who tend to maintain superiority throughout life.
Anna Freud	1895-1982	Austrian	The techniques of psychoanalysis can be applied to children who have emotional problems.
Alfred Strauss	1897-1957	German	Some children show unique patterns of learning disabilities, probably from brain injury, that require special training.

(Source: Kirk, S.A., Gallagher, J.J. and Anastasiow, N.J. (1993) Educating exceptional children. Boston: Houghton Meffin Co.)

In the 20th Century, normalization, integration and more recently inclusion became the trend. Normalization as a philosophy has its origin in Scandinavian

countries, which refers to `use of means which are culturally as normative as possible in order to establish and maintain personal behaviours and characteristics that are culturally appropriate' (Wolfensberger, 1972). To achieve normalization the steps taken has to be systematic and progressive involving deinstitutionalization, integration and inclusion (Refer SESM-03, Block 4, Unit 1).

1.4 DEFINITION – INTERNATIONAL PERSPECTIVE

When we look at the history, the conceptual models of mental retardation included social model – shunning them as subhuman and menace or worthy of charity/pity, medical model – considering them as sick persons, educational model – capable of development through training and education, and an eclectic model looking at them holistically, as human beings first, and then their disability. This brought the concepts of equality, access, opportunity and rights to the persons with disabilities. We have seen the evolution of society's reaction since early years to the current day in brief.

The definitions predominantly followed a medical model in early years and gradually changed to the present day definitions which we see in the following pages.

1.4.1 Historical development of definitions

Let us take a few examples of how the thinking of the day influenced the definition of mental retardation.

Seguin (1907) "The capacity of the mind for development was equal in all new born, but.....the nerves which transmit sensory messages to the brain were deficient or inefficient in some individuals thus preventing the experiences from being effectively transmitted".

Sequin who was a French physician and a student of Itard, (who trained the wild boy of Aveyron) (See box 1) continued the work of Itard in the area of mental retardation. In fact he wrote the first ever book in mental retardation titled "Idiocy and its physiological treatment". Mentally retarded persons were referred to as idiots in those years.

As you can see in the definition, he believed that the brain of the retarded person is intact and it is the defect in the nerves that carry the sensory impulses that are responsible for the deficit in the person.

Tredgold (1937) "Mental deficiency is a state of incomplete mental development of such a kind and degree that the individual is incapable of adapting himself to the normal environment of his fellows in such a way as to maintain existence independently of supervision, control or external support".

In early 1920s Stanford Binet in England developed mental tests at the demand of the queen of England. This led to the concept of mental age and the possibility of discrepancy between the mental age and the actual (chronological) age in a person. Observing the reduced mental ability, Tredgold coined the term mental deficiency. He has included in the definition the aspect of reduced mental ability and therefore, incapability of the person with mental retardation to live without supervision.

British Mental Health Act (1959) "Mental retardation as a condition of arrested or incomplete development of mind existing at the age of 18 years whether arising from inherent causes or induced by disease or injury".

An act generally has legal implication. The act defined mental retardation to highlight its features of lowered mental abilities and limited skills for independent living.

President's Panel on Mental Retardation (1962) indicated retardation as being "significantly impaired in their ability to learn and adapt to the demand of the society".
When Mr.John F.Kennedy was the President of United States, he appointed a committee for the welfare of mental retardation. It is believed that he had the personal interest in mental retardation as his sister was retarded. This committee defined mental retardation as above which enabled funds and facilities to reach the retarded persons.

American Association of Mental Deficiency (AAMD) was formed in 1950s and since then the definitions are formed by AAMD from time to time, changing with the emerging trends. Other definitions by the WHO (International Classification of Diseases, ICD) and Diagnostic and Statistical Manual (DSM) are of significance and they also had the definitions revised from time to time. In India, currently the Persons with Disabilities Act (1995) has a definition which is used fro legal purposes. All of the above mentioned definitions are discussed in the following pages.

What is being highlighted here is that the definition of mental retardation is not constant. It is continuously revised with the trend changes. The reason could be, mental retardation is not just a single problem to be treated and cured with

medicines. It is a medical, educational and social problem. As the condition manifests itself mainly as an incompetency in adapting to the environment, and does not have a conspicuous physical conditions (except for associated problems) many-a-time, it is mistaken or misunderstood, confused with mental illness, shunned as evil or praised as divine.... As the social perception goes in the given region of the world.

What is important for us to understand is that (a) a person with mental retardation has limited mental abilities, (b) therefore, he does not adapt to his environment like his peers – persons of his age, and (c) this conditions has occurred in him during the developmental period, ie., before the age of 18.

Now, let us look at the AAMD/AAMR definitions. As years passed by, the usage of the term `mental deficiency' changed to mental retardation and therefore, AAMD became AAMR (American Association of Mental Retardation).

1.4.2 Understanding intellectual functioning

Before we see the AAMD definition, let us understand intellectual testing. Intelligence tests were the sole determining factor of mental retardation in 1950s to 1970s. Let us briefly orient ourselves to how these tests helped in the diagnosis of mental retardation.

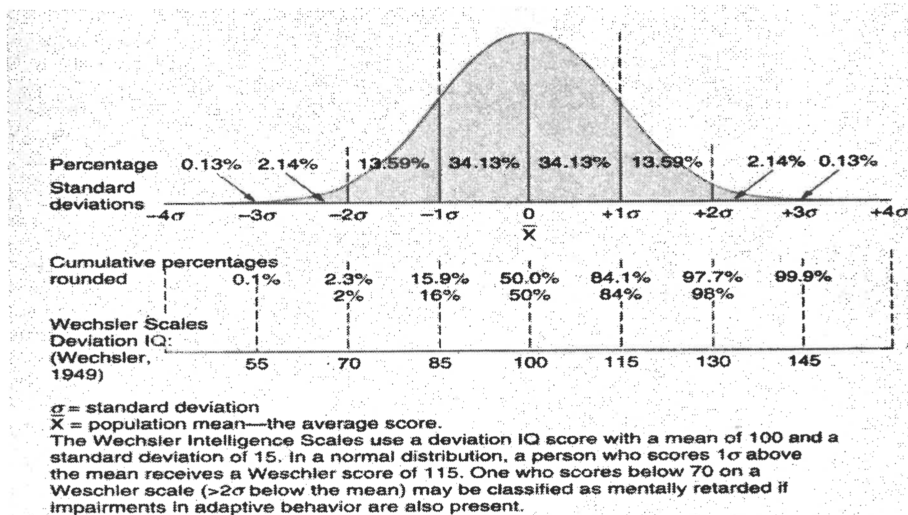
Look at the graph 1. It shows that majority of the population have an IQ between 90-110. As the IQ increases or decreases, the population having that IQ also decreases on either side gradually. What is this IQ? IQ is the Intelligence Quotient – the ratio of the mental age to the chronological age. The mental tests provide mental age when we divide mental age by chronological age and multiply by 100 we get IQ. Therefore IQ = MA/CA X 100. So a 10 years old child with 10 mental age on a standardized test will have IQ 100 (10/10 x 100). If the 10 year old child shows mental age of 6, IQ is 60 and if he shows mental age of 12 he has an IQ of 120. Right?

Now to accommodate individual differences the mean and standard divisions (SD) are established for every standard IQ test. Look at the graph 1 once again. The x axis has SD marked in either side of the centre. With 100 as average IQ with 90-110 considered as range of average, we find that roughly 15 points form a standard deviation. This may vary for different tests and the manual for the test will provide details.

Diagnosis of mental retardation was decided by the cut off point of standard deviation as will be seen in the following descriptions of AAMD/AAMR definitions.

AAMD (1959) "Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairments in adaptive behaviour." Heber.

This definition refers to subaverage intelligence which is explained as one SD blow the mean (approximately 85 and below – 100-15 = 85). The developmental period was described as birth to 16 years. Using this definition for legal purposes, it was observed that a number of persons who were close to normal (IQ 70-85) were receiving support. By incidence too, they are more in number and as the severity increases the number of persons affected reduces (see graph 1). As it was not serving the purposes and the right population, the definition was revised in 1973.



AAMD (1973) "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period." – Grossman.

What difference do you see in this definition when compared to that of 1959? Yes, you see the word `significantly' added before subaverage. By addition of this, the cut off points of SD was raised to two SD below the mean

(approximately 70, 100 – 30). Thus a person with the IQ of about 70 and below in a given standardized test was considered as retarded.

The developmental age was raised to 18 years – birth to 18 years.

The adaptive behaviour deficit by this definition was considered to be existing concurrently, rather than as a result of subaverage intelligence. The professional community made observations against this statement `existing concurrently' and insisted on `resulting in' due to intellectual impairment.

The definition was again revised in 1983.
AAMR (1983) "Mental retardation refers to significantly subaverage general intellectual functioning, resulting in or associated with concurrent impairments in adaptive behaviour and manifested during the developmental period". – Grossman.

By now the association was called AAMR and the definition included the terms `resulting in or associated with concurrent impairments in adaptive behaviour'. The developmental period was considered from conception to 18 years, rather than birth to 18 years as in 1973 definition. This allowed the medical professionals to make decision on treatment when the baby is still in the mothers womb and suspected to be abnormal.

By now, the IQ cut off points alone were not found to be deciding criteria for diagnosis and classification and adaptive behaviour needed focus and consideration. For instance, the adaptive behaviour of one with 67 IQ and the other with 73 IQ may be almost similar. While IQ 67 is considered mild mental retardation, IQ 73 is borderline intelligence and not considered retarded. This was an injustice to the latter. Considering issues like this 5 points of overlap was allowed at cut off for classification (See Table).

Table-1: Comparison of Heber, Grossman, and Luckasson et al. AAMR Definitions of Mental retardation

Term	Heber (1959, 1961)	Grossman (1973)	Grossman (1983)	Luckasson et al (1992)
General Definition	Subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behaviour	Significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behaviour and manifested during the developmental period.	Significantly subaverage general intellectual functioning resulting in or associated with concurrent impairments in adaptive behaviour and manifested during the developmental period.	Substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. mental retardation manifests before age 18.
Subaverage	Greater than one standard deviation below the mean.	Significantly subaveage: two or more standard deviations below the mean.	Significantly subaverage: defined as an IQ of 70 or below on standardized measures of intelligence; could be extended upward through IQ 75 or more, depending on the reliability of the intelligence test used.	Similar to Grossman (1983).
Assessment Procedure	General intellectual functioning; may be assessed by one or more of the standardized tests developed for that purpose.	Same as Heber.	Same as Heber for intellectual functioning. Adaptive behaviour assessed by clinical assessment and	Governed by a series of steps specifying requisite characteristics.

			standardized scales.	
Developmental Period	Approximately 16 years.	Upper age limit 18 years.	Period of time between conception and the 18th birthday.	Similar to Grossman (1983).
Adaptive Behaviour	Impairment in adaptive behaviour refers to the effectiveness of the individual to adapt to the natural and social demands of his environment. May be reflected in: 1.Maturation 2.Learning 3.Social adjustment	Defined as effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his age and cultural group. May be reflected in the following areas: *During infancy and early childhood*: 1. Sensory-motor skills development 2. Communication skills 3. Self-help skills 4. Socialization *During childhood and early adolescence:* 5. Application of basic academic sin daily life activities 6. Application of appropriate reasoning and judgment in mastery of the environment 7. Social skills *During late adolescence and adult life:*	Defined as significant limitations in an individual's effectiveness in meeting the standards of maturation, learning, personal independence, or social responsibility that are expected for his or her age level and cultural group.	Movement from conceptualizing adaptive behaviour as a global entity to specification of 10 different adaptive skill areas – as presented in the definition.

		8. Vocational and social responsibilities and performances.		
Levels of Severity	Borderline retardation IQ 86-84 Mild retardation IQ 52-67 Moderate retardation IQ 36-51 Severe retardation IQ 20-35 Profound retardation IQ < 20	-- Mild retardation IQ 52-67 Moderate retardation IQ 36-51 Severe retardation IQ 20-35 Profound retardation IQ < 20	-- Mild retardation IQ 50-55 to approx. 70 Moderate retardation IQ 35-40 to 50-55 Severe retardation IQ 20-25 to 35-40 Profound retardation IQ below 20 or 25 Cannot be determined	Traditional levels abandoned. System advocates use of intensities of needed support that are subclassified into four levels: ▪ Intermittent ▪ Limited ▪ Extensive ▪ Pervasive These levels are applied to the adaptive skill areas.

The trend continued to change towards more focus on adaptive behaviour deficits and the definition was revised in 1992.

AAMR (1992) "Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18".

The definition was accompanied by 4 assumptions.

1. Valid assessment considers cultural and linguistic diversity, as well as differences in communication and behavioural factors.
2. The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individual needs for supports.
3. Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities.
4. With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve.

As can be seen distinctly the 10 areas of adaptive behaviour deficits are given in the definition. It mentions clearly deficits in any `two or more of the ten' applicable areas, thus giving the diagnostician the liberty to make a decision based on adaptive behaviour deficits and not to totally rely on IQ alone. It highlights that the retarded person's environment in which he lives is important for assessment and decision making.

This definition with its assumption is found more practical, flexible and provides insight into the social competency of the person in relation to his environment and peer group rather than solely an IQ scores.

When you look back since 1959 to 1992 (see table also) you will find that the definitions have undergone changes to reflect the assumptions and thinking of the day. Such changes are likely continue with the emerging trends and developments.

1.4.4 Definition of mental retardation according to the DSM IV and ICD-10

Diagnostic and Statistical Manual of mental disorders (DSM) and International Classification of Diseases (ICD) are the most widely used and accepted classification systems worldwide.

Why should we classify the mental disorders:

The initial impetus for developing a classification of mental disorders was the need to collect statistical information (1840). By 1880, seven categories of mental illness were distinguished – mania, melancholia, monomania, paresis, dementia, dipsomania and epilepsy. In 1917, the American Psychiatric Association together with National Commission on Mental Hygiene adopted a method in which attention was given to the clinical utility. In 1952, the first edition of DSM (DSM-I) was published with a focus on the diagnostic categories and clinical utility. Presently, the DSM-IV, published in 1994, is in use. Contemporaneously, the World Health Organization (WHO) is coming out with series of International Classification of Diseases (ICD), with a focus on nomenclature and description of diagnostic categories of mental disorders. Presently, the ICD-10, published in 1992, is used and accepted worldwide.

DSM-IV

According to DSM-IV, mental retardation is defined as `significantly subaverage general intellectual functioning that is accompanied by significant limitations in adaptive functioning in atleast two of the following skill areas:

Communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety, with an onset before age 18 years"

General intellectual functioning is defined by the Intelligent Quotient (IQ) obtained by assessment with one (or) more of the standardized, individually administered intelligence tests (eg. Wechsler's intelligence test, standford-binet test).

Significantly subaverage intellectual functioning defined as an IQ of 70 or below.

Impairments in adaptive functioning, rather than a low IQ are usually the presenting symptoms in individuals with mental retardation. Adaptive functioning refers to how effectively individuals cope with common life demands and how well they meet the standards of personal independence expected of some

one in their particular age group, socio cultural background, and community setting.

Four degrees of severity are specified reflecting the level of intellectual impairment:

1. mild mental retardation – IQ level 50-55 to less than 70.
2. moderate mental retardation – IQ level 35-40 to 50-55.
3. severe mental retardation – IQ level 20-25 to 35-40.
4. profound mental retardation – IQ level below 2o-25.
5. mental retardation – severity unspecified

strong presumption of mental retardation but persons intelligence is untestable by standard tests.

ICD 10 gives importance to the cultural norms and individual abilities and guidelines were given to make judgments according to the following bands.

Category	Mental retardation	IQ range	Mental age (years)
F 70	Mild	50-69	9 to under 12
F 71	Moderate	35-49	6 to under 9
F 72	Severe	20-34	3 to under 6
F 73	Profound	Below 20	Less than 3

1.5 DEFINITION – INDIAN PERSPECTIVE

Most of the classification systems define mental retardation with an emphasis on significantly subaverage intellectual functioning of the individual (assessed by the standardized intelligence tests). Whereas, in India, majority of population lives in rural areas and are engaged mostly with traditional, semi-skilled vocations. The available adapted Indian intelligence tests are not standardized keeping in view of psychosocial, educational, economic and cultural background of the population. Hence, these tests have limitations in assessing the exact levels of intelligence.

1.5.1 Definition in India – P.D. Act 1995

According to the "Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act 1995", mental retardation means a "condition of arrested or incomplete development of mind of a person which is specially characterized by subnormality of intelligence".

1.5.2 Certification Procedures

As per the rules, framed by the Government of India, the disability certificates (including the certificate of mental retardation) will be issued by a medical board. The medical board constitutes a chairman and professionals from the respective fields as members. These include psychologist/clinical psychologist/psychiatrist, orthopaedic surgeon, ENT Surgeon/Audiologist and ophthalmologist.

As per the rules, district hospital functioning at the district level will be having the medical board and they will meet every fortnight for issuing the disability certificates. The Chief Medical Officer/Superintendent of the district hospital will be the chairman of the medical board. The certificate will be signed by the chairman and also the specialist from the respective field. The certificates issued by the medical board will be valid for all purposes throughout India.

1.6 INCIDENCE

1.6.1 What is incidence and prevalence?

Incidence rate is defined as "the number of new cases occurring in a defined population during a specified period of time". It is given by the formula:

$$\frac{\text{No.of new cases of specific diseases during a given time period}}{\text{Population at risk}} \times 1000$$

For example, if there had been 500 new cases of an illness in a population of 30, 000 in a year, the incidence rate would be:

$$\frac{500}{30,000} \times 1000 = 16.7 \text{ per 1000 per year}$$

Incidence rate must include the unit of time used in the final expression. If you write 16.7 per 1000, this would be inadequate. The correct expression is 16.7 per 1000 **per year**.

The term prevalence refers specifically to all current cases (old and new) existing at a given point of time or over a period of time in a given population.

$$\frac{\text{No. of of all current cases (old and new) of a specified disease existing at a given point of time}}{\text{Estimated population}} \times 100$$

1.6.2 International data

In 1929, in an important survey of school children in six areas of the United Kingdom, E.O.Lewis found that the total prevalence of mental retardation was 27 per 1000. Subsequent studies in many countries have generally shown that the prevalence of mental retardation is about 10-30 per 1000. According to the DSM IV the prevalence of mental retardation has been estimated at approximately 1%. However, different studies have reported different rates depending on definitions used, methods of ascertainment, and population studied.

1.6.3 Estimates in India

Most available data on the prevalence of mental retardation in the country is derived from the psychiatric morbidity surveys conducted by mental health professionals in specific or circumscribed geographical areas or target populations, such as, rural-urban, industrial populations and educational institutions. The prevalence rates of mental retardation reported from these surveys are presented in the following table.

Table: Prevalence Rates for Mental Retardation based on Psychiatric Morbidity Surveys

S. No.	Investigator/s	Year	Target population	Place of study	Prevalence rate/1000
1.	Ramadas et al	1960	Urban general population	Kelod	21.7
2.	Surya et al	1964	Suburban slum	Pondicherry	0.7
3.	Sethi et al	1967	Urban general population	Lucknow	22.5
4.	Ganguly	1968	Industrial population	Delhi	9.17
5.	Gopinath	1968	Rural	Bangalore	4.72
6.	Dube	1970	Urban, semiurban & rural	Agra	3.7
7.	Kapur	1970	Rural general population	Kota (KS)	5.7
8.	Elnagar et al	1971	Rural general population	W.Bengal	1.4
9.	Sethi et al	1972	Rural general population	Lucknow	25.3
10.	Verghese & Baig	1974	Urban general population	Vellore	3.2
11.	Sethi et al	1974	Urban general population	Lucknow	10.5
12.	Thacore et al	1975	Urban general population	Lucknow	14.0
13.	Nandi et al	1975	Rural general population	Calcutta	2.83
14.	Nandi et al	1976	Rural general population	Calcutta	3.7
15.	Carstairs & Kapur	1976	Rural general population	Kota (KS)	10.0
16.	Nandi et al	1980	Rural general population	Calcutta	8.6

17.	Nandi et al	1980	Rural general population	Calcutta	10.7
18.	Shah et al	1980	Urban general population	Ahemedabad	1.8
19.	Isaac & Kapur	1980	Rural general population	Bangalore	32.7
20.	Shalini	1982	Rural general population	Bangalore	32.7
21.	Bhide	1982	Rural general population	Ooty	2.4
22.	Avasthi et al	1983	Rural children 5-14 years	Ambala	52.3
23.	Joshi et al	1988	Urban general population	Allahabad	27.3

Source: Mental Retardation in India: Contemporary Scene. Secunderabad: NIMH.

The differences in prevalence rates reported by the above investigators can be attributed to variations in the definition of the case, assessment procedures, age of the target population, etc.

The National Sample Survey Organization (NSSO) under the Department of Statistics, Government of India, conducts large scale studies and surveys for socio economic planning and policy formulation. The first large scale attempt to collect such information on the prevalence of developmental delays was made in the 47th round of survey by NSSO carried out between July-December, 1991, in the age group of 0-14 years belonging to 4373 villages and 2503 urban blocks.

Table: Prevalence studies based on National Sample Survey Organization

Sl. No.	Investigator/s	Year	Target Population	Place of study	Prevalence rate/1000
1.	NSSO	1991	Stratified rural sample	All India	31.0
2.	NSSO	1991	Stratified urban sample	All India	9.0

Data obtained from various sources indicate that the prevalence rate of mental retardation is about 20 per 1000 general population, while the prevalence of

developmental delays is about 30 per 1000 in the population of children upto the age of 14 years.

1.6.4 Difficulties in obtaining the accurate data

It is difficult to collect the accurate prevalence rate of mental retardation in a country like India. The following are some of the reasons.

- lack of individualized intelligence tests, which can be administered across various psychosocial, educational, economical and cultural groups.
- A small portion of population with mild mental retardation remain unidentified as they may be engaged in a semiskilled vocation and getting along with a structured and restricted environment.

1.7 UNIT SUMMARY

In this unit, we have seen the historic perspectives of the concept of mental retardation. This being a condition with no conspicuous physical features, (excepting certain clinical features) as seen in blindness, deafness and locomotor disabilities, many a time, mental retaration is mistaken for mental illness/madness, or varied social perceptions ranging from devil to god child.

In early centuries, they were killed or abandoned, later they were looked after in institutions, simply meeting their survival needs. Training them to live independently, recognizing their potentials was a development in 1700s initiated by Itard on the `Wild boy of Averyron'. Later, various acts for the disabled persons came about and normalization processes were initiated.

In India, documentation on persons who are mentally retarded are found in the epics.

The definitions of mental retardation has undergone change based on the belief and thinking of the day.

AAMD/AAMR definitions since 1959 to 1992 reflect the changes in the trends. Popularly used other definitions include ICD of WHO and DSM IV. In India, the definition is framed with the implementation of P.D. Act which is used for certification.

The incidence and prevalence of mental retardation is difficult to estimate due to the inconspicuous nature of the condition. However, prevalence is estimated to be 2 ½ to 4% of the population.

1.8 CHECK YOUR PROGRESS

1. Define mental retardation as in AAMR (1992) and explain.
2. Compare all the AAMD/AAMR definition and highlight the differences.
3. How does ICD definition differ from DSM and AAMR?
4. Define incidence and prevalence and explain.
5. The person who trained `wild boy of Aveyron was

   a) Seguin b) Itard c) Grossman d) Tredgold
6. Developmental period refers to

   a) first 6 years b) birth to 16 years c) birth to 18 years d) conception to 18 years
7. Average IQ is

   a) 50 b) 100 c) 120 d) 80
8. Briefly describe in your words what mental retardation is

1.9 ASSIGNMENT/ACTIVITY

1. Compile definitions of mental retardation as used by the Government for legal purposes at least from 5 countries.
2. Suggest methods which can be accurate in finding out the prevalence of mental retardation in India.

1.10 POINTS FOR DISCUSSION

After studying the unit, you may want to make notes of points on which you need clarifications. List them below.

1.10.1 Points for discussion

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1.10.2 Points for clarification

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UNIT 2:DEFINITIONS OF INTELLECTUAL DISABILITY – ICD-10, AAIDD, WHO, PWD ACT 1995, RPD BILL (PROPOSED), DSM (LATEST)

STRUCTURE

2.1 Introduction

2.2 Objectives

2.3 Classification of Mental Retardation

2.3.1 Psychological classification
2.3.2 Medical classification
2.3.3 Educational classification

2.4 Implications of classification

2.4.1 Issues related to classification
2.4.2 Labelling and its implications
2.4.3 Current trends in educational classification

2.5 Screening and identification

2.5.1 Definition
2.5.2 Process and procedures
2.5.3 Advantages
2.5.4 Limitations
2.5.5 Screening tools

2.6 Characteristics

2.6.1 General characteristics
2.6.2 Social implications
2.6.3 Educational implications

2.7 Unit summary

2.8 Check your progress

2.9 Assignment

2.10 Points for discussion and clarification

11 References/further reading

2.1 INTRODUCTION

In the earlier unit we have seen how the concept of mental retardation has undergone changes with the changing trends in the perception of people. We have also seen that about 2-3 persons in every 100 persons are estimated to be mentally retarded.

There are varying degrees of mental retardation, depending on the extent of damage to the brain in the individuals. The causes for such damage will be seen in Unit 3. Here we will see how they are classified based on certain yardsticks. Medical classifications, go by causes/etiology, psychological classifications are made based on IQ. You may recall that we have briefly discussed the concept of IQ in Unit 1. The educational classification goes by potentials of the person and the principle of normalization and delabelling. We will see these classifications and characteristics in detail in this unit.

2.2 OBJECTIVES

After studying this unit you will be able to

- Explain the medical, psychological and educational classification of mental retardation.
- Demonstrate understanding of screening and identification.
- Critically analyze the implications of classification.
- List the tools used for screening and identification.
- Narrate procedures of screening
- Explain the characteristics of persons with mental retardation and its educational implications.

2.3 CLASSIFICATION OF MENTAL RETARDATION

2.3.1 Psychological Classification

We have seen in Unit 1 that, to call a person as mentally retarded these factors should be considered. This includes 1. significantly sub- average general intellectual functioning. 2. Deficit/impairment is adaptive behaviour. 3. Manifested during the developmental period.

The first factor namely significantly subaverage intelligence is determined by intelligence tests. Intelligence quotient (IQ) is derived by such tests. Based on the IQ scores obtained by a person, he/she is classified as having certain degree of mental retardation, the classification includes, borderline

intelligence (not retarded) mild mental retardation, moderate mental retardation, severe mental retardation and profound mental retardation. The lower the IQ the more severe the degree of retardation.

Since 1900s various tests have been used and the classification has undergone change (see table 1)

TABLE – 1 SELECTED SYMPTOM SEVERITY CLASSIFICATION

TABLE - 1 SELECTED SYMPTOM SEVERITY CLASSIFICATIONS

Measured intelligence * (90, 80, 70, 60, 50, 40, 30, 20, 10)

Source					
Terman (1916)	Border line-IQ 70 to 79	Moron IQ 50to69	Imbecile-IQ 25 to 49		Idiot-IQ 24 or below
Wechsler (1958)	Border line-IQ 70 to 79	Moron IQ 50to69	Imbecile-IQ 30 to 49		Idiot-IQ 29 or below
American Association on Mental Deficiency (1961)	Borderline intelligence -1SD IQ 68 to 83	Mildly mentally retarded - 2SD IQ 52 to 67	Moderately mentally retarded -3 S.D. IQ 36 to 51	Severely mentally retarded -4 S.D IQ 20 to 35	Profoundly mentally retarded -5 S.D.,IQ 19 or below.
American Association on Mental Deficiency (1973, 1977) +		Mildly mentally retarded - 2SD IQ 52 to 67	Moderately mentally retarded -3 S.D. IQ 36 to 51	Severely mentally retarded -4 S.D IQ 20 to 35	Profoundly mentally retarded -5 S.D.,IQ 19 or below.
American Psychiatric Association(1980)		Mildly mentally retarded - IQ 50 to 70	Moderately mentally retarded- IQ 35to49	Severely mentally retarded- IQ 20 to 34	Profoundly mentally retarded- IQ below 20

* IQ ranges from Stanford-Binet standard deviations (S.D.)

+ The 1983 AAMD classifications (released at the time this volume was being prepared for press) placed a narrow band of IQ scores at each and of each level but are essentially the same as those in the table

Source: Drew C.J., LoganD.R., Hardman M.L., Mental Retardation a life cycle approach, 1984 Times Mirror/Mosby College Publishing 3rd Ed page 19.

Currently the classification based on IQ is :

90-110	Average Intelligence
70-90	Borderline Intelligence
50-69	Mild Mental Retardation
35-49	Moderate Mental Retardation
20-34	Severe Mental Retardation
Below 20	Profound Mental Retardation

While providing a classification, it is also cautioned that IQ alone should not be the deciding criteria and that adaptive behaviour deficits should be given consideration. In addition, every cut off IQ is given a 5 points overlap. For instance 70-75 can be considered mild mental retardation if adaptive behaviour assessment is suggestive of such a decision. Some of the standardized tests used for assessment of intellectual functioning in India include;

- Binet Kamat Test of Intelligence
- Malins Intelligence Scale for Indian Children
- Seguin Form Board
- Revans Progressive Matrices

To get the correct and reliable score and thus the classification, the test should be conducted only by the trained psychologists and careful interpretation should be made.

2.3.2 Medical classification

Medical classification is usually based on etiology. It can be as follows:

1. Infections and Intoxications
2. Trauma or physical agent
3. Metabolism or Nutrition
4. Grossbrain disease (post natal)
5. Unknown prenatal influence
6. Chromosomal abnormality
7. Gestational disorder

8. Psychiatric disorder
9. Environmental influence
10. Other influences

More details on medical classification can be seen in Unit 1 and Unit 3 of this block.

2.3.3 Educational classification

Historically the educational classification included terms such as slow learners, educable, trainable and custodial mental retardation to refer to those with borderline intelligence, mild, moderate and severe/profound levels of psychological classification respectively. The educational classification is made based on the level of functioning of the mentally retarded persons. For instance, those who need to be totally taken care of for all their needs are called custodial because they are under custody; those who can be trained in certain semiskilled or unskilled jobs are called trainable (TMR); those who can be educated in the basic functional literacy are called educable (EMR), and those who can be educated like other normal children but are slow in learning are called slow learners, or dull normal. (Table-2).

However, there has been a movement by the professionals and parents regarding the issue of classifying and labeling the mentally retarded persons. It is considered to be stigmatizing them with a label and would also restrict the teacher to concentrating on specific abilities only. For example, a child who is labeled `trainable' may get a school programme in training in various skills and the teacher may not try to teach him any reading or writing as the name suggests training only. Thus currently there is a trend towards delabelling (not referring to them by their level of retardation).

Table – 2 CLASSIFICATION BY EDUCATIONAL EXPECTATION

Terminology	Approximate IQ range*	Educational Expectation
Dull normal (Slow learners)	IQ 75 or 80 to 90	Capable of competing in school in most areas, except in the strictly academic areas in which performance is below average Social adjustment that is not noticeably different from the larger population, although in the lower segment of adequate adjustment. Occupational performance satisfactory in non-

		technical areas, with total self-support highly probable.
Educable (Mild MR)	IQ 50 to 75 or 80	Second to fifth-grade achievement in school academic areas.
		Social adjustment that will permit some degree of independence in the community.
		Occupational sufficiency that will permit partial or total self-support.
Trainable (Moderate/ Severe MR	IQ 20 to 49	Learning primarily in the areas of self-help skills, very limited achievement in areas considered academic.
		Social adjustment usually limited to home and closely surrounding area.
		Occupational performance primarily in sheltered workshop or an institutional setting.
Custodial (Profound MR)	IQ below 20	Usually unable to achieve even sufficient skills to care for basic needs.
		Will usually require nearly total care and supervision for duration of lifetime.

*IQ ranges represent approximate ranges, which vary to some degree, depending on the source of data.

Source : Drew C.J., Logan D.R., Hardman M.L., Mental Retardation a life cycle approach, 1984 Times Mirror/Mosby college publishing, 3rd ed., p26.
(Appropriate equivalent titles of psychological classification is given in parenthesis).

Ideally, classification and label should be used only for administrative purposes such as availing of social benefits like travel concessions, maintenance allowance, job reservation and so on.

For an educator the focus should be on the current level of functioning of the child which would help the educator to further develop programme for training the child towards social competence to be as independent as possible in the society.

2.4 IMPLICATIONS OF CLASSIFICATION

2.4.1 Issues related to classification

Classifying persons with mental retardation has certain advantages as well as disadvantages. Fro instance, curriculum development for children with metal retardation demand individualized instruction. However, if the classification is done, the range of skills to be taught to a group of students can be defined. But classification can also be reflecting restrictions on selection of training objectives as mentioned earlier. Actually, classified as moderately retarded may not receive any functional academic training as the classificational label denotes less ability.

Another angle to classification related issue is from the viewpoint of normalization. When we talk of equal opportunities and access, classification tends to segregate the person from the mainstream. It should be noted that an individual is a person first and then he also has a disability. When classification is done, he tends to lose the human identity. References such as he is `moderately retarded' or she is a `Down's syndrome' is commonly seen where the human identity is lost.

2.4.2 Labeling and its implications

Labeling a child as mentally retarded has positive and negative attributes. One obvious advantage is, labels serve as an indicator to professionals for understanding the condition, and exchange views. It is required for teamwork.

Labels are essential for administrative purpose, for certifying a child as mentally retarded, which in turn helps in receiving benefits and concessions offered by the state and central governments.

In the social context, as MacMillan (1977) notes, the label puts the unusual behaviour into perspective. If a child behaves in a manner not appropriate for his age and not acceptable by the non-disabled peer group, and if the peer group knows he is mentally retarded, perhaps the acceptance of the behaviour of the child with mental retardation will be better by the peer group.

On the negative perspective, labels isolate the retarded person from the non-retarded persons. Many a time, labels are stigmatizing. In addition, labeled persons may experience a lowered self-concept. Expectation level in performance from a labeled person will be lower than nonlabelled person. For instance, if a labeled person is engaged as an office boy, and if he misplaces files or hands over to the wrong person, there is a tendency to accept it as `after all done by retarded', whereas a similar error from nonlabelled person will lead to suitable punishment

and corrective measures. Besides, labeled persons are teased and bullied by the peer group-many a time isolated.

Labelling adversely affects integration in schools. Children, who are slow in learning, usually continue in regular school with the teacher providing the support possible by her. The moment the child is referred and diagnosed as 'mentally retarded' the teacher 'gives up' on the child, deciding `it is not her job' to train him/her and refers to special school.

As mentioned earlier, labels create a negative public image of a retarded person. As Neisworth and Smith note `people react to a labeled person as if he or she fulfilled all aspects of the label, thus forcing a trend towards fulfillment of the total label.

2.4.3 Current trends in educational classifications

Historically, as we have seen, educable – trainable – custodial was used as classification labels and children were referred to by these terms. There was also the practice of IQ based classification calling groups as `mild group', `moderate group' and so on.

Such practices were not only derogatory and stigmatizing, but did not lead to appropriate programming. With the evolution of the principle of normalization, grouping practices have undergone changes. The educators show an inclination towards labeling groups that are not derogatory and stigmatizing. Considering the age and the ability levels, groups are made with suitable nomenclature. When we consider the normal school going age, we see that 3 to 18 year old are covered in this range. The regular school system has the classification of pre-primary, primary, secondary and higher secondary levels. Schools for children with mental retardation also have the similar classification currently, with the age ranges 3-6 as preprimary 7-10 years as primary 11-14 yrs as secondary and 15-18 years as prevocational level (instead of regular higher secondary, as retarded children need preparation of job placement).

The curricular content suitably developed for the retarded students, such classification of the class groups help in improving their self esteem, leading towards achieving normalization. Intentions remaining the same, some schools use, alphabet names or colour names or numbers to call the groups based on age and ability levels.

For non-school based classification, as accepted by the legal system mild, moderate, severe and profound are in use.

2.5 SCREENING AND IDENTIFICATION

Very simply explained, screening is a procedure that identifies a person who needs further assessment for diagnosis of a disability. Alternatively said, screening helps in `suspecting' disability in a person. A screening procedure does not `confirm' disability, but helps in short listing for detailed assessment.

Identification is an outcome of screening. It is a process by which children with disabilities are identified for further assessment.

2.5.1 Definition

Identification is finding out children's special needs;

Screening is assessing a whole population in order to identify those individuals for whom some intervention in development would be beneficial. An obvious medical example is the process of screening all neonates for a metabolic disorder such as phenylketonuria. A simple urine test is carried out, enabling a dietary treatment programme to be instituted for babies found to be suffering from the condition.

Similar principles have been applied to special educational needs. Here, two types of screening can be distinguished, immediate screening to identify an existing need, and predictive screening intended to identify (and so prevent) a future need.

(Source: William. P (1991) The Special Education Hand Book).

2.5.2 Process and procedures

Frankenburg as quoted by Neismith and Smith (1982) suggests seven points to be kept in mind prior to screening.

1. The frequency of the condition being screened for
2. Seriousness of the condition
3. Availability of effective treatment
4. Timing of screening
5. Detectability of the condition
6. Value of early detection
7. Cost effectiveness.

Medical screening and diagnostic procedures

A. Pre-natal procedures

1. Blood tests in the mothers

- Haemoglobin levels (Hb%) to defect anaemias
- Blood glucose levels to detect Diabetis
- Blood VDRL to detect syphilis
- Blood group and Rh typing for blood group incompatibilities
- Blood antibody tries to detect specific infections
- Alpha foeto proteins to detect neural tube defects in the foetus

2. Ultrasonography (during pregnancy)

Many types of foetal pathology including those associated with mental retardation later on can be identified during the II trimester of pregnancy by means of ultrasound technique. Some of them are neural tube defects, hydrocephaly, microcephaly, hydranencephaly, holoprosencephaly, porencephaly and some cerebellar lesions. Intra uterine growth retardation can also be detected through such measurements as foetal biparietal diameter, crown rump length and transverse abdominal diameter.

3. Aminocentesis

Is a process which involves drawing of amniotic fluid through per abdominal route. The fluid is then subjected to biochemical and cellular tests. Amniocentesis is indicated in suspect cases of foetal chromosomal aberrations, congential metabolic errors and open neural tube defects and severe Rh incompatibility. It is also conducted in advanced maternal age, previous birth of an abnormal child or a mentally retarded child. By diagnosing conditions early during gestation, the option of termination of pregnancy is available to the mother in abnormal cases. Thus amniocentesis is a technique for early identification and primary prevention.

4. Foetoscopy

Is carried out during II trimester of pregnancy through transabdominal route. By using fiber optive device the foetus is visualized for its external features and for collecting samples of blood and tissues from the foetus. The procedure helps in diagnosing certain physical anomalies, metabolic disorders or biochemical abnormalities.

5. Chorionic villous sampling

Biopsy of chrionic villi is performed either transabdominally of per vaginally. The sample is then subjected to karyotyping and enzyme determination. There are hazards involved in this procedure in inexperienced hands.

B. Neonatal and Postnatal screening & diagnostic procedures

1. Apgar Score
2. Urine screening for metabolic errors – ex. PKU (Phenyle Ketoneuria)
3. Blood biochemistry tests for cretinism, Rickets, jaundice etc
4. Blood antibody titres to detect infections
5. Chromosomal analysis for Downs Syndrome, deletion syndromes etc
6. Neonatal neuro behavioural assessments
7. EEG electroencephalogram for seizure disorder
8. Visual screening for visual impairments (visual acquity, Funds examination, Retinoscopy etc.)
9. Auditory screening – for hearing impairments (Tympanogram, BERA etc.)
10. Utra Sonogram
11. CT scan (computerized tomography)
12. MRI (Magnetic Resonance Imaging) for intracranial pathology and structural abnormalities

1. Apgar score

Apgar has devised a method of scoring which is of practical value. The score is a more accurate index of likelihood of death or neurological residue if it is taken at 5 minutes. At one minute after delivery it is an index of asphyxia and the need for assisted ventilation.

Sign	0	1	2
1. Heart rate	absent	below 100	over 100
2. Respiratory effort	absent	slow irregular	good crying
3. Muscle tone of extremities	limp	some flekion	active motion
4. Response to	No response	Grimace	Cough or

catheter			sneeze
5. Colour	Blue, pale	Body pink	Completely
		extremities blue	pink

Scoring 8 to 10 is normal. Below 7 high risk infant

2. Ultra sound examination

For intracranial pathology real time ultrasound examination of the intracranial contents of neonates and infants is a valuable new technique. It uses sound beam through tissues in a repetitive automated fashion and a continuous image is formed. It is a simple, non invasive technique which can be used even in a critically ill full term new born or a premature infant. This is done through anterior fontenelle as long as it is patent. The technique can be used to detect displacement of brain midline structures, thickness of brain substance, pathological cavities in the brain. Real time ultrasound examination of the head can reveal intracranial haemorohage in the new born.

Ultrasonography has been recommended as a screening test in children with brain symptoms, as follow up method in patients with shunt operations.

3. Biochemical tests in neonatal screening

Blood and urine examinations are conducted in the neonatal period for identifying metabolic disorders. It is not done as a routine examination but in all suspected cases and with previous history of mental retardation in the family. Cretinism is another condition which can be diagnosed in the neonatal period and necessary treatment given.

4. EEG – electro encephalography

EEG is useful not only in Epilepsy but in many other cases as mental retardation and organic brain lesions. In certain cases it also helps in localization of lesions and the severity of cerebal affection.

Incidence of abnormal EEG's is higher in cases of mental retardation associated with epilepsy, encephalitis, severe degree of mental retardation and brain damage sustained before birth or in the neonatal period.

EEG has an important role in the evaluation of neurologically compromised new born infants. It is a simple method to study the rapidly maturing neonatal brain and detect the deviations from anticipated norms.

Sleep patterns are well developed in normal new borns and they indicated degree of brain maturity. Absence of these in EEG is abnormal. The stresses and strain undergone by the neonate brain are also reflected in EEGs.

5. CT – Computed Tomography

CT of the brain defines intracranial anatomy by visualizing structures of different radio densities. The technique consists of acquisition of attenuation data from different views within a single cross sectional plane which are computed to present a recognizable image.

There are many abnormalities which can be detected by CT scan of the CNS such as anoxia of tissue, intracranial haemorohage, hydrocephalous and congenital anamolies like holoprosencephaly, a genesis of corpus callosum. Arnold chiari malformations, congenital cysts, calcifications, etc.

6. MRI (Magnetic Resonance Imaging)

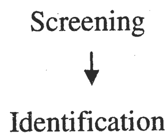
It is a new imaging technique used for display of brain anatomy. It uses radio frequency radiation in the presence of a magnetic field alongwith computation of data. It appears to be a superior procedure to many present techniques.

As mentioned earlier screening leads to short-listing individuals suspected to be having disabilities. The major methods involved in screening include camp approach, group screening techniques, use of mass media such as radio, television, posters and dandoras and individual screening. By these methods, a large number of people can be sensitized, on a condition. Messages on television and radio such as `is your child slow in walking/talking when compared to children of his age. `if so bring him to the camp on ______ (specific date and time). You will be guided suitably', help even the illiterate parents in various parts of the country get support for screening and identification. (See sample screening schedules in figure 1 & 2).

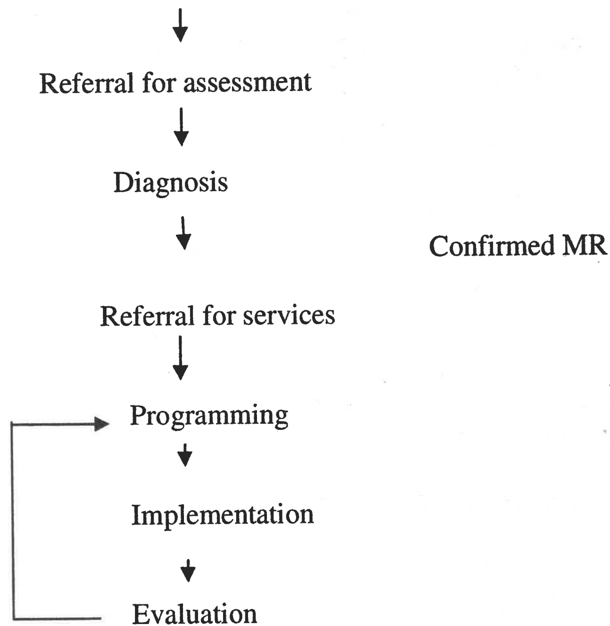
A multidisciplinary team consisting of experts conducts the camp to confirm disability/make further referral for detailed assessment as the case may be. Thus screening helps in identifying large number of persons with suspected disability in a limited time period.

Stages in screening and identification for further service provision

Screening



Identification



2.5.3 Advantages

Screening helps to identify people with suspected problem. This reduces the long and tedious task of door-to-door survey to identify people with disabilities.

When mass screening is done, identification of persons for detailed assessment is done faster and also is cost effective. This is especially true when scholastically backward children are screened for dyslexia or mental retardation. There are a number of group screening schedules for this purpose.

Screening helps in identifying large number of probable disabled persons in less time.

2.5.4 Limitation

All screening tools are not reliable. Many a time false positives are included in the process. If the tool is not reliable, screening can lead to inclusion of wrong persons.

Some untrained or inadequately trained personnel in the field of disabilities tend to use the screening procedure as the diagnostic tool. Thus there is a threat of wrong diagnosis.

Use of inappropriate screening tools also will lead to wrong diagnosis.

When mass screening is done, there is a chance of target persons getting missed out and not getting identified.

If screening tools are not culture specific, it may not serve the purpose of identifying the correct target persons.

2.5.5 Screening tools

Some of the popularly used screening tools include standardized ones predominantly from western countries. The NIMH has developed 3 screening schedules for quick screening, one for those below 3 years, one for 3 to 6 years and one for 7 years and above as seen in the following pages.

Screening Schedule 1 (below 3 years)

Stage No.	CHILD'S PROGRESS	NORMAL DEVELOPMENT Age Range	DELAYED DEVELOPMENT: If not achieved by the
1.	Responds to name/voice	1-3 months	4th month
2.	Smiles at others	1-4 months	6th month
3.	Holds head steady	2-6 months	6th month
4.	Sits without support	5-10 months	12th month
5.	Stands without support	9-14 months	18th month
6.	Walks well	10-20 months	20th month
7.	Talks in 2-3 word sentences	16-30 months	3rd year
8.	Eats/drinks by self	2-3 years	4th year
9.	Tells his name	2-3 years	4th year
10.	Has toilet control	3-4 years	4th year
11.	Avoids simple hazards	3-4 years	4th year
Other factors			
12.	Has fits	Yes	No
13.	Has physical disability	Yes	No

IF THE CHILD IS FOUND TO BE DELAYED IN ANY OF THE STAGES GIVEN FROM 1-11 AND IF THE CHILD HAS FITS OR PHYSICAL DISABILITY, SUSPECT MENTAL RETARDATION.

Screening Schedule – II (3 to 6 years)

1.	Compared with other children, did the child have any serous delay in sitting, standing or walking?	Yes	No
2.	Does the child appear to have difficulty in hearing?	Yes	No
3.	Does the child have difficulty in seeing?	Yes	No
4.	When you tell the child to do something, does he seem to have problems in understanding what you are saying?	Yes	No
5.	Does the child sometime have weakness and/or stiffness in the limbs and/or difficulty in walking or moving his arms?	Yes	No
6.	Does the child sometimes have fits, become rigid, or lose consciousness?	Yes	No
7.	Does the child have difficulty in learning to do things like other children or his age?	Yes	No
8.	Is the child not able to speak at all? (Cannot make himself understood in words/say any recognizable words)	Yes	No
9.	Is the child's speech in any way different from normal? (not clear enough to be understood by people other than his immediate family)	Yes	No
10.	Compared to other children of the same age, does the child appear in any way backward, dull or slow?	Yes	No
IF ANY OF THE ABOVE ITEMS IS ANSWERED `YES' SUSPECT MENTAL RETARDATION			

*Adapted from the International Pilot Study of Severe Childhood Disability – Final Report – Screening for Severe Mental Retardation in Developing Countries.

Screening Schedule – III (7 years and above)

1.	Compared with other children, did the child have any serious delay in sitting, sanding or walking?	Yes	No
2.	Can the child not do things for himself like, eating, dressing, bathing and grooming?	Yes	No
3.	Does the child have difficulty in understanding when you say, "do this or that"?	Yes	No
4.	Is the child's speech unclear?	Yes	No

5.	Does the child have difficulty in expressing, without being asked what the child has seen/heard?	Yes	No
6.	Does the child have weakness and/or stiffness in the limbs and/or difficulty in walking or moving his arms?	Yes	No
7.	Does the child sometimes have fits, become rigid or lose consciousness?	Yes	No
8.	Compared to other children of his age, does the child appear in any way backward, dull or slow?	Yes	No
IF ANY OF THE ABOVE ITEMS IS ANSWERED `YES' SUSPECT MENTAL RETARDATION			

Note: Screening schedule 2 and screening schedule 3 ensure the prompt identification of every single mentally retarded child. Do not worry if the questions sometimes identify persons with handicaps other than mental retardation. Such persons can be later assessed. Our chief concern is the identification of the mentally retarded child.

Some of the other popularly used Western screening tools includes;

a) Cooperative preschool inventory Caldwell)
b) Croydon Scales (Screening Checklist) (Wolfendale & Bryans)
c) Denver Developmental Screening Test (Frankensberg, Dodds and Fandal)
d) Early childhood assessment: A criteria referenced screening device (Schmaltz, Schramn and Wendt)
e) AGS Early Screening Profiles (Harrison, et. al)
f) Developmental indicators for the assessment of learning-R (Mardell, et.al)
g) Early Screening Inventory (Merisels et.al)
h) Brigance K and I Screen for Kindergarten and First grade (Brigance)

In India Developmental Screening Test (DST) by Bharat Raj is a widely used screening tool by professionals. The NIMH schedules noted earlier are used for camp approach for further referral.

2.6 CHARACTERISTICS OF PERSONS WITH MENTAL RETARDATION

As we have seen in classification (Table-2) the characteristics vary depending on the level and degree of retardation. The associated conditions also are to be considered when we talk of characteristics as they are contributing factors. Though there can be certain general

characteristics attributed to their level of functioning, individual differences always exist, as we see in non-disabled persons.

As you know mental retardation is a condition and not a syndrome. This differentiation is important because a "condition" can have varied causation, manifestation, management and preventive measures. Whereas a syndrome is a specific disorder with specific characteristics and clinical features. The criteria/features have to be fulfilled to diagnose a syndrome. It is important to note that there are no physical features specific to the condition of MR but MR can be a feature of some syndromes with specific physical features. Eg. Downs Syndrome wherein typical facial features of upward slanting eyes, depressed basal bridge, thick protruding tongue, low set ears, systemic involvement like congenital heart disease etc may be present along with MR. With the physical and clinical features a provisional diagnosis of Down Syndrome can be made. For a final diagnosis of Down Syndrome, chromosomal analysis (Karyotyping) is essential. And for diagnosis of MR detailed psychometric evaluation is required as there are no specific physical features.

Another point of importance is the degree of MR is not reflected in the degree of dysmorphism (abnormal physical features) a child/person with MR may be absolutely normal to look at with any degree of MR. On the contrary a child/person with severe physical abnormality may be of normal intelligence or have any degree of MR. Thus we rely on some of the features which help us in segregating children who are "suspect" for MR and who need detailed assessment to diagnose MR and its severity. Listed below are some of the features which make him different from the normal stream.

General Characteristics

1. Generally they have a marked delay in their developmental milestones when compared to normal children, such as their sitting, standing, walking, talking and so on. Mildly retarded children usually have their physical characteristics close to their normal peers. Some of the moderately retarded and severely retarded ones might have clumsy gait and poor motor coordination. The profoundly retarded individuals usually have associated physical disabilities and many a time, they are non-ambulatory.

2. The physical characteristics also depend on the causes and the clinical features of the individual. For instance, the one with microcephaly has a very small head with receding chin and forehead, while the one with hydrocephalus has a very large head. As mentioned earlier, a child with Down syndrome has very distinct features such as slanting eyes, flat nose bridge, flabby skin, little finger turned inwards, wide gap between big toe and the next toe and fissured tongue. Those with mental retardation and

cerebral palsy will have spasticity or stiffness of the limb or limbs and may have drooling of saliva.

3. The mentally retarded persons have difficulty in language and communication, which are found more with severely/profoundly retarded and less with mildly retarded persons.

4. A small number of mentally retarded persons have dual or multiple disabilities such as impairment in visual, hearing or motor abilities.

Mental retardation – A manual for multi rehabilitation workers (NIMH) lists ten commonly found characteristics of metal retardation which include, 1. Slow reaction, 2. Absence of clarity, 3. Inability to learn fast, 4. Inability to understand quickly, 5. Inability to decide, 6. lack of concentration, 7. short temper, 8. Inability to remember, 9. Lack of coordination, 10. Delay in development.

2.6.2 Social characteristics:

The social characteristics stand out in a retarded child because of the discrepancy between his abilities and the expectation of the society from him. Following are some major characteristics. Note that all the persons with mental retardation do not exhibit all characteristics.

1. One commonly found characteristic among many retarded children is short attention, and lack of concentration. They will switch from one activity to another without completing any of them.

2. There are also those retarded persons who are lethargic, do not get motivated to do any task or continue to do the same task or have difficulty in changing form one activity to another.

3. Their memory is poor and therefore need to be trained repeatedly in a task.

4. Some of them exhibit problematic behaviour, which are either self-injurious or harmful to others. Self injurious behaviours include hand biting, pulling own hair, nail biting, eye poking, beating on the face, banging head on wall or floor and so on. Those that harm others or destructive are the ones such as beating and pinching others, throwing things, tearing clothes, and breaking articles. Other problematic behaviours include running away from home, stealing and so on. Most of such behaviour can be controlled by systematic intervention.
5. There are some retarded persons who are indifferent to their surroundings and not responding when communicated to, though they may not have

hearing problems. Irrelevant laughing or talking is also found with some retarded persons.

6. While the mild and some of the moderately retarded ones can perform regular jobs they are trained in, their problem solving ability is poor and are found incompetent in taking decisions independently. Even if their work skills are good, many tend to lose their jobs due to poor social competence.

2.6.3 Educational implications

It is essential for the teachers to keep in mind the characteristics of every child she teaches as she is required to plan teaching programme based on the child's all-round profile. To quote an example, there may be a child in her class with epileptic fits who would exhibit certain behaviour just before or after an attack of the fit. Only if the teacher is aware of it, would she be able to take appropriate actions in the right time. She should work in close coordination with medical personnel and other therapists to help the child in total.

As seen in the table of Educational Classification, the characteristics vary with the degree of retardation. A smart teacher will consider the strengths in the retarded person first for educational planning and decide on meeting the needs for independent living.

Since their overall cognitive abilities are limited, the basic processes of thinking, reasoning, memory, understanding, attention, problem solving and communication skills will be affected in them. While planning any activity for teaching, the teacher should keep in mind as a steady objective to enhance these skills.

2.7 UNIT SUMMARY

Persons with mental retardation are classified based on the degree of retardation. Medical classification takes into account aetiological factors, psychological classification consider IQ scores and educational classification includes current level of functioning.

Classification leads to attaching labels to persons with retardation. Labels have positive and negative effects. On the one hand it helps in identifying and certifying the person and on the other it is stigmatizing. Current trends are towards delabelling.

Screening and identification help in locating persons with suspected mental retardation. Varied tools are used for this purpose. Screened persons need to be assessed further for diagnosis and/or educational programming.

Based on the degree of retardation persons with mental retardation have varied characteristics. Most of them have performance difficulties due to poor attention, memory, problem solving abilities and slow and clumsy movements. Some clinical features have certain physical characteristics.

A teacher must take into account the strengths and limitation of the mentally retarded student into account when she plans programmes.

2.8 CHECK YOUR PROGRESS

a) Write psychological classification

b) Write educational classification

c) Discuss two advantages and two disadvantages of labeling

d) What is screening

e) Describe two medical screening procedures

f) Name any two screening tools

g) Describe social characteristics of persons with mental retardation

h) What aspects of characteristics you will keep in mind while planning for education of a mentally retarded student.

2.9 ASSIGNMENT

a. Use a suitable screening schedule for educational purposes for a child/group of children and give a report.

b. Suggest methods you will adopt for organizing mass screening through camp method.

2.11 POINTS FOR DISCUSSION AND CLARIFICATION

After studying the unit, you may want to make notes of points on which you need clarifications. List them below.

2.10.1 Points for discussion

2.10.2 Points for clarification

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2.11 REFERENCES

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UNIT 3:ETIOLOGY CAUSES AND PREVENTION

STRUCTURE

3.1 Introduction

3.2 Objectives

3.3 Biology and mental retardation

3.2.1 Definition of Mental Retardation

3.3.2 Genes and environment

3.3.3 Genesis of Mental Retardation

3.3.4 Nervous system development and its importance

3.4 Causes of mental retardation

3.4.1 Biological risk factors & environmental risk factors

3.4.2 Causes before conception

3.4.3 Pre natal causes

3.4.4 Natal causes

3.4.5 Post natal causes

3.4.6 Psycho social causes

3.5 Prevention of Mental retardation

3.5.1 Primary prevention

3.5.2 Secondary prevention

3.4.6 Tertiary prevention

3.5.4 Pre natal prevention

3.5.5 Natal and peri natal prevention

3.5.6 Post natal prevention

3.6 Unit Summary: Things to remember

3.7 Check your progress

3.8 Assignment/Activity

3.9 Points for discussion/clarification

3.10 References/further readings

3.1 INTRODUCTION

The word "etiology" means causation. Knowledge of the causative factors of mental retardation (MR) is basic and important. It gives you the understanding of what, when, where, why and how of MR. The causes of mental retardation helps you in the following aspects.

1. To understand the child/person with MR with a holistic approach.
2. It gives an insight into the pathology (abnormality) that has affected the person.
3. It provides basis to the present development of functioning of the person with mental retardation.
4. It forms the basis for treatment (medical/surgical) and/or provision of aids and appliances, and selection of teaching and training strategies.
5. It helps in prevention of the condition at various levels (primary, secondary, tertiary prevention)
6. It helps in providing information, guidance, counseling and prognosis of the condition to the parents and important others. (outcome and future course)
7. This information can be utilized in creation of awareness, for sensitization and training programmes professionals, para professionals, and grass root level functionaries.
8. Above all, it helps to improve the "quality of life" for a person with MR.

3.2 OBJECTIVES

After going through the unit you will be able to:

- demonstrate understanding of basic causes of mental retardation
- differentiate the different periods when mental retardation can be caused
- demonstrate understanding of the basic biology/pathology in causation of mental retardation
- apply the knowledge of causation to understand prevention of mental retardation
- find out different levels of prevention of mental retardation
- state the various steps involved in preventing mental retardation

3.3 BIOLOGY AND MENTAL RTARDATION

We have already seen the definitions of Mental Retardation in details in SESM-01, Block 1, Unit 1. Let me remind you once again as it is relevant here.

3.3.1 Definition

Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas, communication, self care, home living, social skills, community use, self direction, health and safety, functional academics leisure and work. Mental retardation manifests before age 18 (AAMD 1992).

If you analyze you understand the existence of 3 important clauses within the definition.

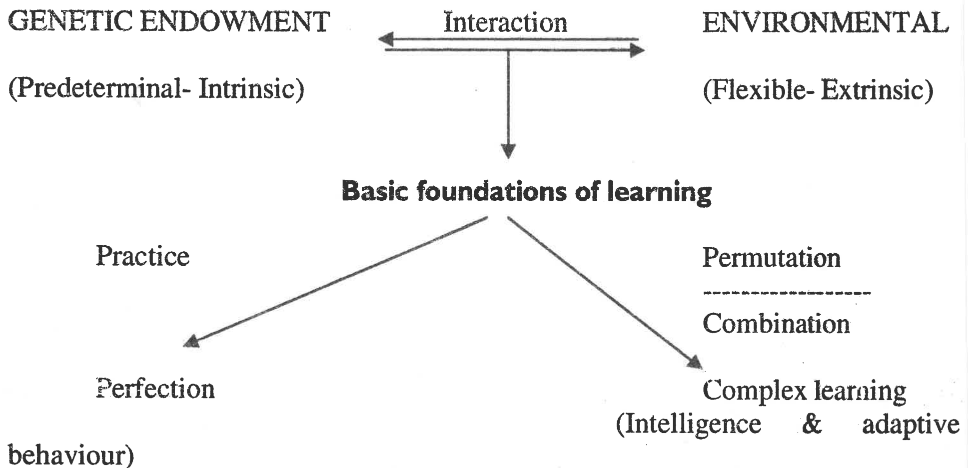
1. Significantly sub average intellectual functioning which is indicated by IQ (Intelligent quotient) which is less than 70.
2. Deficits in adaptive behaviour which the child/person exhibits at various stages of development in day to day living.
3. Manifested during the developmental period i.e. from conception to 18 years of age.

3.3.2 Genes and Environment

Genes are the biological basis for growth, development, learning and performance. Genes are inherited from parents. They are pre determined and cannot be manipulated. But environment provides challenges and stimulation for the genes to unfold and exhibit their characteristics. This interaction between genes and the environment provides the basic foundations of learning. Each learnt behaviour/skill when practised repeatedly leads to mastering or perfection in that skill. A number of individual skills learnt when used in combination and with permutations lead to complex learning which we term as intelligence. The more complex learning the child has acquired, the more intelligent he is considered and he is able to adapt himself to the environment and gain mastery and control over the world around.

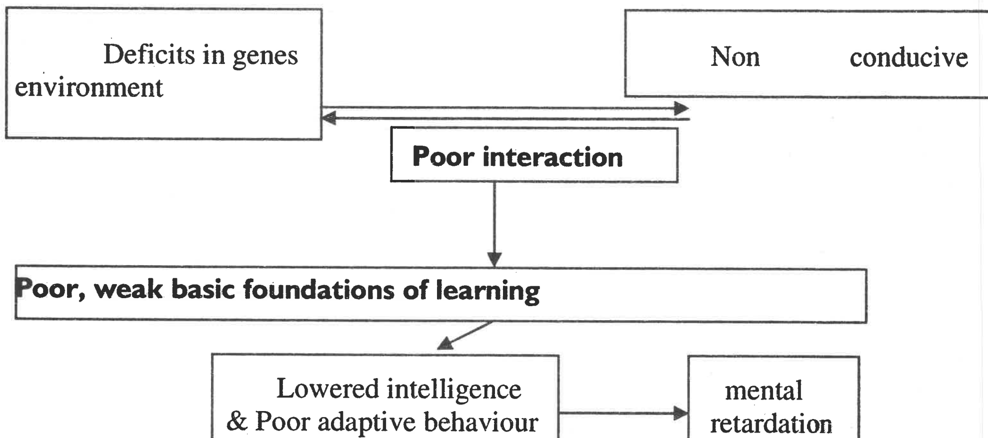
Probe into the development of intelligence and adaptive behaviour gives depth to our understanding the condition of MR. Though an over simplified representation

of development of intelligence, the following gives an understanding of normal intelligence and adaptive behaviour.



3.3.3 Genesis of MR

This concept highlights the importance of the two major factors in determining the intelligence and adaptive behaviour. (1) Genes (2) Environment. Therefore any deficits in either or both of them leads to deficits in learning and poor adaptive behaviour which we term as the condition of MR.



3.3.4 Nervous system development and its importance

Apart from Genes and Environment the third important factor for consideration in causation of MR is its manifestation **during the developmental period**. This

developmental period is taken up to 18 years of age. The term **development** means the changes in the function of the organism and growth means the changes in the size. Together they imply the magnitude and quality of maturational changes. These occur in **various aspects** (physical, intellectual, emotional growth and development and learning) at **different stages** (right from the time of conception) and is of **different grades.**

Thus the understanding of these various factors and their effects on the growth and development of the organism is essential. It is also important to realize that any adverse effect of these will tell upon the growth and development of the organism.

The basic pathology of mental retardation is in the Nervous system. You have studied nervous system in SESM-02, Block I, Unit 1. Let us brush it up once again as it is needed here. The types of insults to the nervous tissue are varied and may occur at any period of growth and development. The degree of the effect also differs. To understand the pathology some of the basic principles of biology of the brain are important.

Types of brain cells : CNS develops from the neuro-ectoderm and begins as a straight hollow tube during the first four weeks of gestation. There are broadly two types of cells in the brain.

1. Neurons or nerve cells (transmitters) 2. Glial or connective tissue cells (conductors)

Human brain consists of 100 billion neurons and 1000 billion supporting tissue cells (glia)

While neurons are the transmitters of impulses and messages, they are very dependent on glial cells for their health and efficiency. One of the functions of the glial cells is to form an insulating sheath of myelin (as fatty substance) around part of the neuron. This increases the speed and efficiency whereby messages are sent from one neuron to another. This process of development of myelin is called myelination. Myelination is completed by two years of postnatal age.

Growth and development of brain

At birth infants brain weighs on an average 350 gms. Brain achieves almost all of its mass in the first few years of life. Tanner (1978) indicates that some 25% of adults' brain weight is reached at birth, nearly 50% at 6 months. 75% at 2 years and 90% at 5 years and 95% by 10 years of age.

During early pregnancy the brain tissue grows almost exclusively by means of an increase in brain cells (neurons) number. Later in pregnancy – chiefly during last trimester (last 3 months of pregnancy) brain size increases as a result of both, an

increase in cell number and an increase in cell size. The final increase in brain size during early years of infancy and childhood occurs exclusively by means of an increase in cell size and interconnections.

The neurons mainly develop prenatally while glial cells largely develop during 2nd half of post natal period. The development of neurons and glial cells together with the increasing complex inter connections between neurons, are the main features of the growing brain that are effected by environmental influence. Severe injuries lead to prenatal death. Mild injuries are compatible with life.

Damage and destruction of brain cells

The first trimester is the period of greatest embryonic sensitivity to environmental insults such as infection, anoxia etc. Any insult in the 1st trimester may irreversibly limit brain growth and organization. These agents affect the tissue by causing lysis (destruction) of cells or altering the function of the cells. It is well known that no further increase in the cell number (neurons) occurs after birth and therefore deficits cannot be made at any stage later. Also neurons do not possess the power of regeneration as seen in tissues of other organs and therefore once a neuron is destroyed is lost forever.

If the harmful agent affects the foetus early in pregnancy (i.e. the period when the cell production is in progress), there may be a decrease in the number of neurons. Structural anomalies occur since organogensis occurs at this age like – anencephaly, encephalococele, meningococele, etc. The later insults usually result in smaller brain cells. When the brain growth is arrested or impeded the baby may be born with small head and low nervous content – known as Microcephaly (Micro-small; Cephaly - head).

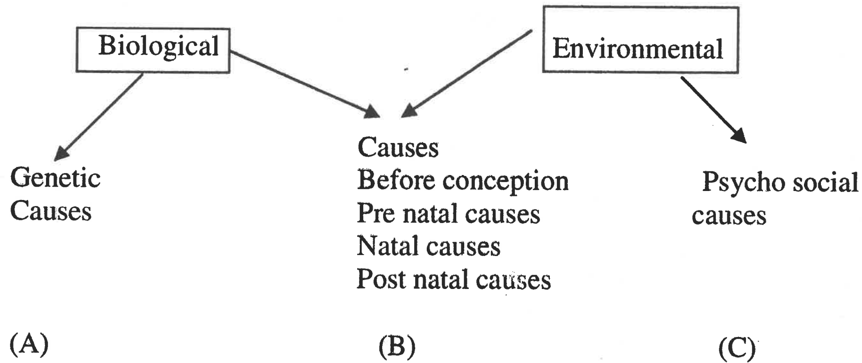
3.4 CAUSES OF MENTAL RETARDATION

Causes of mental retardation can be before, during or after birth.

3.4.1 Biological risk factors and environmental risk factors

The causative factors of mental retardation are varied and widespread. There are factors which affect the foetus at conception or even before conception, such as age of the mother, health of the mother, and/or chromosomal and genetic disorders. The causes may be broadly classified under biological risk factor and environmental risk factors.

Therefore the causes of MR are classified as



(A) Genetic causes are purely biological
(B) There are some biological causes which are enforced with environmental influences
(C) There are some environmental causes which are purely psycho social in nature

Biological risk factors - **are those that develop within the body as part of one's basic biology and organic make up. They include genetic and other inborn features (characteristics) metabolic aspects and interaction of varied complex systems of the body. Many biological risk factors are genetic.**

Environmental risk factors – are health related risks that exist outside the person and over which the individual has little or no control. These includes social and physical factors.

(a) Social environmental risk for disability are a function of the expectations and opportunities that accompany specific socio cultural environment. Attitudes, assumptions, preferences or prejudices encountered throughout society help create social environmental disability risks, for instance occupational settings, certain physical skills, abilities and characteristics. Because of the physical demands and socio cultural expectations of that environment the likelihood or risk of a functional limitations becoming a disability is greater than in cultural setting that assigns less value to these characteristics. Socio environment risk for disability is when individuals are required to perform tasks that exceed their physical or mental abilities.

(b) Physical environment risk – injury or disease can trigger a process that leads to disability. They place individuals in circumstances leading to impairment and functional limitations.

3.4.2 Causes before conception

Age of the mother : The best period for conception is between 20 and 30 years of age. A very young teenage mother is likely to have problems due to biological immaturity. There are high risk group for abortions, premature deliveries giving birth to low birth weight babies, or babies with chromosomal abnormalities etc. Above 30 years of age, as the maternal age advances they are the candidates for high risk pregnancy and deliveries. They may face problems of difficult, delayed deliveries, babies born with chromosomal and other physical abnormalities. Thus age of the mother plays an important role in the delivery of a healthy, normal baby.

Nutrition and health status of the mother before pregnancy are very important for conception and development of the foetus. A healthy mother brings forth a healthy child.

Large families: Limiting of the family size is good for the health of the mother and the well being of the child. As the birth order of the child increases, there is a possibility of increase in the risk factors.

Addictions: Any addictions such as drug abuse, smoking & chewing of tobacco and alcohol consumption can jeopardise the health status of the mother and influence the developing foetus adversely (microcephaly, low birth weight etc.).

3.4.3 Prenatal causes (during pregnancy)

- No or poor antenatal check ups
- Abortions – repeated, attempted, threatened
- Poor nutritional status of mother
- Diabetes
- Rh. Incompatibility
- Hypertension (high blood pressure)
- Convulsions (fits)
- Infections – (Toxoplasmosis, others, Rubella, Cytomegalo virus, Herpes)

- STD (sexually transmitted diseases)
- Physical trauma/injury
- Emotional stress/trauma
- Drugs
- Irradiation
- Addictions – Tobacco/Nicotine – Alcohol
- Potentially harmful medication
- Multiple pregnancies (twins, triplets)
- Maternal mental illness
- System pathology - heart, kidney, liver diseases
- Bleeding during pregnancy

Hypoxia: (Lack of oxygen) Cellular integrity of brain is very easily damaged by changes in the oxygen and glucose level of blood at any time during life. It is that neurons cannot withstand oxygen deprivation for more 5 minutes. The states of total oxygen deprivation (anoxia) or low oxygen supply (Hypoxia) can affect the embryo foetus (antenatally) during the period of delivery or postnatally. These situations are caused by maternal illness or foetal causes.

During pregnancy hypoxia may be caused (such as maternal heart disease, shock, bleeding, low BP, placental insufficiency (dysfunction), toxaemias of pregnancy. Hypertension, or defects in foetal circulations can interfere in growth and maturation.

During labour: Premature separation of placenta difficult and prolonged labour, abnormal presentation etc. may lead to hypoxia.

Post natally – mental retardation may be caused by Trauma, bleeding, blocking of blood vessels, which are grouped under Cerebro Vascular accidents.

Nutrition: Nutrition for the baby is drawn from the mother throughout its stay in the mother's womb via the placenta. We all are well aware that nutrition is very essential for growth and development on the whole. Studies have shown that reduced foetal growth can be corrected by maternal nutrition supplementation. There is a rapid transfer of nutrition to foetus in the last trimester (last 3 months). of pregnancy. Therefore, decreased supply during these periods causes great deficit in birth weight. The findings of the famine studies suggest that while under nutrition in the later part of pregnancy may retard the growth of the foetus. In early pregnancy it affects the capacity for survival and development . Nutrition

deprivation not only results in low birth weight and small for gestational age (SGA) babies but also predisposes these high risk infants to MR through various complications.

Malnutrition in infancy and early childhood can result in mental retardation. In Protein Energy Malnutrition (PEM), the child is dull, lethargic and when PEM is severe and prolonged, causes mental retardation.

Hypoglycemia : Like oxygen adequate supply of glucose to the nervous tissue is vital. The normal brain usually utilizes only glucose for its metabolic requirements. Hence hypoglycemia is manifested principally as CNS dysfunction. The state of hypoglycemia is caused by

- Maternal starvation (during foetal life)
- Impeded blood supply to CNS
- Infants of diabetic mothers
- Food deprivation in children
- Malabsorption (poor and defective absorption of food)
- Glucose metabolism abnormalities
- Juvenile diabetes (Diabetes in children)
- Liver disorders

Metabolic errors: In certain cases of "Inborn errors of metabolism" the CNS is grossly affected leading to MR. In these cases the metabolism of one of these i.e. Proteins (amino acids) Carbohydrates, Fats and other important substances are affected at some stage of their normal cycle, causing accumulation of products in abnormal quantities. This leads to neuronal damage and destruction or may prove to be toxic and cause derangement of their functions.

- may prove to be toxic
- the biochemical or physiological effect of the product may be detrimental
- accumulation of products in abnormal quantities specially intracellular which ultimately cause neuronal damage or destruction or derangement of CNS function. Eg.Phenyl Ketonuria (amino acid metabolism is affected)

  Galactosaemia (CHO metabolism is affected)

  Gaucher's and Neiman Pick's disease (lipids – metabolism is affected)

Mucopolysaccharidosis (GAG – Glycoamino glycans) – Lesch Nyhans syndrome (Uric and metabolism) is affected

Developmental anomalies of CNS

1. Microcephaly (small head) : Defect of brain growth on the whole. Because of less brain tissue and the skull over it also does not grow in size. It can be familial and recessive type of inheritence.
2. Craniastenosis Craniosynastosis : When the growth of the brain is normal but the sutures close early, giving rise to a small head and MR
3. Hydrocephalous : Here the size of the head is abnormally large due to increased fluid secretation (CSF) or obstruction to fluid flow.

Teratogens

A teratogen may be defined as an agent or factor which can cause abnormalities of form and function in an exposed foetus. These agents can be – Infective agents, Chemical, Actinic, Nutritional, Mechanical.

Some of the effects may not be apparent until later in life which may cause difficulty in interpretation of negative reports of drug teratogenicity. Recognition of teratogens offers the opportunity for prevention of related birth defects.

(a) Infections: Can affect the baby either prenatally or postnatally. Prenatal infections are almost always secondary to maternal infection. Severe maternal infections during early pregnancy often result in abortion. Infection during the first 2-3 months of pregnancy usually causes variety of defects and unduly disseminated infection. Infection of the foetus during the later stages of prenatal life causes manifestations which more closely resemble those of post natal life infections. In postnatal life, infection can affect the child at any stage of developmental period and may cause CNS damage

These infections can be due to – viral-cytomegalovirus, Rubella, Measles, Mumps, Chicken pox, Herpes etc.

-Bacterial – (Tuberculosis, Meningococcal, Staphyloloccal, E.Coli.)
-Protozoal – Toxoplasmosis
-Spriochaetal-Syphillis
-Fungal

(b) Chemicals:

- organic mercury compounds can cause prenatal damage (Minamata disease) quinine, ergot, and lead have long been used as abortifacients. It is possible that taken in smaller dozes they fail to induce abortion but injure the foetus
- Chemical contraceptives
- Maternal alcoholism
- Drugs used in cancer
- Insulin, Trimethadions, Paramethadions or other drugs have been confirmed as causative agents of MR

(c) Actinic injuries: Roetgenrays and radium are capable of arresting embryonic development and producing malformations Microcephaly, microphthalmia, mental retardation and deformities of extremities have been ascribed to such intrauterine injuries.

The limited data on human foetuses show that large doses of radiation (10,000-30,000 millirads) are harmful to the CNS. For that reason therapeutic abortion is often recommended when exposure exceeds 10,000 millirads.

3.4.4 Natal causes (during delivery)

- Premature (born before full term)
- Post mature (born after 42 weeks pregnancy)
- Multiple pregnancies (twins, triplets)
- Difficult and prolonged labour (labour for more than 24 hours)
- Forceps/instrumental delivery/vacuum extraction
- Caesarian (delivery by surgery)
- Bleeding during delivery
- Abnormal presentation – Buttocks, Breech, Brow/face, Hand/shoulder, foot/leg .
- Prolapsed cord/kinking/knotting
- Cord round the neck
- Unhygienic delivery – place, instruments, handling
- Convulsions during delivery

Natal causes : The process of delivery of the baby should be one of ease and smooth passage of baby with no harm caused either to the baby or to the mother. Certain conditions which cause difficult labour should be identified early and treated and complications averted.

- abnormal foetal positions or presentation
- abnormally narrow birth passage
- abnormally large head
- bleeding during delivery
- Physical manipulations
- Instrumental deliveries
- Multiple Pregnancy (twins, triplets)
- Unhygienic delivery

3.4.5 Post natal causes (from birth upto 18 years of age)

- Delayed birth cry - birth cry after 5 minutes
- Low Birth weight - <2500 gms
- Prematurity/post maturity
- Colour of the baby – pale, yellow, blue, plethoric
- Activity of the baby – dull, lethargic, jittery irritable, convulsions
- Obvious congenital anomalies – Microcephaly, Hydrocephalous, abnormality of limbs, cleft lip/palate, visual/auditory impairment, system involvements Cardio vascular system, Respiratory system,
- Infections/Septicaemias (Infection in the blood)
- Trauma/Injury
- Feeding problem – (vomiting, colic, spitting, difficulty in sucking and swallowing)
- Convulsions (fits)
- Jaundice
- Nutritional deficiencies
- Developmental delays

Post natal causes: Apart from the causes already discussed such as trauma, infections, metabolic disorders, nutrition etc. which are all contributory factors both prenatally and natally to the development of mental retardation the other causes have to be discussed which affect the child postnatally.

Toxins poison, degenerative

Poisons lead poisoning (H/-Picais +)

- mercury poisoning

Toxic encephalopathy – post immunization (rabies whooping cough)

- post infective slow measles infection

- Infections - (meningitis, Encephalitis)
- Injury/trauma (head injuries)
- Toxins and poisons (lead, mercury etc.)
- Endocrinal causes (cretinism)

Thyroid deficiency – Cretinism

Because of deficiency of thyroid hormone, the child is dull, has rough skin, sparse thin hair, thick protruding tongue. Puffy face and eyes, constipation, rough coarse voice and mental deficiency. If these children are diagnosed early – treatment is possible. If treatment is started within first few weeks of life, mental deficiency can be averted.

Degeneration disorders of CNS

The outstanding characteristics of these illnesses are loss of previously acquired intellectual, motor or sensory functions. Most of them are genetically autosomal recessive; especially enzymatic defects have been demonstrated in some. Effective therapy is lacking for most of them.

These disorders are classified into 2. (i) Those principally affecting the gray matter; (ii) those principally affecting while matter.

Mental retardation and seizures are predominant features in gray matters degeneration. Deterioration of motor functions is predominant features in white matter degeneration

3.4.6 Psycho social causes

Psychosocial causes refer to the environmental influences. These also can lead to mental retardation.

Prenatal factors :

- Relative infertility,
- repeated abortions,
- conception after many years of marriage,
- large family, lack of family planning,
- poor spacing between births,
- illegitimate unwanted child
- only child - a child born after a long period after the earlier pregnancy

- difficulties in previous pregnancy

Child:

- Premature baby
- Low birth baby
- Difficulties & problems in the newborn period such as illness, prolonged stay in hospital, surgery
- Severe congenital abnormalities
- Feeding problems

Parents:

- very young or very old parents
- mental illness
- unpreparedness for the arrival of the baby
- poor general health
- Addictions (drugs and alcohol)
- Poverty
- Single parent (divorce, separation, bereavement)
- Marital disharmony
- Poor family resources
- Poor personal relationships with family
- Poor family support

All the above mentioned conditions play an important role in the development of the child and contribute to causation of mental retardation.

3.5 PREVENTION OF MENTAL RETARDATION

If taken suitable action and precautions in the right time, many a time, mental retardation is preventable.

Preventive services should be administered by the physicians, parents and the community and should be efficiently implemented. They should cover both mother and child health care. Child health care begins right from the stage of unborn child to its full development stage upto 18 years of age. Our efforts are towards producing healthy babies without physical defects or mental retardation. A good health delivery system which has easy access to everyone and gives quality care at minimum cost is very essential.

Prevention strategies can be at various levels.

3.5.1 Primary prevention – This eliminates the occurrence of the problem in the individual and reduces the prevalence in the community. For example, improving prenatal and perinatal care and thereby excluding conditions which lead to mental retardation. Prevention of illnesses, accidents, poisons etc.

3.5.2 Secondary prevention – Here, there is an early identification of problem followed by early intervention which eliminates the potential factor or modify it so that mental retardation is prevented. For example, Early stimulation in high risk infants.

3.5.3 Tertiary prevention is aimed at minimizing the disability or atleast mitigating some of its effects. For example, specific or comprehensive services for individuals.

Steps for prevention can be undertaken at different stages of development.

3.5.4 Pre natal prevention: Inadequate prenatal care has been linked to prematurity and low birth weight which are in turn linked to mental retardation. Prenatal care that will guard the foetus against damage from maternal illnesses and infections and other dangers should be assured for every pregnant women from the start of the pregnancy.

The pregnant woman is advised

i) To go for regular antenatal check ups for early detection of abnormalities, illnesses and infections so that prompt treatment and to good management plan for delivery.

ii) To maintain good nutrition status: Poor nutrition for both the baby and the mother is linked to impaired brain development and retardation. Malnutrition in the mother can give rise to low birth weight baby who in turn is a high risk infant for to mental retardation. Therefore, antenatal programmes and child health programmes should ensure good nutrition and health to both the mother and the child.

A pregnant woman has to take sufficient amounts of nutritious foods to maintain her health and also supply nutrients to the growing foetus. Thus the food requirements of a pregnant woman increases greatly. The diet should contain adequate amounts of

proteins, carbohydrates, fats and minerals to supply the required calories and body building substances. Therefore the diet should contain adequate amounts of cereals, pulses, green leafy vegetables, milk, eggs, fruits and fresh foods. Lack of these nutrients can give rise to anaemia and other nutritional deficiencies. Iron and vitamin supplements may be given in the form of tablets, syrups or injections, to avoid deficiency status in the II trimester of pregnancy.

iii) To get preliminary investigations done (like blood and urine), prenatal diagnosis is essential. This encompasses a number of procedures designed to assess the condition of the unborn baby.

a) Ultra sonography
b) Radiography
c) Amniocentesis – to know chromosomal abnormalities
   - enzyme deficiencies
   - metabolic disorders
   - sex of the baby
   - alpha foeto proteins

If these tests prove that the foetus is normal, the parents can be reassured. If found to be abnormal, the parents are given options for medical termination/treatment which will prevent the occurrence of a child with mental retardation.

Treatment of illness and timely immunization:

a) To get prompt treatment for illnesses and infections

b) To get immunization at appropriate time : During the 7th, 8th and 9th months of pregnancy a pregnant woman should take Inj. Tetanus toxoid (TT) to avoid the tetanus infection during delivery and immediate post natal period. It also gives immunity to the foetus and the new born child as the maternal antibodies pass to the foetus via the placenta.

3.5.5 Natal and peri natal prevention: Delivery should be conducted under hygienic conditions by a trained person. Unnecessary meddling of the foetus should be avoided. The baby should be handled gently with care. The umbilical cord should be cut with a sterile knife. In cases of difficult or abnormal labour or delivery, the woman should be taken to the nearby hospital without delay. Ensure the delivery of pacenta and control of the uterine bleeding after the delivery of the baby. Mother should be allowed to rest for few hours immediately after delivery.

Good perinatal care is an important factor in prevention of mental retardation. Pregnant woman should be advised to get delivery conducted by a trained personnel at home under hygienic conditions or at a health centre. For all complicated pregnancies and labours the delivery should be conducted at hospitals in order to bring down injury and infection which are the causative agents of mental retardation in the child. At present survival rate of babies is very good - especially the premature and low birth weight babies with good perinatal care. They also survive as normal healthy babies thus bringing down the percentage of mentally retarded cases. All high risk infants should be well taken care off and should have a long term follow up for early detection of handicapping conditions and delays in development.

3.5.6 Post natal prevention

Neonatal screening: Some of the conditions of mental retardation like PKU and Hypothrodsim can be prevented from progressing into mental retardation by early treatment. Therefore it is highly important to detect these at the earliest. This is possible with simple tests of blood and urine examination in a new born and treated immediately. Other metabolic errors also can be detected during the neonatal screening and parents counseled regarding mode of inheritance and recurrence risks in order to avoid further occurrence of mental retardation due to these causes.

High risk infants care and follow up: Intensive care should be immediately available to babies who are high risk for mental retardation such as prematurity, low birth weight, birth asphyxia and babies born of prolonged, difficult labour and other complications. There is a need for well equipped neonatal intensive care units to cater to such services. Even after discharge from hospitals such babies need a close follow up to identify delays and abnormalities in development. This helps us in giving the earliest interventions and corrections which reduce the severity of handicap.

Early stimulation and intervention programmes : These programmes are for children with handicaps or developmental delays. The two main components of these programmes are:

1. Directly stimulating the child with enriched environment to enhance development.
2. Teaching the parents the techniques that can be used at home and helping them to have better parenthood.

They cover the child's health, nutritional, psychological and educational needs. These programmes prevent further complication and reduce the severity of handicap.

Immunization: Mental retardation caused by infections like Diphtheria, Tetanus, Whooping cough, Typhoid, Measles and Poliomyclites and Rubella can be prevented by active immunization programmes. Immunization confers protection against the specific viral and bacterial infections.

Rh incompatibility which is one of the causes of mental retardation can be prevented by giving imm. Uno globulin to the Rh negative mother immediately following the birth of her first Rh positive baby.

Early identification and prompt and appropriate treatment of infections lessens the complications and sequlae. Proper environmental and personal hygiene, clean water supply, destruction of insects and animals which carry infections all help in reducing the occurrence of infections and thereby the occurrence of mental retardation as sequlae to infections.

Prevention of accidents and poisoning : Accidents and poisoning can injure the brain and cause irreversible damage and mental retardation. This is one of the preventable causes of mental retardtion. People should be made aware of the potential causes of accidents and poisoning and the methods of avoiding them through various "public awareness programmes". Safety principles, safety equipment and safety requirements should be made known to general public.

More rigorous identification and eradication of toxic substances in the environment, such as lead paint, airborne lead or water borne mercury compounds should be perused. Screening programmes to identify the affected children should be emphasized upon for early treatment and prevention of mental retardation.

Alcohol, drugs, teratogens : These form another major cause of retardation as they have adverse effect on the developing foetus. Therefore these have to be avoided specially during pregnancy to prevent the occurrence of mental retardation in babies.

Nutrition: As mentioned earlier, poor nutrition for both the baby and the mother is linked to impaired brain development and retardation. Malnutrition in the mother can give rise to low birth weight baby who in turn is a high risk infant to mental retardation. Therefore, antenatal programmes and child health programmes should ensure good nutrition and health to both the mother and the child.

Family planning: The best age for the mother is between 20 and 30 years. Having children when younger or older increases the risk of having a mentally retarded child. Pregnancies at very short intervals drawings on the health of the mother leads to complications Therefore the family size should be restricted and children should be properly spaced.

Dissemination of the information: regarding prevention of mental retardation to the general public and the various professionals involved to create awareness and motivation to work towards the goal of prevention of MR is absolutely essential.

Research is needed to further develop strategies for facilitating progress in prevention of mental retardation and developmental delays.

3.6 UNIT SUMMARY: THINGS TO REMEMBER

i) There are various factors which adversely affect the developing brain (from conception to 18 years of age) and cause destruction or dysfunction of the brain cells thus leading to causation of mental retardation.

ii) The basic pathology in brain is due to (a) lack of oxygen (b) lack of nutrition (c) toxic effect, (d) destruction of cells reduction in cell number and size and dysfunction of cells.

iii) The causes are mainly classified as (a) biological causes (b) environmental causes.

iv) According to the period when development of brain is affected the biological causes are subdivided into causes before conception, pre natal causes, natal causes and post natal causes.'

v) The environmental causative factors include physical social, cultural, psycho emotional factors in home, child, parents, family and society.

vi) With proper efforts, many a time mental retardation is preventable. Public education and care before, during and after delivery is paramount for prevention of mental retardation.

3.7 CHECK YOUR PROGRESS

1. What is the biological basis of mental retardation.
2. How do you classify the etiological factors of mental retardation
3. What are the influencing factors before conception

4. Enlist the prenatal causes of mental retardation
5. Enlist the natal causes of mental retardation
6. Enlist the post natal causes of mental retardation
7. What is prevention? How do you classify prevention
8. What are the preventive strategies for mental retardation

3.8 ASSIGNMENT/ACTIVITY

Take a detailed case history of a person with mental retardation including demographic data, prenatal, natal, post natal family and developmental aspects. Critically analyze and find the most probable causative factor of mental retardation and justify your statement. Also enlist what steps if taken would have prevented the condition of mental retardation in that person.

3.9 POINTS FOR DISCUSSION/CLARIFICATION

After studying the unit, you may want to make notes of points on which you need clarifications. List them below.

3.9.1 Points for discussion

3.9.2 Points for clarification

3.10 REFERENCES/FURTHER READINGS

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UNIT 4: CLASSIFICATION – MEDICAL, PSYCHOLOGICAL, EDUCATIONAL (RECENT) AND ICF

STRUCTURE

- **Introduction**
- **Objectives**
- **Assessment – A continuous process**
    - What is pre-referral intervention?
    - Post referral
- **Defining Assessment**
    - What is assessment?
    - What is the difference between assessment and testing?
- **Purpose of assessment**
    - Screening and identification
    - Evaluation of teaching programme and strategies (pre-referral)
    - Determining current performance level and educational need
    - Decision about classification and programme placement
    - Development of individualized educational programme
    - Evaluation of the effectiveness of the individualized programme
- **Different modes of collection of data**
    - Directly testing the student
    - Observation
    - Collecting data from family members and significant others
- **Report writing**
- **Defining Evaluation**
    - What is evaluation?
    - What is the difference between assessment and evaluation?
- **Types of Evaluation**
    - Formative evaluation

- Summative evaluation

- **Methods of recording data**
  - IEP format
  - Checklist used for assessment and programming
  - Task analysis
  - Graphs
  - Work samples
  - Anecdotal records
  - Progress report
- **Unit Summary : Things to remember**
- **Check your progress**
- **Assignment/Activity**
- **Points for Discussion/clarification**
- **References/Further readings**

4.1 INTRODUCTION

Assessment and evaluation are critical components of special educational process. Assessment involves collection and organization of information for specifying and verifying problems and for making decisions about a student. The decisions may include a wide spectrum ranging from screening and identification to evaluation of a teaching plan. The selection of assessment tools and methods vary depending on the purpose for which the assessment is to be carried out.

Evaluation is a thoughtful process involving the comparison of the way things are, to the way they should be. Generally two types of evaluation procedures are used in educational evaluation – formative and summative. Educators use different methods to record the evaluation data.

4.2 OBJECTIVES

After going through the unit you will be able to:

- Understand the scope of assessment – pre-referral and post referral.
- State the definition of assessment and difference between assessment and testing.
- Explain the purposes of assessment.
- Describe different modes of collection of data and write the report.
- State definition and types of evaluation.

- Describe methods of recording evaluation data.

1.3 ASSESSMENT: A CONTINUOUS PROCESS

Assessment is an ongoing process in the classroom ie., the teacher continuously uses assessment to monitor the students progress. When students fail to show the progress as expected, teacher becomes concerned and uses more in-depth assessment to pinpoint the specific difficulty. For this purpose, the teacher may use informal assessment, or curriculum based assessment, error analysis and observation to identify the specific problems experienced by a student. Then the teacher may seek the help of a multidisciplinary team in remediating the problem in the classroom itself. This is called pre referral intervention.

4.3.1 What is pre referral intervention?

Pre referral intervention is a process of developing and implementing a remedial/teaching programme and evaluating the effectiveness of the programme in terms of students' progress. The teaching plan involves changes in environment, curriculum and methods. This process takes place before a formal referral is made for special educational assessment. This process falls well within the principle of normalization and mainstreaming which emphasizes education of disabled children within the least restrictive environment. The NPE (1986) in India also recommends that the disabled children who can cope with education along with non-disabled children with supportive services should be permitted to be in regular classes.

4.3.2 Post referral

If a student continues to exhibit a significant difficulty in learning even after pre referral intervention, he is referred for formal evaluation. The evaluation/screening committee plans an individual assessment plan based on the referral information. The type of assessment that may be used in comprehensive evaluation are varied depending on the students needs. Norm-referred tests and informal methods such as classroom observation, interviews with teachers and parents, and criterion referenced instruments are employed to evaluate the students performance.

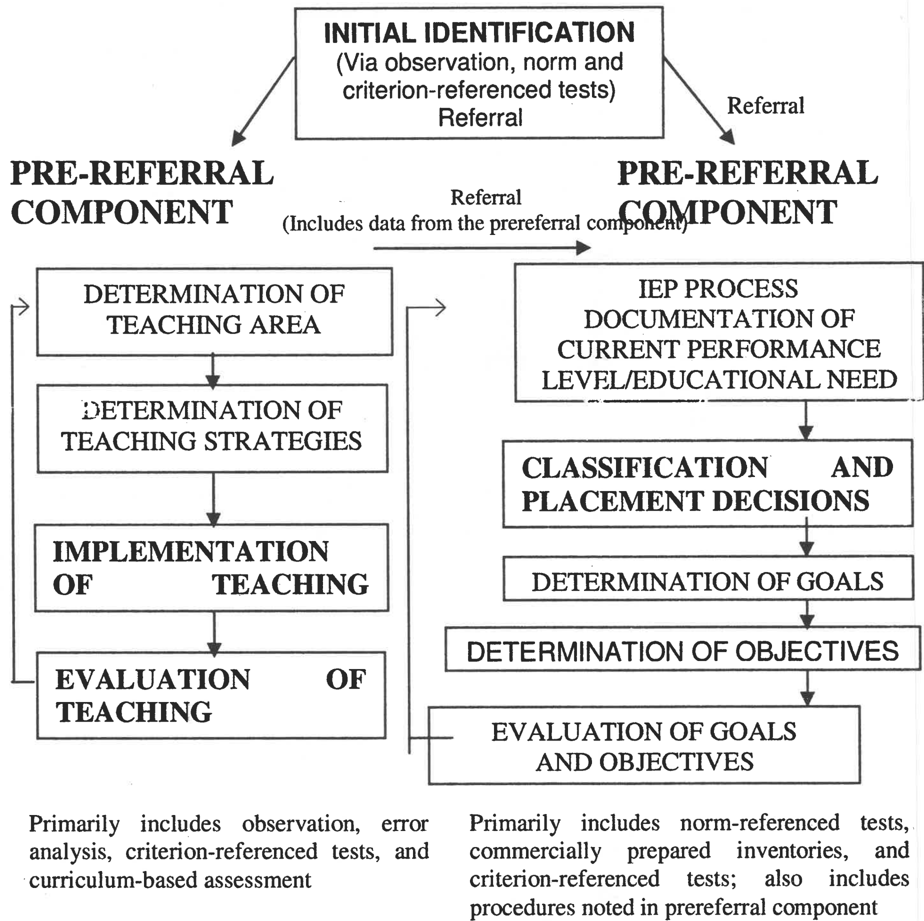

Figure: An Assessment Model

The information collected through evaluation process usually results in making decisions about classification and programme placement. It also might result in the development of IEP, that includes goals and objectives, instructional strategies and time limit for implementation and evaluation.

4.4 DEFINING ASSESSMENT

4.4.1 What is assessment?

In simple terms, assessment means gathering information about a person and his environment to solve problems.

To define, assessment refers to the process of gathering and analyzing information in order to make instructional, administrative and/or guidance decisions about or for an individuals (Wallace, Larsen, and Elksnin, 1992).

4.4.2 What is the difference between assessment and testing?

Often the term testing is used synonymous to assessment by many lay persons, professionals and educators, but assessment is much more than testing an individual (eg. Testing a child to know whether he can read and write numerals). Assessment involves gathering of information in many ways – testing directly the child, observing the child in various environments, and interviewing family members and significant others. Information collected through these means is analyzed to make decisions for which the assessment has been carried out. Therefore, testing is a part of assessment process.

4.5 PURPOSE OF ASSESSMENT

Any one who is involved in assessment process should know clearly the purpose for which he is conducting the assessment. Knowing this is very important as it decides the type of assessment tools and means of gathering information for decision making.

For example, if the purpose is only for screening and identification, we use a short screening schedule, for programme planning we use a checklist which helps in assessing the current performance level and selection of content for teaching.

There are many purposes of assessment. They are:

(1) Initial screening and identification,

(2) determination and evaluation of teaching programmes and strategies (pre-referral intervention),

(3) determination of current performance level and educational need,

(4) decisions about classification and programme placement,

(5) development of individual educational programmes (including goals, objectives and evaluation procedures).

(6) Evaluation of the effectiveness of the Individualized Educational Programme.

4.5.1 Initial screening and identification

- The students who require special attention or special educational services are initially identified through assessment procedures. The procedures involve either informal procedures such as observation or error analysis or formal procedures such as achievement or intelligence tests. In other words, assessment is used to identify the children who warrant further evaluation.
- Assessment is also used to screen children who are considered to be "high risk" for developing various problems. These children would not have yet developed deficiencies requiring special education, but they do exhibit certain behaviours that suggest problems in future. Identifying such children allows continuous monitoring of problem areas and designing of stimulation programme if required to prevent the problem.

Assessment for initial identification purpose, therefore is used to identify individual who might need further detailed assessment or who might develop problems in future. Further, it identifies individuals who with some type of immediate remedial programme might be able to cope with the problem.

4.5.2Evaluation of teaching programme and strategies (pre-referral)

One of the important roles of assessment is to determine appropriate programme and strategies. For this purpose, information is used in four ways.

- First, prior to the referring of a student to special education programme, it can assist regular teacher in determining what to teach and the best method to teach.
- Second, it serves as a method of evaluating the effectiveness of the particular teaching programme or strategy. Many a time a formal referral for special education can be avoided if assessment information is used in this way. That is assessment information can be used to develop and evaluate pre-referral intervention programming. For example, a student X is getting poor marks in subjects as he makes a lot of spelling mistakes.

Before making a formal referral to special education services, thinking that the student may be learning disabled, the regular teacher may assess and analyze the work product (spelling errors) of the student and provide a remediation programme. If student shows progress, further referral to special education services can be avoided.

- Third, in determining appropriate programmes and strategies, assessment can provide pre-referral information to document the need for a formal referral. As explained above, if pre-referral intervention fails to remediate the spelling problem, then there is a need for referring the student for special education programmes.
- Fourth, the pre-referral intervention information can be incorporated into the individual education programme for student who are eligible for and who ultimately receive special education.

4.5.3Determining of current performance level and educational need

The assessment of current performance level of a student in subjects or skills is essential to state the need for special education programme. This information helps the teacher or examiner.

- to identify subject(s) or skill(s) that need special assistance.
- to identify strengths and weaknesses of students.
- to select appropriate strategies and procedures.

4.5.4Decision about classification and programme placement

The assessment data is used for classification and placement of students with special needs in appropriate special educational programmes. Theoretically, individuals are classified to indicate similarities and relationships among their educational problems and to provide nomenclature that facilitates communication within the field (Taylor, 1993). Based on assessment information students are classified and suitable placement decisions are made. For example, a 6 year old child who is diagnosed to have mental retardation needs a placement in special education programme which provides education to children with mental retardation.

4.5.5Development of the Individualized Educational Programme

The most important use of assessment information is to determine the goals and objectives, and strategies to teach children who are identified to have special

educational needs. As each individual child's needs are different, we have to plan educational programme that meets the needs. A systematically planned individualized educational programme is a blueprint for teachers to follow.

Evaluation of the effectiveness of the Individualized Educational Programme

Evaluation procedures are also specified in Individualized Educational Programme along with goals, objectives, methods and materials. Using these procedures, the teacher has to periodically monitor the progress made by the student. The monitoring of the programme gives feedback (positive or negative) to both teacher and student. Based on the type of feed back, the teacher either changes her plan or continues the same plan or select a new activity. For example, on periodic evaluation if the child shows improvement, the teacher will continue with her plan, if no improvement is shown she may have to make changes in IEP.

4.6 DIFFERENT MODES OF COLLECTING DATA

The assessment process involves collection of data through various modes. This is essential as the assessor or teacher aims at collecting information in all the areas of development of a child, which helps the teacher/assessor in making appropriate decisions. These methods include directly testing the child, observing the child in various environments and interviewing parents and significant others.

Directly testing the child

Testing the child and knowing the ability of a child yourself is always recommended as it provides first hand information. For example, instead of asking a parent whether her child can read and write words, or numerals, you test the child yourself using appropriate materials to check. If we depend on parents for information, we may miss out on identifying specific problems/content which in turn hinders further learning. To explain further, the parent may say that her son is able to read and write numerals upto 10. When you ask the boy to read the numerals by pointing not sequentially, he may read incorrectly, but, he could say orally 1-10 in sequence. If we had taken the parents information on face value, we would have selected the content for teaching numerals from 11 to 15 or 20 as an objective, which is inappropriate as per the child's ability. On the other hand, what is required is that, the boy should be taught to read the numerals independently when presented not sequentially upto 10. Hence, it is necessary always to test the child directly by the teacher/assessor to know the current performance level of the child. However, there may be some activities, for which the teacher may not be able to test the child directly (eg. Taking bath, behaviour of a child during social functions in the family, in the community, interaction with friends and neighbours) and has to collect information from family members.

1.6.1 Observation

Observation is an extensively used method to collect data while assessing or evaluating the child's performance. It helps the assessor or teacher to observe the child's performance herself and record the data objectively.

The assessor/teacher may observe the child in structured or unstructured environments depending on the activities to be assessed. For example, the teacher observes the child before, during and after lunch time to assess the child's ability in terms of eating, washing, cleaning, sharing, taking responsibility, which is a structured (structured observation) environment. Observing the child during interval, or games period in the play ground to assess the group behaviour of a child is unstructured observation. However, the teacher may plan a game or a sport event to observe whether the child follows the rules of the game is again a structured observation. To explain further, when the teacher purposefully plans activities or selects or simulates environments to assess a specific ability of a child, it is called structured observation, whereas in unstructured observation, the teacher observes the student with a specific purpose in mind but she does not purposefully plan an activity.

1.6.2 Interviewing

Information about many of the adaptive behaviours, which are neither tested nor observed are often collected by interviewing parents and family members. Collection of birth history, interaction with family members, relatives, friends, neighbourhood and community, are some of the examples.

1.7 REPORT WRITING

Report writing should be done individually. Generally, teachers tend to write stereotyped remarks while writing reports. Comments like `he is poor in writing', `cooperative in playing', `plays with children', `dependent on mother for personal needs', `has good motor ability', etc. do not indicate what exactly an individual student is able to perform in that task. Also using technical terms such as aggressive, hyperactive, destructive, attention deficit, etc. do not indicate the current level of performance, which is a take off point in special educational programming. In addition, while writing report, we need to keep in mind the consumers educational background and should avoid language likely to be beyond their comprehension. The consumers in general who read educational assessment reports are parents and family members, and other professionals involved in teaching and training of students with special needs. Further the content and the understandability reflects on the effectiveness of the report. Also, the tone and flavour of the report affects the reader for better or worse, and thus frequently

determines what the reader derives from the report. Further, the assessment reports should be written so objectively that they directly lead to prescription.

4.8 DEFINING EVALUATION

4.8.1 What is evaluation?

Evaluation is comparison of performance of a student to a prescribed criteria. Howell and Morehead (1987) state that evaluation is a thoughtful process involving the comparison of the way things are, to the way they should be. During evaluation, we collect the data, summarize the results and compare the results with a set criteria to draw conclusions. For example, an objective for student A is "Reads five words correctly after 15 sessions of teaching". On evaluation, it was found that she is able to read only 3 words. When we compare, we say that she is able to read only 3 words and she is yet to learn 2 more words. Here, we have compared the performance of the student (the way the things are) to the expected performance (reading 5 words – the way they should be) to find out effectiveness of intervention programme.

The following figure explains the evaluation process model.

The behaviour represents what the student is doing and the discrepancy represents how much the student has to achieve to meet the standard. Let us discuss the same example given above in the light of evaluation process model. The "**standard**" set is reading five words. On evaluation, the "**behaviour**" shown is reads 3 words. On comparison of the behaviour to the set standard, the "**discrepancy**" is 2 words. Therefore, the comparison of a student behaviour to a standard is central to the process of evaluation and the evaluator makes judgments based on discrepancy to determine the effectiveness of intervention programme.

1.8.2 What is the difference between assessment and evaluation?

Assessment is done before implementing the intervention programme. The assessment data gives the current performance level of the student, which helps in planning the educational programme (IEP) whereas evaluation is done after implementing the planned educational programme to measure the effectiveness of intervention programme.

The effectiveness is measured in terms of students achievement. If student has achieved expected standards, the teacher selects the next task for teaching. If the student has not achieved the set criteria, she may have to question either the

effectiveness of the selected methods (material and their presentation, teaching environment, teacher interaction and continuity of the training programme) or question the correctness of the initial assessment data to know whether the content selected for teaching is within the capacity of the student to learn. These decisions depend on the amount of discrepancy seen between standard and behaviour on evaluation.

4.9 TYPES OF EVALUATION

Assessment should be done before and after instruction. Assessment done after instruction is evaluation. Two types of post instructional evaluation procedures are in use in educational evaluation – formative and summative.

Formative Evaluation

Formative evaluation is conducted during the intervention programme actually being implemented. It facilitates periodic assessment to indicate whether the planned instruction is delivered as planned and whether or not the expected progress is being made by the student. Further, ongoing evaluation give the teacher and student immediate feedback on the adequacy or inadequacy of instruction and learning so that deficiencies or gaps can be quickly remediated.

Summative Evaluation

Summative evaluation on the other hand is a long term, final assessment conducted after a completion of unit instruction. It indicates final degree of learning or achievement.

4.10 METHODS OF DOCUMENTING RESULTS

Various methods of documenting evaluation results are in practice in education of children with special needs.

4.10.1 IEP format

The IEP form has a provision to document evaluation results after a specific duration or time period. The teacher indicates the evaluation procedure and the criteria to be achieved in IEP. As specified in the plan, the student is evaluated, then the performance of the student is compared with the set criteria indicated in specific objective to measure the progress made by the student.

4.10.2 Checklists used for assessment and programming

Activity checklists are used as an alternative method to document progress in students by the educationists. The teachers who use the checklists as basis for selection of content for teaching students, also can use them to note the mastery of activities.

4.10.3 Task analysis checklist

Task analysis checklists are extensively used in pre and post instructional assessment of students with mental retardation. The task analysis checklist is a blue print of content of a task to be taught. It pinpoints objectively the performance level of a student and guides teacher in planning instruction systematically. Daily/weekly recording of the progress of student can be noted which helps in summarizing the results at the end of instruction. Also, it depicts the progress of a student at a glance.

4.10.4 Graphs

Graphing provides a visual representation of student progress and may take many forms. Progress towards a goal may be checked daily or weekly by the teacher or student. The following are some of the advantages of maintaining graphs.

a) Graphing the progress provides a continuous visual indication of progress made by the student towards a specified objective.

b) They are so sensitive that they indicate small changes, which were not apparent to teacher or student.

c) Apart from indicating the progress made by student, it shows the rate of achievement. Constructing graphs for daily recording for all students is time consuming for teaching. However, cumulative records may be developed by teachers.

4.10.5 Work samples

Samples of student's work during instruction can also help in comparing the performance of a student. Areas such as handwriting, written work in language, arithmetic, and work samples are better evaluative devices to decide the mastery of learning.

4.10.6 Anecdotal records

Anecdotal records are brief written records of students' behaviour or incidents. They should be factual descriptions of student behaviour or incident and should be used for recording information about unanticipated behaviour. We keep hearing from special educationists making remarks that ""X" spoke a word to call the attention of other child which he did not do earlier, picked up on his own tiffin box before going to the dining place, etc." Such kind of descriptions will make teachers think and understand the student better in providing instruction.

4.10.7 Progress report is another format used for recording the achievement of students periodically. A class teacher generally records the performance/ achievement of students for giving feedback to parents/family members.

4.11 UNIT SUM MARY: THINGS TO REMEMBER

Children with mental retardation deviate from non-disabled children in the physical/ mental/social and/or in all the areas. Such children need to be identified early and given appropriate education and training. Assessment, planning of an instructional programme and evaluation are part of special education programmes and it is a continuous process.

1. Pre-referral intervention is a process of developing and implementing a remedial/teaching programme and evaluating the effectiveness of programme in terms of students progress. It is necessary before a student is referred for formal special educational evaluation.
2. Assessment is collection and organization of information for making administrative and instructional decisions.
3. Assessment is carried out for various purposes such as (a) screening and identification, (b) determining and evaluation of teaching programmes and strategies, (c) determination of current level performance and educational needs, (d) classification and programme placement, (e) development of IEPs and (f) evaluation of the effectiveness of intervention programme.
4. Assessment and evaluation reports should be written keeping in mind the consumer so that the reader can have a clear understanding of the abilities or inabilities of a child being assessed/evaluated.
5. Evaluation is a process of collecting data, summarize the results and compare the results with a set criteria to draw conclusions.
6. Two types of evaluation procedures are used in educational evaluation – formative and summative. Formative evaluation is conducted during the intervention programme actually implemented and summative evaluation is conducted after completion of a unit instruction.
7. Educators employ various methods for documenting evaluation data. They are IEP form, activity checklists, task analysis checklist, graphs, work samples and anecdotal records.

4.12 CHECK YOUR PROGRESS

1. What do you understand by pre-referral intervention?
2. Define assessment and evaluation. Write how does assessment differs from evaluation.
3. Explain the purposes of assessment.
4. Testing is a part of assessment process. Explain.

5. How do you collect assessment data?
6. When do you employ formative and summative evaluation?
7. Explain two methods of documenting evaluation data.

4.13 ASSIGNMENT/ACTIVITY

Read the assessment and evaluation reports and see the data recording sheets (activity checklists), task analysis checklist, graphs, etc. to understand how the information is presented and recorded.

4.14 POINTS FOR DISCUSSION/CLARIFICATION

After going through the unit, you may want to have further discussion or clarifications of some points.

1.14.1 Points for discussion

1.14.2 Points for clarification

4.15 REFERENCES/FURTHER READINGS

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UNIT 5: SCREENING,IDENTIFICATION, CHARACTERISTICS AND NEEDS OF PWID

STRUCTURE

- **Introduction**
- **Objectives**
- **Clinical Assessment**
- **Psychological Assessment**
  - Intelligence testing movement and emergence of intelligence tests
  - Distribution of intelligence
  - Types of intelligence tests
  - Adaptive behaviour
- **Educational Assessment**
  - Norm referenced assessment
  - Criterion referenced assessment
  - **Error Analysis**
  - **Functional Assessment**
    - Characteristics of functional assessment
    - Conducting a functional skill assessment
  - **Curriculum based assessment**
    - Procedure followed in developing CBA
  - **Observational Assessment**
    - Observational techniques
  - **Behavioural assessment**
  - **Unit Summary : Things to remember**
  - **Check your progress**
  - **Assignment/Activity**
  - **Points for Discussion/clarification**
    - Points for discussion
    - Points for clarification

- **References/Further readings**

INTRODUCTION

In the previous unit, we have discussed the purposes for which assessment is carried out. To call a child mentally retarded, ie., for the purpose of diagnosis, a comprehensive assessment is to be done which consists of medical assessment, psychological assessment and educational assessment. After the diagnosis, the child is referred to an appropriate educational programme for intervention. The assessment tools and procedures employed in diagnosis planning and evaluation of intervention programmes are discussed in this unit.

OBJECTIVES

After going through this unit, you will be able to:

- understand that there is a need for carrying out different types of assessment depending on the purpose.
- understand that a comprehensive assessment which includes medical, psychological and educational assessment is required for diagnostic purpose.
- explain the importance and use of psychological tests.
- describe the advantages and disadvantages of NRTs and CRTs.
- explain the meaning and purpose of functional assessment and curriculum based assessment.
- describe the steps involved in developing functional and curriculum based assessment tools.
- understand the application of behavioural assessment procedures in changing problem behaviours.

CLINICAL ASSESSMENT

Clinical assessment is a part of assessment in the process of diagnosis of persons with mental retardation. It is carried out to identify the cause of mental retardation, refer to further investigations to confirm the cause and other anomalies and to plan and evaluate treatment.

The individual's current health, vision and hearing status are generally assessed by medical members of the assessment team. Medical assessment may include a

health history, physical examination and any necessary laboratory tests. For example, if it is suspected that a persons may have mental retardation due to genetic problems, to confirm he is referred to necessary laboratory tests.

PSYCHOLOGICAL ASSESSMENT

Psychological assessment is the process of systematic collection, organization and interpretation of information about a person and situations, and the prediction of the person's behaviour in a new situation. Psychological assessment encompasses assessment of the three major aspects of the mind namely, cognition, conation and affection. Psychological assessment involves understanding of the causes of the problem and the potential solutions for the problem.

The purpose of psychological assessment is to evaluate an individual or group of persons in relation to a specific issue or problem. These may include intellectual functioning, learning disabilities, special abilities, scholastic achievement, personality functioning, emotional and social areas and questions of normality and abnormality. The psychologist develops hypotheses based upon information on past behaviour, present behaviour and prediction for future behaviour as defined by given situations incorporated in assessment information.

Definition:

The widely accepted and most commonly used definition of Intelligence is as follows:

"Intelligence is the aggregate or global capacity of an individual to act purposefully, to think rationally and to deal effectively with the environment" - David Wechsler (1975).

5.4.1 Intelligence Testing Movement and Emergence of Intelligence Tests:

Before the revolutionary contribution of Binet and Simon in 1905 the word `Intelligence' had not appeared in psychology textbooks because a means for its assessment was not yet available. The first intelligence scale which was developed by Binet and Simon in 1905 was called as the "1905 Scale of Intelligence", having the 30 items in an ascending (increasing) order of difficulty, from very easy to very hard items for children with 3 to 12 years range. This scale was revised in 1908 with standardized 58 items by introducing the concept of "mental age". This was done by listing several items that could be passed by a majority of children at each age level from age 3 to 13. Further revision of this scale was done in 1911 by extending the age range to 15 years. All these scales were primarily scales for quantifying the mental abilities of school children. With the introduction of the 1911 scale, Binet extended the potential use of the 1908 scale to normal adults and suggested its use some day in industrial psychology. Binet, who is considered as the father of `intelligence test, emphasized that,

measured intelligence is not synonymous with overall intelligence. The assessment of the intelligence of an individual child must involve the integration by a compassionate clinician, and information obtained about the child from three totally independent sources like, (a) the results (Mental Age) from the objective psychological examination, (b) indices of performance in the classroom, and (c) relevant medical or related items of physiological function.

Stern: After the death of Binet in 1911, William Stern, a German psychologist, in 1912, converted Mental Age (MA) into an Intelligence Quotient (IQ). Stern recommended that a precise quantitative index of relative ability be computed by dividing the child's earned score on the Binet – Simon Scale (the child's earned mental age – MA – in years and months) by that child's actual chronological age (CA). He also suggested that the resulting value could be multiplied by 100 to remove the decimals. Thus, a formula to calculate intelligence quotient was developed as follows:

IQ – MA/CA X 100

The formula I.Q. equals M.A. divided by C.A. with the sum multiplied by 100 is merely a device for quantitatively relating each child's test age to the child's own actual age.

Terman: Within a year of Binet's death, the 1911 Scale was translated into many languages. The most significant of these translations was by, Lewis M.Terman's (1877-1956) construction and restandardization of American revision of the Binet – Simon scale at Stanford University on a cross section of American children. This scale developed in 1916, was known as the Stanford Revision of Binet-Intelligence Scale. This Scale was widely used in the United States for assessing the intelligence of individual children and for placing slow children in public schools and training schools. In 1917, when United States of America entered World War I, Otis, a student of Terman developed a "paper and pencil test" based on the revised Stanford-Binet test. This "Otis Test" was later developed as the famous "Army Alpha" and "Army Beta" Batteries by Terman, Yerkes, and Boring for illiterate and non-English speaking population, basically for the purpose of war recruits.

5.4.2 Distribution of Intelligence

The normal intelligence or IQ in the general population can be plotted in the form of a bell shaped curve. In a standard intelligence test like WAIS the mean IQ is 100, having a standard deviation (SD) of 15 points. About two thirds (65%) of IQ's are between one SD below the mean and one SD above the mean, that is, between 85 and 115. One sixth (around 15%) are between one SD and two SD below the mean, that is, between 70 and 85 IQ's and one sixth (around 15%) one

SD and two SD above the mean, that is 115 and 130 IQ. About 2.3% of IQ form the mentally retarded and gifted groups.

Levels of Intelligence:

Above 140	Genius
120 – 139	Super Intelligence
110 – 119	Above Average
90 – 109	Average
71 – 89	Borderline intelligence
50 – 70	Mild retardation
35 – 49	Moderate retardation
20 – 34	Severe retardation
Below 20	Profound retardation

(According to AAMR – American Association on Mental Retardation – Bordelrine was classified as mentally retarded till 1973, the present classification does not consider borderline as mentally retarded).

2.4.3 Types of intelligence tests

There are different types of Intelligence tests.

1. **Individually Administered Test**: In Individually administered test, the individual works, alone with the psychologist in answering questions and performing tasks. During the testing session the psychologist can observe the persons behaviour along with any specific difficulties that are encountered. Some of the examples of individually administered test are:

   a) Binet-Kamath Test of Intelligence (BKT): This test is developed by DR.V.V.Kamath in 1967 on Marathi and Kannada population. Stanford-Binet test is the Hindi adaptation done at Bureau of Allahabad by Dr.S.K.Kulshreshtra in 1973. This test is applicable to the age range between 3 to 21 years. The aim is to find out the I.Q. of the client.

   b) Malin's Intelligence Scale for Indian Children (MISIC): This test is an Indian adaptation or WISC, by Fr.A.J.Malin; Hindi adaptation in 1973.

   c) Bhatia's Performance Test of Intelligence: The test is developed by C.M.Bhatia in 1955. This test consist of five sub tests – Block Design Test, Alexander Pass along Test, Pattern Drawing Test,

Immediate Memory and Picture construction Test. The test can be administered on persons of 11 years of the age and above. All five sub tests are administered in a sequence as given above. The obtained raw score are converted into mental age (MA) which can be used to calculate I.Q. (Intelligence Quotient) of a person.

d) Wechsler's Adult Performance and Intelligence Scale (WAPIS): Indian adaptation of WAIS (Pasricha & Pagedar, 1963; Ramalingaswamy, 1975).

2. **Group Administered Test**: Group tests are often administered by classroom teachers, clerks, secretaries and other individuals who may not be trained in testing. There is room for misjudgments in group tests. In a group test, there is more opportunity for error, unless it is administered by a trained personnel. Group tests are generally inexpensive and less accurate, but save time in administration. Some of the examples of group tests are:

a) Raven's Progressive Matrices test: has three versions – Advanced, Standard and Coloured. This test is developed by J.C.Raven et.al. The Standard Progressive Matrices (SPM), which has 60 problems divided into five sets of A,B,C,D and E. Each of these categories contains 12 items in the order of progressive difficulty. The subject is required to choose the right one among the given alternatives which will complete the blanks space of matrices. The raw scores can be converted into percentile scores. Norms are also given. The test was designed to be used with children as well as adults irrespective of their education, nationality or physical condition to cover the widest possible range of mental ability.

b) Columbia Mental Maturity Scale (CMMS): A general intelligence test utilizing pictorial classifications designed for children aged 3 ½ to 10. Items are printed on cards, requiring the examinee to select the one that does not belong (Burgemeister, Hollander, Blum and Lorge, 1972).

3. **Verbal Test**: The verbal tests require the subjects to express their answer in words.

4. **Non-Verbal Test**: The test measures by performance on tasks requiring minimal use of verbal materials is otherwise known as **performance tests**, such as, block designs, picture completion, etc. In the performance tests, the subject is allowed to express his answers through hand movement such as arranging blocks to match a design and placing pictures in a meaningful

sequence. The performance tests are constructed with the aim of making them "culture fair" as it is not possible to make them culture free totally.

5. **Paper and Pencil Test**: A well known paper and pencil test is Draw – A person test developed by Goodenough in 1926. It is easy to administer and has shown high correlation with other intelligence tests. Dr.Pramila Phatak has developed norms for this test for Indian children. Limitation of these type of drawing test in preindustrial countries is the lack of familiarity of children with paper and pencil. However, the use of this test with school children enrolled in formal education system is perfectly justified.

Culture Biased/Culture Fair/Culture Free Tests: Most of the intelligence tests developed had the influence of the culture from in it was standardized. The requirement for a culture free instrument for measuring intelligence was very much felt because, many tests had limited use in studying cross-cultural intelligence. For this purpose, psychologists devised non-verbal, and performance tests, and called these as culture fair tests. The best known among the culture fair tests are - Raven's Progressive Matrices, Proteus Maze Test, Columbia Mental Maturity Scale (CMMS), Seguin Form Board (SFB), Alexander Pass along test, Koh's Block Design Test, etc. It has now been realized that search for a culture free test is elusive and not sensible since culture has its effect on all skill s- verbal and non verbal. In fact, culture free test would mean devising an instrument based on experiences common to all humanity and could be applied everywhere under the sun and universally valid. Actually, culture free test is a contradiction in terms, as intelligence itself is culturally determined. Hence, culture free test means intelligence free. Examples of culture biased tests: (a) Binet Kamath Test (BKT), (b) Weschler's Adult Performance and Intelligence Scale (WAPIS).

6. **Developmental Schedules**: Developmental schedules are inventories for the purpose of assessing the level of development reached by a child. Where formal standardized intelligence tests could not be administered to young children, Developmental schedules are suggested. Information from parents and clinical observations help to assess children's developmental levels. Through the interpretation of the Developmental Schedule, "Developmental Age" (DA) of the infant is obtained. Developmental Age can be converted into "Developmental Quotient" (DQ) by dividing developmental age by chronological age and multiplying by 100 to eliminate the decimals. Thus the formula for calculating the Developmental Quotient can be presented as follows:

   $DQ = DA/CA \times 100$

   Commonly used Developmental Schedules are – Developmental Screening Test, Gesell Developmental Schedule, Denver Developmental

Screening Test, Nancy Bayley Scales, etc. Some of these are standardized in Indian conditions.

a) **Developmental Screening Test**: It is an age scale, that is, test items are given for different age groups. It consist of 88 items, all measuring major developmental areas like motor development, language development, adaptive behaviour, personal-social development. The test materials include – DST Schedule, Pen, Kit (toys which are attractive) and the DQ computation disc.

- Test Administration: The test is mainly administered by observation of the child to test situations. But this has to be supplemented by information given by the care taker/ parents.
- Recording: Put a (✔) for each items passed and a cross (X) for each items failed.

b) **Gesell Developmental Schedule**: The schedule covers five major fields of behaviours – Adaptive, Gross motor, Fine motor, language and personal – social behaviours. Data on these behaviours are obtained through the direct observation of the child's responses through standard toys and other stimulus objects and are supplemented by information provided by the parent or principal caretaker. The age range for the schedule is 4 weeks to 5 years.

c) **Bayley Scales of Infant Development**: The Bayley scale provides three complementary tools for assessing the developmental status of children between the ages of 2 months and 2 ½ years, covering the mental scale, the motor scale and the Infant behaviour record. The mental scale samples are such functions as perception, memory, learning, problem solving, vocalization, the beginnings of verbal communication and rudimentary abstract thinking. The motor scale provides measures of gross motor abilities, such as sitting, standing, walking, stair climbing, and skills of hands and fingers. The Infant Behaviour Record is designed to assess various aspects of personality development such as emotional and social behaviour, attention span, persistence and goal directedness.

5.4.4 Adaptive Behaviour

Definition

The adaptive behaviour in general refers to the way in which an individual functions in his or her social environment. The American Association on Mental Retardation defines adaptive behaviour as, "*the effectiveness or degree with which*

the individual meets the standards of personal independence and social responsibility expected of his/her and culture group".

(i) Assessment of Adaptive Behaviour

The behaviour of an individual changes regularly, depending on the types of social situations to which the individual has to respond. Many behaviours which are appropriate in one setting could be totally inappropriate in another. The time and place and some times the age determines the appropriateness of a behaviour. The behaviour by itself is not `good' or `bad'. For example, sleeping in the bedroom versus classroom. Sleeping, which is an essential biological need becomes an inappropriate behaviour in the classroom, whereas, the same behaviour in the bedroom becomes an appropriate behaviour. The mentally retarded persons are known to exhibit inappropriate behaviour due to skill deficits or inability to perceive the appropriate behaviour for a given situation. Hence, the purpose of measurement is to determine what areas need special help, or special training in a particular situation. Adaptive behaviour assessment determines the current level of functioning of the individual. It reflects the strengths of the individual as well as the weaknesses. Hence, the primary reason for measurement is an effort to help the individual to learn to improve themselves and to function within the socially acceptable norms.

Adaptive behaviour assessment, which is based on the direct reporting of observable behaviours gives specific information on the assets and deficits of the individual. The reason for the deficits or not doing a task may fall into the following categories.

a) The individual may never have had the experience or opportunity to carry out those particular tasks or behaviours.

b) The individual may have certain physical limitations which prevent the performance of those behaviours.

c) The individual may be totally under-motivated for those particular behaviours because of certain cultural patterns or experiences.

(ii) Adaptive behaviour scales / Tools for assessment of adaptive behaviour

The adaptive behaviour, which projects our behaviour in the personal and social areas reflects our ability to respond to the environment. Thus adaptive behaviours come under the broad domains of functional independent skills, personal and social responsibility, and independent living skills. These elements combine to form an organized behavioural pattern of the individual. Some of the popular adaptive behaviour scales used for assessing the mentally retarded persons are:

The Adaptive Behaviour Scale (ABS): The scale was developed to be used for client assessment and individual program planning and assessing the total programming needs of groups of clients for research purposes. It can be used to make assessment of mentally retarded, emotionally maladjusted and developmentally disabled persons of all ages from childhood or adulthood. It is divided into two parts: Part-I, is concerned with matters described as adaptive behaviour and comprises ten domains with a total of 66 items. The domains are independent functioning, physical development, number and time, domestic activity, vocational activity, self direction, responsibility, and socialization, Part-II of the scale is concerned with what are called maladaptive behaviours. These are grouped into 14 domains. They include violent and destructive behaviour, untrustworthy behaviour, withdrawal, stereotyped behaviour, inappropriate interpersonal manners, unacceptable vocal habits, unacceptable or eccentric habits, self abusive behaviour, hyperactive tendencies, sexually aberrant behaviour, psychological disturbances and use of medication. There are 43 items in this section of the assessment scale. The ABS is designed for use by someone who knows the individual being assessed. Thus it can, for example, be completed by a case worker or teacher. The assessor records responses to the item on the questionnaire, and no special training is necessary to complete it.

The Vineland Social Maturity Scale (VSMS): This was developed by Edgar A.Doll in 1935, and has been revised several times since its first publication. It was intended to be used for program evaluation and research. The scale was designed to assess the social competence of individuals of ages from birth to 25 years and above. The Indian adaptation of VSMS, by Fr.A.J.Malin, has an age range of birth to 15 years. There are eight domains with 89 items, grouped age wise: self-help general, self help eating, self help dressing, self direction, occupation, communication, locomotion, and socialization. The information is collected by a trained examiner from an informant who is familiar with the client. Scoring of the items gives the information on social age from which the social quotient could be calculated.

Behavioural Assessment Scale for Indian Children with Mental Retardation (BASIC-MR): This scale, developed by Peshawaria and Venkatesan (1992), is divided into two parts. Part A which has seven domains with 280 items, deals with skill behaviours which are as follows: motor, activities of daily living, language, reading writing, number-time, domestic-social and pre-vocational, and Part B – which deals with problem behaviours, consisting of 10 domains with 75 items, viz; violent and destructive behaviours, temper tantrums, misbehaviours with others, self injurious behaviours, repetitive behaviours, odd behaviours, hyperactive behaviours, rebellious behaviours, antisocial behaviours and fears. The information on the scale is collected through direct observation of the child and by interviewing parents. The items in skill behaviours are rated from 0-5,

whereas, the range of score under problem behaviours is 0-2. The scale is exclusively developed for the assessment and program planning for the persons with mental retardation.

2.1 EDUCATIONAL ASSESSMENT

Two different methods of educational assessment are in practice. One is Norm Referenced Assessment and other is Criterion Referenced Assessment. The selection of these methods of assessment depends on the purpose for which assessment is to be conducted.

2.1.1 Norm Referenced Assessment

Norm Referenced Assessment or Norm Referenced Testing (NRT) is the more traditional approach to assessment. These tests and measurement procedures involve test materials that are standardized on a sample population and are used to identify the test takers ability relative to others. It is also known as formal assessment.

Norm referenced assessment is defined as a procedure for collecting data using a device that has been standardized on a large sample population for a specific purpose.

Every standardized assessment instrument will have certain directions that must be followed. These direction specify the procedure for administering the test and ways to analyze and interpret the results and reporting them. Examples of the more commonly known formal assessment devices are the Wechsler Intelligence Scales for children – Revised (WISC-R), The Illinois Test of Psycholinguistic Ability (ITPA), The Stanford-Binet Intelligence Test and the Peabody Picture Vocabulary Test – Revised (PPVT-R) and Peabody Individual Achievement Test (PIAT).

Advantages of norm-referenced assessment

Norm referenced tests are widely used in special and remedial education for many reasons.

- First, the decision of categorizing the children as exceptional or special is mainly based on the test results of NRTs.
- Second, it is easy to communicate test results to parents and others unfamiliar with tests.
- Third, norm-referenced tests have received the most attention in terms of technical data and research. They are specifically useful in problem identification and screening.

Disadvantages of norm-referenced assessment

The use of norm referenced tests data for the purpose of educational programming is questioned in many instances for the following reasons.

- Information obtained from norm-referenced testing is too general to be useful in everyday classroom teaching. Many educators disregard the prognosis and interpretative types of data provided by standardized tests because the information is often not directly applicable to developing daily teaching activities or interventions. What does knowing a child's WISC-R score or grade equivalent in reading specifically tell a teacher about what and how to teach? For instance, what is important is to know whether the child needs to learn initial consonants or is he having difficulty with comprehension.
- NRTs tend to promote and reinforce the belief that the focus of the problem is within the child. It is because the primary purpose of NRTs is to compare one student with another. However, although a child may differ from the norm, the real problem may not be within the child but in the teaching, placement or curriculum. Educators must begin to assess teacher behaviours, curriculum content, sequencing and other variables not measured by norm referenced tests.

5.5.2 Criterion-referenced assessment (CRTs)

Criterion-referenced assessment is concerned with whether a child is able to perform a skill as per the criteria set, or not. In contrast to norm referenced assessment, which compares one persons performance to others, criterion referenced assessment compares the performance of an individual to the pre-established criteria. In criterion-referenced test, the skills within a subject are hierarchically arranged so that those that must be learned first are tested first. In maths, for example addition skills would be evaluated (and taught) before multiplication skills. These tests are usually criterion referenced because a student must achieve competence at one level before being taught at a higher level.

Advantages of criterion referenced assessment

The criterion-referenced test results are useful:

- to identify specific skills that need intervention.
- to determine the next most logical skill to teach as the implications for teaching are more direct with criterion referenced tests.
- to conduct formative evaluation, that is, the performance of the student is recorded regularly or daily when the skills are being taught.

This makes it possible to note the student progress, to determine if intervention is effective and to help decide the next skill to be taught if achieved, if not to decide what other strategies or methods and materials are to be used for teaching.

Disadvantages of criterion-referenced assessment

- Establishing the passing criteria for a specific skill is a problem in criterion-referenced testing.

For example, if a test were needed to determine, whether student had mastered high school mathematics, there is a problem of determining exactly which skills should be included in the test. Further, should a student pass the test if 90% of the questions are answered correctly or only if 100% are correct? These decisions must be carefully considered, because setting inappropriate criteria may cause a student to struggle unnecessarily with a concept.

- It is difficult to decide exactly which skills should be included in the test.
- There is also a problem that the skills assessed may become the goals of instruction rather than selecting the skills that the child should know. Due to this, the teachers may narrow down their instruction and teach in accordance with what is measured on the test rather than what is truly required for the child to know.

2.6 ERROR ANALYSIS

Although CRTs are helpful in determining specific curriculum areas, they do have certain limitations. CRTs will tell **what to teach** but gives little information on **how to teach** that skill. To put in another way, most CRTs are interested in measuring the product and not the process. The method that is used to determine the process or strategies a student uses while doing the academic tasks is called error analysis.

Why to do error analysis?

It helps in selection and evaluation of teaching strategies, gathering pre-referral information and planning and evaluation of IEP.

Why should teachers use?

A great deal of information can be obtained from the type of errors a student makes in routine school work. For example, see the following computation.

38

+ 95

1213

This would indicate that the student does need instruction in renaming because he added the ones and tens columns separately. The student has not applied the step of carrying over. How did you know? Yes! By analyzing the product of the sum. Now you know what to focus on. Consistency in error pattern is an indicator to the teacher on student's learning style which helps her to adapt teaching style to suit the need.

5.7 FUNCTIONAL ASSESSMENT

A functional assessment is the measurement of purposeful behaviour of a person while interacting with the environment, which is interpreted according to the assessment's intended use. A functional skills assessment model identifies critical skills needed for an individual's natural environments. This assessment model requires comparison of two data sets. The first is an ecological inventory of the target environment, utilizing a top-down analysis of skills needed for that environment. The second set of data is an assessment of the target student's behaviour and the conditions under which such behaviour occurs or does not occur. These two sets of data are used to identify discrepancies between desired performance in the target settings and current performance levels.

5.7.1 Characteristics of Functional Assessment

A functional assessment model differs from a traditional psychological assessment model in the following respects: (a) relationship between assessment and instruction, (b) direct measurement of skills in natural context(s), (c) use of a process-oriented approach to assessment, and (d) role of assessment.

Relationship between Assessment and Instruction

The relationship between assessment and instruction should be direct, that is, skills found to be deficient during assessment should be targeted for teaching.

(i) Direct Measurements of Skills in Natural Context(s)

A second characteristic of functional assessment is its heavy reliance on measurement of the specific skill of interest directly observing the student in specific environments. A direct measurement of behaviour is the most preferred method of assessment. This involves observation of the behaviour in the setting of interest. For example, if the teacher wishes to identify how well an adolescent uses the public transportation system, she must observe this behaviour directly.

Collecting data in any other way (eg. getting responses to a 20-item questionnaire on bus riding) may not yield data reflecting a direct measurement of the target skill (s), that is, riding the bus to and from designated destinations. Therefore, assessments of community, domestic, leisure, and/or vocational skills are often assessed in those environmental contexts where such activities naturally occur.

(ii) Process-Oriented Approach

A functional skills assessment approach can utilize a process approach in addition to the product approach. A product approach to assessment involves merely determining the presence or absence of a skill. Often, for people with mental retardation, this type of assessment generates results that were obvious to many of those involved with them before the assessment. A process approach tries to identify the conditions under which a behaviour can be exhibited by using teaching methods during the assessment. Common process methods involve the use of prompts during assessment which allow the assessor to identify effective instructional conditions under which the use of the skill becomes more probable.

(iii) Role of Assessment

In a functional assessment, the process of assessment leads to instruction. Therefore, the person most apt to conduct assessment is the teacher or the person who will subsequently be involved with the teaching of the child. In contrast, in traditional approaches professionals most often conduct the assessment, who are seldom involved with the child in everyday instruction.

5.7.2 Conducting functional skills assessment

(i) Survey Environment

The first requirement in conducting a functional skills analysis is to identify and survey the target child's or youth's environments and subenvironments. These preliminary activities lead to the identification of skills that are required in the individual's natural environment.

An ecological inventory involves analysis of multiple levels of environments before functional skills are identified. The first level of analysis is to identify the curriculum domain(s). Domains are settings rather than content areas. There are four curriculum domains: (a) vocational, (b) leisure/recreational, (c) domestic, and (d) community utilization. The next level is to identify natural environments with each domain, followed by identification of sub environments within each natural environment. As a next step, the planner identifies activities within each subenvironment and then skills within each activity. One might point out the absence in such an analysis of traditional curriculum areas (as well as the absence of traditional tests covering them). These include such areas as language, motor,

arithmetic, self-care, and social skills. However, their occurrence is measured within a social ecology (ie., within the four domains).

(ii) Assess Target Child's Skills

The second activity in a functional assessment involves collecting data about the target child during the performance of the skills under the natural conditions identified from the above mentioned ecological inventory. The most preferred method of measurement is direct observation. In situations in which direct observation may not be feasible, structured role playing may provide information that can approximate direct observation data. In case the information is elicited from caregivers, ensure accuracy of the data.

(iii) Identify Discrepancies and Select Objectives

The next activity is the discrepancy analysis between the child's performance and the levels of behaviour or skills needed in a given environment. From this, training objectives are placed in order of priority and those requiring more immediate attention are selected. Target objectives would involve not only deficit skills, but also skills not yet under the control of environmental conditions which are operable in the current or future environment. For instance, a 12 year old son of a carpenter may need carpentary skills in his future environment which may not be his current competency.

(iv) Identify Possible Adaptations

Finally, any adaptations that can be made to allow a child with disability to perform a skill more effectively need to be examined. For example, alternate communication systems (communication boards, manual signing, electrical devices) allow individuals who are non-vocal to acquire complex communication skills that might otherwise be unavailable to them.

5.8 CURRICULUM-BASED ASSESSMENT (CBA)

The concept of curriculum based assessment is not new and has been employed for a number of years. CBA has been developed as a means to cope with low-achievers and children with special needs in regular schools. Further, it fits into the non-categorical model that is assessment is focused on testing curriculum-based skills and not on testing for labeling purpose.

The CBA aims to identify children's educational needs and the most appropriate forms of provision to meet those needs. Sality and Bell (1987) describes educational needs as "behaviours which a person lacks which are necessary in

order to function effectively and independently both in the present and in the future".

The starting point for conducting CBA is the child's classroom. It is the suitability of this environment and the child's interaction with it that is assessed and not the child.

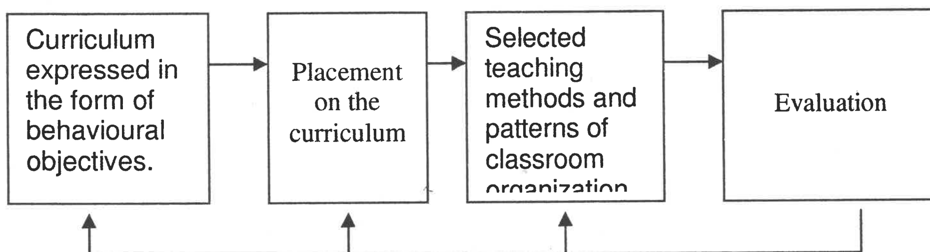
Definition:

CBA has been defined by Blankenship and Lilly (1981) (quoted in Sality and Bell, 1987; pg.35) as the practice of obtaining direct and frequent measures of a student's performance on a series of sequentially arranged objectives derived from the curriculum used in the classroom.

It helps in finding out the current level of a student in terms of the expected curricular outcomes of the school. In other words, assessment instrument is based on the contents of the student curriculum. Some types of CBA are informal, while others are more formal and standardized.

2.8.1 Procedure followed in developing CBA

- The first stage in the process requires that the curriculum be defined as series of tasks which are sequenced and expressed in the form of behavioural objectives.
- Placement in the curriculum helps to identify which skills have been learned and those which need to be taught in the future. It pinpoint exactly where a child is on the curriculum.
- Selection of suitable teaching methods, materials and patterns of classroom organization for teaching.
- Evaluating children's progress – relates to the selection of teaching methods, patterns of classroom organization and choice of curriculum.
- Curriculum Based Assessment can therefore, be seen as a procedure which sets up situations where links are established between various teaching approaches and pupil progress.



(Source: Sality and Bell (1987) pg.36)

5.9 OBSERVATIONAL ASSESSMENT

Observation is a widely used method of assessment. Systematic observation of student behaviour in the classroom yields a tremendous information which helps in

- making observational data useful in determining and evaluating teaching programmes.
- developing and monitoring individual education programmes (IEPs) in both academic and non-academic activities.

5.9.1 Observational techniques

- Observational techniques can be classified as either formal or informal.
- Formal approaches include observational packages that usually include specific coding and scoring systems.
- The informal approaches include observation by the observer already present in the setting, observation by an observer from outside the setting, and observation by the observer not present in the setting. These types of informal approaches are particularly relevant when student behaviour is being observed.

Mehrens and Lehmann (1984) suggest the following advantages of observation.

1. Frequent observation of a student's work can provide a continuous check on progress and can detect errors as they arise which help to take corrective action quickly.
2. Observational techniques are not so time consuming or threatening for the student as are achievement tests and
3. Observational data provides teachers with valuable supplemental information much of which can not be obtained in any other manner.

Bias of the observer is a major threat in this approach and should be consciously avoided.

5.10 BEHAVIOURAL ASSESSMENT

People with mental retardation lack culturally valued skills that are expected from persons of comparable age. Hence, we need to provide a means to enhance the skills and capabilities of persons with mental retardation. Behavioural technology is extensively used in educational programmes for persons with mental retardation in increasing acceptable behaviours and in eliminating maladaptive behaviours.

Behavioural assessment refers to data collection in applied behavioural research. It consists of systematic and repeated recording of predefined behavioural parameters of individuals, with the purpose of either identifying functional stimuli that maintain certain behaviours or demonstrating systematic behavioural changes as a function of planned intervention.

Behavioural assessment has two purposes – 1. to collect information that is needed to select and develop appropriate intervention programmes and 2. to evaluate their effectiveness. Observational techniques are applied for generating data both for planning and evaluation of intervention programmes.

Functional analysis (Behavioural analysis): Functional analysis is the process of understanding the complexity of the problem behaviour to its simpler or most elementary parts. The problem behaviours which are learnt, may have various environmental influences. According to learning theories, learning occurs through association (classical and operant conditioning), and observational learning. There are a number of models available for analyzing behaviour problems. One of the most simple models is known as A-B-C model which is used commonly to analyze problem behaviours of children with mental retardation. This helps to identify the factors which contribute to the occurrence of the problem behaviours.

A stands for the **ANTECEDENT** factors that is what happens **`before'**. The analysis of antecedent factors will help the teacher to find out the factors which contribute to the problem behaviour before its occurrence. The following have to be looked into to get more information in this regard:

a) *When* does the problem behaviour generally occur, during recess, or in the class room when the teacher is busy with another student, or during lunch break, and so on.

b) Are there particular *times* of the day when the problem behaviour tends to occur more? For example, during morning hours or meal times, ...

c) With *Whom* does the problem behaviour occur? That is, does it occur with any particular person, like with the student who is sitting in the front seat, or on the side seat or with grand mother/father ....

d) *Where* does the problem behaviour occur?, that is, are there specific place or situation where the problem behaviour occurs. Example, in the school playground or classroom or at home or when the child is sitting alone ....

B stands for the **BEHAVIOUR**, that is, what happens **during** the problem behaviour. Results from the baseline assessment of the behaviour will help to analyze the `during' factors contributing to the problem behavour, that is, it will answer the following questions: How many times does the problem behaviour

occur, or for how long does the problem behaviour occur and what exactly happens during that period.

C stands for the **CONSEQUENCES** of the behaviour, that is, the factors which **follows** immediately **after** the behaviour. Analysis of `after' factors include answering the following question:

a) What is the reaction of the people around the child *immediately* after the occurrence of the problem behaviour?

b) What *effect* does the problem behaviour have on the given child or others?

c) Does the child *benefit* or gain something by indulging in the problem behaviour?

The analysis of consequences or after factors generally show that most of the behaviour has a link with benefits (reward or reinforcement). As per the operant conditioning theory, if there were no benefits, the behaviour would cease to occur. Thus functional analysis gives the complete details of behaviour which would help in identifying the reasons for the behaviour.

SESM-02 Block 2 Unit 2 gives you more details on applied behaviour analysis.

5.11 UNIT SUMMARY

Assessment is systematic collection and organization of information to make various administrative and educational decisions. Different types of tools are used for the systematic collection of data based on the purpose for which assessment is to be carried out. The different types of assessments are clinical assessment, psychological assessment, educational assessment, functional assessment, curriculum based assessment, observational assessment and behavioural assessment.

- Clinical assessment is a part of assessment in the process of diagnosis of persons with mental retardation. It is carried out to identify the cause of mental retardation, refer to further investigations to confirm the cause and other anomalies and to plan and evaluate treatment.
- Psychological assessment is the process of systematic collection, organization and interpretation of information about a persons and his situation. It encompasses assessment of the three major aspects of the mind namely, cognition, conation and affection.
- Intelligence is the aggregate or global capacity of an individual to act purposefully, to think rationally and to deal effectively with the environment. Intelligence tests, developmental schedules and adaptive behavioural scales are used in measuring the intelligence.

- Educational assessment helps to find out abilities of the student and plan teaching programme accordingly. Norm referenced tests and criterion referenced tests are used in educational assessment.
- The method that is used to determine the process or strategies a student uses while doing the academic task is called error analysis.
- A functional assessment is the measurement of purposeful behaviour in interaction with the environment, which is interpreted according to the assessments intended use.
- Curriculum based assessment is the practice of obtaining direct and frequent measures of a student's performance on a series of sequentially arranged objectives derived from the curriculum used in the classroom.
- Observational assessment involves systematic observation and recording of behaviour in pre-decided environments.
- Behavioural assessment is systematic repeated recording of predefined behavioural parameters of individuals, with a purpose of either identifying functional stimuli that maintain certain behaviours or demonstrating systematic behavioural changes as a function of planned intervention.

5.12 CHECK YOUR PROGRESS

1. Name different types of assessments.
2. Define Intelligence. How is intelligence calculated?
3. Name two tests in each of the following.
   a) Intelligence tests.
   b) Developmental schedules.
   c) Adaptive beahvioural scales.
4. Define the following.
   a) Adaptive behaviour.
   b) Norm referenced tests.
   c) Criterion referenced tests.
5. Write the advantages and disadvantages of NRTs and CRTs.
6. What is functional assessment? Describe the steps involved in conducting functional assessment.
7. What is curriculum based assessment? Explain the procedure followed in developing CBA.

8. Write short notes on:
   a) Observational techniques.
   b) Functional analysis.

5.13 ASSIGNMENT AND ACTIVITY

- Select two children with mental retardation. Develop a functional assessment checklist following the steps described under functional assessment. Use the checklist for assessment and programming.
- Select two children with mental retardation having behaviour problems. Follow the procedure explained under behavioural assessment for analyzing the behaviours.

5.14 POINTS FOR DISCUSSION/CLARIFICATION

After going through the unit, you may want to have further discussion or clarifications of some points.

5.14.1 Points for discussion

5.14.2 Points for clarification

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5.15 REFERENCES/FURTHER READINGS

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BLOCK 2: ASSESSMENT

UNIT 1:CONCEPT, MEANING, DEFINITION AND URPOSE OF EDUCATIONAL ASSESSMENT

STRUCTURE

- **Introduction**
- **Objectives**
- **Assessment tools in Indian context**
  - Psychological Assessment Tools
  - Madras Developmental Programming System (MDPS)
  - Functional Assessment Checklist for Programming (FACP)
  - Behavioural Assessment Scales for Indian Children with Mental Retardation (BASIC-MR)
  - Upanayan – A programme of developmental training for children with mental retardation
  - Portage – Basic training course for early stimulation of pre-school children in India
  - Other tools
- **Problems and implications**
- **Teacher competencies**
- **Unit Summary : Things to remember**
- **Check your progress**
- **Assignment/Activity**
- **Points for Discussion/clarification**
- **References/Further readings**

INTRODUCTION

Selection of assessment tools depends on the purpose for which assessment is to be conducted. As discussed in Unit-2, criterion referenced assessment tools are more suitable and useful for programme planning of children with mental retardation, as the assessment data directly leads to selection of goals and objectives for instruction. Different types of assessment tools are in use in special schools in different parts of the country. The first tool which was developed for use in schools is Madras Developmental Programming System (MDPS). Later, few more assessment tools were developed and are used in special schools for planning instructional programmes. They are Functional Assessment Checklists for Programming (FACP), Behavioural Assessment Scales for Indian Children with Mental Retardation (BASIC-MR), Upanayan – a progamme of developmental training for children with mental retardation, and Portage basic training course for early stimulation of pre-school children in India.

OBJECTIVES

After going through the unit, you will be able to

- understand various assessment tools that are available for use in education of children with mental retardation in India.
- explain each assessment tool in terms of content, application and recording procedures.
- Select and use assessment tool for educational programming of children with mental retardation and developmental delays.

ASSESSMENT TOOLS IN INDIAN CONTEXT

Psychological assessment tools

Psychological and educational assessment tools are developed/ adapted to suit the needs in India. Given below is a list of psychological assessment tools used in India. For details of the tests refer Unit 2 of this block. As you are a prospective special educator, some of the Indian special educational assessment tools are described in detail in this unit.

i. Seguin Form Board Test (Ramachandra, 1967; Bharat Raj, 1971; Vermal et al, 1972; S.K.Goel, 1984).

ii. a) Binet-Kamath Test by Dr.V.V.Kamath, 1967 (on marathi and kannada population).

b) Stanford-Binet Test, Hindi adaptation at Bureau of Allahabad by S.K.Kulshreshta, 1973 (In northern region).

iii. Malin's Intelligence Scale for Indian Children (MISIC), Indian adaptation of WISC, by Fr.A.J.Malin, Hindi adaptation in 1973.

iv. Progressive Matrices Test (J.C.Raven). Development of norms by Bureau of Psychology, Allahabad. It has three sets: a) Coloured, b) Advanced, and c) Standard.

v. Draw – A – Man test; norms by Prof.Pramila Pathak (1962).

vi. Developmental Schedules –

a) Indian adaptation of Nancy Bayley Scale by Prof.Pramila Pathak.

b) Indian adaptation of Gesell development Schedule by NCERT (Murlidharan, 1975).

vii. Gesell Drawing Test (Verma, 1972).

viii. Bhatia's Battery of Performance Test: Sub-test, Koh's Block design and Pass along test.

ix. Developmental Screening Test (DST) by Dr.Bharat Raj, 1983.

x. Upanayan Test developed by Madhuram Narayan Centre, Chennai.

Madras Developmental Programming System (MDPS)

Madras Developmental Programming System (MDPS) is a criterion referenced scale, which is used for assessment and programme planning for persons with mental retardation.

Content

The scale contains 360 items grouped under 18 areas or domains, each domain having 20 items. They are motor skills (gross motor and fine motor), self-help skills (eating, dressing, grooming, toileting), communication skills (receptive, expressive), social interaction, functional academic skills (reading, writing, number, time, money), domestic behaviour, community interaction, recreation and leisure time activities, and vocational activities. Each domain has 20- items. The items are developmentally sequenced. The activities are sequenced in such a way that simple activities are listed first followed by complex ones. Items are stated as positive statements which are observable and measurable. The items listed are functional activities which normally occur in routine life of an individual.

Format

There is a format which is used for recording the performance of the student periodically (I quarter, II quarter, III quarter) and the same can be communicated

to family members and others who are involved in education of the student. On assessment, if student performs the activity, it is marked A, and if he does not perform the activity, it is marked B. The scale has provision for colour coding, i.e., `A' marked in blue and `B' in red. Each quarter the red can be covered by blue based on the progress. The tool also has a manual which helps in grouping and programming. This is useful for special teacher for periodic assessment and planning IEP.

Madras Developmental Programming System
Behavioural Profile

Name :

Date of Initial Assessment :

Observer/s :

Enter 'A' & 'B' as per instruction

Date of I Qr. Evaluation .... Over the red
Date of II Qr. Evaluation .... Over the red
Date of III Qr. Evaluation .... Over the red
Date of IV Qr. Evaluation .... Over the red

Shade 'A' in Blue and 'B' in Red

If the person performs the Activity, Mark 'A' and shade Blue
If the person is yet to perform the Activity, Mark 'B' and shade Red.

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	Ist Ass.		I Qr.		II Qr.		III Qr.		IV Qr.	
																					As	Bs	A	B	A	B	A	B	A	B
1. Gross Motor Activities																														
2. Fine Motor Activities																														
3. Meal Time Activities																														
4. Dressing																														
5. Grooming																														
6. Toileting																														
7. Receptive Language																														
8. Expressive Language																														
9. Social Interaction																														
10. Reading																														
11. Writing																														
12. Numbers																														
13. Time																														
14. Money																														
15. Domestic Activities																														
16. Community Orientation																														
17. Recreation - Leisure Time Activities																														
18. Vocational Activities																														

3. Meal Time Activities

1. Swallows soft foods that do not require chewing.
2. Drinks without spilling, mouthful from a glass or cupwith assistance.
3. Bites required amounts of food item.
4. Differentiates between edible and non-edible substances.
5. Picks up dry pieces of food (biscuits) with fingers and puts food in mouth.
6. Chews solid food.
7. Picks up a filled glass and drinks from it without spilling.
8. Uses spoon /hand to pick up and eat mixed food.
9. Mixes food and eats with little or no spilling (may use fingers/spoon).
10. Eats foods, (cereal preparations) such as idli, dosai, puri, roti (uses fingers to make bits).
11. Eats, supervised in public places without calling attention to eating behaviour.
12. Eats porridge, payasam (milk pudding), ice cream with little or no spilling.
13. Eats a complete meal with little or no spilling using all normal eating equipment dishes and utensils.
14. After eating, empties plate into a trash canand washes it.
15. Takes appropriate quantities, when food is offered.
16. While eating, politely asks for food to be passed, and waits for others to finish.
17. Makes necessary arrangements for and serves food in a family style setting.
18. Identifies drinking water in a public place and drinks it.
19. Selects the required meal items when a variety of food is available.
20. Orders and eats in a public dining facility.

Madras Developmental Programming System

Quarterly Programme Plan Form

Individualized Programme Plan

Check :

Quarter : 1

Quarter : 2

Quarter : 3

Quarter : 4

Name :

School :

Date :

Completed by :

Goal Statement :

Current level of functioning :

Behavioural Objective

Condition :

Person to be Trained :

Behaviour :

Expected Level of Performance :

Deadline :

Staff Responsible :

Date of Teaming :

Date of Review :

Functional Assessment Checklist for Programming (FACP)

Functional Assessment Checklists for Programming (FACP) is an activity based checklist used for assessment and programming of children with mental retardation. The activities listed in the checklist are easy to understand, necessary for daily living, easily observable, age appropriate as far as possible and ultimately contribute to living independently in the community.

Grouping of students

The checklist covers content for various groups namely pre-primary, primary-I, primary-II, secondary, prevocational-I, prevocational-II and care group. The grouping is done based on ability and chronological age of the children. Keeping the principle of `zero reject' in mind, the grouping is made for children of all degrees of mental retardation in the school going age ie., 3 to 18 years.

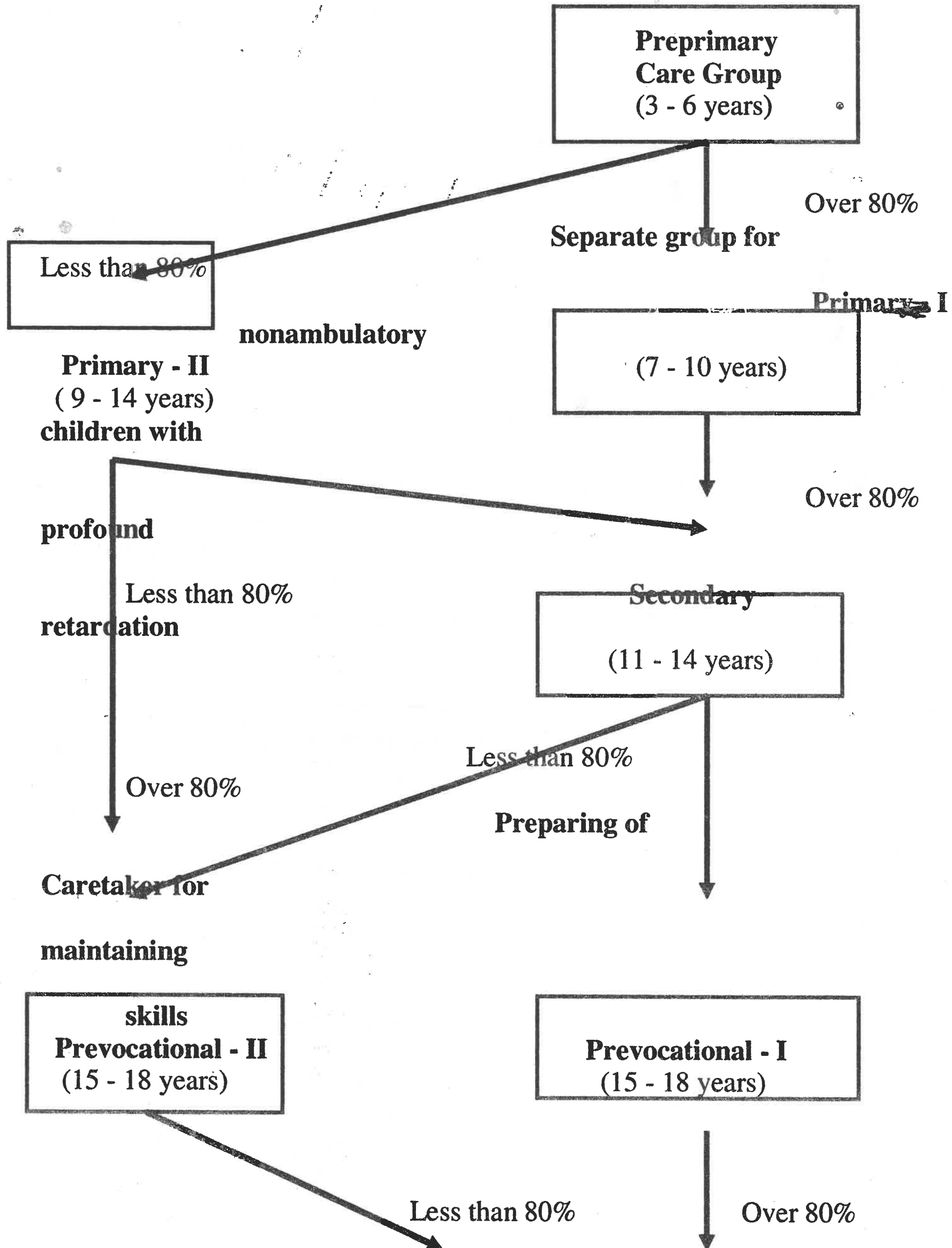
Preprimary - This group consists of children between 3-6 years of age. The coverage of content in the areas of personal, social and academic is more than with occupational area in this level.

Primary-I - Student who achieve 80% of the items in preprimary checklist are promoted to primary-I level and the age of the students entering in this class may be 7 years approximately. In some cases the students may continue one more year in preprimary to fulfill the pass criteria (For example, if a student who is 7 years has achieved about 60% on evaluation in primary checklist he may continue in the same class for a longer time and see whether he/she can achieve the said pass criteria, ie., 80%).

Primary-II - The students who do not achieve 80% of the items in the checklist in Preprimary level even after 8 years of age are placed in Primary-II. Presumably there are children with low functioning abilities. The content in the academic area is minimal for this group. This group covers children from 8-14 years. When they achieve 80% of the items in the primary-II checklist they are promoted to Prevocational-II. In some cases they may achieve 80% before the age of 14 years and may be promoted to secondary group. Even if they achieve less than 80%, at the age of 15, they will be promoted to Prevocational level II.

Secondary group - This group includes students between 11-14 years. It is a mixed group (ie., students promoted from both Primary I and II). On achieving 80% of the items in this class including the items in academic area, the student will be promoted to prevocational-I and those who achieve less than 80% will be promoted to prevocational-II.

PROMOTION PROCEDURE



Vocational Training
(Over 18 years)

Open Employment
Sheltered Employment
Supported Self Employment

Pre-Vocational I and II - Both the groups consist of students in the age group 15-18 years. The primary focus of training is on preparing students in basic work skills and domestic activities. Hence, the major content covered in the checklist are in the areas of occupational, social, and academics. However, the content coverage under academic area will be minimal or need based for prevocational-II group of students.

Mentally retarded persons over 18 years will be sent to vocational training units with their summative evaluation reports for further programming. This curriculum checklist does not cover the vocational area.

Care group - This group includes children with very low ability (bed ridden-profoundly retarded) and the items in the checklist focus on training them in performing partially, the basic skills such as drinking, eating, toileting, and basic meaningful motor movements and communication. If they continue to stay non-ambulatory as the age advances, the parent/caretaker may find it difficult to bring the child to school. In such cases, simultaneously preparation of caretaker for maintaining learned skills is necessary. It is good to have the children of this group distributed one each in each class starting from prevocational group. This would provide a stimulating environment for them. However, they should be assessed using care group checklist, irrespective of in which group they are placed.

Content

The content in each checklist consists of the core areas of personal, social, academic, occupational and recreation. As children come from different cultures and ecological backgrounds, there is a provision for deletion and addition of curricular items in each area depending on the individual needs of a student. By doing so, the teacher plans an appropriate individualized curriculum for every student in her class.

Format

The format is so designed that the programmer can enter assessment information (entry level) and the progress periodically (at every quarter) for about three academic years, as it is assumed that a student stays a maximum of 3 years in a given level. At the end, a table is given to note the progress of individual child in all the areas periodically after evaluation which may be transferred directly on to a progress report, which is also a component of FACP.

PERFORMANCE LEVEL

Number of Activities Passed

S. No.	Area	No. of Activities	First Year				Second Year				Third Year			
			Entry Level (%)	I term (%)	II term (%)	III term (%)	Entry Level (%)	I term (%)	II term (%)	III term (%)	Entry Level (%)	I term (%)	II term (%)	III term (%)
1.	Personal	22	11 (50%)	16 ([illegible])	19 (86%)	20 (90%)								
2.	Social	22	12 (54%)	15 (68%)	17 (77%)	19 (86%)								
3.	Academic	55	15 ([illegible])	23 ([illegible])	28 ([illegible])	36 ([illegible])								
4.	Occupational	12	4 (33%)	5 ([illegible])	8 ([illegible])	9 (75%)								
	TOTAL	111	42 ([illegible])	59 ([illegible])	72 ([illegible])	82 ([illegible])								
	Grade for Recreation :	20	A	A	A	A								

(Note the percentage of pass items under each total in parentheses)

Note : Scoring for recreation is done by counting each grade and whichever grade is maximum in number is given as grade. In case more than one grade happens to have the same total count, the teacher can use her judgement to give the grade.

The checklist has a provision for recording the performance of a student on a continuum of 3 years. If a student performs an activity it is marked `+' and if he does not perform it is marked `-'. However, the student is provided with assistance in terms of prompts to assess the current level of a student. The prompts such as visual prompt, gestural prompting, modeling, physical prompt are provide during the assessment to see with which prompt he is able to perform. For example, if he is performed an activity with gestural prompt it is marked GP against that specific activity.

Items marked `Yes" (or +) are counted as a point, while the others such as PP, VP, NE are noted but not counted for points. As the ultimate aims is that of achieving independence in a given activity area, those activities the child performs independently or with occasional cueing only will be considered for quantifying into scores. The items marked NA are deleted from the total items to be learned while calculating percentage. Similarly, specific items added should be included for calculating percentage. Achievement of 80% of items in the checklist will be considered for promotion fro one level to the next level. For example, the children who achieve 80% of the items, in preprimary checklist will be promoted to the primary level. It is however, cautioned here that poor teaching should not reflect on the child's lack of progress or inability to learn.

The items listed under recreation need not be counted for quantification as these items are interest based. The grades given include A = Takes initiative and participates effectively, B = Participates when others initiates, C = Involves self but not aware of rules, D = Observes with interest, E = Not interested (indifferent), NE = No Exposure. The grades as noted below illustrate the involvement of recreational activities in the child. Such scoring is in line with the system in regular schools. The cumulative score on the last page can be the grade that is obtained maximum among the recreational items. If more than one grading gets equal scores, the teacher may use her judgment and decide.

Writing progress report

Along with the provision of recording facility for recording the assessment and evaluation data periodically, there is also a provision for reporting the progress made by the student. This tool is comprehensive and easy to use by teachers as it has periodic monitoring facility and a simple format for writing brief programme also.

Behavioural Assessment Scale for Indian Children with Mental Retardation (BASIC-MR)

This assessment tool is used for assessing the current level of behaviour and for programmme planning for children with mental retardation between the ages 3 to 16 years (or 18 years).

Content

The assessment tool is divided into two parts - Part A and Part B. Part A includes 180 items grouped under seven domains – motor, activities of daily living, language, reading and writing, number-time, domestic-social, prevocational-money. Each domain consists of 40 items. All items are written in clear observable and measurable terms and are arranged in increasing order of difficulty.

The BASIC-MR Part-B consists of 75 items grouped under ten domains – violent and disruptive behaviour, tempertantrums, misbehaves with others, self injurious behaviours, repetitive behaviours, odd behaviours, hyperactive behaviours, rebellious behaviours, antisocial behaviours and fears. The number of items in each domain varies.

Format of BASIC-MR (Part-A)

Each child with mental retardation may show different levels of performance on every items on the BASIC-MR, Part A. The six possible levels of performance under which each items can be scored are as follows. Use the record booklet to enter the scores obtained by the child on each item.

Level One: Independent (score 5) - If the child performs the listed behaviour without any kind of physical or verbal help, it is marked as independent and given a score of 5.

Level Two: Clueing (Score 4) - If the child performs the listed behaviour only with some kind of verbal hints. It is marked as "clueing" and given a score of 4.

Level Three: Verbal Prompting (score 3) - If the child performs the listed behaivour with some kind of accompanying verbal statements. It is marked as verbal prompting and given a score of 3.

Level Four: Physical Prompting (Score 2) - If the child performs the listed behaviour only with any kind of accompanying physical or manual help, it is marked as physical prompting and given a score of 2.

Level Five: Totally dependent (Score 1)

If the child does not perform the listed behaviour currently, although he can be trained to do so. It is marked as totally dependent and given a score of 1.

Level Six: Not applicable (Score 0) - Some children may not be able to perform listed behaviour at all, owing to sensory or physical handicaps. Wherever an items is marked "not applicable", it gets a score of 0.

Age level in years	Item no.	DOMAIN-IV READING-WRITING (RW)
		Reading
0 - 5	1.	Matches five similar objects*
	2.	Matches five common objects to pictures in a book #
	3.	Matches five colours #
	4.	Recognizes his/her name*
	5.	Reads his/her own name*
	6.	Sorts five similar pictures into same category* #
	7.	Matches five three letter words*#
5 - 7	8.	Identifies five colours #
	9.	Names five colours #
	10.	Reads five printed words* #
7 - 9	11.	Reads names of parents*
	12.	Reads two word phrases* #
	13.	Reads own address*
	14.	Reads names of family members/friends*
	15.	Reads short sentences* #
	16.	Reads sign boards* #
9 +	17.	Reads small paragraphs* #
	18.	Reads large print from magazines, newspapers, etc.* #
	19.	Reads medium sized handwritten paragraphs* #
	20.	Reads short news item from newspapers #

(* Glossary; # Material ; *# Glossary & Material)

Appendix I

BEHAVIOURAL PROFILE ON BASIC-MR, PART - A

Name of the student: V. S. RAVI
Age: 11 YEARS
Sex: MALE

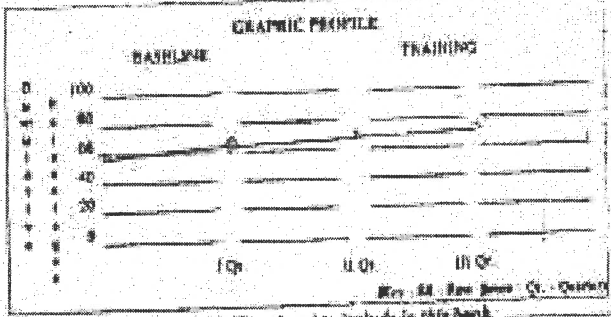
Level/Class: [illegible]

	Date	Evaluated by
Baseline Assessment		
First Quarter Assessment		
Second Quarter Assessment		
Third Quarter Assessment	[illegible]	[illegible]

Item No.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Motor	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
ADL	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Language Receptive	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Reading	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Number	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Domestic	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Pre-Vocational	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]

Item No.	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40
Motor	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
ADL	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Language Expressive	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Writing	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Time	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Social	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Money	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]

Scoring Key: Independent 5 - Cueing 4 - Verbal prompting 3 - Physical prompting 2 - Totally dependent 1 - Not applicable 0



DOMAIN	Baseline		First Qr.		Second Qr.		Third Q.	
	RS	%	RS	%	RS	%	RS	%
Motor	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
ADL	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Language	[illegible]	[illegible]	171	[illegible]	175	81.5	[illegible]	[illegible]
Reading-Writing	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Number-Time	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	57
Domestic-Social	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
Pre-vocational-Money	[illegible]	[illegible]	[illegible]	[illegible]	65	32.5	[illegible]	[illegible]
TOTAL	[illegible]	[illegible]	[illegible]	[illegible]	880	[illegible]	[illegible]	[illegible]

Size of the Behavioural Profile reduced to include in this book.

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SKILL BEHAVIOURS (BASIC-MR-PART-A)

SKILL BEHAVIOUR DOMAINS		MAXIMUM SCORES	BASELINE ([illegible])	I QUARTER ([illegible])	II QUARTER ([illegible])	ANNUAL ASSESMENT
MOTOR		200	[illegible]	[illegible]	[illegible]	[illegible]
ACTIVITIES OF DAILY LIVING		200	[illegible]	[illegible]	[illegible]	[illegible]
LANGUAGE		200	[illegible]	[illegible]	[illegible]	[illegible]
READING - WRITING		200	[illegible]	[illegible]	[illegible]	[illegible]
NUMBER - TIME		200	[illegible]	[illegible]	[illegible]	[illegible]
DOMESTIC - SOCIAL		200	[illegible]	[illegible]	[illegible]	[illegible]
PRE-VOCATIONAL MONEY		200	[illegible]	[illegible]	[illegible]	[illegible]
TOTAL SCORE		1400	[illegible]	[illegible]	225	[illegible]
ATTENDANCE - WORKING DAYS			[illegible]	[illegible]	[illegible]	[illegible]
INITIALS	CLASS TEACHER		[illegible]	[illegible]	[illegible]	[illegible]
	SCHOOL CO-ORDINATOR PRINCIPAL		[illegible]	[illegible]	[illegible]	[illegible]
	CONSULTANT		[illegible]	[illegible]	[illegible]	[illegible]
	DIRECTOR		[illegible]	[illegible]	[illegible]	[illegible]
	PARENT		[illegible]	[illegible]	[illegible]	[illegible]

PROBLEM BEHAVIOURS (BASIC-MR-PART-B)

PROBLEM BEHAVIOUR DOMAINS	MAXIMUM SCORES	BASELINE	I QUARTER		ANNUAL ASSESMENT
VIOLENT AND DESTRUCTIVE BEHAVIOUR	32	0	0	0	0
TEMPER TANTRUMS	6	0	0	0	-
MISBEHAVIOUR WITH OTHERS	16	0	0	0	-
SELF INJURIOUS BEHAVIOURS	20	0	0	0	-
REPETATIVE BEHAVIOURS	16	4	2	1	1
ODD BEHAVIOURS	16	2	2	2	1
HYPER ACTIVE BEHAVIOURS	6	1	1	1	1
REBELLIOUS BEHAVIOURS	12	7	7	2	1
ANTI SOCIAL BEHAVIOURS	16	0	0	0	0
FEARS	6	2	2	2	1
TOTAL	150	16	14	9	5

GREATER SCORES INDICATE BETTER PERFORMANCE IN THE STUDENT.

LOWER SCORES INDICATE LESS BEHAVIOUR PROBLEMS IN THE STUDENT.

Format of BASIC_MR (Part B)

The following is the criteria of scoring which need to be used for BASIC-MR (Part-B):

For any given child with mental retardation, check each items of the scale and rate them along a three point rating scale, viz. never (n), occasionally (o) or frequently (f) respectively given in the record booklet against each items on the scale.

a) If the stated problem behaviour presently does not occur in the child, mark "never" (n) and give a score of zero.

b) If the stated problem behaviour presently occurs once in a while or now and then, it is marked "Occasionally" and given a score of one.

c) If the stated problem behaviour presently occurs quite often or, habitually, it is marked "frequently" and given a score of two.

Thus, for each item on the BASIC-MR, Part B, a child with mental retardation may get any score ranging from zero to two depending on the frequency of that problem behaviour. Enter the appropriate score obtained by the child for each item in the record booklet.

Upanayan – A programme of developmental training for children with mental retardation

This is an assessment tool for young children. This programme covers children in the age group of 0-6 years. The programme consists of a checklist, a user manual, a set of activity cards and material for assessment and training.

Content

The checklist covers five areas of development viz., motor, self-help, language, cognitive and socialization. Each domain has 50 items totaling upto 250. The items are arranged in a sequence based on normal development.

Format

The activity cards are colour coded to separate each domain from the others. The manual contains a list of materials to be used during assessment. The record formats are provided to note the background information and the assessment data periodically. If a child performs an activity it is marked "A" and the child does not perform the task it is marked "B".

USER MANUAL

LANGUAGE

1. RESPONDS TO SOUND BY QUIETENING, BY ATTENTION, BY FOLLOWING DIRECTION OF SOUND, BY EYE AND BODY MOVEMENT
2. CRIES DIFFERENTLY DUE TO DIFFERENT DISCOMFORTS
3. FOLLOWS SOUND, MOVING HEAD.
4. QUIETENS AT THE SOUND OF HUMMING, SINGING AND TALKING
5. COOS AND GURGLES WHEN CONTENT.
6. VOCALIZES, PRODUCING SOUNDS ON HIS OWN INITIATIVE
7. INITIATES VOCAL PLAY WITH TOYS.
8. INITIATES VOCAL PLAY WITH PEOPLE.
9. BABBLES
10. RESPONDS TO NAME BY LOOKING UP OR BY STOPPING ACTIVITY.
11. REPEATS SOUNDS, VOCALIZES.
12. LOOKS AT MOUTH TO GET CUES FOR SOUND PRODUCTION.
13. VOCALIZES TO MUSIC.
14. PRESSES, PURSES OR ROUNDS LIPS IN IMITATION OR ON REQUEST TO PRODUCE SOUNDS.
15. LOOKS AT PERSON NAMED.
16. PLACES TONGUE AGAINST ROOF OF MOUTH TO PRODUCE SOUNDS.
17. IMITATES SPEECH SOUNDS.
18. LOOKS AT AN OBJECT THAT HAS BEEN NAMED
19. IMITATES SOUNDS AND SYLLABLES IN SONGS AND RHYMES.
20. IMITATES MOUTH MOVEMENTS, THROUGH MIRROR-AIDED INSTRUCTION.
21. COMBINES TWO DIFFERENT SYLLABLES IN VOCAL PLAY.
22. RESPONDS TO GESTURE WITH GESTURE.
23. IMITATES INDIVIDUAL SOUNDS AND PHRASES SPOKEN BY OTHERS.
24. IMITATES VOICE INTONATION PATTERNS OF OTHERS.
25. STOPS ACTIVITY WHEN SAID "NO".
26. USES ONE SYLLABLE SOUND FOR AN OBJECT / PERSON.
27. POINTS IN RESPONSE TO SIMPLE QUESTIONS.
28. ARTICULATES, USING SOUNDS, TO INDICATE PREFERRED OBJECTS OR NEEDS.
29. CARRIES OUT SIMPLE DIRECTIONS WHEN ACCOMPANIED BY GESTURES.
30. ANSWERS SIMPLE QUESTIONS WITH NON-VERBAL RESPONSE.
31. POINTS TO FAMILIAR OBJECTS WHEN NAMED.
32. CAN RESPOND TO "GIVE ME" OR "SHOW ME" UPON REQUEST.
33. ASKS FOR MORE.
34. SAYS, "ALL GONE"
35. COMBINES USE OF WORDS AND GESTURES TO MAKE WANTS KNOWN.
36. VOCALIZES IN RESPONSE TO SPEECH OF OTHER PERSONS.
37. SAYS FIRST INTELLIGIBLE SPONTANEOUS WORD.

MADHURAM NARAYANAN CENTRE FOR EXCEPTIONAL CHILDREN

UPANAYAN PROGRAMME ASSESSMENT RECORD - PROFILE

PERIOD

From ______________ To ______________

The programme is computerized so that the parent can be given the respective activity cards needed for training their child. The programme is intended for home training in home based and center based intervention.

Portage Basic Training Course for Early stimulation of pre-school children in India

This is an Indian adaptation as well as translain in Hindi of "Portage Guide to Early Education" by S.M.Bluma, M.Shearer, A.H.Frohman and Jean M.Hilliard (USA). It has also been translated in 9 Indian languages by CBR Network, Bangalore and is available in the form of CD.

Portage guide is basically a system for teaching skills to pre-school children with developmental delays. The portage project is a home based training system which directly involves parents in the education of their children in the early childhood ie., 0-6 years of age. The training is provided by a specially trained teacher or a public health worker with a special training and experience in the field of child development. However, the key person in the home based programme is parents/family members.

It can be used by para-professionals like the staff of anganwadis, balwadis, non-professionals like parents, siblings, professionals such as pre-school educators, psychologists, and doctors.

Content

The portage checklist covers areas such as infant stimulation, self-help, motor, cognitive, language and socialization. In each area, the activities are listed in a sequential order corresponding to the age. In addition to the checklist, there are activity cards for each skill which explains the materials and procedure to be used to train the child. The checklist also provides age norms for each task on the margin which help the trainer estimate the age equivalence of the child's functioning.

Format

The first step is to check through the listed skills in all the areas and record the performance of the student against each skill under the column entry behaviour. There is also the provision to mark date of achievement and remarks. A separate provision is made (Activity chart) to record activities, achievement and targets. As the format accommodates daily and weekly recording of progress, there is close monitoring.

The checklist, activities and record formats are in the form of a booklet in English and Hindi.

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AGE 2-3

TITLE: Points to big and little upon request

WHAT TO DO:

1. Collect big and little versions of the same type of objects, i.e., big and little envelopes, pencils, stones, shoes, coats, dishes, cookies, marshmallows, chairs, cups.
2. Place a big and little pencil in front of child. Ask him to make a mark on paper with the big pencil. Praise success. Repeat activity with other objects.
3. Ask child to find big and little objects around the house.
4. Have parent or teacher name big and little objects for the child for a week. After this have the child begin pointing to the big and little objects.
5. Do motor activities such as taking big steps, little steps, big jumps, sit in a big chair, little chair.

cognitive

PortageGuide

Other tools

Apart from these tests, Grade level Assessment Device (GLAD) is used for find out processing problem in children with learning problems in regular school who, many a time are suspected as mentally retarded.

All the educational assessment tools described above are popularly used criterion referenced tools and have provision for programming and progress monitoring.

In some schools, similar tests are developed by themselves and used to suit their needs. The point to keep in mind is that such tests should lead towards assessment of educational needs and provide link to training and formative evaluation. The teacher must be well trained and competent to use the tests.

PROBLEMS AND IMPLICATIONS

Children with mental retardation as you know, need individualized instruction based on their current level of performance. This in other words means that there cannot be a single fool proof test that will meet the educational needs of all the children and provide training guidelines. However, well developed a test is, it can only serve as a guideline to the trainer. Several items in the test may need modifications based on the socio, cultural, economic background of the child's family. The tester has to be sensitive and alert to such factors while collecting assessment data.

Some of the tests are too long to be used for assessment in one sitting. Taking clue from the child's readiness or fatigue signs the tester should phase out the sessions of assessment.

As far as possible, the assessment should occur in the natural setting. Asking questions with the checklist in hand many a time annoys the parents and they tend to lose patience. Collecting relevant data through organized conversation and observation and recording later without distorting the received information will solve this problem.

Another problem is the overlap of items among the domains. Many motor items for instance will repeat in self-help and many communication items may be found in social domain. One has to see to the context and consistency in the data while collecting the data. While planning the programme, it is essential to see that the activities selected smoothly cover the overlap with simple and easy steps.

One other important point to note in the use of CRTs in the decision making on when the child has reached the optimum ability level. If a child maintains a same prompt level of PP/VP and so on, for more than 3 formative assessment of an activity the trainer is at a loss as to `should I continue?' `should I change activity?' or `should I find alternative methods of training' . This is a tricky

situation. The reason for lack of progress can be inappropriate selection of task, irregularity in training, incorrect strategy for training or lack of extended training at home after school hours. The trainer has to do a careful error analysis instead of continuing with the formative assessment with no progress for years.

It is also observed in many educational institutions that the western tests are used as it is, without adaptation to Indian conditions. The test results of such testing will not lead to appropriate programme planning.

TEACHER COMPETENCIES

The formal assessment tools which are standardized, demand specific, specialized training for testing. In addition, the manual provides step by step guideline for testing with instructions to follow the guidelines. This minimizes the tester bias.

In the criterion referenced tests many a time, the tests are developed by the teacher. If she used the available tests, the items demand keen observation and recording – preferably the observation in the natural settings. This demands extra competencies in the tester – who is ideally the teacher herself. Therefore, the teacher must be alert. A good teacher must have the following competencies to be a good tester.

1. should have good observation skills. The observation must be objective.
2. should not have bias.
3. should prepare herself well in advance for testing with the right materials.
4. should have the skills to put the child and the informant at ease before beginning to test.
5. should respect the feelings and sentiments of the informants.
6. should be emotionally stable – for instance should not break down if a parent weeps during the session.
7. should interact with the student without threatening him with the testing situation.
8. should record precisely without using comparative terms such as `fair', `good', `poor' etc. Should use descriptive terms. For instance, instead of saying `the child is aggressive' should say, `throws objects when needs not met' or whatever is his behaviour that is interpreted as aggression.
9. be aware of signs of distress, fatigue and loss of interest in the child while testing and suspend testing/reschedule it.

10. should not suggest responses to informant or the child. Should not ask leading questions. As far as possible remain neutral while questioning.
11. after eliciting information, recording should not be postponed to another day.
12. if needed home visits should be made to get details of assessment from natural environment.
13. should use the language the family is familiar with and should talk in clear, crisp sentences.
14. above all, the tester should be thorough with the tool used so as not to be referring to the manual in the midst of testing.
15. the tester must ensure that rapport is established with the child and family before beginning to test.

To conclude, India being a country with socio, cultural, linguistic variations we cannot have a single test. Therefore, CRTs to suit the local needs and individual child's needs should be developed. Care should be taken to develop them objectively and make provisions for systematic recording periodic assessment and programme planning for the child.

UNIT SUMMARY: THINGS TO REMEMBER

Criterion referenced tests, checklists and teacher made tests are used for assessment and programme planning of children with mental retardation in classrooms in special schools.

For school age children, the first criterion referenced scale developed to suit Indian conditions is Madras Developmental Programming System (MDPS). Later, Functional Assessment Checklist for Programming (FACP) and BASIC (MR) were developed. Similarly, with the emphasis on early childhood special education, Upanayan checklist and Portage kit, translated in Hindi and adapted to Indian culture are developed and are used for assessment and programming in early intervention programmes.

Assessment tools are not without problems. The tester, testee variables play an important role in arriving at accurate assessment information.

The teachers who test should be trained and competent in assessment.

CHECK YOUR PROGRESS

1. Name two of the Indian tools used for assessment and programme of children with mental retardation.

2. Describe the following: (a) MDPS, (b) FACP, (c) BASIC MR, (d) Upanayan, (e) Portage.
3. List five teacher competencies for testing.
4. What are the difficulties in using assessment tools.

ASSIGNMENT/ACTIVITY

1. Select two cases between the ages 0-6 years and use the checklist Upanayanam and Portage for assessment and write the report. Note, if there are any differences/advantages you notice between using these tools.
2. Select three cases between the ages 4-18 years and use the assessment tools MDPS, FACP and BASIC MR and writ the report. Note, the differences/advantages in using these tools in assessment of children with mental retardation.

POINTS FOR DISCUSSION/CLARIFICATION

After going through the unit, you may want to have further discussion or clarifications of some points.

Points for discussion

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Points for clarification

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UNIT 2:METHODS OF ASSESSMENT - OBSERVATION, INTERVIEW AND RATING SCALE

STRUCTURE

- Introduction
- Objectives
- Mental illness vs Mental retardation : Concepts and differences
- Misconceptions and social practices
- Marriage and MR
- Sexual problems / Exploitation
- Attitude – historical perspective
- Mobilizing community
- Aspects of effective awareness programme
- Unit Summary : things to remember
- Check your progress
- Assignment
- Points for discussion
- References

2.1 INTTRODUCTION

The phenomenon of mental retardation has been known for millennia. It has been observed that the phenomenon has a complex nature and not understood completely by the various sections of the community such as parents, family, professionals etc. There have been a lot of misconceptions and wrong practices seen across the society. However, in recent decades, serious attention has been paid to it. Considerable scientific information has been built up and published.

In the past, no differentiation was made between mental illness and mental retardation. However, currently the two conditions have been recognized as separate entities with distinguishing diagnostic criteria.

The present chapter focuses on the various psycho – social aspects and misconceptions regarding mental retardation found in the community / society.

2.2 OBJECTIVES

After studying this unit, you will be able to

- describe the misconceptions about mental retardation found in community
- identify and differentiate the two conditions – mental illness and mental retardation.
- explain the nature of sexual problems observed in persons with mental retardation.
- narrate the attitudes of public towards mental retardation.
- describe the need, objective and problems in mobilizing the community.
- demonstrate sufficient knowledge to conduct awareness programmes successfully.

2.3 MENTAL ILLNESS Vs. MENTAL RETARDATION : CONCEPTS AND DIFFERENCES

The concept of co morbidity of mental illness and mental retardation is not only theoretical but also a practical issue. Some of the common questions posed to the therapist are – are the two conditions different or same? If different, can a person with mental retardation have mental illness?

In recent decades the issue of mental illness in the persons who have also mental retardation has been given increasing attention.

This is because firstly, the general recognition of the right of person with mental retardation to appropriate health care. Secondly, following the normalization principle, persons with mental retardation are expected to live in the community and use community facilities.

As a result of the recent works in the field, appropriate and convincing answers and explanations were given to the above mentioned questions and concepts.

Persons with mental retardation due to less IQ can have mental illness, which will be manifested in the form of sudden, unpredictable change in the behaviour, mood and / or thinking. The nature and spectrum of the mental illnesses found in the persons with mental retardation will be similar in comparison of general population. However, **`the incidence and prevalence of mental illness amongst the persons with mental retardation is higher than that of general population'.**

Why is incidence of mental illness high amongst persons with mental retardation?

Because of the interaction of biological, psychological and social variables resulting in an atypical path of development for person with mental retardation. This may be manifested with the following deficits:-

1. Poor integration of self
2. Deficits in self regulation
3. Lack of self confidence
4. Inferiority complex
5. Anxiety
6. Difficulty in living independently

Due to the above mentioned deficits, persons with mental retardation are more vulnerable to psychopathology in comparison to the non-retarded individuals. Besides the above factors, the stressful and competitive environment due to disparity between the parental / family expectations to the individual capacity, adds to the problem.

The differences between mental illness and mental retardation

In a country like India, most of the people feel that mental retardation and mental illness are one and the same. This is mainly because of the lack of information, existing among the general public regarding the differences between mental

illness and mental retardation. Hence, it becomes essential to have clear guidelines to differentiate these conditions for developing promising management strategies. The following table shows the distinguishing diagnostic criteria for mental retardation and mental illness

DIFFERENCES BETWEEN MENTAL ILLNESS AND MENTAL RETARDATION

	MENTAL ILLNESS	MENTAL RETARDATION
1.	It is an illness / disease / disorder.	It is a condition, not disease.
2.	Can occur at any age.	Usually at childhood, can occur during the developmental period (up to 18 years)
3.	It is a disease of brain or psyche producing significant behavioral or psychological disturbances associated with socio–occupational deterioration.	Below average general intellectual function originating during the developmental period and associated with impairment in adaptive behaviour.
4.	Causes: Multifactorial – Biological, Psychological, Social.	Multifactorial but primarily biological (genetic, metabolic, perinatal injuries and infections and etc.) Psycho-social factors can also cause. Mental illness can lead to mental retardation.

5.	Clinical features: No developmental delay. IQ level can be normal or below normal. It means mentally retarded can have mental illness, in fact the rate of mental illnesses amongst mentally retarded is very high in comparison to the individuals with normal IQ. Speech can be incoherent or irrelevant. Behavioral change is noted. Examples: Muttering to self, smiling or crying without reason, remaining aloof for a long time, unprovoked aggressiveness, extreme variation in mood and sleep disturbances etc. Will have normal premorbid state.	Usually developmental delay (motor, cognitive, speech, language & communication, personal and social) is noted. IQ level is below 70. Behavioral problems may be there. Deficits in adaptive behaviour and learning are noted. Usually no normal premorbid state.
6	Classification Broadly divided in to **Psychoses** (eg: Schizophrenia, Manic depressive psychosis) and **Neuroses** (eg: anxiety disorders, phobias, obsessive disorder)	Depending on the IQ level, MR is divided in to Mild – 50 to 70 Moderate – 35 to 49 Severe – 20 to 34 Profound – below 20
7	Course: usually fluctuating but can be progressive or static.	Usually static but can be progressive.
8	If identified early and diagnosed correctly it can be treated completely.	If identified and intervened early, development and learning can be enhanced.

2.4 MISCONCEPTIONS AND SOCIAL PRACTICES

Retarded persons live in an atmosphere created by the attitudes held by the people and professionals they come in contact with in addition to those of their families. The person with mental retardation will prosper and improve in quality of life if these attitudes are positive and supportive. But in reality, by and large all sections of society will not accept these persons into the mainstream. Especially in a developing country like India, many misconceptions and wrong practices are seen which are due to their negative attitude, lack of understanding and lack of encouragement.

Misconceptions

Due to the following reasons the condition of mental retardation has been misperceived.

1. The deficits in mental retardation cannot be 'seen' as in case of other handicapping conditions.
2. Confusion between mental retardation and mental illness.

The following are some of the common misconceptions found in the society.

1. Mental retardation is mental illness.
2. Mental retardation is due fate or karma.
3. Medicines only can cure mental retardation.
4. Marriage can cure mental retardation.
5. Person with mental retardation becomes normal as he grows.
6. Mental retardation is infectious.

Due to the misconceptions, people in general underestimate the capabilities of persons with mental retardation, which in turn hampers the process of rehabilitating them. Hence, there is a need to eliminate these misconceptions mainly through awareness campaign, in the society.

Social Practices

In a developing country like ours, the existing societal systems are generally influenced by the factors like religion and culture (multi – cultural society). These, along with other factors such as illiteracy, poverty and over population influence the community / family to follow certain practices particularly in case of families having persons with mental retardation. Some of the existing social practices are as follows.

1. **Consanguinity: -** Since ages, in most of the communities marriage between close blood relatives is been practiced. This has the possibility of increasing the occurrence of disabilities including mental retardation.

2. Most of the people in our society have strong belief in their religion without any other efforts, approaching religious places and faith healers for cure of any kind of illness / disease including mental retardation has been the common practice. To certain extent, this practice may delay / hamper the actual process of management / rehabilitation of the person with mental retardation.

3. Certain families in our society have the belief that marriage cures mental retardation. But in reality marriage will not cure mental retardation. In fact in certain cases the possibility of increase in the stressful and challenging situation following marriage are common in the life of a person with mental retardation.

4. Since the olden days, the practice of isolating the person with mental retardation and putting them in asylums is a known fact. However, institutionalization is gradually transforming into normalization and integration, though, the segregation of these persons within the families still continues. Persons with mental retardation are avoided in social functions and gatherings. This practice restricts the social growth of persons with mental retardation.

5. Though less common, practice of punishing harshly the persons with mental retardation still continues in the community. This may lead to emotional disturbances and personality problems among them.

2.5 MARRIAGE AND MENTAL RETARDATION

Introduction: - Marriage is a responsible physical, psychological, social and spiritual union between a man and a woman. Marriage has a very important place in Indian society.

A human being with a handicap is first a person. Whatever is his handicap, he grows, eats, sleeps, behaves like his fellow man. He also needs affection, friends, recreation, work, sense of success and companion just like the rest of us. As regards marriage of persons with mental retardation, the decision is personalized and family specific. A generalized suggestion / advice cannot be given in this regard.

Generally, professionals in the field do not recommend marriage for persons with mental retardation. In some cases, due to societal pressures, individual capability and preferences, marriages are carried out. However, the ultimate decision solely depends on the family.

Some of the important abilities required for a successful marriage are: -

1. Intellectual, emotional and physical maturity.
2. Ability to adjust with the partner and new family.
3. Ability to carry out the responsibility of daily living and of the role assigned by the new family.
4. Sexual compatibility.
5. Ability to support family financially.

Therefore, family especially parents must strive for development of these abilities in their child with mental retardation if they plan on his/her marriage. Before fixing marriage, it is essential to inform the prospective partner, honestly about mental retardation in their child.

Reason for Marriage

Why do parents think about marriage for their children with mental retardation?

The following are the common reasons in our society:

1. The responsibility of the mentally retarded person's care will be shifted to someone else.
2. The person with mental retardation will be safely looked after (particularly in rural areas and for girls).
3. A new person will be brought into the family to care for the parents in their old age.

The possible combinations of couples are

1. Two persons with mental retardation
2. One person with mental retardation and the other a non – retarded person.
3. One person with mental retardation and the other person with a different disability.

Parenthood

1. It is essential to seek genetic counselling before deciding to have a child. In the presence of high risk genetically, adoption can be the alternative.
2. As a parent, a person with mental retardation may provide effective physical care. But, may not contribute much for the emotional development of the child.

Contraception

This subject cannot be ignored by parents of a mentally retarded child. If he is to be married and after counselling it is decided that a child is a desirable possibility, temporary means of contraception should be practiced. If no child is recommended in a marriage, permanent contraceptive methods should be considered. Whichever method is selected, the mentally retarded person must be able to use it consistently. Ethics demand that the retarded person is informed about the pros and cons of use of contraception.

Premarital Counselling

1. Individual with mental retardation and his parents have to be counselled regarding importance and implications of marriage.
2. Parents have to be helped in matching the abilities of their retarded child with that of prerequisites of marriage.
3. Individual has to be counselled/educated regarding playing an effective role in his/her married life.

It is very essential to provide detailed information about the condition of the retarded individual (assets and deficits) to the non retarded/other partner and their family, prior to the marriage.

1.6 SEXUAL PROBLEMS/EXPLOITATION

Introduction : Sexuality is an instinctive type of behavior. Responses are not related to the level of intelligence. The person with mental retardation can have similar feelings and responses. The expression of sexuality is inhibited, restricted and defined by societal rules. These rules may not be clearly understood by an individual with mental retardation. This may lead to abnormal expression of sexual needs by some of the children/person with mental retardation in certain situations. On the other hand, population in general does not recognize the mentally retarded population as having positive, responsible sexual development.

Unfortunately, mentally retarded persons have the greatest problem in trying to over come the negative attitudes of others because mistakenly they are thought to be childlike or sexless or that their sexual behavior (which usually would be considered appropriate in the normal person) is excessive or perverted.

In early childhood, physical growth and development including sexuality of the mentally handicapped child is generally similar to that of any other child.

Handling of genitals bothers both parents and teachers. At early childhood, touching of and playing with genitals is normal. If it persists, it may be due to

curiosity or pleasure. Some times, a physical problem like itching, tight clothing or irritants may be the cause. These should be checked first. Attention must be diverted to other activities which they may find more interesting.

Some of the specific problem behaviors needing attention are as follows:

Masturbation

Masturbation is the striking of the genitals by the individual, which causes a pleasurable feeling and may or may not lead to ejaculation. This is indulged in boys and girls.

1. Masturbation is not harmful and does not lead to any weakness. The general belief that masturbation is sinful and harmful is incorrect.
2. In the case of persons with mental retardation, where outlets for releasing sexual tension are not available, even in later life, as adults, it may be an acceptable activity.
3. Children must be taught that this is not a behavior to be indulged in public places.
4. Generally, frequency of masturbation should not be considered as a problem.

Night emissions

Parents should know that night emissions are a natural phenomenon. This will not create weakness or harm to the boy in any way. Assurance and maintenance of hygiene are the contributions which parents can make to their son.

Sexual Abuse/Exploitation

Parents should be particularly careful to prevent a situation leading to the sexual abuse of their disabled children. It is very easy to take advantage of these youngsters, hence

1. be very careful with whom you leave your child
2. teach your child to discriminate between strangers and friends
3. teach him/her to scream when assaulted.
4. teach him/her that their bodies should be touched as little as possible by other people
5. encourage him/her to report any unusual happenings.

Sterilization or removal of the uterus are not adequate solutions for sexual abuse, as they merely prevent a pregnancy. Take care to teach them to maintain privacy for changing clothes, stay fully clothed and exhibit appropriate behaviour with a person of opposite sex right from childhood.

2.7 ATTITUDES – HISTORICAL PERSPECTIVE

History reveals four critical aspects of the plight of the persons with mental retardation.

- Survival of the threat of harsh treatment.
- Superstition or wide range of beliefs related to the appearance and the behaviour of the persons with mental retardation.
- Science or attempts to understand and approach exceptionality in a natural lawful and objective manner.
- Service or the provision of human treatment, care, education and social acceptance.

Extermination and superstition Prior to 1700s

The treatment of persons with mental retardation during the ancient times and during the Greek and Roman civilizations has been characterized by Kolstoe and Frey (1965) as extermination, a reaction they attributed to humanity's basic quest for survival. In primitive societies each member was expected to contribute to the community growth. Since persons with mental retardation were nonproductive members they were regarded as a burden to the society. For this reason, the disabled children were removed from the community and left to perish.

Certain development resulting from the renaissance of fourteenth to sixteenth centuries created a new social climate that would eventually have direct implications for the persons with mental retardation.

A new social attitude (1700-1920)

The advent of sensationalism through the efforts of various philosophers provided new group of perceiving. American and French revolution encouraged the philosophy of humanism. An awakening (1700-1800) was

the result of these historical events which established a new social attitude towards the mentally retarded individuals. This attitude created a positive climate for the young idealistic people to put into practice the philosophy of humanism and the ideas of Locke and Rousseau. The awakening created an attitude of optimism during the first phase of the 19th century. The recognized birth of special education and systematic services for the disabled individuals occurred in Europe in the early 1800s.

Recovery from the setback of the previous era was certainly needed. The transition from alarm to guarded enlightenment was affected by a number of events.

1. The view of mental retardation as a unitary, recessive, inherited trait began to fade as the science of genetics grew in scope and precision.
2. New clinical studies demonstrated the significance of other non-hereditary, causes of mental retardation such as trauma, infection and endocrine disturbances.
3. Interpretation of the pedigree studies were becoming more and more apparent.
4. The older research studies that had linked mental retardation with every conceivable social evil were critically reanalyzed.
5. Newer, better controlled and more objective studies failed to reveal the links of the previous era.

Special Agencies

President Kennedy who had a sister with mental retardation, established the President's Panel on Mental Retardation (PPMR) which was to serve as a guide and source for national policy in the U.S.. In 1963, Congress passed the Mental Retardation Facilities and Mental Health Center Construction Act, which established sources for the construction of Mental Retardation Research Centre (MRRC).

Through the 1970s, the field of special education and the provision of services to the mentally retarded persons have made remarkable progress. As the 1980s began, a two part philosophy enjoyed an eagerness to increase services and to maximize the quality of these services and an understanding that it was necessary to constantly reevaluate all actions.

In 1983, the American Association of Mental Retardation issued its definition of Mental Retardation which is most consistent with definition put

forth by the American Psychiatric Association and World Health Organization. It is again revised in 1992 (See SESM-1 Block-1 Unit-1)

Socio, political, research and programmatic influences during 1930-1950 had either an indirect immediate effect or a more direct, latent effect on mentally retarded people. When world war II was over, many families felt the realities of disability. A heightened sensitivity to the needs of disabled veterans developed. World War II also created increased employment opportunities for mentally retarded individuals in war related industries. After the world war second, the demands of parents, the enthusiasm of parents and government and private funding were the forces which brought a turning point to progress in the area of mental retardation.

Institutional changes were beginning to occur. In1950, formation of National Association for the Retarded Children (NARC) consisting of parents of mentally retarded children was one of the most important events. Over the years, social attitude towards the mentally retarded people has changed from fear and repulsion to tolerance and compassion.

In India, the community being an inclusive society, the retarded persons stayed with family. The trend change in the U.S. brought about development in the field all over the world including India.

2.8 MOBILIZING COMMUNITY

Rehabilitation is a joint effort of the government and non-government agencies. The community, the professionals, the parents of the disabled persons and the disabled persons themselves should take active participation to achieve success in rehabilitation services.

How to mobilize community resources?

- Create awareness in the community regarding the needs of persons with mental retardation.
- Emphasize the participatory and social aspect of rehabilitation.
- Identify the local resources.
- Work out the methodology to mobilize the resources.
- Develop a system of mapping and utilizing the resources.

Types of resources

- Human resource – Funds, Materials, Moral support and goodwill of people, Voluntary services.

  Resources can be tapped by creating awareness at all levels.

Creation of public awareness and cooperation

The need

- Mental retardation is basically a social problem. It varies from culture to culture and also among persons with mental retardation. Because of their deviant behaviour, they are at great risk of being devalued by the society. Because of their low mental and physical capabilities, they fall below the expectation levels of society.
- Efforts to improve their ability to adapt to the society, through education and training, need attention, not only from professionals but also from parents as well as of community. People with mental retardation are different but their needs are the same as that of non-retarded persons. Therefore, they should be perceived and treated as normal.
- In our society, considerable amount of ignorance and indifferent outlook exists regarding the concept of mental retardation. This is largely due to lack of or non-availability of proper information and guidance with regard to the causes, prevention, detection, management, and facilities available for persons with mental retardation.
- Lack of awareness results in misconceptions. Parents blaming themselves, considering it as their karma, seeking the help of religious people, faith healers, going from doctor to doctor or looking for a magical cure for their mentally retarded child is very common.

The objective of making parents and general public aware of the condition, education and training facilities, is to facilitate social and economic independence of persons with mental retardation.

How to achieve

1. To achieve this objective, it is necessary to integrate them into the mainstream of normal life and enable them to utilize scientific and technical advances in the area of education and training which would ultimately help them to minimize the effect of mental retardation. It would also assist them in the process of social and economic habilitation. The nation will have to bear the terrible burden of looking after the person with disability if scientific and technical advances are not utilized for preventing or minimizing the effect of the problem.

2. For proper and successful integration and socialization of persons with mental retardation, parents and general public should be suitably prepared, through public education on causes, prevention, early detection, training, misconceptions, and right attitude towards the persons with mental retardation.

Problems

- Heterogeneous population:

  The population is highly heterogeneous because of

  - different degrees/levels of retardation
  - different cultures and beliefs.
  - different languages and dialects.
  - different levels of education.
  - different levels of socio-economic status.

  The heterogeneity makes any single awareness programme inappropriate to the entire population.

- Due to poverty and difficulty to meet basic needs, people pay little attention to the problems of mental retardation.

2.9 ASPECTS OF EFFECTIVE AWARENESS PROGRAMME

Points for consideration

When awareness programmes are organized, the following points are to be considered.

- The target population.
- The objective.
- The content to be given.
- Availability of resources for teaching.
- The length of time of the programme.
- The sex, age, education, motives and other human characteristics and customs of the people to be reached.
- General local conditions, weather, available meeting places, organization and leadership.

- Financial and other resources.

Any awareness on mental retardation should be undertaken from educational, sociological, psychological and medical point of view without giving any emphasis on any particular culture. Message to general public should focus on prevention, early detection, referral and acceptance, whereas message for parents should focus on management and services available for education and training in addition to prevention, early detection.

Method

The campaigner should know what message is to be conveyed.

- After deciding the message to be conveyed, select the mode through which the message will be conveyed.
- Whether it will be through audio-visual programme or only through audio or through written material. It should be decided depending on the target population and the message.
- Films, puppetry, drama and slides are some of the forms of audio-visual progrmames.
- Songs and radio spots are some of the audio programmes.
- Written material can be booklets, pamphlets and porters. Camps organized by professionals with the active involvement of community members are also effective.

Awareness programmes and mass contacts

The following materials can be prepared and used.

- Bulletins.
- Leaflets.
- News stories.
- Circular letters.
- Radio.
- Television.
- Exhibits.
- Porters.

- Going round the community in vehicle with mike arrangement or beating drums (in rural communities) and passing on message.

Base for success

- Success of such awareness programmes depends upon the cooperation of the community and parents of the mentally retarded children.
- Professionals should try to strengthen the cooperation by involving the local leaders and agencies already working in the field.
- Main focus of such programe should be, opportunities for training and education to make them useful and productive citizens of the society.
- Live demonstrations of the abilities of persons with mental retardation can enlighten general public about their needs and rights.
- The main purpose is to ensure social integration, normalization and to make people aware of the needs and rights of persons with mental retardation.

Awareness programme should not be restricted to parents and general public alone. It should also be created among administrators through pressure groups, may be of parents and professionals. They can pressurize the planners and policy makers with regard to the required services for the rehabilitation of persons with disability and appropriate law for the protection of rights for people with mental retardation.

In the year 1995, Parliament has passed a bill to give protection to the rights of persons with disabilities. The National trust Act for the welfare of the people with mental retardation, cerebral palsy and autism and also is another bill passed in the parliament in the year 1999. It is hoped that the implementation of these Acts will go a long way with the cooperation of the public and community in the total rehabilitation of persons with mental retardation.

1.10 UNIT SUMMARY : THINGS TO REMEMBER

1. **The phenomenon of mental retardation is complex and has been misperceived by various sections of the community such as parents, family, professional etc.**

2. Persons with mental retardation with less IQ can have mental illness, which will be manifested in the form of sudden, unpredictable change in the behavior, mood and/or thinking.
3. Retarded persons live in an atmosphere created by the attitudes held by the people and professionals they come in contact with in addition to those of their families. The change in their attitude is imperative for the complete growth of the child.
4. Marriage is a responsible physical, psychological, social and spiritual union between a man and woman.
5. Sexuality is an instinctive type of behavior. Common sexual problems seen in persons with mental retardation are mastrubation, night emissions and exhibiting the genitals.
6. Parents and teachers should be vigilant as it is very easy to take sexual advantage of the children with mental retardation.
7. People around the world held a variety of attitudes, and perceptions towards persons with mental retardation.
8. Certain development from the renaissance of fourteenth to sixteenth centuries created a new social climate.
9. Experience show that majority of people do not have knowledge about the concept of mental retardation, its causes and management.
10. Rehabilitation is a joint effort of the government and non-government agencies.
11. Any awareness on mental retardation should be undertaken from educational, sociological and medical point of view.

1.11 CHECK YOUR PROGRESS

1. What are the critical aspects of the plight of the persons with mental retardation.
2. Can marriage solve the problem of mental retardation. Discuss.
3. How can you mobilize community resources for awareness.
4. List out the main point sot organize an awareness programme.
5. Discuss briefly the various misconceptions seen in our society regarding mental retardation.
6. How do you differentiate the conditions of mental illness and mental retardation?

7. What are the common sexual problems seen in person with mental retardation?

2.12 ASSIGNMENT

1. Collect materials for awareness programmes.
2. Prepare a posture to change the negative attitude towards mental retardation.

1.13 POINTS FOR DISCUSSION/CLARIFICATION

After going through the unit, you may want to have further discussion or clarifications of some points.

2.13.1 Points for discussion

2.13.2 Points for clarification

2.14 REFERENCES

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UNIT 3:TYPES AND APPROACHES - NRT, CRT, CBA & TEACHER MADE TESTS

STRUCTURE

- **Introduction**
  - Legislation
- **Objectives**
- **Legislation – Major milestones**
  - Constitutional provision
  - National Policy on Education
  - Indian Lunacy Act
  - Mental Health Act
  - Rehabilitation Council of India Act
- **Persons With Disabilities (Equal Opportunities, Full Participation And Protection Of Rights) Act 1995**
  - Structure
  - Objectives
  - Contents
  - Implications
- **Persons With Disabilities (Equal Opportunities, Full Participation And Protection Of Rights) Act 1995**
  - Objectives
  - Programmes
- **Other relevant government policies**
- **What is ahead?**
- **Unit Summary**
- **Check your progress**

- **Assignment/Activity**
- **Points for Discussion/Clarification**
- **References/Further readings**

3.1 INTRODUCTION

India, being a democratic country, the Constitution and legislation play an important role in the life of every citizen, irrespective of his being abled or disabled.

The preamble of the Constitution of India states, "We, the people of India, having solemnly resolved to constitute India into a Sovereign Democratic Republic and to serve all its citizens:

Justice, social, economic and political;

Liberty of thought, expression, belief, faith and worship;

Equality of status and of opportunity; and promote among them all;

Fraternity, assuring the dignity of the individual and unity of the nation"

The preamble pledges "equality of status and opportunity to all the citizens of India".

Article 14 of the Constitution states "The state shall not deny to any person equality before the law or equal protection of the laws within the territory of India".

Article 14 guarantees equality before law. Articles 15(3) and (4) deal with special provisions for women and children, and socially and educationally backward citizens respectively. Article 46 deals with special care in the area of education and economic interests of weaker sections of the people. The term weaker section would seem to cover persons with disability.

3.1.1 Legislation

Until recently, there was no exclusive law for protection of rights of persons with mental retardation. They were governed by the Indian Lunacy Act of 1912. In the year 1987, this act was replaced by Mental Health Act 1987. This act did not include any provision to safeguard the rights and interests of persons with mental retardation rather it totally excluded mental retardation from its purview. As a result a vacuum was created which has been filled by the enactment of comprehensive legislation, ie., "The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995". The provisions of the act ranges from prevention, early detection to education, vocational training and employment, preferential treatment and protection from negative discrimination. The Act ensures equality of human rights and dignity of life to people with disability. It will also strengthen the hands of the government to formulate appropriate programme for education and employment of people with disabilities including those with mental retardation.

3.2 OBJECTIVES

After going through the unit you will be able to:

- Understand the importance of Constitution and Legislation.
- State the development of disability legislation – past and present.
- Describe various Acts.
- Differentiate the implications of various acts.
- Find out the programmes for implementing the act.

3.3 LEGISLATION – MAJOR MILESTONES

2.3.1 Constitutional Provisions

Historic background

In pre-independence India, the country had a few special schools for children with intellectual impairment run by non-Government organizations, a few mentally retarded persons admitted to mental hospitals and many stayed at home.

After Independence, when Constitution of India was framed in 1950, 'Right to education and work' was mentioned in Article 41 and 'Free compulsory Education for all children upto the age of 14 years' was quoted in Article 45. However, there were little efforts geared in this direction.

In 1950s, there were about 10 special schools for children with mental retardation, in 1960s 39, 1970s 120 and 1980s 290 and 1990s saw a steep growth reaching 1,100 special schools, most of them run by NGOs.

National Institutes

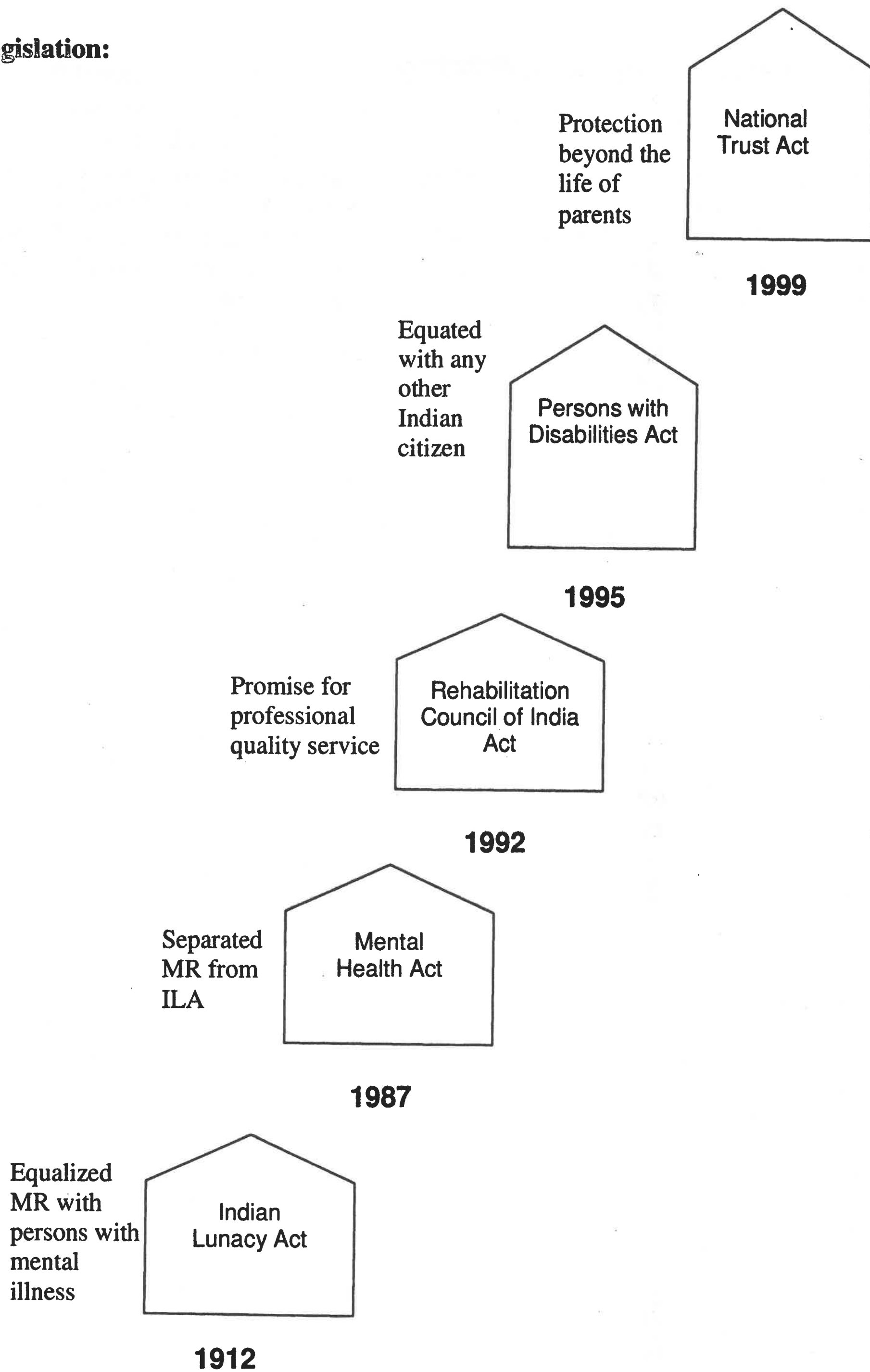
To effectively implement the schemes of the Government for persons with disabilities, to develop human resources to deal with disabilities, to develop service models, to conduct research and to document and disseminate information, the Government of India has set up 4 National Institutes for visual (NIVH), hearing (NIHH), orthopaedic disabilities (NIOH) and mental retardation (NIMH) respectively. The Institute for Physically Handicapped (IPH) and National Institute of Rehabilitation, Training and Research (NIRTAR) are two more National level Institutes of rehabilitation. In addition, the District Rehabilitation Centre (DRC) scheme is initiated in 10 States by the Government of India, aiming at preventive measures and comprehensive rehabilitation. To train manpower for DRCs, four Regional Rehabilitation Training Centres (RRTCs) have been established by the Government.

2.3.2 National Policy on Education

After the Independence, one important turning point was the National Policy on Education (1986). This policy for the first time included a section on disabilities (Section 4.9). Briefly, the points made in this section include; **1. Education of children with mild disabilities will be in regular schools, 2. Children with severe disabilities will be in special schools with hostel facilities in district headquarters, 3. Vocationalization of education will be initiated, 4. Teachers training programmes will be reoriented to include education of disabled children and 5. All voluntary efforts will be encouraged.**

Following the implementation of the policy by the Department of Education, Ministry of Human Resource Development, the Integrated Education of the Disabled Persons (IEDP) gained momentum. Financial support, free aids and appliances, transport allowances and such other facilities were provided by the Central Government for children studying in integrated schools. However, this scheme was not very beneficial for those with mental retardation, as the academic integration of such children was not possible.

Legislation:



3.3.3 Indian Lunacy Act (ILA) (1912)

Mental illness and mental retardation are two distinct conditions. However, in ILA, persons suffering from mental illness and mental retardation are grouped together and similar laws are applicable to the mentally ill and retarded persons.

Mental illness is a deviation from a norm, be it psycho-social, ethical, medical or legal. This deviation can occur at any time in an individual's life and the causative factors can be biological or sonological. Mental retardation on the other hand involves significantly sub-average general intellectual functioning resulting in or associated with concurrent impairments in adaptive behaviour. This condition manifests itself during the developmental period (that is 0-18 years). With education and training an individual with mental retardation can be taught to perform to the optimum of his capacity but the sub-normal capacity cannot be alleviated and cured.

Mental illness involves an opposition of pathology and normalcy. But in mental retardation, due to the permanence of the affliction, the persons with mental retardation constitute a group of clearly identifiable individuals and not a fluctuating population like mentally ill.

Implications

A lunatic was defined under the Indian Lunacy Act 1912 as an idiot or a person with unsound mind. As the persons with mental retardation came within the purview of this law, they were liable to institutionalization in a mental hospital. As a result, a number of persons with mental retardation were confined in mental hospitals/institutions and subjected to a course of treatment appropriate for a mentally ill person.

3.3.4 Mental Health Act (MHA) (1987)

As per the Mental Health Act 1987 (14th of 1987) (MHA), Government of India, Ministry of Law and Justice, "Mentally ill person" means a persons who is in need of treatment by reason of any mental disorder other than mental retardation.

The Mental Health Act clearly excludes the persons with mental retardation from the definition of persons with mental illness. With this exclusion, for the first time, the legal interests of the persons who are mentally ill and those who are retarded are not being jointly considered.

The MHA 1987, primarily deals with (1) treatment and institutionalization of the mentally ill, (2) protection and management of their property. The right to legal aid and representation has also been granted to the mentally ill by this Act. With the enforcement of the MHA, the Indian Lunacy Act of 1912, which was the

operative law on these areas for the persons with mental retardation became non-existent. As the MHA was not applicable for mentally retarded, a legal vacuum prevailed in the areas of with regard to the rights of protection of the persons with mental retardation till the Disabilities Act 1995.

Implications

There are areas wherein the law applicable to the mentally ill was inapplicable to the retarded but no separate law for persons with mental retardation was formulated.

There are areas where the law for the mentally ill and the retarded was the same.

There are areas with regard to which special legislations for the mentally retarded had to be introduced.

We will see more about P.D. Act (1995) a little later.

3.3.5 Rehabilitation Council of India Act (RCI) (1992)

As experienced by many developing countries, historically, **the training of trainers** for rehabilitation was a voluntary effort with varying philosophies, beliefs and view points. Accordingly, the content, purpose and style of training differed. Special schools had a number of untrained teachers. If trained, the teachers had training for a duration ranging from 3 days to three years. The programme did not essentially have recognition from government or board of education. The training institutes were few in number. In the area of mental retardation at one year diploma level, there was one teacher training programme, in 1970s there were 2 and gradually the training programmes increased. Today there are about 37 diploma programmes in the field of special education and about 3 offering the B.Ed. degree through universities.

The Rehabilitation Council of India (RCI) is a statutory body under the Ministry of Social Justice and Empowerment to regulate and introduce uniformity in the human resource development in the country. Under this act, every rehabilitation practitioner including special educators are expected to register with RCI after qualifying from Training Institutes recognized by RCI. The training institutes are inspected by RCI to ensure maintenance of standards. The RCI act is a major move by the Government of India for quality assurance in the education, training and management of persons with disabilities.

RCI Act has 3 chapters. The preliminary section gives the definition. Chapter II explains the matters related to the constitution, execution and related committees. The functions of the Council is given in detail in the third section.

A list of recognized rehabilitation qualifications granted by universities or institutions in India is also approved by Rehabilitation Council of India Act.

B.Ed. Special Education, Diploma in Special Education, Bachelor degree in Rehabilitation Services (Mental Retardation) and Diploma in Vocational Training and Employment (Mental Retardation) are recognized by RCI. After passing the RCI recognized courses, the professionals are required to register with RCI to work in the field of disability rehabilitation.

Functions of RCI

1. Recognition of qualifications granted by university, etc. in India for rehabilitation professionals.
2. Recognition of qualifications granted by Institutions outside India.
3. Rights of persons possessing qualifications included in the schedule to be enrolled.
4. Power to require information as to courses of study and examination.
5. Inspectors at examinations.
6. Withdrawal of recognition.
7. Minimum standards of education.
8. Registration.
9. Privileges of persons who are registered in register.
10. Provisional conduct and removal of names from register.
11. Appeal against order of removal from register.
12. Maintaining register.
13. Information to be furnished by council and publication thereof.
14. Cognizance of offences.
15. Protection of action taken in good faith.
16. Employees of council to be public servants.
17. Power to make rules.
18. Power to make regulations.
19. Laying of rules and regulations before the parliament.

2.4 PERSONS WITH DISABILITIES (EQUAL OPPORTUNITIES, FULL PARTICIPATION AND PROTECTION OF RIGHTS) ACT 1995

2.4.1 Structure

As seen earlier, the persons with mental retardation were governed by the Indian Lunacy Act of 1912. In the 1987, the Lunacy Act was replaced by Mental Health Act.

The Persons with Disabilities Act 1995 has come into enforcement on February 7, 1996 as an important landmark and significant step in the direction to ensure full participation of persons with disabilities in the nation building.

The act provides preventive and promotional aspects of rehabilitation like education, employment, and vocational training, reservation, research and manpower development, creation of barrier free environment, unemployment allowance, special insurance scheme for the disabled employees and establishment of homes for person with severe disabilities.

Provisions.....

- Prevention and early detection of disabilities.
- Education.
- Employment.
- Non-discrimination.
- Research and manpower development.
- Affirmative action.
- Social Security.
- Grievance redressal.

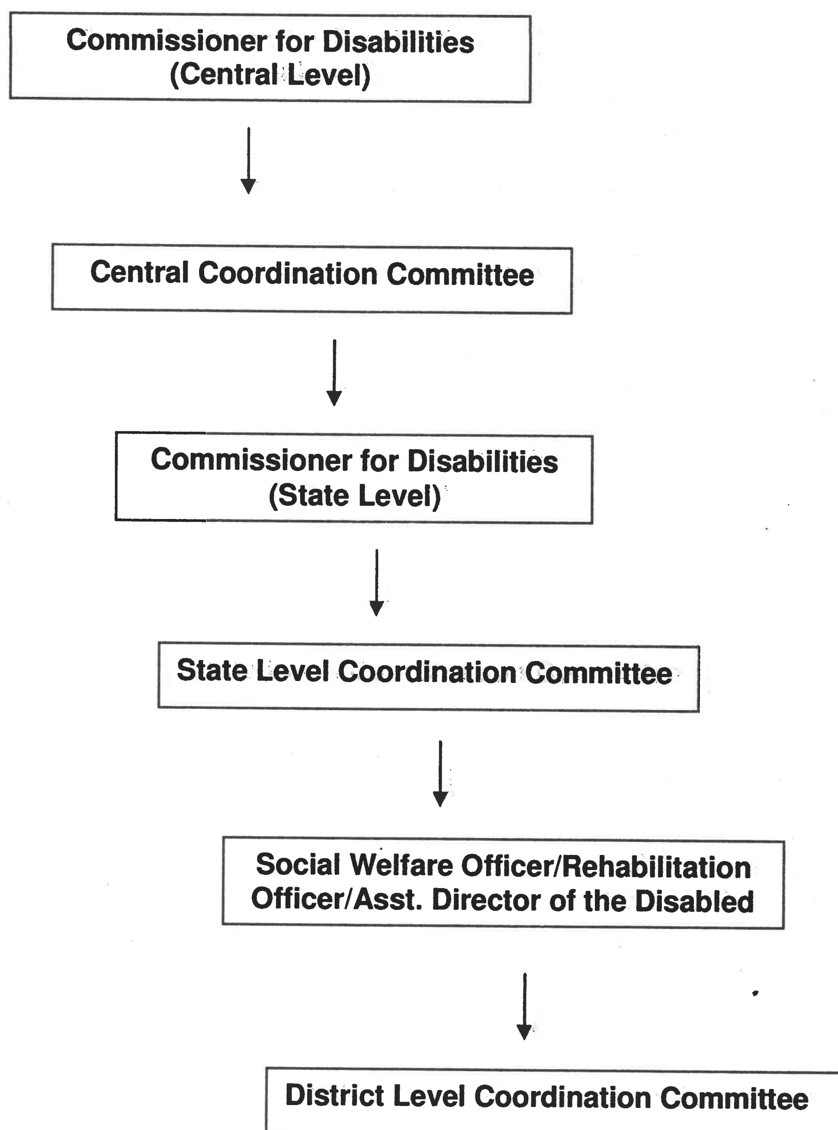
The Economic and Social Commission for Asia and Pacific (ESCAP) at its forty-eighth session held at Beijing adopted a resolution proclaiming the period 1993-2002 as the Asian Pacific Decade of Disabled persons with a view to giving impetus to the implementation of world programme of action concerning disabled persons in Asian and Pacific region.

The agenda for action for decade of the disabled persons laid emphasis of enactment of legislation aiming at equal opportunities for people with disabilities protection of their rights and prohibition of abuse and neglect of these persons and discrimination against them.

The Ministry of Social Justice and Empowerment proposed comprehensive bill after discussion with state/union territories, Government, NGOs, prominent people with disabilities and other central government departments.

The Bill was passed in the parliament in 1995 winter session and received the consent of the President on 1st January, 1996 as Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) At 1995.

Implementation of P.D. Act



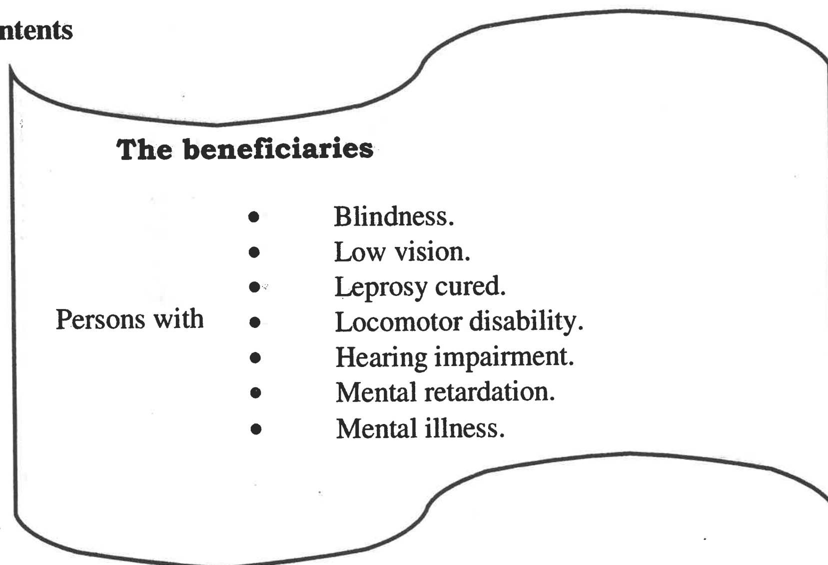
3.4.2 Objectives of the Act

1. To spell out the responsibility of the State towards prevention of disabilities, protection of rights of persons with disabilities, medical care,

education, training, employment and rehabilitation of persons with disabilities.

2. To create barrier free environment for persons with disabilities.
3. To remove all discrimination of persons with disabilities in the sharing of development, benefits, vis-à-vis non-disabled persons.
4. To counteract any situation of abuse and exploitation of persons with disabilities.
5. To lay down a framework for comprehensive development of strategies, programmes and services for and equalization of opportunities for persons with disabilities.
6. To make special provisions for integration of persons with disabilities with the mainstream.
7. To provide for better protection of rights of persons with disabilities and to enable them to enjoy equal opportunities and full participation in national life and to provide for their social security and matters connected to these or incidents thereto.

3.4.3 Contents



The chapters 1, 2 and 3 give the definitions and explain about central and state coordination committees.

Chapter 4 – Prevention and early detection of disabilities

- Surveys, investigations and research shall be conducted to ascertain the cause of occurrence of disabilities.
- Various measures shall be taken to prevent disabilities. Staff at the primary health center shall be trained to assist in this work.
- All children shall be screened once in a year for identifying "at risk" cases.
- Awareness campaign shall be launched and sponsored to disseminate information.
- Measures shall be taken for pre-natal, peri-natal and post natal care of the mother and child.

Chapter-V – Education

Right to free education.

- Every child with disability shall have rights to free education till the age of 18 years in integrated school or special schools.
- Appropriate transportation, removal of architectural barriers, restructuring of curriculum and modifications in the examination system shall be ensured for the benefit of children with disabilities.
- Children with disabilities shall have the right to free books, scholarships, uniform and other learning materials.
- Special schools for children with disabilities shall be equipped with vocational training facilities.
- Non-formal education shall be promoted for children with disabilities.
- Teacher training institution shall be established to develop requisite manpower.
- Parents may move to appropriate for a for redressal of grievances regarding placement of their children with disabilities.

Chapter VI – Employment

- 3% of vacancies in government shall be reserved for people with disabilities, 1% each for person suffering from blindness or low vision, hearing impairment, locomotor disability/cerebral palsy. As of now, persons with mental retardation are not covered here.
- Suitable schemes shall be formulated for ensuring their welfare.

- Government educational institutes and other educational institutes receiving grant from government shall reserve atleast 3% seats for people with disabilities.
- No employee can be sacked or demoted if they become disabled during service, although they can be moved to another post with the same pay and condition. No promotion can be denied because of impairment.

Chapter-VII – Affirmative Action

- A people with disabilities.
- Allotment of land shall be made at concessional rates to the people with disabilities for – house, business, special recreational cetnre, special schools/factories by entrepreneurs with disability.

Chapter-VIII – Non-discrimination

- Public building, rail compartments, buses, ships and air-crafts will be designed to give easy access to disabled people.
- In all public places and in waiting rooms, toilets, shall be wheel chair accessible. Braille and sound symbols are also to provided in lifts.
- All the places of public utility shall be made barrier free by providing ramps.

Chapter-IX – Research and Manpower Development

Research in the following areas shall be sponsored and promoted.

- Prevention of disability.
- Rehabilitation including CBR.
- Development of assistive devices.
- Job identification.
- On site modification of offices and factories.
- Financial assistance shall be made available to the universities, other institutions of higher learning, professional bodies and non-government research units or institutions for undertaking research for special education, rehabilitation and manpower development.

Chapter-XIII – Social Security

- Financial assistance to non-government organization for rehabilitation of persons with disabilities.

- Insurance coverage for the benefit of the government employees with disabilities.
- Unemployment allowance to people with disabilities registered with the special employment exchange for more than a year and could be placed in any gainful occupation.

Chapter-XIV – Grievance Redressal

In case of violation of rights as prescribed in that act, people with disabilities may move an application to

- Chief Commissioner for persons with disabilities in the center.
- Commissioner for persons with disabilities in states.

Implications

The coordination committee at central and state level have been formed and commissioners are being appointed to implement the P.D. Act 1995 in each State and Union Territory.

The persons with disability can exercise the human rights as per the law.

3.5 NATIONAL TRUST FOR WELFARE OF PERSONS WITH AUTISM, CEREBRAL PALSY, MENTAL RETARDATION AND MULTIPLE DISABILITIES ACT 1999

It is well known that some of the disabilities need life long care of varying degrees, despite best of training and rehabilitation efforts. Parents always have the big question in their mind, of **"what will happen to our child after us???"** The National Trust Act is an answer to this question. India is a country with close knit families and the children are always with the families. Institutionalization is not a practice in the country. We may even say that community based rehabilitation is not a recent trend in India, but the age old tradition has been that the child with disability is at home as part of the family and community. With the current trend towards a shift from joint family to nuclear families, the fear of parents on care of their dependent children after them, has become a challenge.

The National Trust Act has made provisions for appointment of guardians for those who have applied, and residential facilities by organizations who will have to maintain minimum standards prescribed by the trust in terms of space, staff, furniture, rehabilitation and medical facilities.

This is an act to provide for the constitution of a body at the National Level for the welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities and for matters connected therewith or incidental thereto.

3.5.1 Objectives

- To enable and empower persons with disabilities to live as independently and as fully as possible within and as close to the community to which they belong.
- To strengthen the facilities to provide support to persons with disability to live within their own families.
- To extend support to registered organization to provide need based services during the period of crisis in the family of persons with disability.
- To deal with the problems of persons with disability who do not have family support.
- To promote measures for the care and protection of persons with disability in the event of death of their parent or guardian.
- To evolve procedure for appointment of guardians and trustees for persons with disability requiring such protection.
- To facilitate the realization of equal opportunities protection of rights and full participation of persons with disability.
- To do any other act which is incidental to the aforesaid objectives.

3.5.2 National Trust Act Programmes

Highlights

- Conducive environment
- Counselling and training
- Residential hostels
- Individual and group homes.
- Respite care, family care, day care services.
- Self help groups.
- Local level committees to grant approval for guardianship.

3.6 OTHER RELEVANT GOVERNMENT POLICIES AND SCHEMES

National Handicapped Finance and Development Corporation (NHFDC)

This is a scheme introduced by Government of India for enhancing employment of persons with disabilities. Any Indian with disability in the age range of 18-55 years with 40% or more disabilities is eligible for the scheme. Specific jobs have been identified for persons with intellectual impairment for availing the facility of loan through the scheme.

Scheme of Assistance to Disabled persons for purchase/fitting of aids and appliances (ADIP)

Provision of aids, appliances and assistive devices at low cost has been an objective of Government of India. With the enactment of P.D. Act, the need for support to persons with disabilities became essential. Under this scheme, persons with mental retardation may receive free of cost, assistive devices (if there is an associated locomotor disability), educational kits and supplies for daily living skills.

National Programme for Rehabilitation of Persons with Disabilities (NPRPD)

India is a huge country with 29 States and 6 Union Territories with a population of one billion people, out of whom 50 million are considered to be disabled. About 75% of this population lives in rural areas, while the services available are clustered in urban areas leaving a large group unattended.

The NPRPD aims to create infrastructure to provide rehabilitation facilities at state, district, block and gram panchayat (village) level. In the programme, center based as well as community based programmes are encouraged and the scheme is implemented at the state level with finance from the center. By this, it is envisaged that the unreached villagers with disabilities will have access to services, and the community will be empowered. A total six Composite Rehabilitation Centres (CRCs) have been established in different parts of the country to implement the programme.

District Centres for Rehabilitation of persons with Disabilities

Another step towards reaching the villages by the Government of India, Ministry of Social Justice and Empowerment is the establishment of **District Centres in 107 districts** from different states in the country. These centers will provide assessment, fitment of aids and appliances and maintenance, establish linkage with existing schools or establish new schools for education and training and identification of jobs suitable for persons with disabilities, including mental

retardation. Focus is also on development of barrier free environment, which would include, roads, public buildings, and transports. The scheme has been launched recently by the National level apex institutes for disabilities in the country.

Science and Technology Project in Mission Mode

To reach out to the persons with disabilities in rural areas with the indigenous and effective methods being on the one hand, keeping pace with the technological advances for ensuring access and quality in their life is focused on the other. The Science and Technology Mission Mode of Government of India supports projects in Science and Technology that leads to equal opportunity and access to disabled person. The NIMH has a project funded by S&T on development of computer assisted instruction for persons with mental retardation. A total of 6 softwares for functional academics and independent living in community will be taught through these softwares. It has proved that, this effort not only disproves the common belief that children with intellectual disabilities cannot use computers and generalize, but also improves their self-esteem as they use the computers – like anyone else.

Special Education for children with Intellectual Disabilities

The UN Declaration `Education For All' is a big challenge to meet, when it comes to children with intellectual disabilities, that too in a developing country. The challenge is being faced by the Government with various schemes.

From the technical point of view, the educational efforts for these children need focus from different dimensions. As noted earlier, in NPE, children with mild mental retardation can be educated **in regular schools** with curriculum modification, while those who cannot cope with regular academic activity require **special schools** with functional academics. Those children with severe intellectual disabilities, or those who live in such places with no access to schools require **home bound instructions**.

The Integrated Education for Disabled Children (IEDC) is a scheme implemented by the Ministry of Human Resource Development. The trained resource teachers support the regular class teachers so as to provide appropriate education to children with disabilities.

The National Open School (NOS) is a programme of open education, which includes children with intellectual impairment. Those with borderline intelligence can study at their own pace with a reduced curricular content. Vocation oriented education is also planned.

The District Primary Education Programme (DPEP) is another major step towards universalization of primary education wherein the children with special

needs are also included and a number of districts are implementing the programme. Inclusive education being the concept world over, the DPEP aims at including the children at primary level (up to Class V) with suitable teacher preparation, infrastructural facilities and aids and appliances.

The child who cannot cope with regular curriculum, attends special schools. There are over 1,100 special schools run by NGOs with Government support.

Empowering parents, early intervention and training at home where there is no access to school is a major mode of reaching out to children with special needs in India. The intention here is to reach the children at home for their special educational needs, if they cannot reach the schools. Thus by training the carer or the parent, the precious time in the child's developmental period when learning occurs maximum, is not wasted. In addition, parents also develop a positive attitude and develop confidence in training their retarded children. Such training can be center based where parents come with the child periodically, learn the demonstrated skills and carry out at home. Another method is to send the teachers periodically to the homes of the children and train the parents using locally available material, which is economically viable and cost effective. Thus no child with special need will remain unattended.

Community Based Rehabilitation (CBR)

This is not a new concept in India, as children are always with families and the neighbours naturally extend helping hands when the family needs. However, the programme is made more structured with funds allocated and local village leaders empowered.

Vocational training and employment of persons with intellectual impairment

As for anyone, the ultimate aim of education and rehabilitation is to lead towards economic independence. The curricular focus from childhood to adulthood includes **personal adequacy, social competence and economic independence.** Therefore, vocational training and employment has gained importance. In the past, vocational training was an extension of school programme. Traditional routine skills such as weaving and crafts were taught with no market demand and were sold as charity. Today the trend has changed to think in terms of training and employment based on the ability levels. Thus ranging from mild to severe levels of retardation, **open employment, sheltered employment and supported family/self employment** are being enhanced respectively. The Government has introduced 3% job reservation in government sector for physically disabled but not for mentally retarded persons as yet. However, encouragement through technical support and NHFDC are making a positive change.

Prevention, Early Detection and Intervention

All the above said programmes cater to those who have a disability. Government of India takes effort to **prevent disabilities** through various schemes by Ministry of Health. Public awareness, immunization, pulse polio sensitization to grass root level workers and PHC doctors about prevention and early detection, appropriate treatment and management of epilepsy and related medical problem in children with intellectual impairment are included in the scheme. Training professionals and parents on simple early intervention techniques assists in reducing and/or arresting the severity of the condition.

3.7 WHAT IS AHEAD.....

Since independence, India has made considerable progress in bringing quality in the life of people with mental retardation. Families having persons with mental retardation are empowered, self advocacy measures are taken and independent living skills are imparted for these individuals.

However, considering the size of the country with its geographic, socio, cultural, linguistic variations, a lot more is yet to be achieved.

Reaching the unreached in remote rural, tribal and hilly areas is a priority of the Government of India. Educational and training programmes which are suitable to the respective region and ecology are being developed, so that person with mental retardation develop competencies to live independently in their environment.

Translating the policies, and training materials in Indian languages in print and non-print media to reach out to every disabled person and his community is of prime importance.

Updating professionals on current trends and developments in the field of intellectual disabilities by periodic in service training programmes on regular basis is another important need of the day. This will in turn enhance the quality of life of persons with mental retardation.

Continuous **research and development** in all dimensions of mental retardation is of utmost importance for future development.

Introduction of new government schemes **for the benefit of persons with mental retardation from time to time is another important move.**

Continuous efforts towards **empowering parents** and families on management of person with mental retardation is an unending task and should continue through future.

In short, the future aims at **zero reject** in provision of suitable services for persons with mental retardation of all age range and severity levels.

3.8 UNIT SUMMARY

Since Independence, our country has come a long way in providing rights to people with disabilities. Our Constitution has provision for equality of opportunities but specifics were spelt out for disabled persons only later through various Acts and Policies.

The significant Acts include Indian Lunacy Act (1912), Persons with Disabilities Act (1995), Rehabilitation Council of India Act (1993) and National Trust Act (1999).

In addition there are benefits and concessions for persons with disabilities.

The persons with disabilities now have a right to equal opportunities, protection of rights and full participation. There is a separate Act for persons with mental retardation, cerebral palsy, autism and multiple disabilities.

3.9 CHECK YOUR PROGRESS

1. Expand

   ILA – 1912

   MHA – 1987

   RCI – 1993

   PD Act – 1995

   NTA – 1999

2. ILA and MHA – State the implications for persons with mental retardation.
3. Explain the objectives of PD Act.
4. What are the functions of RCI?
5. Narrate the need of National Trust Act.
6. Who are the beneficiaries of PD Act?
7. What is `Rehabilitation Register'?
8. Who are the Rehabilitation professional?
9. List the programmes under National Trust Act.

3.10 ASSIGNMENT/ACTIVITY

Study the legal provision of another country and compare with the ones in India. Critically analyze and write a report.

3.11 POINTS FOR DISCUSSION/CLARIFICATION

After going through the unit, you may want to have further discussion or clarifications of some points.

3.11.1 Points for discussion

3.11.2 Points for clarification

3.12 REFERENCES/FURTHER READINGS

1. Indian Lunacy Act (1912) Government of India.

2. Mental Health Act (1987) Government of India.

3. Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (1995) Government of India.

4. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (1999) Government of India.

5. Constitution of India (1950) Government of India.

6. Government of India (1998) National Handicapped Finance and Development Corporation, Ministry of Social Justice and Empowerment.

7. National Policy on Education (1986) Ministry of Human Resource Development, Government of India.

8. Reddy, S.H.K., Narayan, J. and Menon, D.K. (1990) Education in India: A survey of facilities for children with mental retardation. Mental Handicap, vo.18, pp.26-30.

UNIT 4: AREAS OF ASSESSMENT - MEDICAL, PSYCHOLOGICAL, EDUCATIONAL, BEHAVIOURAL & ECOLOGICAL

STRUCTURE

- **Introduction**
- **Objectives**
- **Magnitude of the problem**
  - A challenging task
  - Views of parents
- **Guidance and Counselling**
  - Nature and purpose
  - Principles and techniques
  - Group counseling and guidance
- **Empowerment of special needs families**
  - Role of families
  - Impact of mental retardation on family members
  - Attitudes of the society
  - Stress reactions
- **Needs of families across life cycle**
  - Support services
  - Support for religions organization
- **Equalization of opportunities**
- **Unit Summary**
- **Check your progress**
- **Activity/assignment**
- **Points for discussion/clarification**

References/Further readings

INTRODUCTION

The general assembly of United Nations in its resolution of 3rd December, 198, showed its concern that no less than 500 million persons are estimated to suffer from disability of one form or another, of whom 400 million are estimated to be in the developing countries. Rehabilitation services have barely touched even the fringe of the problem in the rural areas of the third world countries.

Experts opined that atleast one person out of ten of the population of any country is affected by some kind of physical or mental handicap. The world programme of action states that the problem of disability in developing countries need to be especially highlighted. As many as 80% of all disabled people live in isolated rural areas in developing countries. In some of these countries, the percentage of disabled population is estimated to be as high as 20 and thus if families and relatives are included, 50 percent of the population could be adversely affected by disability.

As structured services have not yet reached all corners of the country, supporting and empowering the families of disabled persons is one way of reaching out to assist them. By this, the family will also develop positive attitude towards the disabled persons. In case of mental retardation, it is further stressed that family should be empowered as these persons are dependent on them to a large extent.

In this unit, you will learn about the families of persons with mental retardation, the types of problems they face and the ways and means of assisting them through, guidance, counseling, training and management.

OBJECTIVES

On studying this unit, you will be able to:

- Demonstrate understanding the magnitude of the problems and the challenges ahead.
- Show awareness of the nature, purpose, principles and techniques of counseling and guidance.
- Narrate the role of families in the empowerment of mentally retarded persons.
- Explain the supports needed to them across the life cycle.
- Relate the equalization of opportunities to empower families.

MAGNITUDE OF THEPROBLEM

3.1.1 A challenging task ahead

To be a parent of a child with mental retardation today is vastly different from being a parent before 1900s.

- The predominant view of the children with mental retardation has been one of the issues worth of discussion. The mentally retarded individual was seen as being less than a person due to low intelligence and some of the physical characteristics associated with mental retardation.
- Another view of the mentally retarded person was based upon economics. They were seen as being unable to care for themselves, despite the fact that organized care was custodial rather than habilitative.
- They were looked down as though they were not able to work and to contribute to society economically, despite the fact that they were denied opportunities to work.
- In addition, the persons with mental retardation were denied their rights. They were not allowed to speak for themselves by virtue of being institutionalized, but again the view that predominated was that the persons with mental retardation were incapable of making knowledgeable decisions or speaking for themselves.
- The general attitude of the persons with mental retardation was overwhelmingly derogatory and negative. Parents, siblings and professionals were influenced by these views and could not help them with a positive attitude.

The Result..........

As a result of these views mentioned above, the treatment of persons with mental retardation was generally custodial and not habilitative. There were only few options for parents.

- One possibility was to maintain the child at home without any outside service which meant that often one parent was forced to remain at home full time.
- A second option was to institutionalize their offspring either at a young age or later.
- Both possibilities usually meant a total and often final separation since the institutions were away from the community and there was rapid deterioration of abilities in the persons institutionalized. To maintain

contact in these circumstances, parents would repeatedly have to question and rationalize their earlier decision. Many parents, due to these practical and emotional issues, did not maintain contact with their offspring.

In India, however, institutionalization was not a practise but residential schools exist.

3.3.2 Views of Parents

The views that can be read from the literature include that the parents of the mentally retarded children are themselves somehow different from other parents because of having a mentally retarded offspring (Farber, 1959, 1960); that it is axiomatic (ie., self evident truth) to have a mentally retarded offspring is to feel that disaster has struck (eg. Schell, 1981) and that the best that a parent of a mentally retarded person could do was to institutionalize that person (Anonymous, 1973).

The early literature on parents of the mentally retarded persons presented the view that being such a parent somehow made them different from other parents. The early literature influenced as it was by the psychoanalytic view that children were extensions of the parents, implied that something was different about the parents (Benedek, 1959; Solnit and Stark, 1961; Waterman, 1948). Although there was no explicit doctrine indicating that these parents were different from other parents, this attitude has been adopted by some parents themselves as attested to by their own statements of worthlessness.

View that it must be a trauma to have a mentally retarded offspring

Another commonly held attitude is that having a mentally retarded child is traumatic. When people become parents, they have expectations regarding that the child.

Later in development, if there is difficulty, these expectations may change and it is at this time that such labels as developmentally delayed, slow learner and mentally retarded may be used with the parents. Parents are ill prepared for such words and for their implications regarding psychological, educational, or medical services. When a child's delay is confirmed, parents have to enter systems that vary from those to which they have been accustomed and that are usually segregated form services used by other parents whose children do not carry such labels.

The reason for this divergence is the belief that special services are required for children bearing these labels. Segregation leads to low-self-esteem. Parents may resist the view on their own psychological capabilities or previous experience or support systems. They may accept professional help, but not the implications of that help.

On the other hand, those parents without support systems or strong psychological capabilities, might come back to believe in their own differences or the justification for low self-esteem.

Although the birth of a mentally retarded child usually requires some adjustment on the part of the parents, the reactions attributed to parents may be exaggerated and one still not well understood. The commonly held attitude is that it is evident that having a mentally

retarded offspring is traumatic, derives from the psychoanalytic view mentioned above that the child is an extension of the parents.

The view that it is best to institutionalize

The view that can be read from the early literature is that institutionalization was the best alternative for parents of the children with mental retardation. This view was influenced by the lack of services in the community. They only other alternative was to maintain the children in the home and to have the child participate in one of the few special education programme available.

GUIDANCE AND COUNSELLING

The problem of helping the child with mental retardation is a stupendous one, but it is worth, all our efforts, enthusiasm and zealous pursuit. A child with mental retardation needs to enjoy the fundamental rights of existence, care, education and other opportunities for intellectual, emotional and social adjustment, in his family and outside, as much as any non-retarded.

A child with mental retardation shows a condition of incomplete or less than normal mental development. He has a limited capacity to understand, to learn, to think, to reason, to judge and to discriminate. He cannot therefore, profit much from his experiences or ordinary schooling. This is, then the first problem that he presents - the problem of intellectual deficiency resulting in poor educability.

Social maladjustment

Poor educability, in most cases, leads to the problem of social inadequacy and immaturity and the consequent social maladjustment. Both these problems are accompanied by non-acceptance or rejection at the hands of his parents and siblings and foster a sense of insecurity in the child. Other factors are feeling of intense guilt in parents and an atmosphere of frustration, conflict and unhappiness in the home. If these parental feelings and attitudes persist, all efforts to improve the functioning of the child with mental retardation can prove useless. Hence, there is a great need for counselling the parents of the child with mental retardation. It is recognized more and more that professional, and at the same time human attention should be given to the parents to change their attitudes and accept their children with disability.

Nature and Purpose of Counselling

Counselling is not merely giving advice or information. It does not mean just the communication of results of psychological examination of the child in terms of mental age or I.Q. It means more than that. It implies assistance or guidance to a parent so that he may gain insight into the problems of the child with mental retardation and may change his attitudes and behaviour which is maladaptive at

the moment, through a number of personal interviews. A good counselling interview is like any other therapeutic interview in which the gaining of insight is the main objective. The counsellor should not allow himself to be into the role of advisor. The parent should not feel that he/she is being forced to accept what has been told. The parent should feel that he has played an equal role in decision making.

Counselling is not	Advising
	Moralizing
	Ordering
	Praising
	Criticizing
	Logical argument
	Reassuring
Counselling is	a relationship
	Characterized by genuineness

Counselling Parents

Counselling parents of children with mental retardation will have the following purposes :

a. Clarifying issues involved in mental retardation, such as what it means in terms of present conditions and future expectations.

b. Clarifying issues with regard to family and community relationships, the effect on other siblings and the effect of siblings on the mentally retarded child.

c. Getting the parents to accept emotionally the child's retardation by enabling them to see that the creation of a defective child need not be considered as badge of dishonor or failure.

d. Getting the parents to accept emotionally the child's academic limitations.

e. Getting the parents to dispel feelings of shame, embarrassment, disappointment, guilt and personal responsibility, by resolving their conflicts.

f. Getting the parents to realize that in some measure they are as much a problem as their child.

g. Getting the parents to live more harmoniously with each other and their child.

These objectives or aims of counselling are undoubtedly difficult to accomplish, but they may be realized, to a great extent, if the counsellor is sympathetic, patient, tactful, understanding and sensitive. This implies that he understands that parents go through many reactions in the rearing of a mentally retarded child and in their struggle to cope with the situation. He realizes the feelings and attitudes of parents and works sincerely with them to make a change.

Parental feelings

It will be pertinent here to describe the parental feelings. Most parents experience feelings of confusion, shock, disbelief, guilt, bitterness and envy.

Although most parents suspect that something is wrong with their child and even have tangible proof of the fact, many of them are afraid to face the truth. They fear to face reality. Instead of meeting the situation and consulting some expert, they go through a lot of wishful thinking. "It can't be! I am sure he will outgrow it......" They are bewildered and confused. The period of confusion is prolonged on account of relatives supporting their wishful thinking. Most of the parents, fortunately, or unfortunately, are blissfully ignorant of mental retardation. Hence for a long time they do not take any particular notice of the phenomenon.

When parents are informed that their child is mentally retarded, they are terribly shocked. The blow is really hard. Although the doctor's pronouncement has merely confirmed a suspicion they have had for a long time, they find it difficult to take it, initially.

After the initial shock, other reactions set in. Some parents are so tensed that discussing the problem with them is out of question. Others seem calm outwardly but remain pent up till they "collapse". Quite a large number of parents at first refuse to accept the diagnosis of the doctor that their child is mentally retarded. They disbelieve the doctor and hope he may be wrong. They even try to convince him that there is nothing wrong with their child, that he is just not understood. They try to convince themselves that they have known other children who had been similar to their child in early childhood but who later grew to be normal. This disbelief is bolstered up by relatives and friends. It is because of this refusal to accept the doctor's verdict, that they look for someone who will tell them that the child is normal and that even though he shows certain signs of retardation, he will grow out of it in the near future. Looking behind this disbelief is the realization that something is wrong with the child. This reaction causes conflict.

Questions Asked

Once the parents accept the fact, many questions arise that they cannot answer. "What will be his future?" "What will their friends and neighbours think?" They are filled with "shame" at this thought. Often they blame themselves or each other. They feel guilty. At this stage, disagreements between the parents may arise. Quarrels and arguments become a daily routine. The family life gets disturbed.

The guilt feeling may be accompanied by a sense of inferiority, of inadequacy and of failure. This may result in withdrawal from society. The mother or the father who may have been a very sociable person previously, shuts himself or herself with the trouble. She becomes a loner, refusing to see or to be seen by friends and neighbours.

Withdrawal from society or social contacts, may lead to parents diverting all their time to the retarded child. In the process, other members of the family may be neglected. "Some parents on the other hand, may react in the opposite way and pull away from the confusion and uncertainty by becoming deeply involved in outside activities that keep them away from home". This is particularly true of fathers of the upper middle class in our country.

Outstanding reaction

Another outstanding reaction on the part of many parents is one of bitterness, resistent and envy. They often exclaim, "why did my child have to be like this? Why did God inflict this punishment on us ? Why is did everybody else's child normal ? Why can't our society or state do something about such children ? Thus, on the one hand they reject the child, and on the other, become antagonistic towards society. They often tend to be oversensitive about what others think and say and imagine that other people are discussing their problems whispering behind their backs.

While some parents 'reject' the mentally retarded child, others are sorry for him and get overwhelmed with pity for him that they almost over protect him with affection to the extent of making him completely unfit to learn or achieve anything.

It is such feelings and attitudes that necessitate counselling which will help them to make adjustment, by inducing them to be realistic, to accept the fact of the child's handicap, having up hope on some limited improvement - the hope that comes through faith and courage. Good counselling recognizes their feelings and attitudes as due to the strange ego involvement of the parents e.g.: personal pride which causes a great deal of emotional resistance to accept the bitter truth.

Principles & Techniques

Although the approach of the practicing counsellor, a psychologist or a psychiatrist or a medical practitioner will vary in individual case, yet certain general principles of good counselling can be laid down. They are as follows.

1. There is no need for haste in making such pronouncements to parents as "the child will never talk" or "he will never grow up". It is important that the counsellor proceeds slowly and whenever possible refrains from making statements which may further threaten the parents and thus intensify their feelings of resistance.

2. At the same time, the counsellor should always attempt to present a realistic picture of the overall situation. It is a good principle to give the factual and true details when parents themselves have noticed that all is not well and are anxious to seek advice.

3. It is essential to deal with both parents together. If a joint interview is not possible, it is necessary to ascertain the views and wishes of the other parent first hand, before talking to the one parent only. This may bring about various discrepancies in parental attitude and may prejudice the stability of the home.

4. The matter should be first discussed with the parents sympathetically at their level of understanding, after a full examination of the particular situation. It is wrong to take any decision for the parents on the basis of general principles, for example if the advice concerns the question of further children, a very important factor is how much these particular parents wish to have another child.

5. As far as possible, the solution of the problem, whatever it is, should be the solution that has been arrived at by parents themselves. The counsellor should only guide the discussions and place facts before parents. The counsellor's efforts should be directed not toward a decision or solution, but rather toward a resolution of the conflict and consequent relief of anxiety. It is necessary to recognize and respect the parent's right to decide what to do in terms of their total situation, including their own ambivalence and conflict, whenever possible, the final course of action should be one which the parents themselves have decided upon and accepted emotionally as a result of lengthy discussions with the counsellor.

6. What is necessary is to take account of the total family situation in counselling - the total family situation of the particular child.

7. The choice of words is a significant issue. It is desirable on the whole to avoid using words which are traumatic in their effects - e.g.: 'feeble

minded' 'idiot' 'moron' and so on or such general statements as, "He cannot grow", "He will never learn to talk", "He is almost nil etc."

Group Counselling and Guidance

A mention may be made here of the various techniques of counselling with parents of the mentally retarded children. Generally, counselling with such parents is in the form of individual guidance.

But experiments and researches have brought out the importance of group guidance or group counselling as an effective technique, as parents do not stand alone. They are part of the child's life and difficulties. Together with the child, as a family, they are part of a community life and even more important, members of groups of individuals who, because of the presence of the retarded child in their midst, have special interests and problems.

Again it is a fact that many of the attitudes of the parents towards their mentally retarded child are due to demands of community. It is, for e.g. the group pressures that have basically forced the family of a retarded child to withdraw from normal social contacts and isolate itself with the child. Hence, the utilization of group approaches which are organized directed and channelized for therapeutic ends should logically offer some effective means of changing these parental attitudes and relieving some of the family pressures as well as more effectively reintegrating the family into the community.

Group guidance has helped the parents to accept themselves as parents of mentally deficient children without feeling guilty or devaluated, to accept their mentally retarded child, to adjust parental levels of aspiration for the child to his actual abilities, and to see more realistically the problem centering around normal siblings and concerning the placement of the child in an institution. It has enabled parents to see what they can do in the home to help the child and what they can do to help the school where their mentally retarded children study.

Scope of Counselling

This can be understood from the numbers of question which parents generally ask when seeking advice of the physician or the specialist. It is true each situation of counselling is unique and that different parents come with different problems, yet the following are some of the questions which have been asked, again and again with a great deal of feeling and with a desire to get straight forward answers.

1. Why is my child mentally retarded ?
2. Is it due to heredity or attempted abortion or forceps delivery ?

3. Why did this have to happen to us ?
4. Is it safe to have another child ?
5. Do you think that our normal children's offspring might be similarly affected ?
6. How is his or her presence in the home likely to affect our normal children ?
7. Don't you think he will teach wrong patterns of behaviour to other children ?
8. How should we explain to our other children, friends and neighbours ?
9. Is there any drug that might help ?
10. Will this child ever talk like a normal person ?
11. Can't we expect him to pass the high school examination ?
12. Supposing we engage a whole time tutor to teach him, won't it ease the situation ? Won't he improve ?
13. Is there any special school where he can learn ?
14. Is there any institution where he can live away from the home ?
15. What do you think about her marriage ? Will she be mature enough to marry ?
16. What is our state doing to rehabilitate such children ?
17. He is otherwise intelligent, but why cannot he learn to add 2 and 2 ?
18. Why does he have very poor memory ?
19. Why is he hyperactive and why can't he concentrate ? and a host of others.

Try answering these questions sincerely with the correct information. Give adequate time to parents to express their findings and queries. Be honest in your responses.

Overview of helping model and skills

Stage	1	2	3
Skills	**Listening**	**Understanding**	**Problem solving**
Techniques	• Open posture • Eye contact • Facial expression • Voice tone • No distractions • Attentive silence • Minimal encouragement • Open questions • Classifying questions • Paraphrasing • Active listening	• Summarizing • Information giving • Identifying themes • Expressing implications • Making connections • Noting contradictions • Suggesting alternative interpretations • Suggesting new perspectives • Suggesting tentative conclusions • Self disclosure • You-me-talk	• Brain storming • Classifying options • Evaluating options • Developing plans for action • Facilitating assertion • Evaluating progress • Recycling the process • Arranging for further contact • Referring on • Terminating contact
Aims	• Exploration • Acknowledgement	• Understanding • Analysis	• Action • Action
Hornby, G., Murray, R. and Cunningham, C. Machester: Hertes Adsian Research Centre.			

EMPOWERMENT OF SPECIAL NEEDS FAMILIES

The term `special need families' refers to the families having children/members with disabilities especially with developmental disabilities and additional disabling conditions particularly epilepsy, cerebral palsy and sensory impairment.

Empowerment is operationally defined as the ability to identify needs, display competencies to mobilize resources to meet needs and gain a greater sense of intrapersonal and interpersonal control over life events involving interactions with personal, social, religious network members.

Role of families

Families are the most appropriate agents for transmitting basic human competencies to these children (Fewell, 1986). When families have members with very special needs all family members will be affected.

For many children, the presence of an impairment, leads to rejection or isolation from experiences that are part of normal development. This situation maybe worsened by family and community attitudes and behaviour during the critical years when children's personalities and self images are developing (World Programme Action No.46).

The nurturing mission

The universal role of families is to nurture the young child. The family provides for the child's physical needs and foster the development of an integrated person capable of living in society and transmitting culture.

The birth of an infant with impairments has an immediate effect on the early interactions. The family's dream and expectations are threatened by the initial diagnosis. The information is shocking and is never forgotten. Feelings of intense emotional upset are described by parents. With time, equilibrium returns and the parent and child begin to know one another. The parents will take longer time to learn to communicate effectively to the special needs of the child.

Impact of mental retardation on family members

Because of the stigma or physical evidence of the child's handicap, fathers and mothers may experience hostile stages, judgmental comments, murmers of pity, and intrusive requests for personal information whenever they accompany the child to the store, on the bus or at the park. Fathers according to Gunz and Gulbrium (1972) have a tendency to perceive mental retardation on an instrumental basis. They are especially concerned about the cost of providing for the child, the child's future success and the child's ability to be self supporting in future. Mothers have a tendency to experience the birth of a handicapped child,

and the desire that he gets along well with others, and be happy regardless of academic achievement or job success.

Impact on siblings

Siblings are influenced by parents' spoken or unspoken feelings of acceptance, disappointment, denial or grief. Some siblings become more tolerant while others tell gently about their feelings towards their parents. Having a handicapped siblings is a significant source of stress across the age span. It demands extra care, adjustments, experience of teasing and embarrassment, and future responsibilities.

Impact on the extended family members

Grant parents often experience actual grief – a mourning for the loss of an expected grand child who would carry on the family tradition, and a sorrow for the life long burden and reduced opportunities their own child faces in rearing the grand child. When the relatives do not seem to understand or enter into a supportive role, their reactions to the child can be extremely painful for parents.

Family relations and the society

Families with special needs face a number of obstacles in the efforts to help their handicapped child to get into society and to obtain needed resources. It involves special policy for the handicapped in the society and assumptions about family responsibilities.

Attitudes of the society

The stigma of the handicapped persons is one of shame and inferiority. Such views are not consistent with normal societal roles of friend, lover, co-worker, or adult and society is reluctant to change its views. The most devastating consequences of being handicapped are often not the direct physical or mental result of impairment itself, but rather the attitudes and reactions of those who are not handicapped.

A child with special needs impose demands, which stress the family's ability to function effectively. The entire family becomes more vulnerable to the situations and transactions of the environment.

Stress reactions

Family stress reactions are defined as crisis marked by change in the family's structure, such as divorce or family break up or by distress between family members. Four major indicators of distress have emerged from relevant research on families:

1. early out of home placement

2. divorce
3. social isolation
4. child rejection or over protection

Institutional placement

The families of disabled children appear to lead to higher than normal rates of family break up. Children with severe mental retardation are frequently placed out of their natural home with institutional and foster care settings.

Divorce

There is also some evidence that rate of divorces may be higher among families with children with severe handicaps.

Social isolation

Social isolation has been documented as a problem for some families of disabled children. Isolation can be attributed to various reasons such as scarcity of respite care and perception of negative community attitudes, lack of time and money for recreation. It has been implicated repeatedly as a contributor to health and emotional problems in adults and children.

Child neglect

Disabled children are at greater risk for child abuse and neglect than on the general population. Incidents of abuses and neglect indicate a break down in one of the major functions of family to provide for basic needs fulfillment and reasonable socialization experiences to children.

Family stress – directly related to child condition

- Behavioural problems in child
- Night time disturbance
- Social isolation
- Adversity in family
- Child's ill health
- Problems with child's appearance
- Financial problem

All families have strengths and capacities that constitute resources which could be used to meet the needs of others. The main theme calls our attention to the

strengths of special needs families rather than counting the deficits. It is the best way of empowering special needs families.

Individual and family adaptation

Until the late 1980s the research has focused primarily on the various negative outcomes associated with care giving, and stress in families of severely disabled children. Some of the individual adaptations are:

- Some individuals and families seem to perceive their life with a handicapped relative as mutually beneficial (Simons, 1987).
- Some marriages are strengthened in the past, through cooperation and a joint sense of purpose in parenting a handicapped child (Kazek and Marvin, 1989).
- Some families become more cohesive and adaptive in response to stresses linked to a handicapped member of the family (McCuffin, McCuffin et al, 1988).

In a content analysis of 60 books written by parents of children with a wide variety of disabilities Mulin (1987) identified 4 major themes:

1. Realisitic apprisal of the disability
2. Extra ordinary demands on families
3. Extra ordinary emotional stress
4. Resolution and growth

With regard to the last theme, Mullins (1987) found the majority of authors felt their lives were enriched and became more meaningful, regardless of the type or severity of child's disability.

Positive Outcome

A study by Turnbull et al (1988) reveals that parents of children with disabilities identified their children as either sources of or reason for:

1. increased happiness.
2. greater love
3. strengthened family ties
4. strengthened religious life
5. Extended social net work
6. Greater pride and accomplishment
7. Learning not to take things for granted

8. Learning tolerance and sensitivity
9. Learning to be patient
10. Expanding career development
11. Increased personal growth
12. Assuming personal control
13. Living life more slowly
14. Cognitive coping skills for improvement

A sense of control

A sense of mastery or control may be a vital coping strategy for families who have children with disabilities. People who believe that they can control what happens to them in life are not likely to persist inspite of the difficulties and may be less likely to be affected by stress.

A positive outlook

The identification of positive aspects of a situation – the silver lining effect – may be one of the most powerful cognitive coping strategies of all. Service programmes that adopt positive and optimistic attitude can go a long way towards enhancing the family's capacity to focus on the positive outcome (Dysen and Fewell, 1986).

NEEDS OF FAMILIES ACROSS THE LIFE CYCLE

Supports for families can be organized in two broad categories - those that are relatively continuous and stable needs, and those that emerge at different stages of family cycle. When a child first enters the family, parents are often concerned about obtaining an accurate diagnosis and information about the effects of a handicapped condition. During infancy, they need the early intervention programmes. Then the child enters the school life. When the individual with disability is finishing school years, the family is more concerned about employment options.

Fiscal assistance and generic community services are likely to be relatively stable or fluctuate unpredictability in ways unrelated to child's age.

Support services

Social support or self-help groups have been increasingly popular forms of family support among families who have children with disabilities. Support groups may be organized by a professional or may arise informally through association among family members.

Family members who meet others in similar situations have opportunities to make comparisons with others and to share positive experiences. Support groups may help to achieve a mastery or control over the situations. The sharing of information that often occurs in support groups may also lead to a sense of empowerment.

Family education and information services

Educational programmes providing family members with information about participating in decision making for their child's educational or habilitation programmes may directly enhance a sense of mastery and control through empowering family members.

Family professional relationships

One of the most important aspects of family support is the relationship between the professionals serving a child with a disability and the family. A shift in attitude, with professionals seen as consultants can lead to empower families who really make a difference on the overall life of their children.

Support from religious organizations

Bronfenbrenner, Moen, and Garbarino (1984) suggest that "researchers concerned with the well-being of families would do well to attend to the part played by religious institutions within the community". Membership in a religious organization may offer parents of disabled children several different kinds of support including instrumental support, emotional/social support, educational support, structural support.

Beliefs, regardless of their origins appear to be particularly important to persons who face stress due to events they do not expect, or cannot easily explain.

The nature of religious organizations and of personal belief systems suggest why these are so highly valued. For some parents, religions provides support directly related to the parents role as a member of a religious group. For other parents support comes from both the contributions of the group and the beliefs which groups member share. Yet for other parents, support is provided by their personal belief systems alone. Though many professionals overlook these supports, it has not been forgotten by the parents, and from these sources they often derive much of the strength they need to nurture their child with special needs.

EQUALIZATION OF OPPORTUNITIES TO EMPOWER SPECIAL NEEDS FAMILIES

a) Legislation

Through legislation, attention should be given to specific rights, such as right to education, work, social security and protection from inhuman or degrading treatment, and should examine, these rights from the perspective of disabled persons.

In this regard, the Government of India passed the bill in the winter session of the Parliament 1995 – Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (Refer Unit 2 of this Block for details).

b) Physical environment

Creation of barrier free environment for persons with disabilities would help them to live as independently as possible in the community.

c) Social security

Easily accessible arrangements are needed by which disabled persons and their families can appeal, through impartial hearing against decisions concerning their rights and benefits.

d) Education and training

Individualized, locally accessible and comprehensive educational services should be provided to all persons with disability irrespective of age or degree of disability (Refer to SESM-3 Block-4 Unit-1 for educational provisions). Parents should be given the necessary support to provide as normal family environment for the disabled child as is possible. Personnel should be trained to work with the special needs families.

e) Employment

Employment services for the persons with mental retardation should include vocational assessment and guidance, training, placement and follow up. Laws and regulations should promote the employment of such persons.

f) Recreation

The disabled person should have the same opportunities for recreational activities as other citizens.

g) Culture

The disabled persons should have the opportunity to utilize their creative, artistic and intentional potential to the full, not only for their own benefit but also for the enrichment of the community.

h) Religious

Measures should be undertaken to ensure that the disabled persons have the opportunity to benefit fully from the religious activities.

i) Sports

All forms of sports should be encouraged and organized for the benefit of the disabled persons.

The developing countries are experiencing increasing difficulties in mobilizing adequate resources for meeting the needs of these families in these countries. Other pressing demands form high priority sectors such as agriculture, rural and industrial development, and population control concerned with basic needs. The efforts therefore should be supported by the international community, to do justice to persons with mental retardation and their families.

Persons with mental retardation should not be separated from their families and communities. The system of services must take into account problems of transportation and communication, and the need for supporting social, health, and educational services. The existence of primitive and often hazardous living conditions especially in urban slums, social barriers may inhibit peoples readiness to seek or accept services.

An equal distribution of these services to all population groups and geographical areas according to need, certainly will empower the families, having disabled children.

When strategies are discussed to strengthen families at the beginning of the 21st century, empowerment of special needs families is also an important areas of concern to be seriously analyzed, planned and worked out.

UNIT SUMMARY

Becoming a parent of a child with mental retardation is not a choice of the parent. Many a time it comes as a shock to them. Parents go through a number of stages such as denial, guilt, shame, and ambivalence before accepting the child. They may reject or over protect the child too.

Early years institutionalization was an option to parents. Currently, the trend is towards providing family support and empowerment.

Counselling the parents needs competency in the councellor to provide the correct information and helping parents to make their own decisions.

Families react differently to stress and the counselor should help them cope with the stress. They should be informed of various support services and legislation leading towards equalization of opportunities.

CHECK YOUR PROGRESS

1. Are parents of a child with mental retardation different from parents of non-retarded children? Justify your statement.
2. What is your opinion on institutionalization?
3. Narrate the purpose of counseling.
4. State briefly the techniques of counseling.
5. What are the qualities of a good counselor?

ACTIVITY/ASSIGNMENT

1. Visit three families of children with mental retardation, talk to all the family members regarding the child. Critically review your visit.
2. Plan a common programme for siblings of five persons with mental retardation. Narrate your experiences.

POINTS FOR DISCUSSION/CLARIFICATION

After going through the unit, you may want to have further discussion or clarifications of some points.

Points for discussion

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Points for clarification

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UNIT 5: DOCUMENTATION OF ASSESSMENT, RESULT INTERPRETATION & REPORT WRITING– IMPLICATION OF ALL THE ABOVE FOR INCLUSION

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

- **Introduction**

Assessment in Primary Schools has been developed in the context of · the Education Act 1998 · the Primary School Curriculum (1999) · reports and documents that chart relevant developments in assessment in Ireland since 1990. Education Act 1998 The Education Act redefines, radically, the responsibilities of principals and teachers in relation to the assessment of

children. The Act states 22.—(2) … the Principal and teachers shall— (b) Regularly evaluate students and periodically report the results of the evaluation to the students and their parents. In the past, it was common practice for schools to assess pupils and issue reports to parents. Notwithstanding common practice, the generally agreed benefits of assessment in the teaching and learning process, and the desirability of informing parents about children's progress and attainment, it is now a statutory requirement that every school must assess its pupils and periodically report the results of that assessment to parents. This requirement has significant implications for teachers and schools. The more important of these are · the statutory entitlement of parents to regular information on the progress and attainment of their children · a requirement that schools put assessment procedures in place that will provide an accurate account of children's progress and attainment · a requirement that schools will establish individual records of children's progress and attainment on a continuing basis during the period they are attending the school · a responsibility on the school to provide parents with accurate and clearly accessible information about their children's progress and attainment. Section 9 of the Education Act places another requirement on schools. It states 9.—A recognised school shall provide education to students which is appropriate to their abilities and needs and … it shall use its available resources to— (a) ensure that the educational needs of all students, including those with a disability or other special educational needs, are identified and provided for … 10 This provision has considerable implications for schools in developing and implementing a policy on assessment. The most significant of these include · developing mechanisms

for identifying pupils with learning difficulties · liaising with NEPS, where appropriate · co-ordinating the monitoring of pupils' progress and attainment by the class teacher, learning support teacher, resource teacher(s), and other professionals · developing an efficient system for recording and storing the results of assessment. Primary School Curriculum (1999) The Primary School Curriculum contains a statement on assessment in the curriculum for each subject. This assessment statement outlines the formative, diagnostic, summative and evaluative functions of assessment. The curriculum emphasises formative classroom-based assessment and its use in providing feedback to inform the next stages in children's learning. The wider purposes of assessment are also formally acknowledged and emphasised. The methods and tools of assessment recommended in the curriculum range on a continuum from less structured, informal methods such as teacher observation to more formal structured methods such as the use of standardised tests and diagnostic tests. These statements on assessment in the curriculum outline in general terms the principles and strategies that should govern the approaches to assessment in the curriculum. Developments in assessment since 1990 This topic is dealt with in greater detail in Section 2 of this document. It is pertinent to note here that the documents examined, represent considerable agreement regarding what are seen as desirable and undesirable features of assessment. In particular, there is agreement, within the documents, that approaches to assessment should involve neither mandated, high-stakes assessment, nor the publication of assessment results on a school-by-school basis. Rather, the discussion of assessment in these published documents concerns the preparation and implementation of an assessment policy within each school

which is tailored to the specific needs of the school population. Sections 4 and 5 of this document discuss important considerations in developing a school policy on assessment. Context and purpose of an overarching statement on assessment Taken together, the Education Act, the Primary School Curriculum, and the recent developments in assessment, provide a key context and purpose for the development of this overarching statement on assessment in primary schools. The Education Act places a statutory requirement on schools to assess children and report the results of assessment to parents, thereby underlining the need for a policy within which this can be accomplished most effectively; the Primary School Curriculum provides the educational rationale and imperative for assessment in the teaching and learning process; and successive reports and documents delineate, in broad terms, both the development of thinking on assessment in Ireland since 1990, and the principal concerns that a policy statement on assessment should address. 11 The structure of the document Section 2 of this overarching assessment statement discusses in more detail Recent developments in assessment, identifying some of the principal issues on which there is broad agreement. Under the heading Re-envisioning assessment, Section 3 attempts to give a balanced and coherent approach to the functions of assessment, categorised alternatively as assessment for learning and assessment of learning. Section 4, outlines briefly General considerations in developing a policy on assessment in primary schools. Finally, Section 5, Developing a school policy on assessment, offers detailed recommendations on developing a school policy on assessment.

- **Objectives**

The assessment of children's learning has long been a feature of primary education in Ireland. Many teachers construct and administer their own tests, administer standardised tests, and report the results of these assessments to parents and to others. Teachers also engage in their own informal assessments of pupils and use the ir findings to inform ongoing teaching and learning activities. Recent legislation (the Education Act, 1998), the ongoing implementation of the Primary School Curriculum (1999), the promotion of whole school policies in all aspects of education, and research findings on the value and uses of assessment, point to a need to review and refocus assessment of children's learning at primary level. The purpose of this section is to review these recent developments and thinking, and to consider their implications for assessment practice at school and class levels. Attempts to refine policy on assessment in primary schools are not new. Since 1990, several documents have addressed assessment policy. These include · The Report of the Review Body on the Primary Curriculum (DES 1990) · Curriculum and Assessment Policy. Towards the New Century (NCCA 1993) · Charting our Education Future, White Paper in Education (DES 1995) · Assessment in the Primary Curriculum: Primary Assessment Subcommittee Report (NCCA 1996, unpublished) · Primary School Curriculum (DES 1999) · Learning-Support Guidelines (DES 2000). Taken together these documents represent shared thinking regarding assessment, and are in broad agreement on the following: · Assessment is integral to teaching and learning. · Assessment relates to all aspects of the curriculum and encompasses the cognitive and affective domains. · There is a variety of assessment modes, each of which

is appropriate in particular circumstances. · Assessment can play a critical role in the early identification of learning difficulties. . · Schools should implement procedures both at school and classroom levels for recording and reporting assessment outcomes. · It is important for teachers to recognise the technical qualities of different assessment instruments. · Teachers need support in the implementation of assessments, and in the recording and reporting of assessment outcomes. 16 A further concern, addressed in some of the documents but not all, pertains to developing and implementing an approach to assessment that will provide a reliable summative assessment of individual pupils and at the same time serve the essential formative function of assessment in teaching and learning. The following is a summary of the thinking on the assessment issues outlined in the six documents identified. Assessment for teaching and learning The view that assessment contributes significantly to teaching and learning is strongly supported by research and is endorsed in recent policy documents, including the Primary School Curriculum. There is agreement that assessment has a central role to play in the teaching and learning process. In particular, the Introduction to the Primary School Curriculum (1999) states Assessment is central to the process of teaching and learning. It is used to monitor learning processes and to ascertain achievement in each area of the curriculum. Through assessment the teacher constructs a comprehensive picture of the short-term and long-term needs of the child and plans future work accordingly. Assessment is also used to identify children with specific learning difficulties so that the nature of the support and assistance they need can be ascertained, and appropriate strategies and programmes put in place to enable them to cope with the particular difficulties they are

encountering. Assessment assists communication about children's progress and development between teacher and child, between teacher and parent and between teacher and teacher ... (Primary School Curriculum, 1999, page 17) This document recognises that assessment is an integral part of teaching and learning; significant importance is ascribed to assessment for learning which is discussed in detail in Section 3, Re-envisioning assessment. Assessment across the curriculum The Primary School Curriculum echoes the concern expressed in recent policy documents and reports, that assessment should mirror the full range of the child's learning, encompassing the cognitive, creative, affective, physical and social dimensions of his/her development. The Primary School Curriculum notes that assessment in each subject should reflect the child's attainment of objectives, particularly in terms of knowledge, concepts and skills, as well as taking account of the full range of his/her abilities. The Primary School Curriculum was developed as an integrated learning construct. The structure of the curriculum, the choice of curriculum areas and the subjects they comprise, and the strands, strand units and detailed content objectives reflect a particular view of the child and his/her learning needs at different stages of development. This view of the child as a learner is set out clearly in the aims, 17 principles and features of the Primary School Curriculum (Introduction, pages 6-11). It is based on the two fundamental principles of the curriculum: that each child is unique and that the potential of each child should be fully developed. It is a central concern of the curriculum, therefore, that all dimensions of the child's life should be nurtured. Assessment should mirror this view, and all aspects of the child's learning and development should be assessed. In relation to the areas to be assessed

the introduction to the curriculum states Assessment is integral to all areas of the curriculum and it encompasses the diverse aspects of learning ... In addition to the products of learning, the strategies, procedures and stages in the process of learning are assessed. Assessment includes the child's growth in self-esteem, interpersonal and intrapersonal behaviour, and the acquisition of a wide range of knowledge, skills, attitudes and values. (Primary School Curriculum, 1999, page 17) This broad perspective on assessment, represented in the Primary School Curriculum, will not only ensure a consonance between learning and assessment but will further stress the equal claims of the various dimensions of the child's learning and development. If assessment is to have such a broad focus, implications arise for both the range and choice of assessment modes.

- **Definitions**

There is agreement in the documents that a broad continuum of modes of assessment is necessary in order to create a picture that will reflect the full range of the child's progress, attainment and development. Such a continuum would include · teacher observation · teacher designed tasks and tests · work samples, portfolios and projects · curriculum profiles 18 · standardised tests · diagnostic tests. No single form of assessment is adequate in developing a comprehensive profile of the child. The documents suggest that the mode of assessment should match the purpose of the assessment. Assessment and the early identification of learning difficulties The documents examined, are unanimous in stressing the importance of identifying learning difficulties at the earliest possible stage and of providing the learning supports to deal with these difficulties. This

issue is addressed in detail in the Learning-Support Guidelines (2000) issued by the DES. The guidelines recommend · the preliminary screening of pupils by their class teacher, using checklists, rating scales, screening profiles or curriculum profiles in the case of very young children, and standardised norm-referenced tests from the middle of first class onwards · the selection of pupils for diagnostic assessment · an initial diagnostic assessment by the learning-support teacher, the interpretation of the outcomes of the assessment, and a determination of the most appropriate form of learning support for each pupil · a review of each pupil's progress at the end of an instructional term, comprising assessment of the pupil's progress, evaluation of the learning programme which has been implemented, consideration of the level of learning support the pupil may require in the future, and revision of learning targets · the construction of an Individual Profile and Learning Programme for each pupil in receipt of support from the learning-support teacher. Some children may be in need of further assessment and support. In such cases the learning-support teacher and the class teacher should decide, on the basis of their assessment of an individua l child, whether the NEPS psychologist for the school, or another professional, should be consulted by teachers and parents, in order to consider further possible approaches and interventions, including the option of psychoeducational assessment. In this event, the NEPS Model of Service Code proposes a three-stage process for individual casework, which complements the recommendations in the LearningSupport Guidelines. Stage One involves the class-teacher and parent(s). Concerns are shared on the basis of screening results and observation of the child's work and personal development. An individualised approach to the child's needs is

developed collaboratively resulting in an Individual Education Plan (IEP). At this stage, the educational psychologist may 19 have an advisory role, but would not normally be involved directly with the individual pupil. Stage Two involves more specialised teachers, for example the learning-support teacher, along with the class-teacher and parent(s). The effectiveness of the initial IEP is reviewed and, if appropriate, more diagnostic testing is carried out. At this stage the Educational Psychologist would not normally be involved directly with the individual pupil. The psychologist's role continues to be advisory, but may involve indirect support for the child on the basis of the information available. A new IEP is developed collaboratively to address the child's needs. Consultation about the possibility of more formal casework may take place at this stage. At Stage Three, the NEPS psychologist, subject to parental consent, will become involved directly with the individual pupil, and a formal individual assessment of the child's needs may take place. Based on the total information available, a programme of support will be drawn up in consultation with the class teacher and the learning support teacher to address the child's needs. The implementation and review of this programme are implicit in this stage. Recording and reporting the results of assessment The different documents are in agreement that each school should adopt a systematic approach to recording children's progress and attainments, and to reporting on the outcomes of assessment to parents at regular intervals, which, as has been noted, is now a statutory requirement under the Education Act 1998. If the reporting of the results of assessment to parents is to be helpful in informing them of their children's progress and attainment, there needs to be some consistency in the manner and form of

the reporting. For example, the Report of the Primary Curriculum review Body noted that the Record Card system, introduced after the abolition of the Primary Certificate Examination, had fallen into disuse. The development of a nationally-standardised report card would provide some level of consistency in teachers' assessments across schools and across classes within schools.

- **Summary**

In order to use assessment competently in the classroom, both in assessment for learning and in assessment of learning, teachers need to develop a range of assessment competencies. These should include the ability to · choose, develop and administer assessments as well as score and interpret assessment information · use assessment information to make decisions about future teaching and learning · communicate assessment information to children, their parents, and others who may require this information. In developing the ir ability to choose good assessments, teachers should be skilled in recognising unethical or otherwise inappropriate assessment methods. They should also be aware of the limitations of assessments when taken in isolation. Developing 20 these assessment competencies will include becoming familiar with the technical language employed in assessments and reports provided by other professionals, including psychologists. Professional development for teachers It has already been noted that teachers use assessment consistently in the classroom. However, in the context of the issues referred to above, it is important to provide support to teachers and schools to enable them to use assessment in the most effective way to enhance teaching and learning, and to construct and

communicate useful and helpful summarised records of children's progress and attainment across a range of curriculum areas. This document defines, in broad terms, teachers' needs in this area. It will form the basis for the development of practical guidelines on assessment for teachers and schools. Such guidelines will be directed at improving teachers' understanding of the importance and uses of assessment, in developing their knowledge in the various assessment competencies, and in enabling them to develop an effective system of reporting the results of assessment. It is important, however, that the advice contained in the guidelines forms the basis for professional in-career development for teachers in assessment, linked to the programme already under way in supporting teachers' implementation of the Primary School Curriculum.

- **Revision**

The term 'assessment' derives from the Latin word 'assidere' which means 'to sit beside'. In many respects that simple phrase tells us a lot about the essence of assessment in the context of the primary school classroom. Its tone is non-threatening and affirming, and it suggests a partnership based on mutual trust and understanding. It reminds us that there should be a positive rather than a negative association between assessment and the process of teaching and learning in schools. In the broadest sense assessment is concerned with children's progress and achievement. More specifically, classroom assessment may be defined as the process of gathering, recording, interpreting, using and communicating information about a child's progress and achievement during the development of knowledge, concepts, skills and attitudes. Assessment, therefore, involves

much more than testing. It is an ongoing process that encompasses many formal and informal activities designed to monitor and improve teaching and learning in all areas of the curriculum. The remainder of this section addresses the functions of assessment in the context of teaching and learning in school. It presents a re-envisioning of assessment that recognises two principal functions of assessment, assessment for learning and assessment of learning, instead of the more familiar categories of formative, diagnostic, summative, and evaluative assessment. The use of these two functions of assessment highlights and emphasises the contribution that assessment can make to the day-to-day process of teaching and learning, while giving due weight to its role in helping to create a cumulative record of children's progress and attainment. This new categorisation does not replace the more familiar description of the functions of assessment; rather, they are subsumed into the new categorisation. Assessment for learning and assessment of learning This description of the functions of assessment is comparatively recent in educational thinking and is related to educational theory and ideas that have come to the forefront during the last twenty-five years. These ideas arise from a view of learning that posits the child as an active agent in constructing his/her own learning in the context of social interaction with peers, the teacher and the wider community. Central to this view of learning is the role of the teacher in providing a range of supports designed to maximise both the extent and the rate of learning. The teacher establishes the degree to which the child has acquired particular knowledge, has understood particular concepts or has mastered certain skills, identifies the next step in learning, and helps the child engage in new learning in the most

successful way. This is the general theory of learning reflected in the aims, principles and defining features of the Primary School Curriculum. In this view of learning the role of assessment is crucial. The teacher can only establish the child's stage of development in any aspect of learning through a process of assessment, and that assessment information will then be used to 'scaffold' the next step in the learning process. 24 Such an approach in no way lessens the importance of assessment of learning: using assessment to provide a cumulative record of the child's progress and attainment at different stages in his/her development. Rather, it extends the role of assessment and seeks to harness the potential of assessment in contributing to the child's learning. This broader view of the role of assessment envisages assessment for learning and assessment of learning as two complementary and interrelated processes. Assessment for learning Assessment for learning involves an ongoing process of recognising and responding to the child's learning in order to enhance his/her development. For the teacher, this process involves engaging children in their own learning by providing rich feedback, using effective questioning, and engaging children in peer and self-assessment. The goal of assessment for learning is to enable learners to further their own learning. Assessment for learning is concerned with applying the information gained from the different modes of assessment to the learning and the teaching process. Planning for assessment for learning is critical to its success. Through assessment for learning, the teacher will gather extensive, continuous information about a child's progress and attainment through observing his/her performance in and engagement with the day-to-day learning activities in the classroom. In evaluating the child's response to the

teachers' questions, the quality of his/her involvement in class and group activities, and the questions he/she poses in the learning situation, the teacher can obtain a wealth of information in relation to the minutiae of individual children's learning. Tasks and tests undertaken both in the classroom and at home will be directly related to particular learning objectives, and will add a further dimension to the picture the teacher constructs of the progress of the individual children. Correspondingly, portfolios, accumulated work samples, and projects will provide information regarding the progress the child is making over a longer period such as a month or a term. In using assessment for learning the teacher takes account of all this information about the child's progress, attainment and possible areas of difficulty in providing regular and high-quality feedback to the child, and in planning for future learning experiences. Assessment for learning includes that function of assessment known as formative assessment, but is wider in scope since it would also include diagnostic assessment and evaluative assessment. Although the term evaluative assessment is usually associated with the evaluation of schools and of educational systems, the teacher can also use assessment information to evaluate the effectiveness with which he/she is mediating the curriculum. Based on this evaluative information, the teacher can make decisions regarding the sequenc ing of content and the choice of appropriate teaching approaches and methodologies. The term assessment for learning has the merit, therefore, of combining the different ways assessment can be used to enhance teaching and learning, and at the same time defining this as one of the major functions of assessment. Relating modes of assessment to assessment for learning The essence of assessment for learning lies in its

effective use to improve the quality of the child's learning experience. The information obtained from assessment can be 25 used to enhance the child's opportunity to advance his/her knowledge, to understand a concept, or to master a skill; and this can involve a variety of timescales. Information gained from the child's response to generative, rich questioning by the teacher, as well as ongoing dialogue between the teacher, the child and the child's peers may be used in the immediate classroom situation. The quality of the child's answer can, for example, suggest further questions that can lead the child to a greater understanding of an idea in the context of a single phase of a lesson. In the same way, observation of a child's errors in oral reading can be used to enhance the nature and quality of feedback that the teacher provides. In these cases the micro elements of teaching and learning are being addressed and improved through the assessment process. Such continuous interaction will also form a part of a more extensive application of assessment when used in conjunction with a task or test. In the writing process, for example, after discussion of the subject, audience and purpose of a piece of writing, the child will produce an initial draft. This will be used as the basis for a discussion between the child and the teacher. In the course of this process the teacher will, through questioning, discussion and suggestion, help the child to see how the writing can be improved by providing greater detail, conveying thoughts and feelings in a more expressive form, sequencing the writing in a clearer way, using punctuation to provide greater clarity of expression, choosing vocabulary and syntax more appropriate to the audience and purpose of the writing, and using correct spelling. The child will then redraft his/her writing using what he/she has learned from the discussion process. In this way the teacher

assesses writing in an interactive way with the child, and the assessment is related directly to the next stage of learning. Furthermore, when a task or test, whether in a written or more interactive form, is used for assessment purposes it will be in the context of the information the teacher has already obtained through observation in a lesson, or indeed in a series of lessons. This wider picture of the child's progress and attainment can, in turn, be used to identify learning activities calculated to advance the child's understanding and capability in the area concerned. When, at the end of a longer period of learning, portfolios, work samples and projects are used for assessment purposes, the information gained from them will be informed both by the teacher's observation of the child, and the different tasks, tests and activities with which the child has engaged during the period in question. The information obtained about the child's progress using these modes of assessment can be used to plan future learning experiences designed specifically to address the stage of learning and development the child has attained. A crucial element in using assessment for learning is the extent to which the child is actively involved in the learning process. It is important that the child understands the purposes of his/her learning and the use of assessment to support that learning. The use of good questioning and quality feedback is vital to enabling the child to develop effective strategies for self-assessment. If this practice is incorporated as a consistent feature of assessment throughout the primary school, children should become reasonably good self-assessors by the time they reach sixth class. This will not only 26 assist the child in constructing his/her learning on an on-going basis but will provide a strong motivational factor in learning. Parents have an important contribution to make to assessment for learning. Their

knowledge of their own children's personalities, strengths, learning styles, home experience, and any difficulties they may be experiencing can be used to inform the teacher's own assessments. This will help to provide a fuller picture of each child's learning needs and guide the teacher in constructing learning experiences that will best promote the child's development. Keeping records for the purposes of assessment for learning Much of this assessment will involve a series of related judgements and responses on the teacher's part that will impact directly, often instantaneously, on the teaching and learning process. Such judgements will, for the most part, apply specifically to individual children or groups of children, but may also involve the whole class when children are learning a new or difficult concept or skill. During this process of supporting the child's learning through Assessment for Learning, it may be useful for the teacher to record significant observations that can be referred to as an aide memoire when reviewing and discussing the child's progress or when planning future learning experiences. Relating formal modes of assessment to assessment for learning Standardised tests are most often associated with the summative aspect of assessment, or assessment of learning. This has tended to obscure their value in assessment for learning. Information gained from a child's performance on a standardised test will provide a measurement of the child's mastery of particular concepts and skills. In many cases these may confirm the judgements the teacher has made on the basis of other forms of assessment evidence. The value of standardised tests lies not just in their potential to quantify a child's performance. They can also provide information on the child's performance in specific aspects of learning, including individual test items. Some mathematical tests, for example,

allow the teacher to document the performance of each pupil on each item. An item by item analysis of a child's performance on standardised tests can sometimes enable the teacher to identify areas of particular difficulty. Moreover, an error analysis by the teacher of a child's incorrect responses can be particularly informative in illuminating the precise nature of a child's misunderstandings or difficulties. The teacher can then draw inferences about the content or processes that should be emphasised in teaching and learning, either for an individual child, or for a class or a smaller group. Another way in which standardised tests can be used to plan for teaching and learning arises from a comparison of subtest scores. For example, individuals or groups may perform well in certain aspects of reading (for example, word identification) and poorly on others (for example, higher order comprehension processes). This information is useful to the extent that an aspect of learning on which children perform weakly can become the focus of subsequent teaching and learning. However, in general, there should be a large gap between subtest scores before it can be concluded that a child has performed better on one subtest than on another, since, like 27 test scores themselves, there is error associated with differences between subtest scores. The administration of formal diagnostic tests in curriculum areas such as reading or mathematics can facilitate an interpretation of the nature of children's learning difficulties, and enable the class teacher or learning-support teacher to form hypotheses about how such difficulties can be addressed during the teaching and learning process. Diagnostic assessment information can also be obtained using the progress tests that accompany mathematics and other textbooks. These might be described as an informal type of diagnostic test, since, typically, there are

no norms. Other diagnostic tests may be of a more formal nature, with the possibility of scores being interpreted with reference to the performance of a clearly defined norm-group. Like standardised tests, diagnostic tests can confirm conclusions drawn on the basis of the teacher's own informal assessments. In general, more formal diagnostic tests are administered to pupils who are experiencing learning difficulties. Finally, it is important to note that the standardised test is only one of the many assessment tools used to gather information about a child's progress. A child's completed standardised test does not provide an absolute measure of his/her achievement. Given the limitations of standardised tests, for example, cultural bias inherent in test questions, it is important that the outcomes of these tests (and of teacher-designed tests) must be considered in the broader context of the student's overall performance and progress. Assessment of learning The assessment information the teacher gains from the various modes of assessment will be relevant to both assessment of learning and assessment for learning. Similarly, records of assessment the teacher makes for the purposes of assessment for learning will also be used in assessment of learning. However, the two differ essentially in the purposes for which assessment is used. In recording assessment information for the purposes of assessment for learning, the teacher's focus is on using the assessment information gathered to provide ongoing feedback to the child and to plan learning experiences which meet his/her learning needs. Assessment information in relation to assessment of learning will, on the other hand, constitute a record of the child's progress and attainment, whether at class or school level, at the end of a given period of learning, as at the end of a unit of work, at the end of a term, or at the end of a year. It might, for

example, involve any or all of the following activities · reviewing a child's written work for a term, making an overall judgement according to agreed and specified criteria, and assigning a grade · administering a group-administered standardised test of reading, and generating a standard score and percentile rank for each pupil · reviewing a child's portfolio of work for a year, making an overall judgement, and after discussion with the child, assigning a grade. 28 Although both assessment for learning and assessment of learning will involve the recording of assessment information, the nature of the record and the language in which it is recorded will be quite different for each. A further defining feature of assessment of learning is that assessment recorded for this purpose will form the basis for reporting to a variety of recipients, including parents, other teachers, other schools, and other professionals associated with the education of the child. It is important, therefore, that the recording of such assessment information is consistent and readily communicable to such a varied audience. Although, as indicated earlier, summative records of achievement such as standardised test scores or overall grades for a term or a year may be of some value in the context of assessment for learning, their primary value is in the area of assessment of learning. The quality of education the child receives in primary school depends on many factors, not least amongst them, a coherent experience of education from class to class. This coherence will depend, in great measure, on the relevance and quality of assessment information about the child that is passed from one teacher to another as he/she progresses through the school or transfers from one primary school to another. Such assessment information should comprise a summative record of the child's progress and attainment together with

relevant information pertinent to particular learning needs and characteristics of the child. Schools have, in the past, commonly reported to parents on their children's progress and attainment. However, as has been noted already, the Education Act 1998 places a statutory obligation on schools 'to regularly evaluate students and periodically report the results of the evaluation to students and their parents'. Such a requirement further underlines the importance of assessment of learning. Parents have a right to be informed of their child's progress and attainment in a form that is clear and accessible. It is important, too, that the process of reporting to parents affords parents the opportunity to discuss the content of a written report with the teacher. The transition from primary school to post-primary school can present particular challenges for the child, the teacher and the school. In ensuring that this transition provides for a coherent learning experience, it is important that a reliable and informative record of the child's progress and attainments in the primary school is available to the post-primary school to which he/she transfers. Assessment and Information and Communications Technology (ICT) ICT has the potential to play an integral role in both assessment of and for learning. ICT is relevant to assessment in three particular areas: · the use of electronic portfolios in contributing to assessment · the use of ICT as an assessment tool, including diagnostic assessment · the use of ICT for recording and analysing the results of assessment. 29 Electronic portfolios of children's work provide the teacher with a further means of monitoring children's progress and attainment. Individual children should have some autonomy in deciding what is to be included in their portfolios. This will both stimulate their interest in using ICT for learning and foster their ability to assess their own work. The

earlier discussion in relation to traditional types of portfolios, work samples and projects are equally relevant to electronic portfolios. A number of ICT software programmes are available which provide instantaneous test-feedback and progress report information to teachers and children. Diagnostic testing software can be used to record the child's cognitive skills, including short term memory, phonological awareness, decoding skills, reading comprehension rate and fluency. The software records each child's responses and generates a graphical profile of his or her cognitive abilities using standardised norms. Teachers and children can use this test-generated information to identify gaps in their learning and to plan appropriate learning activities. ICT also provides teachers and schools with an effective means of recording and storing the results of assessments. Assessment records can be stored in a manageable and easily accessible form, and databases and spreadsheets can be used to analyse and extrapolate information on the progress and attainment of individuals, groups and classes in the different curriculum areas. All such records are subject to the Data Protection Acts 1988 and 2003. (See page 28.) Access to assessment information With the accumulation of personal and educational information about children in schools, consideration needs to be given to the accessibility and confidentially of records. Both the Primary School Curriculum and recent legislation recognise the rights of parents to assessment information, while recent legislation refers to the assessment needs of inspectors and other professionals such as psychologists in the NEPS and officers of the Education Welfare Board. The Primary School Curriculum and parents The Introduction to the Primary School Curriculum states Parents are the child's primary educators, and the life of the home is

the most potent factor in his or her development during the primary school years. There is a continuing process through which the child's formal learning experience in school interacts with the less formal developmental experience of home and the family. It is widely recognised that significant educational, social and behavioural benefits accrue to the child as a result of effective partnership between parents and teachers. Close co-operation between the home and the school is essential, therefore, if children are to receive the maximum benefit from the curriculum. Regular consultation with parents helps teachers to come to a deeper appreciation of children's needs and so to plan for more effective learning experiences. It also provides the means by which teachers keep parents fully informed about children's progress. (Primary School Curriculum, 1999, pp 21-22) 30 In relation to assessment, the Introduction states Assessment assists communication about children's progress and development between ... between teacher and parent ... It also helps to ensure quality in education. (Primary School Curriculum, 1999, page 17) The curriculum, therefore, posits a role for parents in children's education that presupposes a free flow of information between teachers and parents about children's educational experiences. An essential element of this involves regular reporting to parents about children's progress and attainment. In this context the Education Act 1998 and the Data Protection (Amendment) Act 2003 are of particular relevance in relation to the access parents should have to the assessment information that schools hold about their children. Access to assessment information about children can also be seen as central to the relationship between inspectors and schools. The following is a summary of the statutory implications of the Education Act 1998 for schools in relation

to the provision of access to assessment information. Access for parents Under the Act parents of primary school children are accorded access to records of their children's progress that are kept by the school. Section 9.—(g) of the Act requires schools to Ensure that parents of a student, or in the case of a student who has reached the age of 18 years, the student, have access in the prescribed manner to records kept by the school relating to the progress of the student in his or her education. This provision raises two issues: · the types of records that are envisaged · the manner in which parents should have access to such records. Given the breadth of the curriculum and the central position accorded to assessment in all curriculum areas (as outlined above), it seems probable that assessments of children's acquisition of knowledge, concepts and skills, records of their social, emotional and physical development, as well as information on their behaviour, attitudes and relationships with teachers and other children will be detailed in school and class records.

- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

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Points for Clarification

- **References / Further Readings**

NATIONAL COUNCIL FOR CURRICULUM AND ASSESSMENT

BLOCK 3: ASSESSMENT AT PRE-SCHOOL AND SCHOOL LEVELS

UNIT 1: IMPORTANCE OF ASSESSMENT AT PRE- SCHOOL AND SCHOOL LEVEL

STRUCTURE

- **Introduction**
- **Objectives**
- **Portage A Comprehensive Inclusive Approach For Early Identification And Intervention**
  - Assessment
  - Precision Teaching Method
  - Home Teaching Process
  - Developmental Curriculum
- **Summary**
- **Check Your Progress**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- **References / Further Readings**

1.1. Introduction

One of the most frequent questions asked is how did Portage get its name. The original Portage model was developed in Portage, Wisconsin in the United States. That is only coincidental to the name. The main reason is the definition of the word Portage. Webster's New World Dictionary defines Portage as "The act of carrying or transporting". This definition is the true reason that we chose to call it the Portage project. It wasn't because of where it was located, but instead it was because it signified that we were developing a home based intervention model where we carried or transported the information and intervention into the home, in the child's and family's natural environment and carried it from professional to parents.

1.2. Objectives

- The key components of the original Portage model
- The basic premise of the Portage model
- The key components of the original Portage model

1.3. Portage A Comprehensive Inclusive Approach For Early Identification And Intervention

The basic premise of the Portage model was and remains:
Parents care about their children and want them to attain their maximum potential,

Parents can, with instruction, modeling and reinforcement, learn to be more effective teachers of their own children,
The economic, educational or intellectual level of the parent does not determine their willingness to teach their child nor the extent of gains the child will attain as a result of parental instruction.

Today, the Portage scheme still operates under the same premises. In fact, in its beginning, most of the components of the Portage Model were thought to be revolutionary. Such components as ongoing assessment, individualized curriculum planning, parents as the child's primary teacher, and embedding developmental activities into the child's and family's daily routine are widely accepted and used by today's early intervention programs as "standard practice". The components are so enmeshed in current intervention practice that professionals no longer associate them with the original Portage Model. Indeed many early interventionists today may view Portage as "outdated" or "unfashionable" when, in fact, what they consider to be today's accepted standards of current practice originated in the Portage Model.

So what are the key components of the Portage Model?
The key components of the original Portage model include:

Parents as Primary Teachers: From its inception, Portage has emphasized the parent's role as the child's primary teacher. Parents as teachers can motivate children, can reinforce newly acquired skills in the home and can provide valuable information for others working with the child. Research has shown that intensity is a critical element that is typically missing in early intervention projects. In the Portage Model, the potential for larger

and longer lasting effects in the child increases because of the amount of time spent with the parent and the amount of opportunities to practice what was learned.

The role of parents as the child' s primary teacher is not dichotomous, differentiated by presence or absence of participation. Involvement is a continuum along which parents can progress based on their individual needs and circumstance and with the expectation that they do not wish to remain static at any given point.

1.3.1. Assessment

Assessment:- A systematic measurement of the child' s developmental status is a critical component in Portage and occurs through four types of assessment: formal – the use of a standardized instrument designed to determine the child' s strengths and needs, informal – observations of the child and how the child interacts with his environment and family members, Curriculum based – is the use of a developmental curriculum which guides the parents and teacher in planning the child' s program, and on-going – measuring the child' s progress regularly. Information from these procedures provides the means by which a curriculum can be developed to meet the child' s individual needs. One important change in assessment is the

expansion of assessment procedures beyond the individual child. The inter relatedness and impact of family support and the home environment upon the child' s developmental outcomes has been widely discussed. Consequently, comprehensive assessment includes a survey of family concerns and available resources as well as evaluation of key elements in the child' s environment.

1.3.2. Precision Teaching Method

Precision Teaching Method: Precision teaching is an established approach that is based on behavioral principles and has been particularly successful with children with disabilities. This method utilizes a set of simple but effective procedures that teachers or home visitors and parents follow to identify, monitor, and make decisions about critical skills or behaviors a child needs. All of us who work in early childhood intervention need to be reminded that development proceeds rapidly during the first years of a child's life. Intervention approaches that facilitate development are heavily based on theory and methodology and support a tendency toward "trial and error". Infants and young children cannot afford to wait 3 to 6 months to see if a particular intervention is successful.

Precision teaching reduces the use of trial and error. It emphasizes watching and recording behavior to identify the unique strengths or problems of the child and recording their responses to determine results of the intervention.

1.3.3. Home Teaching Process

Home Teaching Process – the centrality of the home teaching process to the other components is not by accidental design. The home teaching process is the " heart and soul" of Portage, the point which all of the components converge and where successful intervention occurs. This process focuses on teaching the parents the teaching skills of particular activities so that they can serve as the child' s main teacher in the home throughout the week.

Reporting Recording, reporting and evaluation are ongoing activities that provide documentation of the services to all children in a program and their families.

1.3.4. Developmental Curriculum

Developmental Curriculum - Professionals and others often confuse the Portage materials, particularly the Portage Guide to Early Education with the Portage Model. I'd like to make it clear that the Portage Guide is not the Portage Model. The Portage Guide can be an important part of the system but not central to the model. In fact, we encourage the use and supplementation of other curricula because of the need to apply the Portage model to populations with specific disabilities or needs. It is our belief that in the context and presence of the other components of the model, such substitutions and supplements expand the application of the model rather than hinder it.

These adaptations are a result of what we have learned to be necessary services and skills that must be found in a program when serving all children with disabilities. These adaptations have been tested and implemented in several programs in the United States and in other countries. Because there may be several different agencies that are involved with the child and family there is a need to have someone who is coordinating these services to avoid duplication and conflicting therapies. We have also found that the disability field at large rarely addresses the unique health care needs of young children with disabilities.

2.4. Summary

The health services should be planned and integrated into the child's daily routine of services. Additionally, we have learned that staff needs to have special training in physical management and behavior management in order to assist families with these areas in the home.

2.5. Check Your Progress

Self- Help (Mutual support group of people with disabilities) Self Help groups provide a forum for people with disabilities in rural/tribal areas.

The objectives of Self Help Groups (Mutual support group of people with disabilities) are:

1. To provide a forum for sharing experiences and identification of needs concerning the individual and the community. It identifies strength and abilities and builds on them.

2. To act as a Nodal Organizations to meet the immediate needs of Adults with disability.
3. To facilitate mutual support in times of crisis.
4. To promote self and group advocacy and networks with other advocacy groups.

How to promote Self-Help Groups in CBR programs:

1. Start in known village.
2. Discus with adults with disability(above 16 years)
   a) What is self-help Groups?
   b) The need to start Self Help Groups
   c) And explain the objectives of a Self Help Groups.
3. Let the group meet once a week at a place convenient, which could be one of the homes of a disabled member. Let the group identify a facilitator for arranging meetings, sending information, documenting the proceedings etc.
4. Organize together with them First Level Leaders Advancement Workshops for all members with disabilities.
5. Let the group identify and classify the needs and problems into – individual, family and problems, which are common to all disabled people in the entire village.

It is necessary in south Asian context for women with disabilities to meet exclusively and join the general group once a week.
(Frequency of the meetings: weekly Self- Help Groups meetings is ideal)

6. Strategic plans to meet the needs should be planned and implemented systematically and with cooperative effects of the members in the groups.

Self Help Group activities should flow like a river finding its own course. There is no need to give formal setup to Self Help Groups by giving labels and designations should be avoided. The principal of equality within the group is the key to organize successful self-help groups.

A Core Committee should not be formed but it should evolve as an outcome of selfless efforts of concerned people with commitments, who should consistently and collectively work, to find solutions to the problems of people with disabilities.

2.6. Assignment/Activity

Some activities with SHGs can take up in a village.

1. Working collectively as a group to start self and small group.
2. To start Regular Recreation Groups.
3. To establish Counseling Centres.
4. Initiate distant education, Braille and Talking Libraries, Toy libraries, learning materials and other useful equipment.
5. Create an information centre especially for Government schemes.
6. Build up pressure groups.
7. Promote Trusts of families and members with disabilities with severely disabled members to find solutions to problems of care and support after their parent's death.

Resources for Self Help Groups/Mutual Support Groups:

1. Voluntary Services of adults with disabilities and families of members with disability.
2. Existing facilities available in the village community such as school building, community building integrating recreation activities into the existing recreation centres.
3. Government's schemes for poverty alleviation to assist self and group empowerment, insurance for mentally handicapped persons, Self Help Group loans to the members.
4. Mobilizing family trades and local employers to generate employment for the disabled members in the group.

Parents and siblings can become members, if the member of their family with disability has severe mental handicap. People with mental handicap should be encouraged to participate in all the activities of the Self Help Group and importance should be given to the opinions and suggestions that concerns their lives. Atleast 50% members should be women.

- What are the different approaches used to derive definitions of disability?
- What is the difference between the functional and medical definitions of disability?
- According to Disability ACT 1995 passed by the government of India in the winter session of the Parliament, what is the definition of disabilities?
- What are the recent updates on the definition of disabilities in your

country?

- Debate the issues concerning the definition of disability in your country.

2.7. Points For Discussion And Clarification

After going through this Unit you might like to have further discussion on some points and clarification on others

2.7.1. Points for discussion

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2.7.2. Points for clarification

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UNIT 2: DEVELOPMENTAL AND ADAPTIVE BEHAVIOUR ASSESSMENT

STRUCTURE

- Introduction
- Objectives
- Functional Training
- Special Needs Education Of Children With Disabilities
- Income-Generation
- Translation Into Service Planning
- Behavioral Modification skills
- What is counseling?
- Self Help groups/Mutual Support Groups For Adults with Disability in CBR Programs
- Summary
- Check Your Progress
- Assignment/Activity
- Points For Discussion And Clarification
- References / Further Readings

1.1 Introduction

The purpose of many CBR programs is to empower People with disabilities. The process of empowerment of adults with disability and families with a member with Mental Handicap essentially depends on well defined plans and strategies to promote and sustain Self Help groups in their own communities.

The advocacy groups are by and large urban based. But in reality, more than 80 % of people with disabilities live in rural areas. That is why we need self -Help Groups in rural areas.

1.2 Objectives

- To study about functional training of Self-Care
- To Identify Children Using Training and behavior
- To Learn about Special Needs Education Of Children With Disabilities
- Understand the conceptual differences between the terms
- Provide suitable examples to describe each term

1.3 Functional Training

Functional training includes all the efforts to improve the abilities for self-care, mobility, behaviour and communication, including provision of appliances and technical equipment to facilitate training and/or to alleviate the consequences of disability. Also included are environmental interventions in respect of individuals, such as removal of physical barriers for a disabled person.

To calculate the requirements for services concerning functional training 8 , we need to know:

- the number of newly (moderately and severely) disabled people each year;
- how many of these people could benefit from training, and
- the length of time needed for training and follow-up.

Based on a cautious estimate, the **initial target for provision** of such training could be set at about 30 per cent of the group of newly (moderately or severely) disabled people. This corresponds, in 2000, to about 16 million people. Future plans should allow for an expansion of that number to about 40 million by the year 2035.

The estimate suggested here corresponds to approximately 20 per cent of the total prevalence.

The people belonging to the target group will need attention for more than one year. The length of time for training and follow-up varies considerably from one individual to the next.

Some will need but short periods of training, say, six to twelve months. Others, such as children with cerebral palsy, pareses, mental retardation, congenital deafness; adolescents and/or adults who have been victims of accidents causing brain damage, paraparesis, or who have arthritis, or a degenerative neurological or mental disease; elderly with stroke, amputations or Parkinson's disease, will need longer training. Yet another group of newly disabled people will have mental health complications, such as depression, that delays the process of rehabilitation.

After completion of the training period, many disabled people need to be followed-up to make sure that the results gained are maintained. Or they have to be provided with regular technical service, such as repairs and

maintenance of a leg prosthesis, (about every three years a new prosthesis is required).

Based on these considerations, I propose three years as the average time period required for functional training and follow-up.

These estimates allows us to conclude that the target set for 2000 would be service provision for about 45 million (15 million multiplied by 3), while the service needs would increase to about 120 million (40 million multiplied by 3) by the year 2035.

1.4 Special Needs Education Of Children With Disabilities

To set targets for provision of education of children with disabilities is difficult. From certain studies it appears that in some schools in the industrialised world more than 10 per cent of children are experiencing problems, which need to be addressed by the school. At least 20 per cent of all children entering primary school in the developing countries will have difficulties passing their examinations. Of these, a large group is composed of children with psychological complications as a result of family problems.

Other groups are made up of children with delayed development, or of children belonging to underprivileged sections of the population and those with general learning or speech difficulties or social behaviour problems.

Estimating the needs for the education of this group is further complicated by the fact that existing institutions provide a combination of functional training and schooling. For some children, the principal content of the education they receive is, in fact, functional training. The estimated needs for those services are already included above.

We have opted for using the prevalence rate for moderately and severely disabled children aged 5
to 14 as the basis for calculating the target. In 2000, the prevalence is 28 million children in the developing countries. In 2035, their number will be 32 million. Some of these have some verybasic problems in school, related to severe reduction of vision or hearing, or to mental retardation.
In addition, there is a proportion of children with development delay or, with social and family problems and or on behaviour problems, etc.
In trying to set a target for these needs of education, We have assumed that, during the period when they are in the age group 5 to 14, the disabled children (in 2000 = 28 million) will receive schooling for a total average period of seven years. Using these estimates, the size of the target group, in 2000, will be 19.6 million (28 million multiplied by 7/10); in 2035, it will be 22.4 million (32 million multiplied by 7/10).
The target group of disabled children with needs for special education is currently forecast
To increase by about 10 per cent between 2000 and 2035. This relatively modest increase is explained by the projected considerable decline in the natality rate over the same period.
On the other hand, the scope of special needs education may be expected to widen with economic development, as more children with special needs (such as those mentioned above) are included. As a result, the increase might very well exceed the estimate of 10 per cent.9
It should be mentioned that there are also many adult disabled people who are illiterate and wish to have education. Given the virtually total absence of field studies on the number of such people and the scarcity of resources available for them today, We have refrained from estimating the size of this group.

The crude estimates given do not indicate the number of places required and cannot be directly used to calculate the needs for trained teachers.

Such calculations can only be made after a strategy decision has been taken.

1.5 Income-Generation

Income-generation measures will comprise:

assessment, informal and formal training, job placement, market assessment, assistance to self-employment and follow-up to ensure maintenance of rehabilitation gains.

The tally of people needing interventions for income-generation likewise reflects a cautious view of what may be achieved in realistic terms. There is widespread unemployment in the developing countries, reaching in some cases 20 per cent or more of the existing potential labour force. Underemployment is another common phenomenon. The population grows by two to three per cent annually in many of these countries.

The levels of investment and economic growth are not high enough to absorb the 95 to 120 million young men and women (in the developing countries) who try to enter the labour market every year 11 . At the same time, employment opportunities for agricultural workers stagnate. The young rural population is moving to urban areas - a factor that tends to increase the competition for the jobs available in the service and industrial sectors.

The conclusion to be drawn from this situation is that, in the developing countries, with low, stagnant, or negative economic growth, only those disabled people who are able to compete on a basis of equal competence will succeed in entering the labour market.

In some countries, where the investments are higher and GDP growth reaches three per cent, or more, the prospects for finding a job are better.

The disabled people who will have the abilities to participate in ordinary work are mainly those with moderate and slight disabilities, and vocational measures should be targeted at this group.

To set a quantitative target for income-generation for persons with disabilities rehabilitation, the following calculations have been made. In the developing countries, such measures are almost exclusively given to a group of adolescents and youths aged 15 to 29. Later on, such measures are rare and consist mainly in returning a newly disabled person to his or her old job. Thus the target group for the estimates in this book is based on the age group 15 to 29.

We have not provided any estimate for the prevalence or incidence of moderate and slight disability in the previous chapter, but we will assume these rates approximate those for moderate and severe disability. The prevalence of the last-mentioned is 27 million, in 2000, and 37 million, in 2035.

Income-generation measures are directed at many sectors, e.g. household activities, agriculture, small enterprises, manufacturing and services. It is proposed that the average time period needed for these measures and for follow-up be set at three years. These services for all moderately and slightly disabled people in the age group 15 to 29 years. It would be reasonable to calculate for a period of services and follow-up of 3 years.

Using these estimates, the size of the target group for vocational measures may be set at 5 million (27 million multiplied by 3/15 = three years of services and follow-up), for 2000, and at 7.4 million (37 million multiplied by 3/15), for 2035.

The dominating need is for functional training, those for special needs education and income-generation are much smaller.

Based on these estimates, we might calculate that services for rehabilitation are needed for close on 70 million disabled people in 2000 and that the need will increase to about 149 million in the year 2035. These global indicative figures should be taken with caution.

They are based on modest assumptions and estimates, and on field experience. They correspond to permanent service provision targets of 1.5 per cent of the total population in 2000. In 2035 the provision should be for 1.9 per cent of the total population. In these targets, we have not included other types of services for disabled people, such as home care or their participation in general, mainstream development programmes.

The rehabilitation process is seen as a preparation for disabled people's participation in services and opportunities offered to all citizens - with or without a disability.

The needs calculated here do not include the accumulated ones. In situations where services are virtually non-existent, or neglected, many people are "on the waiting list". For some of them – for example - those with contractures, or those beyond school age - it will, at some point, be too late to intervene. The others, particularly those with slight disability wanting a job, the chances of reaching results may still exist. A large number of disabled people have yet to receive the

technical appliances and aids they need, such as crutches, braces, spectacles and hearing aids.

In conclusion: specific services to cover the essential needs for functional training, special education, vocational measures were, in the developing countries, estimated to be needed

- ***in 2000, for about 70 million disabled people*, and**
- ***in 2035, for about 149 million***

An enormous gap exists today between what is provided and what is required. The requirements **grow by about 2.3 million a year, or by over 6,000 a day**. 2.3 million is a number probably close to the estimate of all existing provision of active rehabilitation in the developing countries now. The gap is widening rapidly.

1.6 Translation Into Service Planning

Translation into service planning:- It should be possible to recalculate the target estimates in each developing country and, based on this, to make some rough predictions regarding the requirements for personnel, budgets and facilities. These requirements will depend on the strategy for delivery of services used. Institution-based services will require other resources than community-based ones.

The targets proposed here should be seen as temporary. As countries develop, the demand will grow, services may become more time-consuming, and the target groups will widen.

Based these calculations and on experience, it should be **realistic to plan for a system that will at the present time be capable of providing services for about 1.5 per cent of the population.** About one third of these represent newly disabled persons and about two thirds follow-ups.

Before these requirements can be translated to budget estimates and requirements of personnel, an effective technology and an efficient and sustainable service delivery and management system have to be designed.

We would like to reiterate that, in the absence of precise data, the estimates made above and the targets proposed are based on professional experience and on field work. They should be seen as indicators of the needs for services in the future and not as a final, exact calculation. Far more research is needed in order to provide accurate numbers.

Indicative global targets regarding the number of disabled people for whom permanent rehabilitation services are required in the developing countries

1 **Type of rehabilitation services**

2 **Basis for calculation**

3 **Period over which services and follow-up are required**

4 **Services targets, million people needing rehabilitation 2000 2035**

5 **Functional training**

6 30% of incidence moderate and severe disability, all age groups 3 years 45 120

7 **Special needs education**

8 All children with moderate or severe disability aged 5-14 7 years 20 22

9 **Ability training and other vocational measures**

10 All adolescents and youths with moderate or slight disability aged 15-29 3 years 5 7

TOTAL 70 149

INDIVIDUAL ASSESSMENT/PROGRESS FORM

IDENTIFICATION: **FUNCTION/ACTIVITY LEVEL**

	FUNCTION/ACTIVITY LEVEL	
1.	Feeds himself or herself(including eating & drinking) 0 Alone 1 With little help 2 With some help or sometimes 3 With a lot of help(Over 2 years) 4 Not at all	0 2 3 4
2.	Keeps himself or herself clean(including washing & bathing) 0 Alone 1 With little help 2 With some help or sometimes 3 With a lot of help(Over 2 years) 4 Not at all	0 2 3 4
3.	Dresses and undresses 0 Alone 1 With little help 2 With some help or sometimes 3 With a lot of help(Over 2 years) 4 Not at all	0 2 3

		4
4.	Uses latrine 0 Alone 1 With little help 2 With some help or sometimes 3 With a lot of help(Over 2 years) 4 Not at all	0 2 3 4
5	Controls urine and faeces 0 Controls both all the time 1 Controls urine most of the time, faeces all the time 2 Frequent problems to control urine(Over 4 years) 4 Cannot control urine at all 8 Cannot control faeces	0 2 4 8
6	Understands simple instructions 0 Easily 1 With little difficulty 2 With some difficulty(Over 1 year) 3 With great difficulty 4 Not at all	0 2 3 4
7.	Expresses needs 0 Easily 1 With little difficulty	0

	2 With some difficulty(Over 1 year) 3 With great difficulty 4 Not at all	2 3 4
8.	Speaks? 0 Easily 1 With little difficulty 2 With some difficulty(Over 1 year) 3 With great difficulty 4 Not at all	0 2 3 4
9.	Understands movements and signs for communication? (For hearing impaired) 0 Easily 1 With little difficulty 2 With some difficulty 3 With great difficulty 4 Not at all (Over 2 years)	0 2 3 4
10.	Lip reads? (For hearing impaired) 0 Easily 1 With little difficulty 2 With some difficulty 3 With great difficulty 4 Not at all (Over 2 years)	0 2 3 4
11.	Uses movements and signs for	

	communication which others understand? (For hearing or speech impaired) 0 Easily 1 With little difficulty 2 With some difficulty 3 With great difficulty 4 Not at all (Over 2 years)	0 2 3 4
12.	Sits? (Sitting up from lying down) 0 Alone 1 With little help 2 With some help or sometimes 3 With a lot of help(Over 6 months) 4 Not at all	0 2 3 4
13	Stands? Including standing up from sitting 0 Alone 1 With little help 2 With some help or sometimes 3 With a lot of help 4 Not at all (Over 1 year)	0 2 3 4
14.	Walks at least ten steps? Help means with the help of a person or using walking aids 0 Alone and without walking aids	0

	1 With little help 2 With some help or sometimes 3 With a lot of help 4 Not at all (Over 1 ½ years)	2 3 4
15	Moves inside the home? Including walking, crawling, etc. using trolley, wheelchair etc Help means with the help of a person or using walking aids 0 Alone and without aids 1 With little help 2 With some help or sometimes 3 With a lot of help 4 Not at all (Over 1 ½ years)	0 2 3 4
16.	Moves around the village? Including walking, crawling, etc using trolley, wheelchair, etc. Help means with the help of a person or using walking aids 0 Alone and without aids 1 With little help 2 With some help or sometimes 3 With a lot of help 4 Not at all (Over 4 years)	0 2 3 4

17.	Has aches and pains in the back or the joints? 0 Very rarely or not at all 1 Sometimes but can still work 2 Disturbs work but not sleep 3 Disturbs sleep 4 Cannot work at all because of pain (All ages)	0 2 3 4
	Quality and Cost Control	
18	Plays like other children at the same age? 0 Yes 1 Plays slightly below his/her age 2 Plays much below his/her age 3 Plays very much below his/her age 4 Does not play at all (0nly for under 10 years)	0 2 3 4
19.	Shows strange or unusual behaviour? 0 Never 1 Yes, but rarely (once a month or less) 2 Yes, sometimes (once a week)	0

	3 Yes, often (every day) 4 Yes regularly (several times a day) (Over 10 years)	2 3 4
20.	Has fits? 0 Never 1 Yes, less than 3 times/year 2 Yes, about once a month 3 Yes, about once a week 4 Yes, daily (All ages)	0 2 3 4
21.	Goes to school? 0 Yes, in a regular class 1 Yes, in a special class/unit in a regular school 2 Yes, in a special school/institution 3 Informal education only 4 No education (For children of school age)	0 2 3 4
22.	Joins in family activities? 0 Yes, as other members of the family 1 Quite a lot 2 Sometimes 3 Very seldom 4 Not at all (Over 2 years)	0 2 3 4

23.	Joins in community activities? 0 Yes, as other members of the family 1 Quite a lot 2 Sometimes 3 Very seldom 4 Not at all (Over 6 years)	0 2 3 4
24.	Does household activities? 0 Yes, all 1 A lot but not all 2 Some, but not all 3 Very few 4 Not at all	0 2 3 4
25	Has sufficient skills for income generation? 0 Yes, for qualified job 1 Yes, for moderately qualified job 2 Yes, for simple job 4 No (Over 15 years)	1 2

26.	Has a work or as an income? 0 Full-time work with adequate income for his/her needs income? 2 Full-time work but inadequate income for his/her needs 4 Part-time work or seasonal work or some income 6 Very infrequent work or income 8 No work and no income (Over 15 years)	0 4 6 8
27.	Protection against violence and abuse 0 Does not need protection or is fully protected at all times 2 Protected most of the time 5 Some protection some of the time 8 No protection and needs it (All ages)	2 5 8

1.7 Behavioral Modification skills

Behavioral Modification skills are widely used in changing a behavior. We can change only operand behaviors. Operand behaviors are those behaviors that are seen. For example, sits in a chair is an operand behavior whereas the boy is sad is not an operand behavior unless the behavior manifests itself in the form of operand/observable behavior such as boy is crying.

Behaviors can be added or changed. Behavioral modification skills are a double-edged sword. Skinner's behavioral modification skills are used worldwide in many sectors- in education, in HRD, management of animal behaviour, so on so forth.

Now let us understand, how a behavior is formed. Generally behaviors are formed by repetition and repetition takes place only when there are positive reinforcements. These conditionings get consolidated when the behavior occurs repeatedly. Behavioral modification skills are also used to modify undesirable behavior. There are 10 important skills one needs to know, which are extremely useful in teaching and learning environments.

1. Reward Assessment
2. Reward Training
3. Features of appropriate reward
4. Task Analysis
5. Backward and Forward Chaining
6. Prompting
7. Imitation
8. Discrimination and generalization
9. Time out

10. Over correction

Reward Assessment

There are basically two types of rewards a) social b) concrete reward.

a) Social rewards are those rewards which are appreciative in nature such as "good boy, well done, great job" etc. These rewards can be given in any place consistently. Since these do not cost any money it is easy to sustain social rewards. The other advantage of giving social rewards is that the person repeats the activity.

b) Concrete rewards are those rewards that are materialistic such as money, foodstuff, toys etc. These rewards not only cost money but it is very difficult to strengthen them and the weakening of this reward results in failure.

It is important to understand what kind of reward works for each individual. For example, what is a reward to one person can be punishment to another person. Let us take the example of a person who is not fond of sweets, if these sweets are given, it acts as a punishment and the person will not repeat the activity. Similarly even in social rewards, if the reward is not appreciated by the person, it acts as a punishment. Therefore it is very important to give a couple of rewards and find out if the child responds to those rewards. It is always advantageous to give social rewards. Token economy is also a form of a reward. A combination of social rewards helps the person to repeat the activity.

Reward Training

It also becomes important to train a person to work for rewards. This is especially relevant while working with children with intellectual deficiencies. Here we need to train children to respond to "The cause and effect theory" For example, we need to say "if you do this activity I will appreciate it by saying 'good boy'. In order to get appreciation from me you need to do this activity." This training will help a child to understand, "if I show this behavior I will get this response. Therefore to get responses that will make me happy I need to repeat the desired behavior." Such repetition leads to consolidation.

Features of appropriate reward

There are four features of a good reward.

1. A reward should be strong enough to make the person happy.
2. A reward should be consistent.
3. A reward should be attention catching.
4. A reward should be immediate

1. It is important to give a strong reward so that the individual enjoys the reward. For example, while giving a social reward, if one says "well done" in a volume that is hardly audible, that kind of reward will have no impact. Similarly a grandmother broke one small chocolate into several pieces and gave a tiny bit every time the

grandson performed an activity. Needless to say this kind of weak reward also fails to evince the appropriate response.

2. The consistency is another feature that we should bear in mind in teaching and learning environments. Forgetting to reward a person consistently each time the person performs the activity also leads to frustration and confusion, as a result the person will not learn because of lack of repetition of the activity.

3. A reward should be attention catching. This means when we give a reward the position, posture, distance, the facial expression should support the reward. For example, you should not reward a person turning your back and you should not reward a person when you are occupied with some other activity.

4. A reward should be immediately given after the child performs the activity. If there is any delay, the child will have difficulty to associate the activity and the reward. Sometimes the child might associate reward given to undesirable activity that has occurred between the first activity and the reward.

Task Analysis

Task analysis is a skill of breaking a task into small achievable steps. This approach helps a child to learn step by step. It is important to break the task into smaller steps taking into account the skill/prerequisite a child already knows. This is known as baseline or understanding the current levels of learning of the child. It is important to remember that the steps should not be too small or too big. If a step is too small the child

loses interest, if the step is too big the child finds it difficult to learn then we cannot reinforce the child and the activity will not be repeated and eventually learning will not take place. While analyzing a task and arranging the steps it is intrinsically important to remember the sequence. From step to step the difficulty level should gradually increase helping a child to learn from simple to complex task.

While presenting an activity we should to move to the next step only when the child achieves the criterion of success. After presenting the task, encourage the child to repeat the activity by giving appropriate rewards. When the child is able to perform without help, test the child against a set criterion. For example, if I ask Sita to give 5 seeds on request she will be able to give them without help 5 out of 5 times or 8 out of 10 times. Remember to set this criterion of success before starting an activity. Unless the child achieves it, do not move to the next step. Some of the reasons for a child not able to learn are as follows:

1. The prerequisite for an activity is absent.
2. The steps are too small or too big.
3. Inappropriate rewards
4. Incorrect prompting
5. Inappropriate teaching learning materials
6. Incorrect evaluation

Backward and Forward Chaining

There are many activities in which the activity can be given using the backward chaining method. This technique is useful because the satisfaction of completing an activity goes to the child so that we can reward the child and the child repeats the activity and the activity gets consolidated. For example, while helping teach a child how to put on a

shirt we should complete 98% of the activity and the child should complete the remaining 2 % such as straightening the shirt by pulling it. The backward chaining technique can be used to teach most of the activities of self-help. The forward chaining technique is straightforward where all activities that have a difficulty of performance that ranges from simple to complex are given. This technique is useful in helping to learn activities in the cognitive, language, and motor development areas, etc. In backward chaining, each step in the task analysis has same difficulty level whereas in forward chaining there is a progressive increase in the difficulty level from one step to another step.

Prompting

Prompting or graded support is a very useful skill. There are 3 types of graded support given to the child.

a) Verbal prompting
b) Gestural prompting
c) Physical prompting

Verbal prompting is given verbally to the child to help perform the activity. In gestural prompting a gesture is used to help the child perform the activity such as pointing your finger, drawing dots, etc.

Physical prompting means actually physically helping the child to perform the activity. It is important to remember to reward the child irrespective of the nature of help given to perform the activity.

Imitation

Imitation is like a mirror image. Whatever we expect the child to perform, it is important to provide a model by actually performing the activity. Each step in the task analysis should be shown to the child and then ask the child to do it. It is also important to remember the commands used such as "do it, you do it," etc., in a consistent manner so that the child is not confused with different commands.

Imitation skill is used to help a child to learn all the activities. It also helps to keep a large mirror while helping a child learn speech and language. This helps the child to see your image and his/her own image. The same technique is also used in teaching self-help skills.

Time out

One can modify any undesirable behavior by using two methods.

1. By removing the child from the reward
2. By removing the reward from the child

A problem behavior needs to be understood before planning a strategy for eradication of the behavior. A problem behavior is a behavior that is

a) Injurious to self

b) Injurious to others

c) Injurious to environment

Children are full of energy, and will always engage themselves in activities either planned by you or by themselves. A child performing an activity that does not have the above-mentioned features is not a problem

behavior. A problem behavior usually occurs to get the attention of others. In other words, problem behavior is attention-seeking behavior.

Discrimination and generalization

Discrimination and generalization is a skill that helps a child to repeat an activity using different materials and settings so that the learning is generalized. For example, if a child understands a square or a triangle in the class room setting, unless the child is able to identify these shapes and objects in different setting the child will not be able use this learning as a foundation for learning other concepts.

Over correction

Over correction is a skill to correct an undesirable behavior. For example, if an individual spills coffee on a table, asking the individual to wipe the entire table is an over correction method. By doing this an individual will not perform the undesirable activity because of the over correction response.

ABC Analysis

Antecedent behavior consequence (ABC) analysis is a technique developed by Dr. Chris Kiernan, Thomas Coran Research Institute, University of London. In this technique we identify the behavior, change the antecedent so that we can change the behavior, and as a result, change the consequence. The consequence of one behavior becomes an antecedent for the next behavior. This kind of chaining antecedents and consequence is very useful in changing the behavior. ABC technique is also used monitoring epilepsy. For example, when an epileptic attack occurs, the antecedent should be documented for a period of 4 to 12 weeks. Antecedents that trigger epileptic attack if controlled can change the behavior as well as the consequence. By using ABC Analysis we can prevent the somatic causes of epilepsy.

Common Screening forms

FORM A

Brief record of identification of disability of children under 6 years.

Village________ House No__________

Number of the child ________

a) Name of the child ____

b) Age (Date of birth) ____

c) Father's Name ____

d) Mother's Name ____

Mark [ ] against the correct answer for the following questions

Did delivery take place before full term?	YES [ ]	NO [ ]	DON'T KNOW [ ]
Compared to other children was there a delay in the following - a) Neck control? b) Sitting? c) Walking?	YES [ ]	NO [ ]	DON'T KNOW [ ]
Does the child turn his/her head or eye towards the direction of sound?	YES [ ]	NO [ ]	DON'T KNOW [ ]

Question			
Is there any difficulty for the child to understand when someone talks to him/her?	YES [ ]	NO]	[DON'T KNOW [ ]
Compared to other children, does your child have difficulty in - a) Reading? b) Understanding? c) Remembering? d) Carrying out daily activities?	YES [ ]	NO]	[DON'T KNOW [ ]
Is there any difficulty in hearing?	YES [ ]	NO]	[DON'T KNOW [ ]
Is there any physical disability?	YES [ ]	NO]	[DON'T KNOW [ ]
Does the child mix well with others?	YES [ ]	NO]	[DON'T KNOW [ ]
Is there any deformity in the eye/eyes?	YES [ ]	NO]	[DON'T KNOW [ ]
Is there any difficulty in seeing?	YES [ ]	NO]	[DON'T KNOW [ ]
Is there any difficulty for others to understand your child's talk?	YES [ ]	NO]	[DON'T KNOW [ ]
Is there any spasm in any of your child's organs?	YES [ ]	NO]	[DON'T KNOW [ ]
Is there any problem in understanding your child's talk by people outside the child's family?	YES [ ]	NO]	[DON'T KNOW [ ]

FOR THOSE WHO FILL THE FORMS

Do they refuse to give information?	YES [ ]	NO]	[DON'T KNOW [ ]
Do the family members feel that there is no use in providing information to you?	YES [ ]	NO]	[DON'T KNOW [ ]

REMEMBER:

Even if there is a single [ ] mark in the brief record, a form 2 has to be filled.

FORM B

Detailed form for the identification of impairment in children in the age group of 0-6

Village Name: **House Number:**
Number of child:

a) Name of the child: Age of child:

b) Sex of the child:

c) Father's Name:

d) Mother's Name:

Mark {□} against the correct answer for the following questions.

1	Did the child cry immediately after delivery?	Yes	No	Don't know
2	Is the size of the head of this child unusually larger than the size of the head of another child of the same age?	Yes	No	Don't know

3	Is the size of the head of this child unusually smaller than the size of the head of another child of the same age?	Yes	No	Don't know
4	Is there any lump or injury in the back of the child?	Yes	No	Don't know
5	Does the child stiffen his/her body when the mother carries the child?	Yes	No	Don't know
6	Does the child roll over to the side?	Yes	No	Don't know
7	Does the child attempt to reach for the toys placed near him/her?	Yes	No	Don't know
8	Does the child recognize familiar people?*	Can identify	Can't identify	Don't know
9	Does the child look at the light when a torch is moved to and fro, drawing the child's attention towards it?	Yes	No	Don't know
10	Does the child respond when his/her name is called from behind at a distance of 10 feet?	Can respond	Can't respond	Don't know
11	Does the child respond when his/her name is called from behind at a distance of 5 feet?	Can respond	Can't respond	Don't know
12	Does the child talk clearly?	Yes	No	Don't know
13	Is there any difficulty for others to understand child's talk?	Yes	No	Don't know
14	Does the child have fits?	Yes	No	Don't know
	If yes, Does the child have an attack			
	a) Daily?	Yes	No	
	b) Once a week?	Yes	No	Don't
	c) Once in a month?	Yes	No	know
	d) Once in six months?	Yes	No	Don't

	e) Does the child take medicine?	Yes	No	know
	f) Is the child examined by the doctor?	Yes	No	Don't know Don't know Don't know Don't know
15	While working petty jobs, does the child spill, drop not having the articles? [?]	Yes	No	Don't know
16	Does the child keep quiet when there is a discharge from the nose?	Yes	No	Don't know
17	When compared to other children of his age, does the child seem to be less intelligent?	Yes	No	Don't know
18	Does the child appear to be dull always in his/ her activities?	Yes	No	Don't know
19	Is there any difficulty for the child to concentrate on work when compared to other children of his/her age?	Yes	No	Don't know
20	Compared to other children of his/her age, does the child play mischief?	Yes	No	Don't know
21	Does the child like to mix with younger children instead of his/her own age children?	Yes	No	Don't know
22	Does the child know the dangers of fire, water, etc.?	Yes	No	Don't know
23	Can the child tell his/her name?	Tells	Does not tell	Don't know
24	Does the child suffer from utter discharge from the eyes?	Yes	No	Don't know
25	Does the child always rub his/ her eyes?		Does	Don't

		Rubs	not rub	know
26	Is there any serious eyesight problem in reading, writing and seeing?	Yes	No	Don't know
27	Does the child walks on his own without anybody's help?	Walks	Does not walk	Don't know
28	Is there any difficulty in running and doing exercises at school?	Yes	No	Don't know
29	Compared to others, is there less progress in studies/ play?	Yes	No	Don't know
30	Even though there is interest in doing all works, can't do any work?	Can do work	Can't do work	Don't know
31	Can he/she keeps the books and articles carefully and clearly just like other children of his/ her age?	Yes	No	Don't know
32	Compared to other children of his age, does he/she work slowly?	Yes	No	Don't know
33	Does the child suffer from earache?	Yes	No	Don't know
34	Is there any discharge from the ears?	Yes	No	Don't know
35	Is there any difficulty in telling stories and arithmetic?	Yes	No	Don't know
36	Does the child turn away completely to the sides while listening to talks?	Yes	No	Don't know
37	Does the child hurt himself/ herself often?	Yes	No	Don't know
38	Does the child produce sound, while talking to himself/ herself continuously?	Yes	No	Don't know
39	Does the child use spectacles?	Yes	No	Don't

				know
40	Does the child use hearing aids?	Yes	No	Don't know
41	Is there slight difficulty in hearing?	Yes	No	Don't know
42	Can the child have total hearing problem?	Yes	No	Don't know
43	Is there any problem in one leg?	Yes	No	Don't know
44	Is there any problem in both legs?	Yes	No	Don't know
45	Does he/she not walk properly?	Yes	No	Don't know
46	Is there any problem in both hands?	Yes	No	Don't know
47	When compared to others of his/her age, is there any difficulty in writing?	Yes	No	Don't know
48	Is there any difficulty in carrying out daily activities?	Yes	No	Don't know
49	Does he/she have polio in childhood?	Yes	No	Don't know
50	Does he/she have tuberculosis in childhood?	Yes	No	Don't know
51	Does he/she have brain fever (meningitis) in childhood?	Yes	No	Don't know
52	Does he/she have any lump in his/her back?	Yes	No	Don't know
53	Does he/she understand, remember and learn well?	Yes	No	Don't know
54	Have polio drops been administered?	Yes	No	Don't know
55	Has a triple antigen being given?	Yes	No	Don't know

1. Name of the person who filled this form:

2. Teacher's name:
3. School Address:
4. Is she an Anganwadi worker?

   Experience:

   Address:

   Qualification:

5. Name of the person who gave information about the child:

   Teacher:

   Mother:

   Father:

   Others:

6. Date of survey:

In the opinion of surveyor, what kind of disability does the child have?

7. Mental Retardation Yes No
   Don't know
8. Physical Handicap Yes No
   Don't know
9. Hearing impairment Yes No
   Don't know
10. Visual impairment Yes No
    Don't know

Other (specify)

Child Symptom Checklist

(To determine whether a vision evaluation should be administered)

Has your child ever reported, or have you or anyone else noticed any of the following?

1. _______Skips lines while reading or copying
2. _______Loses place while reading or copying
3. _______Skips words while reading or copying
4. _______Substitutes words while reading or copying
5. _______Rereads words or lines
6. _______Reverses letters, numbers, or words
7. _______Uses a finger or marker to keep place while reading or writing
8. _______Reads very slowly
9. _______Poor reading comprehension
10. _______Difficulty remembering what has been read
11. _______Holds head too close to paper when reading or writing (within 7-8 inches)
12. _______Squints, closes, or covers one eye while reading
13. _______Unusual posture or head tilt when reading or writing
14. _______Headaches following intense visual activities such as reading
15. _______Eyes hurt or feel tired after close work
16. _______Feels unusually tired after completing a visual task
17. _______Double vision
18. _______Vision blurs at distance when looks up from near work
19. _______Letters or lines "run together" or words "jump" when reading
20. _______Print seems to move or go in and out of focus when reading

Stuttering Attitudes Checklist

Agree or Disagree: Put a plus (+) sign in front of the statements you agree with, and a minus (-) sign in front of the statements you don't agree with. Make your decisions quickly. Even if you can't decide which answer is right for you, check the answer that seems to be closest to your feelings.

□□I sometimes feel that my stuttering is my own fault.

□□My teachers should not make me answer questions in class if they think I will stutter when I answer.

□□I think people who stutter should plan to take jobs that do not demand a lot of talking.

□□I feel that it is best if I do not talk about my stuttering with my friends.

□□People who stutter should not accept leadership jobs where they must give orders.

□□It is wrong for my teachers to talk about the problems of stuttering to my classmates.

□□People seem to make more fun of us who stutter than they do of people with other kinds of problems.

□□I think my stuttering is one of my biggest problems.

□□My stuttering is my biggest problem.

□□Sometimes I think the best way to help someone who stutters is to do nothing or say nothing about it.

□□I think if I could stop worrying about my stuttering, it would go away.

□□Sometimes I feel I should be able to stop my stuttering on my own without help.

□□I doubt if I will ever be able to talk without stuttering being a big problem for me.

Need assessment form to be used for persons of age 60 years and above:

Self Help Skills:

1. Can feed With full help ☐ With Partial help ☐ Without help ☐
2. Can dress Withfull help ☐ with Partial help ☐ Without help ☐
3. Can use toilet With full help ☐ With Partial help ☐ Without help ☐
4. Can help in simple daily living,activities like cooking, cleaning, washing etc.
   With full help ☐ With Partial help ☐ Without help ☐

Other Functions:

1. Can walk With full help ☐ With Partial help ☐ With no help ☐
2. Can see With full help ☐ With Partial help ☐ With no help ☐
3. Can hear With full help ☐ With Partial help ☐ With no help ☐
4. Can speak With full help ☐ With Partial help ☐ With no help ☐
5. Can remember important information
   With full help ☐ With Partial help ☐ With no help ☐

Chronic illness if any

- Cancer ☐ Yes ☐
  No

- Diabetic ☐ Yes ☐
  No

- Hypertension ☐ Yes ☐
  No

- HIV ☐ Yes ☐
  No
- Paralysis ☐ Yes ☐
  No
- Parkinson ☐ Yes ☐
  No
- Alzamarizm ☐ Yes ☐
  No

QUALITY OF LIFE

1. Married Yes ☐ No ☐

2. Unmarried Yes ☐ No ☐

3. Single Yes ☐ No ☐

4. Widow Yes ☐ No ☐

5. Live with family Yes ☐ No ☐

6. Have an income to sustain? Yes ☐ No ☐

7. Have support from the family? (Both financial assistance and care) Yes ☐ No ☐

8. Do they feel lonely and secluded? Yes ☐ No ☐

9. Do they feel depressed? Yes ☐ No ☐

10. Are they part of any groups, clubs, Bhajan mandal of senior citizens? Yes ☐ No ☐

11. Do they want to be a part of any such group? ☐ Yes No ☐

12. Do they need an old age home? Yes ☐ No ☐

13. Do they need some help in sharing the care in day-to-day activity? Yes ☐ No ☐

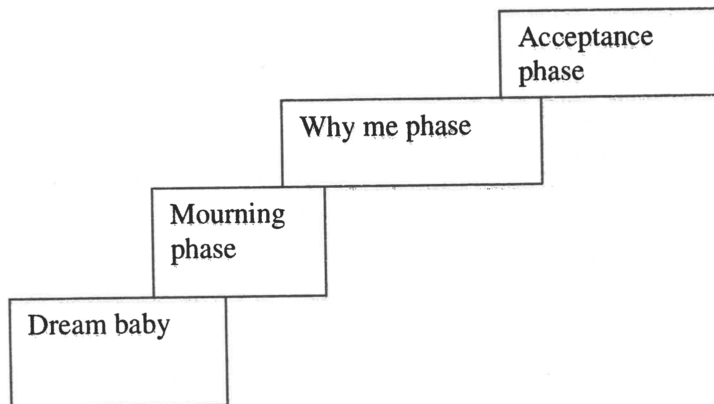
1.8 What is Counselling?

What is Counselling?

'Counselling' means many things to different people. The word is used to mean anything from a cup of tea and a chat to seeing a psychotherapist three times a week! This is why we have written this section to make it clear what we mean when we talk about counselling.

Counselling is a way of helping to find more effective ways of coping with any problems, which may be causing emotional difficulty. It can also be used for helping families with a child with disability or persons with a disability to make decisions or changes in life, such as in relationships or at work.

Four Phases of coping process



Counselling is not advice, but a safe and confidential environment in which families with a child with disability or persons with a disability can explore feelings and options, without being judged. Counselling can help families with a child with disability or persons with a disability to move towards new goals, and develop more effective ways of coping with those issues, which may at present seem unmanageable.

1.9 Self Help Groups/Mutual Support Groups For Adults With Disability In CBR Programs

Guidelines prepared by CBR Network-South Asia

Preamble: The purpose of many CBR programs is to empower People with disabilities. The process of empowerment of adults with disability and families with a member with Mental Handicap essentially depends on well defined plans and strategies to promote and sustain Self Help groups in their own communities.

The advocacy groups are by and large urban based. But in reality, more than 80 % of people with disabilities live in rural areas. That is why we need Self -Help Groups in rural areas.

What is empowerment?

Empowerment is ongoing process, which enables an individual to fulfill his duties, responsibility and protest her/his rights in the society.

CBR AND EMPOWERMENT

Empowerment of people with disabilities is the ultimate goal of any CBR program. The road to empowerment compels the community to create and promote equal opportunities so that people with disabilities get an access to:

Health services, education, housing facilities work placements emotional securities, family bonds, marriage leisure/free personal time, recreation and other needs. And above all the right to choose-Full participation in decision -making on, issues concerning self, family, community.

1.10 Summary

Counselling can help families with a child with disability or persons with a disability to move towards new goals, and develop more effective ways of coping with those issues, which may at present seem unmanageable.

1.11 Check Your Progress

Stuttering Attitudes Checklist

Agree or Disagree: Put a plus (+) sign in front of the statements you agree with, and a minus (-) sign in front of the statements you don't agree with. Make your decisions quickly. Even if you can't decide which answer is right for you, check the answer that seems to be closest to your feelings.

□□I sometimes feel that my stuttering is my own fault.

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□□Sometimes I feel I should be able to stop my stuttering on my own without help.

□□I doubt if I will ever be able to talk without stuttering being a big problem for me.

3.12 Assignment/Activity

To perform all activities which has be mentioned in Form A and Form B, in section 3.7 Common Screening forms.

3.13 Points For Discussion And Clarification

After going through this Unit you might like to have further discussion on some points and clarification on others

3.13.1 Points for discussion

3.13.2 Points for clarification

____

____

____

____

____

3.14 References / Further Readings

- Government of India. Handbook on Disability Rehabilitation. New Delhi: National Information Centre on Disability Rehabilitation, Ministry of Social Justice and Empowerment.
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UNIT 3:ASSESSMENT TOOLS AT PRE-SCHOOL LEVEL – UPANAYAN, AARAMBH, PORTAGE, MDPS, FACP

STRUCTURE

4.1. Introduction

4.2. Objectives

4.3. Common Technology Used In CBR

- **4.3.1.** Needs Assessment
- **4.3.2.** Needs Of People With Disabilities

4.4. Felt Needs

4.5. Expressed needs

4.6. Assessed needs

4.7. Summary

4.8. Check Your Progress

4.9. Assignment/Activity

4.10. Points For Discussion And Clarification

4.11. References / Further Readings

UNIT 4

To Assess the Needs of Persons with Disability Using the Need Assessment Staircase Given In the Who Manual

4.1. Introduction

A thorough study of disabled people's needs should be the starting point of any plan for a rehabilitation programme. In the past, few such studies were made in the developing countries. Instead, experts straightaway proposed technical solutions, construction of facilities and training of personnel. Services were supplied in accordance with conventional ideas rather than with realities. People's needs are manifold, and each society sees its priorities differently. The problems are many. Examples are: lack of clean and safe drinking water and basic sanitary conditions, proper nutrition, inadequate education, lack of jobs, poverty, difficulties in communication, access to health care, security concerns, or repression of human rights. These problems are not unique to disabled people but are shared by other community members.

4.2. Objectives

- To study of need assessment in India
- Definitions of The term "needs"
- We will distinguish between three different types of needs

4.3. Common Technology Used In CBR

Rehabilitation needs are specific to disabled people. In developing countries, rural communities are often very well organised, their members sharing the same values and traditions, with a close-knit network of social relations providing support and protection. This does not work to quite the same extent for marginal urban settlements; even there one finds a local culture and a power structure, but far less social control. For anyone intending to study the needs of disabled people, it is essential to have an understanding of the social structures, the cultural traditions, the organisation and the lines of authority prevailing in the communities where they live. This knowledge can only be acquired from people who have been living in the particular community for a long time, who share the culture, and who are familiar with local conditions. Outsiders will need many years of experience, and to evaluate the specific needs of disabled people they must work with the local people.

4.3.1. Needs assessment

Where a rehabilitation programme is to be managed by the community, utilising its own resources, it must be planned, structured and implemented in line with local customs and needs. This implies that any general rehabilitation programme should be described in such a way as to allow both adaptations to local conditions and preservation of local influence. It should build on existing technology, allow for a service delivery system opted for by the community and apply a management system that fits into traditional approaches. This will

facilitate the integration of programmes designed to meet the specific needs of disabled people.

Definitions:-The term "needs" may be used in various ways. In this context, we will distinguish between three different types of needs. "Felt needs" are those verbalised directly or indirectly by the disabled person or his or her family or community, or needs observed over a long-term period, preferably by a community member. "Expressed needs" are those manifested by the disabled person and his or her family by the search for help in solving the particular problem. This help can come through traditional healers, religious or community leaders, modern medicine, or specialised facilities. "Assessed needs" are the rehabilitation needs assessed by a person with professional training in rehabilitation. To be able to give a qualified opinion as to the likely outcome of rehabilitative measures undertaken in the disabled person's setting; the person carrying out this assessment must have experience from developing countries. These needs should be studied before starting to design a technology. In the past, the "felt" and "expressed" needs tended to be neglected. Also, most experts (expatriates and nationals alike) did not take the trouble to visit homes and communities of disabled people when assessing needs and evaluating the likelihood of success of proposed interventions. Mostly they based their views on studies of institutions for disabled people, of school populations, or of the working population, which are not very representative. In the text below, some experience of studies, observations and conclusions on the subject of needs are presented.

4.3.2. NEEDS OF PEOPLE WITH DISABILITIES

A STUDY OF NEEDS

A thorough study of disabled people's needs should be the starting point of any plan for arehabilitation programme. In the past, few such studies were made in the developing countries.

Instead, experts straightaway proposed technical solutions, construction of facilities and training of personnel. Services were supplied in accordance with conventional ideas rather than with realities. People's needs are manifold, and each society sees its priorities differently. The problems are many. Examples are: lack of clean and safe water and basic sanitary conditions, proper nutrition, inadequate education, lack of jobs, poverty, difficulties in communication, access to health care, security concerns, or repression of human rights. These problems are not unique to disabled people but are shared by other community members.

Rehabilitation needs are specific to disabled people. In the developing countries, rural communities are often very well organised, their members sharing the same values and traditions, with a close-knit network of social relations providing support and protection. This does not work to quite the same extent for marginal urban settlements, but even there one finds a local culture and a power structure, but far less social control. For anyone intending to study the needs of disabled people, it is essential to have an under-standing of the social structures, the cultural traditions, the organisation and the lines of authority prevailing in the communities where they live. This knowledge can only be acquired from people who have been living in the particular community for a long time, who share the culture, and

who are familiar with local conditions. Outsiders will need many years of experience, and to evaluate the specific needs of disabled people they must work with the local people. Where a rehabilitation programme is to be man-aged by the community, utilising its own resources, it is vital for it to be planned, structured and implemented in line with local customs and needs. This implies that any general rehabilitation programme should be described in such a way as to allow both adaptations to local conditions and preservation of local influence. It should build on existing technology, allow for a service delivery system opted for by the community and apply a management system that fits into traditional approaches.

This will facilitate integration of programmes designed to meet the specific needs of disabled people. The term "needs" may be used in various ways. In this context, we will distinguish between three different types of needs.-

> Sometimes the 'rehabilitation' that families and communities figure out by themselves works better in their situation than do methods or aids introduced by outside professionals. In India, I met a villager who had lost a leg in a house-building accident. Using his imagination, he had made himself an artificial leg with a flexible foot out of strong wire with strips of an old cotton blanket for padding. After several months, he had the chance to go to a city where a professional 'leg maker' (prosthetist) made him a costly modern fiberglass leg. The man tried using the new limb for a couple of months, but it was heavy and hot. It did not let his stump breathe like his 'wire cage' leg. And he could not squat to eat or do his toilet, as he could with his homemade leg. Finally, he stopped using the costly new leg and went back to the one he had made. For the climate and customs where he lived, it was more appropriate
>
> **David Werner**

1."***Felt needs***" are those verbalised directly or indirectly by the disabled person or his or her family or community, or needs observed over a long-term period, preferably by a community member.

2."***Expressed needs***" are those manifested by the disabled person and his or her family by the search for help in solving the particular problem. This help could come through traditional healers, religious or community leaders, or modern medicine or specialised facilities.

3."***Assessed needs***" are the rehabilitation needs assessed by a person with professional training in rehabilitation. To be able to give a qualified opinion as to the likely outcome of rehabilitative measures undertaken in the disabled person's setting; the person carrying out this assessment must have experience from developing countries.

These needs should be studied before starting to design a technology. In the past, the "felt" and "expressed" needs tended to be neglected. Also, most experts (expatriates and nationals alike) did not take the trouble to visit homes and communities of disabled people when assessing needs and evaluating the likelihood of success of proposed interventions. Mostly they based their views on studies of institutions for disabled people, of school populations, or of the working population, which are not very representative. In the text below, some experience of studies, observations and conclusions on the subject of needs will be presented.

4.4. Felt Needs

The way people in the developing countries verbalise their needs is culture-dependent. Often they employ specific words or expressions to indicate symptoms, difficulties and problems, many of which relate to the interpretations or ascribed causes made locally. Hence, direct answers to

a list of Western medical or social questions may not tell the whole story. What arestriking, however, are the very high proportion of people with health complaints and the long-term duration of those complaints. Studies 2 initiated by the author and carried out by a national scientific group in Indonesia yielded some interesting and perhaps unexpected results.

The list has been compiled on the basis of a representative household sample survey of impairments, disabilities, and handicaps. The complaints listed are so common (appearing in 55 per cent of the population surveyed) that they are almost accepted as "normal". Among the people with such chronic symptoms, about one third (18 per cent) consider the symptoms as severe. As a rule, they are treated with local medicines such as herbs. These problems are rarely mentioned spontaneously. Those suffering from them are not normally seen as having "special difficulties" or a disability. Such severe chronic symptoms do, of course, contribute to social and economic underdevelopment since they lower the productive, physical and psychological performance of those affected. There are a host of studies dealing with the prevalence of moderate and severe functional limitations. The information is mainly based on the results of screening procedures carried out in the context of several CBR programmes. These numbers are a conservative estimate based on field experience and should be taken with caution. It should also be noted that the conditions cited vary widely from country to country:- moving difficulties are more common in countries which continue to have poliomyelitis and poor perinatal care (causing cerebralpalsy); or in countries with a recent history of civil or liberation wars (causing amputations,etc.);

- seeing difficulties are more pronounced in countries with poor hygienic conditions

(causing trachoma), a high incidence of cataract or avitaminosis A (causing xerophthalmia) and

certain communicable diseases (such as measles or onchocerciasis);-

hearing/speech difficulties are more pronounced where meningitis, for example, is common, as well as in countries where ototoxic medicines are used indiscriminately;- learning difficulties are more prevalent if there

is a tradition of consanguineous marriages. Children suffering from a combination of infectious disease and malnutrition also experience learning difficulties. This is often reversible, and if so, should not be counted as a disability;- fits are very common among children and among adults with high alcohol consumption.

The low prevalence mentioned here reflects only people with long-term, high frequency fits;- strange behaviour is more often seen if there is a high consumption of addictive drugs which cause psychoses. The low prevalence rate in the Table reflects mainly people with chronic mental disease of other than drug-related causes;

- feeling difficulties reflect the prevalence of leprosy, which world-wide is very unevenly spread and now on its way to eradication.

When people in developing countries mention needs in connection with such difficulties, the

most oft-cited concern is the burden to the family -physically, psychologically and economically.

Dressing and feeding a disabled person, and attending to his or her personal hygiene, are time-consuming tasks. Mobility problems often remain unsolved, with the disabled person simply never leaving the house. Communicating with a deaf child takes time, even though most families invent

Type Of Complaint Per Cent Population With This Complaint

Teeth problems 14.2

Chronic cough 9.2

Headache 7.7

Pain in arms and/or legs 6.9

Abdominal pain and/or diarrhoea 6.5

Backache 5.4

Breathlessness at rest or after effort 5.4

Skin symptoms 5.0

Chest pain 4.2

Malnutrition 3.8

Eye symptoms 3.5

Ear symptoms 2.2

Lame, weak, spastic muscles 1.6

Missing limbs and/or fractures 1.2

Table 3.2: Estimate of prevalence based on observed ranges of moderate and severe functional limitations among people in the developing countries

TYPE OF LIMITATION PREVALENCE %

Moving difficulty 2.0 - 2.5

Seeing difficulty 0.5 - 0.8

Hearing/speech difficulty 0.5 - 0.8

Learning difficulty 0.2 - 0.4

Chronic fits 0.3 - 0.6

Strange behaviour 0.1 - 0.2

Feeling difficulty (in hands or feet) 0.1 - 0.2

Combinations of the above 0.2 - 0.3

TOTAL 4% - 5%

Functional problems in daily life activities

- self-care (eating, drinking, dressing, keeping clean)
- mobility
- communication, comprehension, ability to follow instructions
- behaviour.

Educational needs

- schooling
- ability training

Needs for income-generating activities

- participation in household duties, jobs, self-employment

Lack of family and social integration

Concerns relating to participation and representation in community affairs

Security needs (protection against abuse, promotion of human and legal rights)

a sign language of their own. For economic reasons, schooling of disabled children is seldom considered. As most disabled people are seen as unable to perform any work at home or outside

(begging is, however, an alternative), they receive no ability/vocational training.

Some families have tried to find solve the disability problem by applying "spontaneous"

rehabilitation technology 3 . But the majority of the disabled people in the developing countries

receive no such attention. The fact that there may not be much spontaneous rehabilitation is not contrary to the fact that families may provide all the care.

Examples of the felt needs of disabled people are given. Many of these are overlapping. It should be explained that the concept of "independent living" is still very

much a Western idea that has not yet much of a following in the developing countries. There is no "push" to send disabled youths out to live on their own; they are welcome to stay. Families normally live a life characterised by interdependence. Still a programme that will lead to independence in ADL, mobility and communication is seen as great progress.

Community action and involvement should form the basis of the local rehabilitation programme, and therefore each community should carry out a study of the "felt" needs.

4.5. EXPRESSED NEEDS

"Expressed needs" are displayed in the action taken by the disabled person or his or her family to seek help. In this context, it might be useful to consider an example that illustrates how a child with an acquired disability is perceived, and what remedies may be sought.

In the developing countries, it is common to find children sick over long periods of time, in particular in the age group under five. Infectious diseases, malnutrition, asthma, diarrhoea and intestinal parasitosis, alone or in combination, have the effect of making the child weak and feverish for weeks or months. Such a child often lags behind in his or her development milestones

such as ability to walk, to communicate and to self-care. This delay may be accentuated by the

lack of physical and psychological stimulation and may be accompanied by behaviour problems.

It is not at all rare for a disabled child to be primarily perceived as sick and for the family to wait for its condition to improve. If there is no improvement in sight, the family will gather together to discuss what is to be done and will also consult any outsider believed to have some experience. In the end, a "diagnosis" may be established, and an appropriate remedy may be sought. The latter may consist in giving the child some herbs or in fetching some medicines from the local pharmacy. Should these fail to relieve the child, the family might consult a local healer or a religious leader. If this too gives no result, the family might next approach a more specialised healer or have resort to modern medicine, if available. The latter is normally costly and may require travelling to a far-away place, which explains why such action is often delayed.

It may be that the disabled child is none the better for all these interventions, upon which the family may conclude that a spell or a curse is the cause of the child's disability. To remove it, somebody with magic power has to be consulted, but such a person may not be easy to find, and the costs could be heavy. So, again, the consultation may be delayed for a long time.

Meeting such a family as an outsider, one often has the impression that what the family is looking for is a magic cure - some sort of intervention that will make the disability disappear.

At first contact, the family may therefore express its expectations of a cure for the disabled child, and it might be quite some time before they get back to the initial problems and a description of their initially "felt needs". What one may hear then is, for example: "the problem is that

my child does not walk at all," "... does not eat or drink," "... needs help with everything, occupying an adult full time," "... cannot go to school," or "... has a behaviour problem".

This example further illustrates the amount of energy, time and proportion of their meager resources a family may have to spend in looking for a solution to the needs of a disabled member.

4.6. ASSESSED NEEDS

A well trained and experienced rehabilitation professional would be able to assess the needs of disabled individuals, to identify the priorities among felt needs, and to evaluate the likelihood of success of certain rehabilitative interventions carried out locally or following a referral. For an example of calculations of such needs. The data presented derive from a study of Mendis. The sample consisted of 77 disabled people, of whom 45 were under and 32 over the age of 15.

The prospects for achieving success depend, however, on the presence of a service delivery system and trained personnel. The key factor for a successful outcome is a competent community worker with knowledge of the local culture and social structures, who is able to correctly interpret "felt" and "expressed" needs and to provide an adequate training programme, as well as other interventions. He or she should also be part of a wider system that gives him/her access to other people who can help with problems that cannot be resolved locally. Without outside support, the person assessing needs may have a difficult time arriving at a conclusion as to the potential success of a given approach.

It is necessary to point out that disabled women are more disadvantaged than disabled men are and that they have other types of needs.

The reasons for this are described, which also reviews some of the recommendations 7 for specific action for this group.

From these reflections upon the different types of needs it is clear that relevant studies are bound to be complex. In the past, when such studies were largely omitted, researchers used to come up with a series of supply-generated solutions, which tended to distort the situation.

4.7. Summary

In the developing countries, it is common to find children sick over long periods of time, in particular in the age group under five. Infectious diseases, malnutrition, asthma, diarrhoea and intestinal parasitosis, alone or in combination, have the effect of making the child weak and feverish for weeks or months. Such a child often lags behind in his or her development milestones

4.8. Check Your Progress

True/False:

1. The **Rehabilitation Council of India** (RCI) passed in 2001

   [ ]

2. The council has reportedly registered around 12,000 such professionals across India

   [ ]

3. Article 24 of the convention is about the Rights on Education which highlights that the States Parties recognize the rights of

persons with disabilities to education

[ ]

4. RTE Act is Right to Equality Act, 2005

[ ]

5. NGOs working in the area of disability, representatives of family or parent associations and experts and professionals

[ ]

4.9. Assignment/Activity

To study about Rehabilitation history in other countries like US, UK, and Ireland.

4.10. Points For Discussion And Clarification

After going through this Unit you might like to have further discussion on some points and clarification on others

4.10.1. Points for discussion

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4.10.2. Points to Clarification

4.9 References / Further Readings

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UNIT 4:ASSESSMENT TOOLS AT SCHOOL AGES – MDPS, BASIC-MR, GLAD, SUPPORT INTENSITY SCALE

STRUCTURE

- **Introduction**
- **Objectives**
- **Prevocational Skills**
    - Training Adolescents to Live in the Community-TALC check list
    - Common Guidelines To Follow
        - **Communication**
        - **Social Behavior**
        - **Self-Help Skills**
        - **Functional Academics**
        - **Domestic Skills**
        - **Safety Skills**
        - **Vocational Skills**
- **Summary**
- **Check Your Progress**

- **Assignment/Activity**
- **Points For Discussion And Clarification**
- **References / Further Readings**

1.1. Introduction

Successful sustainable employment is the ultimate goal in any rehabilitation program. Economic independence of a person with disability is one of most important factors that lead a person with a disability on the road of empowerment. Economic independence protects human rights. Financial independence facilitates a person to lead a life with respect and dignity.

1.2. Objectives

- To study about TALC and its functionalities
- Understand the conceptual differences between the terms
- Provide suitable examples to describe each term

1.3. PREVOCATIONAL SKILLS

1.3.1. Training Adolescents to Live in the Community- TALC check list

(Training Adolescents to Live in the Community- TALC check list)

There are two stages through which we can assist a person with a disability to achieve sustainable employment. Sustainable employment in the South Asian context cannot always be measured only in terms of salaries and perks.

South Asia has a predominantly agro-based economy. In an agro-based economy the usefulness of an individual in agro-based activities at different levels is more important than the money earned by these activities. In south Asia more often than not families become the main employer and family members are not paid salaries. However, the overall needs of an individual, such as housing, food, clothing and health, are taken care by the family. More than 70% of families in south Asia have some family trade. People with disabilities need to be trained to contribute to the trade/ business. This will help the families to strengthen business and fight poverty.

This will also help the people with disabilities disintegration from families and the communities, needless to say such an approach will also help the development of underdeveloped areas through the government and NGOs.

The first stage is to train a person with a disability in the areas of self-help, i.e. money concept, socialization, prehensile co-ordination, etc. The second stage is to identify the appropriate vocation in the market and train persons with disabilities with adequate competence to sustain the employment.

The TALC was developed by University of Manchester in order to provide prevocational skills in systematic way.

This checklist has two parts.

a) Criterion reference checklist in different areas with concepts and learning outcomes.

b) How to do it cards for each learning outcome with methodology materials.

The TALC will be of immense use for personnel working in disability sector.

Please note this material is [not?] disability-specific and can be used to assist all adolescents with or without disabilities.

An Indian adaptation of TALC checklist is developed by the CBR Network.

GLOBAL OBJECTIVES FOR VOCATIONAL PLACEMENT:

Concept	Sub concept	Learning Outcome
1. Communication	Using gestures appropriately.	1.Can communicate using gestures as an adjunct to verbal communication
	Using both gesture and words	2. Can speak by using words and can be understood by strangers.
	Using language for conveying	3.Can combine gestures and verbal communication to make self understood.
		4. Can express self by forming sentences.
		5. Can express feelings in the right manner at the right time.
		6. Can express self in meaningful conversations with 2 or 3 persons.
2. Social Behavior	Sitting in an acceptable manner	1. Can sit in an acceptable manner in a classroom situation.
	Greeting people	2. Can greet people of all ages in an appropriate manner.
	Helping people	3. Can offer help with appropriate [?], and is aware of being generally helpful.
	Behaving socially	4. Can behave in a socially acceptable manner without prompting.
	Interaction with people	5. Can ask the permission of the concerned persons when using their property. 6. Can maintain adequate distance with individuals while interacting.
	Taking care	7. Can take care of own property.
3. Self-Help skills	Aware of personal needs	1. Can anticipate and be aware of own needs and use the bathroom appropriately.
	Aware of personal hygiene	2. Can maintain personal hygiene – (Brush, Bath, Comb, Shave for boys, care of nails etc.).

Concept	Sub concept	Learning Outcome
	Aware of menstrual hygiene	3. For girls menstrual hygiene – Aware of particular exercises.
	Dress consciousness	4. Can dress unaided and maintain a neat appearance.
	Identification of washing clothes	6. Can identify clothes that need to be washed and wash clothes.
	Folding of clothes	7. Can fold dried clothes.
	Repairing of	8. Can identify clothes that need repair /
4. Function		
a. Reading Skills:	Reading name	1. Can read own name.
	Reading address	2. Can read own address.
	Reading and recognize survival words	3. Can read and recognize survival words and symbols for independent functioning, e.g. fire, electricity or power, hot, medicines, etc.
	Recognition of alphabets	4. Can recognize alphabets.
	Reading of simple sentences	5. Can read simple sentences.
b. Writing Skills	Writing legibly	6. Can write own name legibly.
	Writing addresses	7. Can write addresses.
	Writing all alphabets	8. Can write all the alphabets.
	Signature	9. Can sign own name.
c. Number Skills	Counting of numbers up to 10	10.Can count meaningfully up to 10.
		11. Can count up to 100.
	Recognition of numbers and writing numbers up to 100	12. Can recognize the numerals and write up to 100.
	Simple addition with single digit number	13. Can do simple addition with single-digit numbers.

Concept	Sub concept	Learning Outcome
	Addition with double digit number	14. Can do addition with double-digit numbers.
	Use of addition daily	15. Can make use of addition in everyday situations.
	Subtraction with single digit.	16. Can do simple subtraction with single-digit numbers.
	Subtraction with double digit	17. Can do simple subtraction with double- digit numbers.
	Use of subtraction daily	18. Can make use of subtraction in everyday situation.
d. Money.	Use of coins	19. Can identify coins of all denominations.
	Identification of coins	20.Can identify coins of all denominations.
	Identification of rupees up to 100	21. Can identify rupee notes up to 100.
	Exchange of coins	22. Can exchange coins in various combinations for 1 Rupee
	Exchange of coins and notes	23. Can exchange coins and notes in various combinations up to 5 Rupees.
	Exchange of money in various combinations	24. Can exchange coins and notes in various combinations up to 10 Rupees.
	Making purchases	25. Can make purchases and offer appropriate coins or notes up to 1 Rupee.
	Purchasing and getting balance amount	26. Can make purchases and get the balance for 1 Rupee.
		27. Can make purchases and get the balance up to 5 Rupees.
		28. Can make purchases and get the balance up to 10 Rupees.
e. Time:	Associating morning, evening etc. with events	29. Can answer correctly by associating morning, evening, afternoon, night with events in a day.
	Reading of calendar	30. Can read a calendar meaningfully.

Concept	Sub concept	Learning Outcome
	Observation of time.	31. Can say time by hours.
	Association of time with routine work.	32. Can associate time with the routine of a day.
f. Color:	Identification of primary secondary colors	33. Can identify primary and secondary colors.
	Matching of colors	34. Can match primary and secondary colors.
	Naming of colors	35. Can name primary and secondary colors.
	Use of colors in variety of situations	36. Can use colors in a variety of situations.
5. Domestic Skills	Making ready for lunch and dinner	1. Can set the place with cups and mats for lunch/ dinner.
	Washing	2. Can wash utensils.
	Sweeping and swabbing	3. Can sweep and swab the floor.
	Preparation of soft drinks	4. Can prepare soft drinks.
	Preparation of hot drinks	5. Can prepare hot drinks.
	Preparation of list for grocery	6. Can prepare a list of things necessary for cooking and buy them.
	Cooking	7. Can cook food without help or prompting.
	Making of Bed	8. Can spread own bed without help.
	Keeping things in order and doing simple work.	9. Can keep things in order and carry out simple work at home.
6. Vocational Skills	Understanding and remembering work assigned.	1. Can understand and remember instructions given at work and carry out accordingly without prompts.

Concept	Sub concept	Learning Outcome
	Matching and discriminating of objects while working.	2. Can match and discriminate objects when necessary in a work situation.
	Use of tools	3. Can use the tools that are necessary in a particular vocation.
	Coordination	4. Has the coordination to perform a given task.
	Attending to the work without disturbing others	5. Is able to attend to the assigned task for one hour without disturbing others.
	Aware of daily routine	6. Is aware of own daily routine at work place.
	Importance of speed at work	7. Can understand the importance of speed at work and carry out duties accordingly.
	Communication between office and home	8. Can commute between his workplace and home independently.
	Maintaining quality	9. Can maintain quality of work.
	Safety measures	10. Can safeguard self from machines, tools and other equipment in a work situation.
	Regarding rules and regulations	11. Can adhere to rules and regulations in a work situation.
7. Safety Skills	Aware of danger and avoiding danger	1. Is aware of dangers in his environment and avoids them.
	Understanding danger of fire.	2. Can understand the danger of fire.
	Aware of potential danger	3. Is aware of the potential danger while he is on the street and avoids it.
	Staying away from poisonous substance	4, Can stay away from poisonous substances.

1.3.2. COMMON GUIDELINES TO FOLLOW

COMMON GUIDELINES TO FOLLOW

(*) The person has to be given guidance in a graded manner in the following manner:

a) Demonstrate the activity to the person,

b) At first the person is physically guided to perform the task,

c) Then he/she has to be guided with gestured prompting,

d) If necessary, give physical help.

1.3.2.1. Communication

1. COMMUNICATION

COMMUNICATION-1

Age: 12 + **Activity: Communicates using gestures as an adjunct to verbal communication**

What to do

1. Play a game using directions, i.e. rolling ball, marching, pointing, raising arms, etc.
2. Play obedience games (sit down, stand up, come here and give me). Show the person how to do the activity, giving physical help if necessary.
3. Combine gestures with verbal directions, for instance, pointing to a chair and saying, "sit down". Praise the person when he follows the direction. Gradually reduce the number of gestures given and continue to praise success.
4. Ask the person if he is able to carry out these simple directions in structured situations and begin to give him similar directions involving his daily activities. For example, "get your shoes". Initially, you may have to take the person and help him get the shoes. As you continue making the request over several days, allow the person time to initiate and carry out the activity before helping him. Praise him for completing the activity when he does.
5. Choose a set of 5 to 6 directions and only use these commands with him at first. As he becomes with these add one or two new ones. [?]

COMMUNICATION-2

Age: 12 +
Activity: Speaks by using words and can be understood by strangers

What to do

1. After carrying out an activity with the person (going to store, swimming, etc.) have person tell you or another person what he did. Initially provide him with cues if necessary.
2. Begin by having the person tell you about immediate experiences. Gradually delay having him tell you what he did.
3. Establish a special time (before dinner, etc.) when person can tell experiences to the other parent when he/she arrives home.
4. Initially accept a short description of major events. Aid the person with cues to give more details. Gradually withdraw cues as the person gives details spontaneously.

COMMUNICATION-3

Age: 12 +
Activity: Combines gestures and verbal communication to make himself understood

What to do

1. Choose an activity that the person enjoys, like playing ball. If the person says ball, you say, "who wants the ball?' Point to the person and say ball. Wait for person to point to himself and say ball before you throw the ball to him. If he does not to do this take his finger and point it toward him and you say ball. Then throw it to him. After he knows what is expected just wait for him to say it and point before throwing or model again.
2. Use the same procedure while playing with bubble blow. Require a word and a gesture from the person before letting him blows the bubbles.
3. Use small manipulative toys like a playhouse. Set up the house, but keep the people, furniture, etc. Place one or two items in the house. Let the person see that you have more. If he puts out his hand ask, "what do you want?' Model the name of an item if he cannot name it and encourage him to either say his name or me or point to the object or let him point to himself or you and name the object. He could also name the item and point to where he wanted it or point to the item and name where he wanted it.
4. When the person understands what is required of him, gradually require him to do the same thing to have his daily needs met. Going outside, getting a biscuit, a drink, or a favorite toy should be withheld until he lets you know what he wants by combining a word and a gesture. Start out with 3 to 4 specific situations and add new ones as he becomes proficient with them.

COMMUNICATION-4

Age: 12 +
Activity: Expresses himself by forming sentences

What to do

1. **Listen to the person talking. When you hear where he could have used a conjunction (such as "and" or "so") or an adverb, repeat the sentence with the conjunction or adverb inserted. E.g.: We went to the store and we bought candy.**
2. **Talk and explain events to the person using compound sentences.**
3. **Ask person to tell you two things he did at the---------.**

COMMUNICATION-5

Age: 12 +
Activity: Expresses his feelings in the right manner at the right time

What to do

1. **Have the person name the food before it is placed on his plate.**
2. **Say the name of the food; "This is-----------." Ask, "What is this?" "That's right, you can eat ---------------."**
3. **Find and cut out pictures of familiar foods from magazines for the person to name; let him match these food pictures to the food he is eating.**
4. **When the person indicates he wants a snack, hold the item out to him and name it for him. The person should at least approximate the word before giving it to him.**
5. **At meal times serve the person very small portions so he will have to ask for more. Initially model the food name for him and have him repeat. As he becomes proficient at this level begin to require him to say the name before you give him the food item.**

COMMUNICATION-6

Age: 12 + Activity: Engages himself in meaningful conversation with 2 or 3 persons
What to do 1. Ask two or three persons to talk about their daily routines. 2. Ask the person to wait for he turn to speak. 3. Encourage expressing daily routines such as "get up at 6 AM" and "I had bath at 9 AM" etc.

1.3.2.2. Social Behavior

[2.] SOCIAL BEHAVIOR

SOCIAL BEHAVIOR- 1

Age: 12 + Activity: In a classroom situation he sits in a acceptable manner
What to do 1. Explain how to sit without touching others hands, feet & belongings etc. 2. Explain how to sit decently. 3. Explain how to keep shoes, books, bags, lunch box, etc. in the correct place.

SOCIAL BEHAVIOR- 2

Age: 12 + Activity: Greets people of all ages in an appropriate manner
What to do 1. Role-play, pretend father is coming home and let the person pretend to be father and then himself. 2. Use puppets and cutouts to act out situations in which the person greets people. 3. Model the activity and have person imitate you and you are greeting people. 4. When you know that a person familiar to the person will be arriving, inform the person. If a familiar adult is at the door inform the person as you go to give him an opportunity to greet him/her.

SOCIAL BEHAVIOR-3

Age: 12 +
Activity: Offers help when appropriate and is aware of being generally helpful

What to do

1. If friend is hurt, suggest ways person can comfort, such as to go get a Band-Aid, help him wash with soap and water, give him a hug, bring him a toy, etc.
2. Read the person a book in which situation arises where someone needs help. Ask the person what he would do if he were there. If person suggests something, praise him! Give him more appropriate suggestions if necessary.
3. Let him role play using dolls and comforting them

SOCIAL BEHAVIOR-4

Age: 12 +
Activity: Behaves in a socially acceptable manner without prompting

What to do

1. Explain that some things are best done in private such as picking his nose, scratching, belching, etc. Remind quietly when necessary.
2. If person does something unacceptable intentionally or for attention in public, ignore him, remove the person from the situation or hold person firmly and remain silent. Have no eye contact with person until the behavior stops. Then give the person another opportunity to behave appropriately.
3. Be a good model for the person.

SOCIAL BEHAVIOR-5

Age: 12 +
Activity: To use others property ask the permission of the concerned person

What to do
1. Do not allow person to keep others' belongings without asking.
2. Other family members should ask the person's permission to use his possessions, and adults and brothers and sisters should ask each other.
3. Knock on his door before entering.
4. Tell him "this is mine" and he must ask to use or play with object.

SOCIAL BEHAVIOR - 6

Age: 12 +
Activity: Maintains adequate distance with individuals while interacting

What to do
1. Explain to her to maintain a respectable distance while talking to others.
2. Reward to correct behavior

SOCIAL BEHAVIOR-7

Age: 12 +
Activity: Takes care of his own belongings

What to do
1. Keep his/her clothes clean.
2. Keep his/her shoes in the correct place.
3. Keep his/her books bags in its correct place etc without reminder.

1.3.2.3. Self-Help Skills

[3.] SELF-HELP SKILLS

SELF-HELP SKILLS –1

Age: 12 +
Activity: Anticipates and is aware of own needs and uses the bathroom appropriately

What to do

1. Dress the person in waist pants for easy removal. Keep the person in training pants.
2. Gradually stop placing person on toilet regularly, allowing him to begin to tell you when he needs to use the bathroom. If a toilet is being used, be sure to provide him with stool or steps so he can get on by himself.
3. If person is playing outdoors, watch carefully for signs of need and ask him at regular times if he has to use the bathroom.
4. Use reminders, praise and rewards for telling you that he has to go; i.e., keep wall chart and mark a happy face when he tells you he has to go and then does.
5. When you take person to an unfamiliar place make sure to tell him where the bathroom is or to let him know that one is available so accidents can be avoided.

SELF-HELP SKILLS-2

Age: 12 +
Activity: Maintains personal hygiene (Brushing, bathing, combing, shaving for boys, care of nails)

What to do

1. Wash your hands and face and encourage the person to imitate your movements.
2. Give verbal directions as person washes hands and face until he no longer needs verbal help. Praise person for washing hands and face without verbal or physical help.
3. Let person look in mirror. Put a colored chalk mark on face and let him see if he can wash it off.
4. Put stopper in sink. Fill sink with water for the person. Let him wash his hands and face independently and drain the water. Put chart in bathroom where he can record that he has done so. Put pictures on wall of the steps he is to follow so won't require as much supervision.

SELF-HELP SKILLS-3

Age: 12 +
Activity: For girls, menstrual hygiene - Aware of particular exercises

What to do

1. Explain how to know when she is menstruating.
2. Explain how to use pads.
3. Explain how and when to change pads.
4. Explain how to prevent accidental stains.

SELF-HELP SKILLS-4

Age: 12 +
Activity: Dresses unaided and maintains a neat appearance

What to do

1. Begin with a short-sleeved shirt. Use garment one or 2 sizes too big.
2. Have person put one arm into coat; reach behind with other arm and place arm into second armhole. Hold coat for him initially. Gradually decrease aid.
3. Place coat on low table with collar towards person and the opening facing up. Have him place his arms in the sleeves and flip coat over his head.
4. Put shirt over head, continue holding it while he puts in his arms and pulls the shirt down.
5. Place his coat on floor, neckline facing the person. He bends, places arms in holes and flips coat overhead. Praise the person, as he is able to do more without help. Encourage person to dress without help. Praise success. Describe how fasteners work as they are fastened. Encourage the person to try fasteners.
6. Puts small treats for person in things that can be unfastened (purse, snap pockets, etc.).
7. Even if it takes more time for the person to dress himself, allow him to do it. Let him know that you expect this of him. Plan your schedule to allow for the extra time this may take in the morning so that you don't have to do it for him because of lack of time.

SELF-HELP SKILLS-5

Age: 12 +
Activity: Is aware of acceptable eating habits and display in situations

What to do

1. Have person eat his/her meals with the family. Set a place for him with a spoon, plate and tumbler.
2. Encourage eating by him/herself. Give him more attention for eating by himself than for not doing so. If he doesn't eat by himself, verbally instruct him to do so and physically guide him.
3. Put chart by table. Put smiling face or animal sticker on chart for each meal that he eats all by himself.
4. Give person a small helping of each food.
5. Put a treat (sticker or picture) under the person's plate he can have if entire meal is eaten.

SELF HELP SKILLS-6

Age: 12 +
Activity: Identifies clothes which need to be washed and washes clothes

What to do

1. Explain that after a bath, cloths should be washed.
2. Explain to soak, scrub and rinse and dry cloth.
3. Explain how to bring the dried cloth and to fold.

SELF-HELP SKILLS-7

Age: 12 +
Activity: Folds dried clothes

What to do
1. Explain how to dry cloth. 2. Draw lines using a chalk piece to assist in folding cloths. 3. Show the correct place to keep the folded cloth. 4. Reward correct response.

SELF-HELP SKILLS-8

Age: 12 + Activity: Identifies clothes that needs repair/repairs them
What to do 1. Check for miner, buttons, hook etc. 2. Check for tears, holes. 3. Can use needle, thread to repair

1.3.2.4. Functional Academics

[4.] FUNCTIONAL ACADEMICS

[*reading skills 1, 2 and 5 have same instructions]

FUNCTIONAL ACADEMICS: READING SKILLS-1

Age: 12 + **Activity: Reads his name**
What to do 1. Begin with only two or three words. Put the printed word by a picture of the item. Then cover the picture and let person "peek" at the picture only if he can't tell you the word. As person learns the words add new ones. 2. Use the names of colors. Initially write the name of the color in that color. After person has practiced this have him match the colored word to the word written in black. Then present the person with only the word written in black. Let him look at the colored word to find out what the word is if he can't tell you. 3. Begin with words that are important to him and print 3 times on strips of lined tag board such as Amma, amma, and amma, Appa, appa, appa. Also use his own name. Gradually add new words such as can, run, and. Print sentences on the strips such as Mom can run. Mom and Dad can run. Staple strips together in book form. Let person read his book to parents, siblings and grandparents. 4. Help person recognize familiar printed words that are usually seen on a sign or with certain colors, such as STOP, or name of his favorite cereal. Then show him what the word looks like printed in regular letters; and see if he can recognize it.

FUNCTIONAL ACADEMICS: READING SKILLS-2

Age: 12 +
Activity: Reads his address

What to do

1. Begin with only two or three words. Put the printed word by a picture of the item. Then cover the picture and let person "peek" at the picture only if he can't tell you the word. As person learns the words add new ones.
2. Use the names of colors. Initially write the name of the color in that color. After person has practiced this have him match the colored word to the word written in black. Then present the person with only the word written in black. Let him look at the colored word to find out what the word is if he can't tell you.
3. Begin with words that are important to him and print 3 times on strips of lined tag board such as Mom, mom, and mom, Dad, dad, dad. Also use his own name. Gradually add new words such as can, run, and. Print sentences on the strips such as Mom can run. Mom and Dad can run. Staple strips together in book form. Let person read his book to parents, siblings and grandparents.
4. Help person recognize familiar printed words that are usually seen on a sign or with certain colors, such as STOP, or name of his favorite cereal. Then show him what the word looks like printed in regular letters; and see if he can recognize it.

FUNCTIONAL ACADEMICS: READING SKILLS-3

Age: 12 +
Activity: Reads and recognizes survival words and symbols for independent functioning. E.g. fire, electricity or power, hot medicines etc

What to do

1. Take him to public place and explain about the words and symbol.
2. Help him to follow the symbol and directions with help.

FUNCTIONAL ACADEMICS: READING SKILLS-4

Age: 12 +
Activity: Recognizes alphabets

What to do

1. Encourage the child to make correct sound for specific alphabet
2. Help the child to pair the sound and the alphabet.
3. Teach 3 to 5 alphabet and help the child to associate word, object and sounds.
4. Encourage him to identify sounds in words and associate sounds with the alphabet.

FUNCTIONAL ACADEMICS: READING SKILLS-5

Age: 12 +
Activity: Reads simple sentences

What to do

1. Begin with only 2 or 3 words. Put the printed word by a picture of the item. Then cover the picture and let person "peek" at the picture only if he can't tell you the word. As person learns the words add new ones.
2. Use the names of colors. Initially write the name of the color in that color. After person has practiced this have him match the colored word to the word written in black. Then present the person with only the word written in black. Let him look at the colored word to find out what the word is if he can't tell you.
3. Begin with words that are important to him and print 3 times on strips of lined tag board such as Mom, mom, and mom, Dad, dad, dad. Also use his own name> Gradually add new words such as can, run, and. Print sentences on the strips such as Mom can run. Mom and Dad can run. Staple strips together in book form. Let person read his book to parents, siblings and grandparents.
4. Help person recognize familiar printed words that are usually seen on a sign or with certain colors, such as STOP, or name of his favorite cereal. Then show him what the word looks like printed in regular letters; and see if he can recognize it.

FUNCTIONAL ACADEMICS: WRITING SKILLS-6

Age: 12 +
Activity: Writes own name

What to do

1. Show how to write name.
2. Give prompting by drawing dots and ask to join.
3. Gradually make few dots.

FUNCTIONAL ACADEMICS: WRITING SKILLS-7

Age: 12 +
Activity: Writes address

What to do

1. Show how to write address.
2. Give prompting by drawing dots and ask to join.
3. Gradually make few dots.

FUNCTIONAL ACADEMICS: WRITING SKILLS-8

Age: 12 +
Activity: Writes all the alphabets

What to do

1. Show how to write name.
2. Give prompting by drawing dots and ask to join.
3. Gradually reduce the help by drawing few dots.

FUNCTIONAL ACADEMICS: WRITING SKILLS-9

Age: 12 +

Activity: Signs own name

What to do

1. Show how to write name.
2. Give prompting by drawing dots and ask to join.
3. Gradually make few dots.

FUNCTIONAL ACADEMICS: NUMBER SKILLS-10

Age: 12 +
Activity: Counts meaningfully up to 10

What to do

1. Count to 3 frequently during day as activities are happening, i.e. count dishes as you wash or dry them, count towels as you fold them, count letters that come in the mail. Encourage person to imitate saying one, two, and three.
2. Have person imitate one, two and add numbers one at a time after person masters imitation task.
3. Place 3 objects in front of person and point to each one as you count to three. Ask him to repeat after you—pointing and counting.
4. March with person counting to three. Ask him to count along with you.

FUNCTIONAL ACADEMICS: NUMBER SKILLS-11

Age: 12 +
Activity: Counts up to 100

What to do

1. Can count quantities and arrange in 1 to 10 ascending order.
2. Can count 10, 20, up to 90 and arrange cards in ascending order.
3. Encourage him to give on command 10s and units.
4. Train the child to express the names for different combinations of units and tens (10+5 is also known as 15, 9 + 5 is also known as 14).

FUNCTIONAL ACADEMICS: NUMBER SKILLS-12

Age: 12 + **Activity: Recognizes the numerals and writes up to 100**
What to do 1. Present number cards 1-10. Ask person to find cards and name numeral on each card. 2. Cut thick sponge into cubes. Write numerals 1-10 on sponge. Toss in air as die and name numerals. 3. Use numerals cut from sandpaper or cards with raised numerals. Have person trace numerals with finger as he names them. 4. Use cards with indented numerals or templates. Have person follow outline with pencil as he names them.

FUNCTIONAL ACADEMICS: NUMBER SKILLS-13

Age: 12 + **Activity: Does simple addition with single-digit numbers**
What to do **1. Help the person to add single digits using beads or seeds (1+1+1=3 and so on).**

FUNCTIONAL ACADEMICS: NUMBER SKILLS-14

Age: 12 + **Activity: Does simple addition with double-digit numbers**
What to do **1. Help him to add double digit in simple way (e.g. 10+1=11, 10+2=12, 5+5=10, etc.)**

FUNCTIONAL ACADEMICS: NUMBER SKILLS-15

Age: 12+
Activity: To enable the person to make use of addition in everyday situations

What to do

1. Ask the person to bring two or more things, e.g. two glasses and three plates. Then ask the person to bring one more glass and one plate. Let the person ask you totally how many glasses and plates are there. In case she/he finds the task difficult, guide him/her by counting the items.
2. The task may be repeated with different items in different situations till he/she has learnt the skill. Appreciate the task is completed successfully.

FUNCTIONAL ACADEMICS: NUMBER SKILLS-16

Age: 12+
Activity: To enable the person to do simple subtraction with single digit numbers

What to do

1. Ask the person to bring three coconuts/ tomatoes/ bananas from room/kitchen. Tell him/her to give one to mother for cooking and keep the other one in front of deity for pooja. Let the person tell you the number of coconuts remaining. Guide the person for doing the activity.
2. The activity may be repeated with other items and different numbers. Reinforce when the person does the activity independently.

FUNCTIONAL ACADEMICS: NUMBER SKILLS-17

Age: 12+
Activity: To enable the person to do simple subtraction with double digit numbers

What to do

1. Let the person to make a heap of 25 tamarind seeds. Tell him/her to give you 12 seeds from the heap. Then let him/her tell you the remaining seeds. The person should write the remainder.
2. Guide the person in the activity till he/she can do the same independently. Reinforce when he/she has performed the activity independently.

FUNCTIONAL ACADEMICS: NUMBER SKILLS-18

Age: 12+
Activity: To enable the person to make use of subtraction in everyday situations

What to do

1. Ask the person to bring 15 bananas. Tell him/her to distribute the bananas 2 per person to 6 persons. Let them say the remaining number of bananas.
2. The exercise may be repeated with different items and different numbers until the person can do the task independently.

FUNCTIONAL ACADEMICS: MONEY – 19 & 20

Age: 12+
Activity: To enable the person to identify coins of different denominations and use them

What to do

1. Give the person coins of different denominations that are in currency.
2. Ask the person to separate and group the coins according to their value. Let the person say and write the value of the coins. Ex. 5 paise, 10 paise, 20 paise, 25 paise, 50 paise, 1 Re, 2 Re coins, 5 Re. Coins etc.
3. Let the person count the number of coins in every group and write down the number of coins. For example, if there are 10 coins in 10 paise group, let him/her write 10.

FUNCTIONAL ACADEMICS: MONEY – 21

Age: 12+ **Activity: To enable the person to identify1 rupee notes up to 100**
What to do 1. Help the person to pair the currency notes of the following denomination 1 re [?], 2 Re, Rs.5, Rs.10 2. Present the value of each note. 3. Ask the person to identify the correct currency. 4. Next give the person notes in a random order and ask him/her to tell you the value. 5. Then introduce the person to notes of denominations. Rs.20, Rs.50, Rs.100 Repeat the above mentioned.

FUNCTIONAL ACADEMICS: MONEY – 22

Age: 12+ **Activity: To enable the person to exchange coins in various combinations for 1 Rupee**
What to do 1. Give the person coins of different denominations, which are in currency. Ex. 10 coins of 10 paise, 5 coins of 20 paise, 4 coins of 25 paise, 2 coins of 50 paise 2. Demonstrate to the person that 10 coins of 10 paise, 5 coins of 20 paise, 4 coins of 25 paise, 2 coins of 50 paise make 1 Rupee. 3. Next ask the person to give you 1 rupee worth of 25 paise coins, 50 paise coins etc. The exercise may be repeated for different denominations. 4. Repeat the exercise till the person is able to perform the task independently. Reinforce when he/performs the task.

FUNCTIONAL ACADEMICS: MONEY – 22

Age: 12+ **Activity: To enable the person to exchange coins and notes in various combinations upto 5 Rupees**

Methodology:

1. Say the person that 50 coins of 10 paise, 20 coins of 25 paise, 10 coins of 50 paise make 5 rupees.
2. Demonstrate that 5 one rupee notes make Rs.5, 2 two rupee notes and 1 one-rupee note make Rs. 5.
3. Give the person coins and notes. Ask him to give you Rs.5 in various combinations of coins and notes. Repeat the task till the person does independently.

FUNCTIONAL ACADEMICS: MONEY – 24

Age: 12+

Activity: To enable the person to exchange coins and notes in various combinations up to 10 Rs.

Methodology:

1. Give coins and notes of various denominations.
2. Ex.20 coins of 50 paise, 10 coins of one-rupee coins, 20 coins of 50 paise make 10 rupees.
3. Demonstrate that 10 one rupee notes make Rs.10, 2 five rupee notes make Rs.10 etc.
4. Present the person with different coins and notes. Ask him to give you Rs.10 in various combinations of coins and notes. Repeat the task till the person does independently.

FUNCTIONAL ACADEMICS: MONEY – 25

Age: 12+

Activity: To enable the person to make purchases and offer appropriate coins or notes upto 1 Rupee

Methodology:

1. Give the person coins of different denominations upto 1 rupee
2. Show the child a 50 paise coin. Teach the person to buy biscuit for 50 paise and ask him/her to give 50 paise coin to the shopkeeper.
3. Ask the person to buy bananas for 80 paise and give the shopkeeper the appropriate coins i.e. one 50 paise coins and 3 ten paise coins or 4 twenty paise coins etc.

(The person should be asked to buy different items for different values and offer appropriate coins. The person should be guided till he/she is able to perform the task independently. When the task is performed correctly, reward the correct response.)

FUNCTIONAL ACADEMICS: MONEY – 26

Age: 12+
Activity: To enable the person to make purchases and get the balance for 1 Rupee

Methodology:

1. Teach the person to buy biscuit/banana for 50 paise and obtaining the remaining change.
2. Tell the person to buy bananas for 80 paise and obtain the change of 20 paise

(The person should be asked to buy different items for different values and obtain change. The person should be guided till he/she is able to perform the task independently. When the task is performed correctly, reward the correct response.)

FUNCTIONAL ACADEMICS: MONEY – 27

Age: 12+
Activity: To enable the person to make purchases and get the balance up to 5 Rupees

Methodology:

1. Give Rs.5 and ask the person to buy chilies for Rs. 3 and obtain the change.
2. Ask the person to purchase a pencil for Rs4 and bring back the change.
3. In this way ask the person to make different purchases of different values and obtain appropriate change.

FUNCTIONAL ACADEMICS: MONEY – 28

Age: 12+
Activity: To enable the person to make purchases and get the balance up to 10 Rupees

Methodology:

1. Give the person coins and notes totaling Rs.10
2. Guide the person in buying pencil and rubber for Rs.7 and obtain

the change.

3. Ask the person to purchase a pen for Rs6 and bring back the change.
4. In this way ask the person to make different purchases of different values and obtain appropriate change.

FUNCTIONAL ACADEMICS: TIME - 29

Age: 12+ Activity: To enable the person to answer correctly by associating morning, evening, afternoon, night with events in a day
Methodology: 1. Show the person that sun rises and 2. Sun shines during the daytime. When we get up after the sleep in the night it is known as morning time. When you see the watch during morning time 5 to 12 noon. After 13 up to 4 P.M. it is known as afternoon after 4 to 7 P.M. it is known as evening. In the evening we see lesser and lesser sunlight and sky becomes darker and darker. After 8'oclock the sky becomes pitch dark and is known as night. 3. Ask the person to tell you as when the above events occur. Guide the person till he/she is able to associate the natural events with the time of the day.

FUNCTIONAL ACADEMICS: TIME - 30

Age: 12+ **Activity: To enable the person to read a calendar meaningfully**
Methodology: 1. Guide the person to tell the day of a certain date ex. Let the person tell you what day of the week 15 the august 2002 etc. 2. Similarly let the person tell the day and date of different festivals of India. 3. Ask the person to tell you the day and date of Republic Day, Independence Day, Gandhi Jayanthi etc. Guide the person till he/she is able to perform the task independently. Reinforce when the person performs the task.

FUNCTIONAL ACADEMICS: TIME - 31

Age: 12+ Activity: To enable the person to say time by hours

Methodology:

1. Begin by telling the person that the big hand in the clock shows minutes, the small hand shows the hour. The person should be told that when the big hand is on 12 and the small hand is on any other number ex. 2 then tell the person that it is 2 'O' Clock. In this way, explain the person that when the small hand is at 5 and the big hand is on 12, it is 5 'O' Clock.
2. Let the person tell you the time whenever he/she is asked. Teach the person till he/she is able to tell the time independently.

FUNCTIONAL ACADEMICS: TIME – 32

Age: 12+

Activity: To enable the person to associate time with the routine of the day

Methodology:

1. Begin by telling the person that you should brush your teeth in the morning as soon as you get up, people offer worship after having bath in the morning.
2. Tell him/her that we have lunch in the afternoon.
3. Persons who have gone to offices, schools return home in the evening.
4. We have dinner in the night.
5. The person is told the above facts repeatedly till he/she is able to associate the time of the day with the routine.

FUNCTIONAL ACADEMICS: COLOUR – 33

Age: 12+

Activity: To enable the person to identify primary and secondary colors

Methodology:

1. Begin by taking materials of the same quality but different colors in order to introduce the color concept. Ex marbles colored red, green and blue
2. Then introduce the person to primary colors –red, yellow and blue ex. Red beads, yellow beads and the blue beads etc.
3. Keep a few things, which are colored yellow, red and blue in front of the person. Tell him to give you the red beads/paper, blue paper/beads etc. If he/she cannot identify, guide him/her.
4. When the person is able to identify the primary colors independently appreciate the correct response.
5. The person should be able to identify the primary colors in different objects.
6. Next introduce the person to secondary colors belonging to different shades of primary colors. After the person identifies all the primary and secondary colors introduce the person with tertiary colors (remember to use materials which has all its physical properties common only differing in color. This helps the person to focus only on colors).
7. Repeat the process so that the person can identify the colors independently and in different objects.

FUNCTIONAL ACADEMICS: COLOR - 34

Age: 12+

Activity: To enable the person to match primary and secondary colors

Methodology:

1. Begin by taking materials of the same type ex paper pasted on the card board of different colors
2. Help the person to match primary colors.
3. Help the person to match Secondary colors.
4. Help the person to match Tertiary colors.

FUNCTIONAL ACADEMICS: COLOR - 35

Age: 12+

Activity: To enable the person to name primary and secondary colors

Methodology: 1. Begin with introducing primary colors such as red, green, and blue. 2. The person should be able to identify and name primary colors in different objects. 3. Introduce the person to secondary colors Repeat the process so that the person can identify the secondary colors independently and in any situation. 4. Introduce tertiary colors in the same way. .

FUNCTIONAL ACADEMICS: COLOR - 36

Age: 12+ Activity: To enable the person to recognize and use colors.
Methodology: 1. Begin by drawing an outline of the picture of a leaf. Ask the person to color it with green color. 2. In the same way draw a picture of rose and ask the person to color it with red. 3. Draw a picture of landscape and ask the person to fill in the respective colors ex leaves with green, sky with blue, brown for branches of trees etc 4. Demonstrate to the person the art of drawing with rangoli and filling with colors. 5. Give the person a book with outline drawings and ask the person to fill with colors. 6. Let the person decorate a room with colored ribbons, balloons, papers etc. 7. The person should be guided till he/she is able to use colors in an effective manner. Reinforce for a job well done.

1.3.2.5. DOMESTIC SKILLS

5. DOMESTIC SKILLS

DOMESTIC SKILLS – 1

Age: 12+ Activity: To enable the person to set the place with plates, cups and mats for lunch/dinner
Methodology: 1. Begin by asking the person to clean the place first. Demonstrate. 2. Ask the person to place the mats, plates, and glasses at the place. 3. Guide the person until the person does the task independently and reinforce when the task is done successfully.

DOMESTIC SKILLS: 2

Age: 12+

Activity: To enable the person to wash utensils

Methodology:

1. Ask the person to place all the vessels to be washed at the washing place.
2. Guide the person in washing the vessels by washing one or two vessels with soap nut powder/ soap powder etc and then rinsing with water.
3. Guide the person to wipe the utensils with a clean cloth.
4. Then let the person do the task independently. When he/she does the task independently offer reinforcements.

DOMESTIC SKILLS: 3

Age: 12+

Activity: To enable the person to sweep and swab/mop the floor

Methodology:

1. Demonstrate the activity by sweeping and swabbing the floor of a room.
2. Let the person sweep a small portion of room gradually increase the area for sweeping.
3. Reinforce when the person does the job.

* Note: It helps if you sweep 90% portion of area and ask to sweep 10% of the area so that he get the satisfaction of completing the activity.

DOMESTIC SKILLS: 4

Age: 12+

Activity: To enable the person to prepare soft drinks/juices

Methodology:

1. Teach the person how to prepare lemon juice. Show him/her the ingredients to be used.
2. Tell him/her that sugar should be dissolved in pure water, then juice of lemon has to be added to prepare lemon juice.
3. Similarly show that juices can be prepared with different fruits.
4. Let the person prepare the drink independently. When he/she prepares a drink, appreciate by drinking a sip and say "tasty."

DOMESTIC SKILLS: 5

Age: 12+ Activity: To enable the person to prepare hot drinks.
Methodology: 1. Initially show the person how to prepare tea. Tell him/her that water has to be boiled first and then tea powder should be added. Tea decoction has to be strained using a strainer and milk and sugar should be added.(Teach them to use a pair of tongs to hold hot utensils also remember to show the use of measuring cups for measuring water , tea powder, sugar & milk). 2. Let the person prepare tea independently. When the person prepares tea independently, reinforce.

DOMESTIC SKILLS: 6

Age: 12+ Activity: To enable the person to prepare a list of things necessary for cooking and buys them.
Methodology: 1. Explain the person how to cook rice. 2. Ask the person to prepare a list of all those items for the preparation of rice. 3. Let him/her prepare a list of all the material available and make a list of the materials that has to be purchased. 4. Encourage him to go to shop and purchase the required material. 5. Ask the person to clean the one cup of rice and add three cups of water and place on the stove (Help the person to light the stove). Dip long spoon in the rice pot so that starch doesn't over flow. Show the person how to test whether rice is cooked by taking one spoon of rice. When rice is cooked strain the excess water using the strainer. 6. Teach the person to cook rice using pressure cooker, rice cooker etc. 7. Using the similar method teach the person to prepare chapathi, dal, etc.

DOMESTIC SKILLS: 7

Activity: To enable the person to cook food without help or prompt
Methodology: 1. First determine the dish to be prepared. 2. Then arrange all the items that are required and also the vessels needed. 3. Teach the person the method of preparing rice and sambar. First let the person learn to prepare rice. Guide him/her initially. Demonstrate the activity by cleaning the rice and keeping it in the cooker vessel with adequate amount of water. If cooker is not used, then teach him/her the method of cooking in an open vessel. 4. Next allow the person to cook without any help and you be an onlooker. Reinforce when he/she is able to cook rice. 5. Then demonstrate the method of cooking sambar. 6. Ask the person to prepare sambar himself/herself. When he/she does the job independently, reinforce.

DOMESTIC SKILLS: 8

Age: 12+ Activity: To enable the person to spread his bed without help
Methodology: 1. Begin by telling the person that the bed has to be dusted and cleaned - demonstrate the activity. 2. Then let the person spread a clean bed sheet on the bed and place a rug at one end of the bed.

DOMESTIC SKILLS: 9

Age: 12+ Activity: To enable the person to keep things in order and carry out simple work at home

Methodology:

Explain the person how to keep the vessels, food grains in the kitchen in order.

Let the person keep things such as clothes brush, soap in its place after use.

(Simple tasks such as folding dry clothes and keeping in the cupboard, cleaning the sink, to water the plants etc can be assigned to the person.)

1.3.2.6. VOCATIONAL SKILLS

6. VOCATIONAL SKILLS

VOCATIONAL SKILLS: 1

Age: 12+ Activity: To enable the person to understand and remember instructions given at work and carry out accordingly without prompts
Methodology: 1. Give 5 instructions to the person such as conveying a message, giving a file, answering telephone, cleaning the table, etc. Write down these instructions on a piece of paper, read out the instructions and explain the task and make sure the person understands all instructions and method of performing. After completion of each task ask the person to report to you. Give graded help if necessary. Reinforce correct response. 2. After completion of the first task successfully give the second task. Do not forget to explain the each task before starting of the task.

VOCATIONAL SKILLS: 2

Age: 12+ Activity: To enable the person to match and discriminate objects when necessary in a work situation
Methodology: 1. In a work situation, if the job is to send books, forms to different addresses, the person is taught to segregate them and send to the respective addresses. 2. When working in the fields, agricultural implements are arranged and provided at the time of need. 3. In the field of sericulture, the person is able to provide mulberry leaves, baskets, mesh etc needed for the job.

VOCATIONAL SKILLS: 3

Age: 12+ Activity: To enable the person to use the tools which are necessary in a particular vocation.
Methodology: 1. Different vocations use different tools. Let the person learn to use simple tools. 2. If the person is in the laundry business, demonstrate how the iron box is prepared for use, how the clothes are arranged for ironing etc. 3. If the person is working in an office with Xerox machines, computers etc., teach him/her how to take photocopies, how to make simple operations in the computer like taking a print out, sending e-mail messages etc. 4. If the person is working in the fields, the person should learn to use the agricultural implements required for cultivation, farming. 5. For each activity a) first the activity should be demonstrated b) the person should be guided physically in the beginning, c) then the person should perform under supervision, d) should perform under the guidance of peers e) the person should perform independently

VOCATIONAL SKILLS: 4

Age: 12+ Activity: To enable the person to have the coordination to perform a given task
Methodology: 1. The person should be taught to work in coordination with the others at the work place. Explain the task role and responsibility of each person by describing who will do what and when. He/she should complete the task assigned to him/her. 2. In a printing press his/her job may be to arrange the papers, applying gum etc. Guide the person to complete his/her task so that others may complete the whole job. 3. If the job is in the fields, the person should assist in the harvesting, to separate the grain from the chaff, etc.

VOCATIONAL SKILLS: 5

Age: 12+ Activity: To enable the person to attend to the assigned task for one hour without disturbing others.
Methodology: 1. Explain what is disturbance to others - such as talking loudly, interfering with job etc. 2. The person should be made to understand that while performing a task, he/she should not disturb others around at least for one hour. 3. The task may be threading flowers, making agarbathies, removing weeds from the fields etc

VOCATIONAL SKILLS: 6

Age: 12+ Activity: To attend to the assigned task for one hour without disturbing others.
Methodology: 1. Prepare a chart of all the daily activities a person needs to perform. Explain each task before starting. Give graded support whenever necessary. 2. The person should be able to perform the task without help. In order to achieve this withdraw support gradually.

VOCATIONAL SKILLS: 7

Age: 12+ Activity: To enable to understand the importance of speed at work and carryout duties accordingly.

Methodology:

1. The person should understand that speed and accuracy is of the utmost importance at the work place.
2. Ex. a) Letters should be dispatched without the delay to the addressees
   b) If the person is in tailoring business, sewing buttons, stitching borders etc
   c) If the person is in the laundry business, arranging the clothes, ironing the clothes, handing over the Clothes to the customers.

VOCATIONAL SKILLS - 8

Age: 12+

Activity: To enable the person to commute between his/her workplace and home independently

Methodology:

1. In the beginning, the person should be aware certain basic rules to be followed on the road.
2. The mode of commuting between workplace and home should be first determined i.e. by walk or by cycle or motorized two-wheeler. First he/she should be very familiar with the route to the office. If the person walks to and from the workplace, he/she should be careful while crossing roads and should cross only at the pedestrian crossings, he/she should walk on the footpath, should cross only when the green signal comes.
3. If the person uses vehicle, he/she should be apprised of all the rules of driving and road signs and then only should he/she be allowed to go by vehicle.
4. If the person uses public transport, he/she should be at the bus stand at the correct time; he/she should know where to alight and where to get down.

VOCATIONAL SKILLS - 9

Activity: To enable the person to maintain quality of work
Methodology: 1. Explain the meaning of quality work such as following instructions, completing the task in time, seeking help whenever necessary in order to complete the task to the satisfaction of the trainer/ supervisor. (E.g.1.If the job of the person in an office is to send and receive post, then it is important that correct addresses are written on the cover and stamped correctly. If it is receiving post, then the respective letters should be to the correct person at the office so that no letter is lost or goes to the wrong person. 2. If the job is preparing tea, coffee etc. then the quality of the drink must be good. 3. The task may be sewing buttons at the tailor's, washing and ironing clothes at the laundry – every task should be done diligently and with care.)

VOCATIONAL SKILLS - 10

Age: 12+ Activity: To enable the person to safeguard himself from machines, tools and other equipment in a work situation
Methodology: 1. If the person in using tools in the work situation he should be trained not only in using tools but also on safety measures in order to prevent hurting self, others and environment. 2. In order to help a person on safety measures use color strip bands and light indicators to maintain safe distance from the tools and handling the tools appropriately. Watching for danger signals Etc. (E.g.1.When the person Work is working on a power loom, she/he should be made aware of the dangers arising out of use of power. 2.When working in the fields, she/he should be aware of the dangers that may arise when using implements. When operating pump sets, care has to be exercised so that the person does not receive shocks.)

VOCATIONAL SKILLS - 11

Age: 12+ **Activity: To enable the person to adhere to rules and regulations in a work situation**
Methodology: 1. The person should be explained the office rules such as timings, signing the attendance register, etc. 2. The person should be trained to follows the rules and regulations of the organization in he/she works ex. in a library silence has to be maintained, time should not be wasted in offices, every task has to be done systematically and in a diligent manner.

1.3.2.7. SAFETY SKILLS

[7.] SAFETY SKILLS

SAFETY SKILLS: 1

Age: 12+ **Activity: To enable the person to be Aware of danger in his/her environment and avoid it.**
Methodology: 1. Hazards are many and can have many origins, ex. water, fire, electricity, vehicles, wild animals etc (Examples: a. Water: Tell the person about the dangers arising from water – lakes, river, well, sea etc. and teach him/her how to safeguard himself/herself. b. Fire: The person should be taught to be careful when he/she is lighting a fire in the hearth, using gas stove etc. He/she should be trained in the use of these gadgets. c. Electricity: switches, naked wires, machine tools/gadgets running on electricity are some of the areas in which the person has to be careful while operating.) 2.The person has to be trained intensively before he/she is allowed to use /work with hazardous materials and in hazardous conditions. * Color strips should pasted on the tools and the person should trained

not to touch the parts of the tools which could hurt, maintaining safe distance from the tool should be explained color strips must be used to maintain the distance).

SAFETY SKILLS: 2

Age: 12+
Activity: To enable the person to understand the danger of fire

Methodology:

1. Teach the person to exercise care when using gas stoves, while lighting a fire in the hearth etc. Demonstrate the activity first before allowing him/her to work.
2. While lighting a fire in the hearth using firewood, tell him/her the distance he/she should maintain from the hearth, the caution to be exercised while blowing etc
3. While using gas stove, teach him/her a) to examine the gas pipe to see if there are any leaks, b) the method of lighting and turning off.

* Use the same guide lines as given in card 1 under safety skills.

SAFETY SKILLS: 3

Age: 12+
Activity: To enable the person to be Aware of the potential danger while he/she is on the street and avoid it.

Methodology:

1. Apprise the person the dangers that may arise while he/she is on the street and the caution to be exercised. Some of the basic rules he/she should follow are:
   a) He/she should not walk in the center of the street/road
   b) He/she should not throw anything on the street in order to avoid accidents caused to vehicle users and pedestrians. c) he/she should drive/ride only on the left side of the street d) h/she should cross the road very carefully looking to the left and right and only at the pedestrian crossings. e) At busy intersections he/she should cross only when the green signal is on.

SAFETY SKILLS: 4

Age: 12+
Activity: To teach the person stay away from poisonous substances

Methodology:

1. Tell the person that chemicals used daily should be kept in a safe place ex. Phenyl, bleaching powder etc. The person should be taught the method of using these chemicals and the care that he/she should exercise.
2. The person should be apprised about the danger that may arise when using ingredients used in the kitchen such as baking soda, oils etc
3. The person should be made aware of the hazardous nature of the chemicals used in agriculture ex pesticides and weedicides etc.

1.4. Summary

To do the demonstrate the activity to the person, at first the person is physically guided to perform the task, then he/she has to be guided with gestured prompting, if necessary, give physical help.

5.5. Check Your Progress

True/False:

1. To teach the person stay away from poisonous substances [ ]
2. Do not enable the person to be Aware of danger in his/her environment and avoid it [ ]
3. Do not enable the person to safeguard himself from machines, tools and other equipment in a work situation [ ]
4. To enable the person to be Aware of the potential danger while he/she is on the street and avoid it [ ]
5. NGOs working in the area of disability, representatives of family or parent associations and experts and professionals [ ]

5.6. Assignment/Activity

To do survey near about your surroundings area on TALC.

5.7. Points For Discussion And Clarification

After going through this Unit you might like to have further discussion on some points and clarification on others

5.7.1. Points for discussion

5.7.2. Points to Clarification

5.8 References / Further Readings

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UNIT 5: DOCUMENTATION OF ASSESSMENT, RESULT INTERPRETATION & REPORT WRITING– IMPLICATION OF CLASS LEVEL ASSESSMENT & ITS RELATION TO INCLUSION WITH RESOURCE SUPPORT

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

- **Introduction**

In the last decade the professional knowledge concerning the problems of mental health among persons with intellectual disability has significantly grown. Behavioural and psychiatric disorders in these individuals can cause serious obstacles to their social integration Clinical experience and research show that the existing diagnostic systems of DSM-IV and ICD-10 are not fully compatible when making a psychiatric diagnosis in people with intellectual disability. This may be one of the reasons why the evidence-based knowledge on the assessment and diagnosis of mental health problems in people with intellectual disability is still scarce. This is the reason for the European Association for Mental Health in Mental Retardation (EAMHMR) supporting the current project to produce a series of Practice Guidelines for those working with people with intellectual disability to encourage and promote evidence-based practice. The first publication of the series is entitled Practice Guidelines for the Assessment and Diagnosis of Mental Health Problems in Adults with Intellectual Disability. This work was undertaken very skillfully by Dr Shoumitro Deb, Dr Tim Matthews, Dr Geraldine Holt and Professor Nick Bouras. Comments were received from an international panel of experts in the field of mental health and intellectual disability. On behalf of the Executive Committee of the EAMHMR I would like to thank all contributors. I believe that their hard work will influence the quality of care provided to people with intellectual disability and mental health problems and will further evidence-based practice and research. This document is the first in a series of practice guidelines that the European Association for Mental Health in Mental Retardation (EMHMR) wishes to develop. These guidelines are based on the current evidence on the subject, and consensus opinion from clinicians working in this field. Unlike the procedure used in the Health Evidence Bulletins Wales – Intellectual Disability (Hamilton-Kirkwood et al, 2001), we have not critically appraised the evidence in this document but used the following convention (Cochrane Library, 2001) to categorise the type of evidence: Most of the comments received from members of the expert consensus panel have been incorporated in the text. Because of lack of information we could not categorise all evidence according to the convention mentioned above. The list of evidence in this document is by no means an exhaustive one, and not all references listed are quoted in the text. Some references are taken from the Health Evidence Bulletins Wales – Intellectual Disability (Hamilton-Kirkwood et al, 2001) and some are crossreferences cited in other papers. This document is focused on the description of psychiatric illnesses that could affect adults with intellectual disability. The issues related to the diagnosis of psychiatric illness among children with intellectual disability are different, and therefore have not been covered in this document. Aspects of treatment, pervasive developmental disorders and behaviour problems are also not covered. These topics will be the subject of future guidelines. Recently, the American Journal of Mental Retardation (Aman et al, 2000) published consensus

guidelines for the diagnosis, assessment and treatment of mental illness in people with intellectual disability. These guidelines, however, do not describe in detail various symptoms that are associated with different psychiatric illnesses. In this document we have described various features of mental illnesses in adults with an intellectual disability in a descriptive fashion so that the readers find it easy to read and could use this as a reference point. Whilst the guidelines in this document are primarily intended to help psychiatrists and psychologists specialising in psychiatric diagnosis and treatment of adults who have intellectual disability, it is our hope that other professionals and carers working with adults with intellectual disability could also use this document as a point of reference. Hopefully, this will raise awareness about adults with intellectual disability who develop signs of psychiatric illness, and consequently promote referral to specialists for further assessment and treatment. The guidelines in this document should not be confused with diagnostic criteria such as DCR-10 (Diagnostic Criteria for Research-10th revision) (WHO, 1992); DSM-IV-TR (Diagnostic and Statistical Manual – 4th text revision) (American Psychiatric Association, 2000); or the recently published DC-LD (Diagnostic Criteria – Learning Disability) (Royal College of Psychiatrists, 2001). The latter has recently been developed as a specific tool for use in people with intellectual disability. Neither should these practice guidelines be confused with diagnostic instruments such as the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) (Moss et al, 1993). While this document makes reference to standardised classification systems – especially the International Classification of Diseases – 10th revision (ICD-10) (WHO, 1992) – it is clear that these systems are not always useful in intellectual disability. Some features might not always be apparent, or be difficult to elicit, making diagnosis difficult, particularly in those who have severe intellectual disability, and impaired communication. This document tries to describe clinical features of psychiatric illness, with especial reference to where these may differ from their presentation in the general, non-intellectually disabled population. Perhaps these guidelines might be useful in further development of the ICD system and particularly for developing a special ICD-11 for adult people with intellectual disability.

- **Objectives**

Intellectual disability, or 'mental retardation' as it is described in ICD-10 (WHO, 1992) and the Diagnostic and Statistical Manual – IVth revision text review (DSM-IV-TR) (APA, 2000) – is not a psychiatric illness, despite being part of the psychiatric classification system. The quoted prevalence of psychiatric illness

among adults with intellectual disability varies widely between 10% and 39% (Corbett, 1979; Jacobson, 1982; Eaton & Menolascino, 1982; Lund, 1985; Göstason, 1985; Inverson & Fox, 1989; Reiss, 1990; Borthwick-Duffy & Eyman, 1990; Bouras & Drummond, 1992; Hagnell et al, 1993; Borthwick-Duffy, 1994; Cooper, 1997; Roy et al, 1997; Deb et al, 2001a). This fourfold discrepancy in the quoted prevalence rate is caused by methodological difficulties, particularly in the areas of sampling error and case ascertainment. Up until recently, most prevalence studies of psychiatric illness among adults with intellectual disability included primarily people from institutions or from a clinic population, therefore causing sampling bias. Case ascertainment has also been a problem because of the difficulty of detecting adults with mild intellectual disability in the population. Many studies were based on case-notes scrutiny. Direct patient interviews were seldom used. Even where direct patient interviews were used, these often depended on screening instruments such as the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson et al, 1984), Reiss Scale (Sturmey et al, 1995), Mini-Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Mini-PAS-ADD) (Prosser et al, 1998), and PAS-ADD checklist (Moss et al, 1998), therefore increasing the chance of detecting a higher rate of psychiatric illness in the study population. Some studies, however, used direct patient interviews using instruments such as PAS-ADD (Moss et al, 1993) or Medical Research Council-Handicap and Behaviour Schedule (MRCHBS) (Wing, 1980) and made psychiatric diagnoses according to the DSM-III (APA, 1980) criteria. The difficulty of diagnosing psychiatric illness using these criteria in adults who have severe and profound intellectual disability is well known. Some authors included personality disorder, behavioural disorders, autism, attention deficit hyperactivity disorder (ADHD), Rett syndrome, dementia, and pica in their overall diagnosis of psychiatric illness. This caused wide discrepancy in the quoted prevalence rate. It appears that if diagnoses like behavioural disorder, personality disorders, autism, and ADHD are excluded, the overall rate of psychiatric illness in adults with intellectual disability does not differ significantly from that in the nonintellectually disabled general population, (Deb et al, 2001a). Compared with the general population, there seems to be a higher rate of schizophrenia among adults who have mild to moderate intellectual disability (Turner, 1989; Doody et al, 1998; Copper, 1997; Deb et al, 2001a). However, if behaviour disorders are included within psychiatric diagnoses, the rate of psychiatric illness seems significantly more prevalent among adults with intellectual disability compared with the general population (Meltzer et al, 1995; Deb et al, 2001b). Whether or not behavioural disorders are included in the overall diagnosis of psychiatric illness, behavioural problems are common causes for psychiatric referrals (Kohen, 1993; Deb, 2001a). Studies show controversial evidence as to whether or not psychiatric illness is more common among severely, compared with mildly, intellectually disabled adults. Göstason (1985) and Lund

(1985) both showed higher rates of psychiatric illness among more severely intellectually disabled adults, whereas, Inverson and Fox (1989), Jacobson (1982), and BorthwickDuffy and Eyman (1990) all showed a higher prevalence of psychiatric illness among adults with a milder degree of intellectual disability. Corbett (1979) found no relationship either way. The problem may lie in the fact that the authors used the same psychiatric diagnostic criteria for adults with all degrees of severity of intellectual disability, which may not be appropriate.

- **Definitions**

It is worth remembering that in diagnosing psychiatric illness, it is important to differentiate which symptoms could be part of such an illness, and which can be explained by the intellectual disability. Signs and symptoms (which are common in psychiatric illness) – such as social withdrawal, excessive agitation, lack of concentration, stereotyped movement disorders, abnormal sleep, and certain other behaviours – can be the expression of underlying brain damage rather than symptoms of an illness ('diagnostic overshadowing'; Reiss & Sysko, 1993). It is therefore important to establish a 'baseline' of what the subject was like, and look for any change from this. For example, a patient may have a longstanding history of difficulty getting to sleep. However, carers have noticed in recent months that she has also been waking more early than usual, which is a change from baseline, and could be a symptom of a psychiatric illness ('baseline exaggeration'; Sovner & Hurley, 1989).

- **Summary**

The assessment will detect most information when it is done in a systematic and comprehensive way. There may already be a lot of background information about the patient, from previous assessments and records. There are various standardised psychiatric histories. A brief outline of useful areas in the history is discussed below. It should be noted that this is not a comprehensive list. In the general population, making a psychiatric diagnosis depends primarily on the account given by the subject. Many psychiatric diagnoses rely on patients describing quite complicated internal, subjective feelings or cognitions (such as thought broadcasting, obsessions or derealisation etc). Whilst many subjects with a mild intellectual disability will be able to describe such phenomena, those with a more severe intellectual disability may either not have had such experiences or be able to adequately describe them. It is important at the outset to assess the subject's communicating abilities, hearing, vision, memory, and ability to concentrate, as

these will all affect their responses during Schizophrenia has a point prevalence in the general population of about 0.4% (Meltzer et al, 1995), and in the population with intellectual disability of about 3% (range between 1.3% and 3.7%) (Deb, 2001a). It is characterised by particular, fundamental distortions in thinking, perception, mood and behaviour. The course is variable, but in many individuals, the disorder follows a chronic relapsing and remitting course. First episodes of schizophrenia often, but not always, present with an acute picture, characterised by what are called 'positive' symptoms. These include hallucinations, delusions and thought disorder. In some individuals, the disorder will develop into a more chronic picture, characterised by apathy, lack of communication, social withdrawal, and blunted mood (negative Several authors (Reid, 1972; Royal College of Psychiatrists, 2001) have noted the difficulty in diagnosing schizophrenia in those with a moderate or more severe intellectual disability. The diagnosis is based upon the presence of a number of complex subjective symptoms (delusions, thought broadcasting etc), and thus a certain level of communicative ability is needed to describe such symptoms to an interviewer. This compares with the affective disorders, where theoretically, diagnosis is even possible in profound intellectual disability, due to observable behavioural elements of such disorders. The aetiology of schizophrenia in intellectual disability is probably similar to that of the general population, but the higher prevalence suggests that this population have an increased risk. Part of this may be through increased rates of obstetric complications (O'Dwyer, 1997) and genetic risk factors (Doody et al, 1998). Abnormal thought process Delusions are false, fixed, unshakeable beliefs, and held with conviction, despite evidence to the contrary. They are not in keeping with a person's social, religious and cultural background. Classically, delusions in schizophrenia are delusions of control (also known as passivity), where a person believes that some external force controls their body or mind. However, other types of delusions commonly occur, including persecutory and grandiose. ICD-10 states that where delusions of other than delusions of control are present, they must be 'culturally inappropriate and completely impossible' to make a diagnosis. Related to this, a delusional perception is where an ordinary perception suddenly leads to an abnormal belief that is totally unconnected, for example 'I saw a black cat run across the road, and that means that I am the King of Belgium'. In thought interference, patients believe that their thoughts are being 'tampered' with. This includes thought insertion (something or somebody directly putting thoughts into their head, and disrupting their train of thought), thought withdrawal (their own thoughts being taken out suddenly), and thought broadcasting (their own thoughts are apparent to others as soon as they think them, which may be via such mediums as the TV or radio). Thought disorder is manifested through disordered speech, due to an underlying disorganisation in the thought processes. In severe cases, speech can be totally incomprehensible, known as a 'word salad'. For example, 'This is my

cup door train went in going round can have to make'. Thought disorder may contain examples of neologisms (non-existent words), for example 'solix'. Delusions (or ideas) of reference are often seen as soft psychotic signs. Here, for example, a person thinks wrongly that his/her name has been mentioned in the media or newspaper. If a person with intellectual disability reports that his/her name has been mentioned in the media or in the newspaper it is worth checking that indeed that is not the case. If the subject says that people in the street look at them, this may be true (if the person has a specific disability or manifests abnormal behaviour). To elicit paranoid delusions the subject may be asked whether they feel someone is trying to harm them or plotting against them. It is however possible for an adult with intellectual disability to think that someone is trying to harm them if they do not get on with care staff or a relative or one of their peers. This is not a psychotic symptom. The same can apply to passivity phenomenon (delusion of control by others). In grandiose delusions the subject matter can be quite simple in the case of an adult with intellectual disability. For example, instead of thinking they can control the world they might think they can read a book (which is a false belief) ('psychosocial masking'). It is important to distinguish 'psychotic-like' symptoms from true 'psychotic' symptoms in adults with intellectual disability. Certain types of 'fantasy thinking' can be part of the symptomatology of autistic spectrum disorder. However, it is also important to recognise that adults who show autistic features may also show genuine psychotic symptoms.

- **Revision**

- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

Points for Clarification

- References / Further Readings

Block 4: Assessment at Adult and Vocational levels

Unit 1: Significance of Assessment for Independent living of PwIDs

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

- **Introduction**

As a worker in a drug and alcohol service, you're most likely to come into contact with people with borderline (IQ 70 to 80) or mild intellectual disability (IQ 55 to 70). About 85% of people who have an intellectual disability are classified as having a mild disability (IDRS 2011) and make up approximately 2% of the general population. Most people with borderline or mild intellectual disability are able to, with support, learn the many skills necessary to live in the community relatively independently (IDRS 2011).

People with moderate (IQ 40 to 55) and severe (IQ 25 to 40) levels of disability are less likely to present to drug and alcohol services due to their high support needs and their reliance on carers to support many daily functions.

The Diagnostic and Statistical Manual of Mental Disorders IV defines intellectual disability as consisting of three elements:

- *A person has an IQ below 70 (2 standard deviations below the mean)*
- *A person displays at least 2 deficits in adaptive functions (such as communication, self-care, home living, social/interpersonal skills, self-direction, functional academic skills, health and safety), and*
- *A person acquires the disability before 18 years of age.*

These criteria are used by Ageing Disability and Home Care (ADHC) to determine NSW government disability service eligibility for people with intellectual disability. As such, people with borderline intellectual disability are not eligible for ADHC services, but they face many of the same disadvantages and struggles as those who are eligible for services and support.

The medical or diagnostic definition of intellectual disability focuses on the deficits of a person and does not take account of the level of support available to a person in their environment. A social perspective considers intellectual disability to reflect the interaction between the capabilities of a person and the structure of their environment.

In drug and alcohol services, adjusting a person's environment and support can increase their capacity to participate in treatment and reduce the effect of intellectual disability (IDRS 2009).

- **Objectives**

Intellectual disability affects the way that a person learns. This includes:

- *The time taken to learn something*
- *The ability to read and write*
- *Communication and understanding*
- *The ability to plan and solve problems*
- *The ability to adapt to new and/or unfamiliar situations (IDRS 2009).*

Stigma (negative social attitudes about people with intellectual disability)

Social stigma has a big impact on the lives of people with intellectual disability. Historically speaking, this has meant being socially shunned, segregated from the rest of society, and institutionalised. The reasons for these practices have focused on ideas of difference, deficits, and deviation from what is considered 'normal'. This has had extremely negative effects for people with intellectual disability.

While supports and services are moving away from former beliefs and practices like institutionalisation, and towards inclusive, human-rights-based approaches, the social stigma attached to intellectual disability is still acutely felt.

Little or none of the right kind of support

People with mild or borderline intellectual disability may not be eligible for the support they need, depending on their IQ and the scope of supports currently available. An absence of formal diagnosis, or no evidence that there has ever been diagnosis (e.g. evidence of having had a diagnosis

would be available if a person had received services in the past from ADHC), are also barriers to specific support. This group is at high risk of falling through the gaps in service delivery. There is an increased risk of imprisonment due to the lack of access to support services, including access to drug and alcohol treatment services.

Other reasons for lack of support include:

- *Natural supportive relationships having broken down*
- *Being unlikely or unable to form and maintain a range of positive supportive relationships without facilitation*
- *Gravitating towards, or attracting, those who may influence, manipulate and take advantage of their vulnerability.*

Avoiding support

There are people who may avoid services and support because they fear that past uncomfortable or shameful experiences will be repeated.These may include when the person has:

- *Not understood what's been said or written down*
- *Had minimal say in shaping or controlling plans and support*
- *Been unable to comply with service agreements and therefore exited from programs*
- *Been belittled, bullied and/or abused by staff or other service users*
- *Felt uncomfortable grouped with other people of similar disadvantage.*

Emotional, social and health effects

Without suitable life options and individualised, flexible and adaptable supports that promote a feeling of some authority over their own lives, people are likely to experience:

- *Lack of self-determination*
- *Poor self-esteem*

- *Loneliness*
- *Boredom*
- *Anxiety and depression*
- *Poverty.*

- **Definitions**

Successfully supporting a person with an intellectual disability to complete treatment will often rely not only on the person's motivation but on the ongoing support offered by workers. Your expertise in being able to support clients to generalise the treatment program learnings to everyday life situations and address multiple life issues is key to improving and maintaining their health outcomes.The focus should be on engagement, individual strengths and self-determination.

Focus on strengths

A functional assessment of a person's strengths and limitations will allow you to develop a profile of the supports they need to complete the treatment program. If the appropriate supports are in place, their level of functioning, and therefore success in treatment, will generally improve.

Masking of disability

When you're working with a person with intellectual disability or a person who displays indicators of intellectual disability, don't make assumptions about their level of disability. Some people develop strategies to mask the effects of their disability, due to stigma and discrimination. For example, even if they appear to give all the right responses to your questions, it may not mean they understand what you've asked them.

To improve communication with people with intellectual disability:

- *Build rapport*
- *Allow plenty of time - don't rush your interaction*

- *Ask open questions, requiring more than a yes or no response*
- *Deal with one piece of information at a time*
- *Don't pretend you understand them if you don't.*

- **Summary**

A more constructive and pragmatic definition is to define intellectual disability in terms of the support needs of an individual. This approach sees the effect of the disability as something that will vary and can be increased or decreased by external factors. It does not view intellectual disability as an unchangeable characteristic of the individual. This definition does not rely on the capacity of the person being set in stone, but also on the environment and the support that they receive. So, adjusting the environment and the support to meet the person's needs can increase the person's capacity and reduce the effect of the disability! The social model sees the 'cure' to the problem of disability in the restructuring of society. Unlike medically based 'cures', which focus on the individual and their impairment, this is an achievable goal and to the benefit of everyone. This approach suggests that the individual and collective disadvantage of people with a disability is due to a complex form of institutional discrimination as fundamental to our society as sexism, racism or heterosexism. The use of appropriate language is not just an exercise in political correctness. It is exercising respect for the people that you are speaking about or to. Language is not fixed and changes with time to reflect changes in government policy, public perception and, for many groups, a move towards more equal opportunity. Up to the 1980's policies of institutionalisation for "handicapped" people were the norm. People lived in cramped wards where their basic physical needs were met and little else. These people were seen as numbers in many cases. They were seen to have no value in society; they could not work or contribute in any way. Words like "mongol", "retard", "spastic" and "handicapped" were socially acceptable. Today, due to new models of disability and a move towards people with intellectual disability living and working in the community, we have come to realise that people with intellectual disability have a place in society and make valuable contributions in daily life. People with intellectual disability have families, get married, get divorced, get emotional and get in trouble the same as everyone else!!! Disability is not an illness. It is part of a person's identity but it is not all that a person is. People with intellectual disability do not suffer, are not afflicted with and are not victims of their disability.

- **Revision**

- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

Points for Clarification

- References / Further Readings

Unit 2: Assessment for Transition from School to Work

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

• Introduction

Work is a central part of adult life, consuming as much as half of our waking hours. People often identify themselves by the work that they do. A job can provide a sense of accomplishment and pride and have an enormous effect on our overall life satisfaction, or it can serve as a source of frustration and dissatisfaction. Finding the right job—simply knowing what it might be—is not easy, even for highly skilled individuals. Doing so is even more difficult for those who lack adequate training or face special challenges, such as a disability. According to nationwide studies, as many as 66% of working adults never had a career plan and are currently working at their jobs because of chance factors or the influence of others or because it was the only job available. Only about half of these workers are satisfied with their job situation (Brown & Minor, 1989; Hoyt & Lester, 1995). Preparing students for the workforce is an important role for

schools—or at least it should be. However, most U.S. high schools emphasize college preparation, which often overshadows attention to actual workforce readiness. Although a college degree is an excellent advantage in finding a rewarding job for a great number of people, postsecondary education is not the optimal or even possible choice for many students. Unfortunately, about half of U.S. students leave high school without the knowledge or skills needed to find and maintain a job (U.S. Department of Labor, 1991), and onethird of students are not prepared for even entry-level work (U.S. General Accounting Office, 1993). Transition Services for Students With Disabilities Compared to their nondisabled peers, students with disabilities are more likely to experience unemployment or underemployment, lower pay, and job dissatisfaction (Dunn, 1996). Many students with disabilities—as well as those with chronic achievement problems—drop out of high school before graduating, leaving them even more unprepared for and less likely to obtain a job. High schools can better engage and support these students by helping identify their strengths and interests and providing them with the skills (or a plan for gaining them) they need to succeed in the workplace. According to the Twenty-First Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (U.S. Department of Education, 1999), only about one-fourth of students with disabilities graduate from high school with a diploma; however, these students were less likely to drop out of school and more likely to be competitively employed if they received adequate vocational education training in high school. Further, there are key legal entitlements—the Carl D. Perkins Vocational Act and the Individuals With Disabilities Education Act (IDEA)—that mandate workforce preparation for students with disabilities. School administrators should be familiar with these provisions for vocational assessment and training and ensure that school programs are consistent with these mandates. Of course, many students with disabilities do go to college and have great success, and school personnel should never downgrade their expectations for these students. It is important for principals to build the capacity of their staff members to help students and their parents accurately determine what vocational and life skills training is appropriate. The core elements of workforce preparation for students with disabilities are the same as those for their nondisabled peers—awareness of interests and aptitudes, exposure to career options, and assessing and building skills—but they require more extensive and individualized support from school personnel and other adults.

- **Objectives**

A major ingredient of a successful school-to-work transition program is a comprehensive, transdisciplinary vocational assessment that integrates a variety of school and community agency personnel into the assessment process. The assessment process should include teachers, counselors, and psychologists—as

well as representatives from community mental health/mental retardation, vocational rehabilitation, and social services agencies—who work together to identify relevant transition needs and plan appropriate services. Parents, state agencies, employers, business organizations, and students must also be involved in the vocational assessment to some extent. The goal of the vocational assessment is to facilitate educational and vocational planning that will allow a student to make a successful adjustment to work, postsecondary education, and community living. Without a comprehensive assessment of a student's skills, it is difficult to identify the needs that should be addressed in the student's transition plan. Team members' roles in the assessment and transition planning process will vary according to their interests, expertise, and the amount of time each has to devote to the process. Principals can assume a leadership role by encouraging and establishing links with community agencies, promoting a transdisciplinary approach to the assessment and planning process, assisting in the development of specific policies and procedures relevant to the process, and ensuring that adequate resources are devoted to assessment and planning. Although principals may oversee the assessment and planning process in their schools, special education coordinators and transition coordinators may share some of the responsibility for case management and oversight of the process for individual students. School psychologists should be involved in conducting psychoeducational assessments, explaining assessment results, and making recommendations to the team. In particular, school psychologists can assist in gathering information relevant to a student's cognitive, academic, and interpersonal skills. Counselors can also assist in data collection by administering vocational interest and aptitude measures, providing career guidance, coordinating career days or career fairs, and matching the student with appropriate classes. Liaisons from state agencies, such as representatives from the state offices of vocational rehabilitation, mental health/mental retardation, and social services, should also be involved in the process. Such agencies provide case management services and funding for services that students will need when they leave high school. Representatives from these agencies can help arrange community living, job training, education, transportation, and employment. For example, many vocational rehabilitation agencies are involved in training students for employment, helping students obtain and maintain employment, and transitioning them into work settings. Further, these representatives can help students and their families file the necessary paperwork and application materials to ensure that all necessary services are available to the students when they leave school. Finally, the student should be actively involved in the transition planning process and attend all meetings. It is the student's future that is at stake, and he or she should begin to take School administrators and staff members can help students prepare for the world of work in a number of ways. To do so effectively, however, they should have a working knowledge of the stages of career development and of the

general career-related objectives that exist at these various stages. In general, the three most important goals for students are to gain an understanding of themselves and their abilities, interests, and values;-gain an understanding of the world of work; and acquire effective decision-making skills. Each of these areas is important to students' ability to make realistic and informed decisions about work, and school-based activities should focus on these three areas. Principals can promote the importance of staff member attendance and provide input at transition planning meetings. Teachers are an integral part of forming and implementing many of the student's goals, and they can provide valuable feedback and recommendations about the strengths and interests of their students. It is also imperative for for teachers to support students' career development. Many students tend to have unrealistic career expectations and either overestimate or underestimate their potential for a certain career. Teachers can help encourage, guide, and redirect students with unrealistic expectations toward more realistic career goals. For example, a student may aspire to be a veterinarian, but the teacher may know that the student has not attained the level of achievement necessary to enter college. In this case, the teacher might redirect the student to more attainable goals, such as becoming an animal groomer, working or volunteering at an animal shelter, or working at a pet store. Again, a proper assessment and interview process can help to determine the basis of a particular career interest. Principals can encourage classroom teachers to get students thinking about realistic careers. For instance, when teaching math or reading skills, teachers can emphasize how those skills are necessary in everyday life and in most jobs. Teachers should incorporate real-world applications into their instruction and discuss how the skills that are being taught are used in occupations that are of high interest to students. Teachers can also introduce a career theme for a day and talk about how the subject they are teaching is used in that career. For example, if food service is the theme, a teacher might talk about measuring quantities, keeping track of stocked goods, making change, balancing the books, and even discussing such areas as statistics (e.g., calculating what the busiest time of day is and trying to predict how much food will be needed). Such real-world applications of subject matter can also be incorporated into homework and tests. Guest speakers can be invited to speak to students about various careers and the skills that are required to pursue these careers. Teachers can also provide students with work experiences by setting up a simulated work environment in the classroom. Students can be "paid" for "work," academic performance, social skills, or classroom chores. Field trips can be an effective way to expose students to various occupations. Finally, teachers can have students read job advertisements, fill out job applications, create résumés, and role-play job interviews and provide feedback to students about their performance on these activities.

- **Summary**

- **Revision**

- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

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Points for Clarification

Unit 3: Assessment Tools for Independent Living –BASAL-MR, VAPS

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**

- **Introduction**

Training based on occupation or employment prepares people for specific trades, and careers at various levels. One very important factor for the dignity of the person is work. Work must be guaranteed if there is to be an authentic promotion of the person. This task is incumbent on the society as a whole. The culture of the work together with that of social assistance entails an education from a young age, guidance in work, dignity for any work activity and sharing work. Without work there is no dignity. Equality of every human being irrespective of nationality, race, color, gender, religion and health is a universally accepted natural law. The constitution of India gives the same considerations to all citizens of India whether or not they are healthy and normal or differently abled irrespective of religion, caste, gender and creed. A society which has special provisions for the integration of persons with disabilities into the social mainstreams is a sign of highly developed society. A good government has to ensure the full participation of differently abled in the nation building and for that purpose it has to protect the rights of the differently abled, provisions for medical care, education, vocational training, employment and rehabilitation of differently abled. The government has to lay down strategies for comprehensive development of programs and services and equalization of opportunities for person with disabilities. Thus a civilized

society has to create an environment without barriers. Cornelius D. J. K (2002) presented a paper at the 16th national conference on mental retardation at Calicut on vocational approach for the persons with mental handicap. Vocational training and employment of persons with mental retardation is required to realize their full potential and to make them integral part of the society. The author pointed out that access to global market and latest technology can change the employment scenario for mentally challenged people. In this context trainers have to be retrained to impart the skills required to the mentally retarded persons. It should help in developing appropriate work behaviours and skills. Aluri U. and Karanth P. (2002) conducted a survey on rehabilitation facilities available for children with autism/Patterns of Delay and Deviance PDD in Bangalore city. Open ended questionnaire was formulated to interview 30 parents of children with autism/PDD. Study indicated that parents consulted pediatricians initially and other professionals were consulted later. It was felt that rehabilitation service centers are few in number. Behavioural training, skill training in communication and special education programs are the management services available, but not at one place. The study noted that there is an urgent need to provide rehabilitation services through team approach under a single roof. Our rehabilitation programs have to look into the possibility of incorporating the existing social systems and we have to develop and implement indigenous methods. There is a changing scenario in the field of vocational training in India. Computers became the preserve of the educated and affluent society. The specter of cyber space and information technology transforms the world. In the web media culture the old dimensions of work function no more. It invites us to pursue new ways of vocational training for the mentally challenged in the fast growing cyber world. The aim of the present study is to analyze the impact of computer training in the behaviors of mild mentally challenged adults and the exploration of the impact of their rehabilitation. Thus the problem under investigation is entitled as "Impact of computer training in the behaviors of mentally challenged adults". Mental retardation, by its very nature, shows impairments in adaptive behavior. Impairment in adaptive behavior may be either a deficit behavior or an excess behavior. Vocational training is systematic training, by which an individual acquire such skills and behaviors which are necessary for particular vocation. According to Oxford dictionary of psychology behaviors are the physical activity of an organism, including overt bodily movements and internal glandular and other physiological process, constituting the sum total of the organism's physical responses to its environment. It is the actions and mannerism made by organism. In present study, the term behaviors include physical harm towards others, damages property, misbehaves with others, temper tantrums, self- injurious behaviors, repetitive behaviors, odd behaviors, inappropriate social behaviors, inappropriate sexual behaviors, rebellious behaviors, hyperactive behaviors and fears. Mentally challenged: According to American Association on Mental

retardation "Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub average intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18". In this present study the term mentally challenged has been used inorder to eliminate the negative connotation of the term mental retardation. Vocational Rehabilitation: Vocational Rehabilitation means that part of continuous and coordinated process of rehabilitation, which involves the provision of those vocational services, e.g., vocational guidance, vocational training and selective placement, designed to enable a disabled person to secure and retain suitable employment. (Mukhopadhyay A., 2010).

- **Objectives**

The curriculum of computer course includes basics in computer, desktop publishing, power point and adobe. Special training is given in functional literacy, personality development, agricultural work and group dynamics. The trainees were selected after screening. Admission criteria include aptitude to creativity and computer knowledge. The class time was scheduled from 9.30 a.m. to 3.30 p.m. Theory classes were conducted in the morning and practical classes were held in the afternoon. Practical and theoretical tests were held monthly in order to assess the performance and improvement of the trainee. The curriculum of computer theory classes were simplified and presented according to their level. The teacher training ratio was 1:5. Duration of the course was one year and evaluation and follow up were conducted monthly. The first two month, teachers introduced computer software and hardware to students. They were given training in painting. In the third and fourth month, the main curriculum was wordpad and notepad. From the fifth month onwards they were trained in power point, photo shop, and Page maker. After each exam the evaluation will be done. The multidisciplinary team of teachers, psychologist, vocational trainers and social workers evaluated the final outcome and progress in their training and personality development by the use of behavioural assessment scales for adult living-mental retardation (BASAL-MR) in accordance with the final evaluation, decision is made for placement and extension of training. Case study method was followed. After recording the baseline measures and analyzing the antecedents and consequences of behavior, the behavior management has planned. 5 individuals were randomly selected for the purpose of the present study. The researcher had trained the vocational instructors in the use BASAL –MR. The vocational instructors are introduced about the meaning and need of behavioral assessment

and BASAL –MR. Special training is given to them about individual aspects of administration, use of glossary and scoring of it. Behavioral strategies and curriculum was prepared for them. The base line assessment was conducted in the initial stage. The post training assessment for 5 selected mentally challenged adults was conducted after every third months of training.

- **Definitions**

Work is essential for every human being, because it bequeaths self-esteem and self-dignity to individuals with disability. The self-esteem and self-dignity is substantial to their psychological wellbeing. An attempt was made to examine the effect of computer training in the behaviours of mentally challenged adults. Five individuals with mild mental challenges from Ernakulam district were selected as sample. The Intervention computer training, has been given for them for a period of one year. Case study method was employed and Behavioural Assesment Scales for Adult Living – Mental Retardation (BASAL –MR) was the tool used. The present study laid its emphasis to explore the need of vocational training and vocational rehabilitation in the behavior modification of mentally challenged adults.

- **Summary**

The present study assesses the impact of computer training in the behaviors of mild mentally challenged adults. It can be concluded that computer training is effective in modifying the behaviors of the mentally challenged adults. After the pre and posttest assessment of 5 mild mentally challenged adults, case study was conducted to know the progress in the behaviors. The results in BASAL MR part B show that training was effective in behavioral changes. Vocational training of mentally challenged adults is required to realize their potential and help them to be make them integral part of society. It is an effective technique to get rid of behavior problems. To conclude, the finding of the present study strongly recommends that vocational training is pivotal for the behavior modification of the mentally challenged adults and so that they can become independent in their social, personal, emotional life and in employment. The study opens the path for research in vocational rehabilitation. Multi disciplinary approach is to be employed and vocational assessment and training is to be designed according to the individual needs.

- **Assignment/Activity**

- References / Further Readings

1. Aluri U & Karanth P. (2002) Rehabilitation facilities for Children with Autism/PDD in Bangalore City: A survey. Asia Pacific Disability Rehabilitation Journal, 13, 115-124. 2. Colman, A. M. (2009) Oxford Dictionary of Psychology, Oxford: Oxford University Press. 3. Corenelius D. J. K. (2002) Vocational approach for the persons with mental handicap. Paper presented at the 16th National conference on mental retardation – Mainstreaming the delayed, Calicut. 4. Mukhopadhyay, A. (2010) Principles of Vocational Training Part -2, New Delhi: Kanishka Publishers. 5. Peshawwaria, R., at al. (2000) Behavioural Assessment Scales for Adult Living – Mental Retardation, Secunderabad: NIMH. 6. Rao L.G., & Sivakumar T.C. (2004) Reengineering the Vocational Training for Mentally Retarded. Journal of Community Guidance and Research, 21, 5-20. 7. Thressiakutty, A.T., & Rao, L.G. (2001) Curriculum for Vocational Education. Transition of Persons with Mental Retardation from School to Work, Secundrabad: NIMH.

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

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Points for Clarification

Unit 4: Provisions & Schemes of MoSJE for Vocational Skill Development

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

• Introduction

1. This summary presents a brief synopsis of the different sections of the paper and highlights key constraints faced by the vocational education and training system as well as the potential options to address some of these constraints.

2. Realizing that it is not feasible to implement all these options immediately, the last section of the summary aims to provide a possible timeline in which reforms should be sequenced: – (i) an initial phase – focusing on reforms that need to be addressed in the very near future; and (ii) a medium-term phase consisting of interventions that can be implemented over the next 2- 3 years.

3. The Government has a clear vision regarding the vocational education and training system. Recognizing that the system is outdated and resembles a closed, centrally planned system for a centrally planned economy, the Government is keen to reform the system. While the system is relatively small, it is clear that major reforms are needed before any thoughts are given to expanding the system. What is needed is the development of a system where the Government plays a key role in policy development, standards setting, financing and monitoring and evaluation, while engendering greater competitiveness and accountability by training providers. For reforms to succeed, close involvement of the private sector at all levels – from policymaking to being involved in running institutions, is critical and the Government is working closely with the private sector to move forward in transforming this vision into reality.

I. The Labor Market Context and Supply of Skills

4. Largely because of the growth in factor productivity, India's economy has grown rapidly over the past decade. Continuing to raise labor productivity while at the same time generating enough jobs for a growing labor force is proving a massive challenge. This issue has come into sharp focus over the previous decade when economic growth accelerated but employment growth fell to less than half that of the 1980s, raising fears that India is witnessing jobless growth.

5. Education and skill acquisition are important determinants of firm productivity. The wages of workers with qualifications beyond primary school have grown far more rapidly than those of workers with primary school or less; the greatest increases being for workers with tertiary qualifications. This movement in wages shows that education and skill acquisition are important determinants of job prospects.

6. There is evidence of growing demand for workers with secondary education but the same cannot be said of workers with technical/vocational skills. Since the early 1980s, the relative wages of workers with secondary education have been growing even as these workers have become relatively more abundant. However, the relative supply of workers with technical/vocational skills has declined throughout this period while their relative wages have also come down since the early 1990s. This may be due more to the fact that workers with technical/vocational qualifications do not have skills that meet the labor market (often because of the poor quality of training provided) than that there is little demand for skilled ii While India has improved its performance in education, its competitors have made much larger gains in this area over the previous decade. workers. It is also possible that students see little labor market benefits from undertaking VET courses and opt for other more attractive educational options.

7. Although the number of workers with some education has grown, the overall educational attainment remains low in absolute terms and by comparison with other countries. Analysis shows that India has only marginally improved its performance in education since 1995, whereas countries such as China, Mexico, South Africa, and Russia have made much larger gains in strengthening their education pillar – not only in terms of quantity but also in terms of quality.

8. Although productivity has been increasing and education levels rising, India still needs to improve education and training quality. While significant improvements will need to be made on quantitative indicators, little is known about qualitative indicators – e.g. because India does not participate in standardized international examinations, there are no good comparative measures of quality. Providing more education and skills cannot, by itself, be enough – quality and labor market relevance is crucial. The education and skills provided must be relevant to the labor market. Acquiring skills is essential, provided those skills are not out-dated or do not meet industry requirements II. Vocational Education

9. The vocational education stream is quite small enrolling less than three percent of students at the upper secondary level. Vocational education courses are offered in schools at Grades 11 and 12 (in most states with vocational streams, vocational and general courses are offered by the same institution). These are aimed at preparing students for entry into the labor market. There are 6800 schools, almost all in the public sector, enrolling close to 400,000 students in the vocational education scheme – utilizing just 40 percent of the available student capacity in these institutions. These schools offer a total of over 100 courses in various areas - agriculture, business and commerce, humanities, engineering and technology, home science and health and para medical skills.

10. Vocational students appear intent on entering higher education rather than entering the labor market. Overwhelmingly, students who get through the vocational stream want to proceed to further education. This is not surprising given the relatively weak labor market outcomes. The few rigorous evaluations of program impacts that have been undertaken point to low levels of gainful employment of these graduates.

11. Despite the poor outcomes, policymakers remain keen to expand vocational education. The Central Government has planned to increase enrollments in the vocational education system to about 25 percent of total secondary enrollment. Even though enrolments in vocational education in India are small when judged by international comparisons, expanding the numbers or re-targeting the program would not be justified unless a model is found that would substantially improve outcomes.

12. International experience suggests that employers mostly want young workers with strong basic academic skills, and not necessarily vocational skills. What employers are looking for are individuals who have the ability to communicate, solve problems and teamwork, – and

- **Objectives**

The objectives of the study are the following: Summarize the key challenges and issues facing persons with disability in Indian labour markets;• Provide an overview of the major organizations and institutions acting for persons with disability in• India and the services they provide; Identify strategic opportunities to improve and expand persons with disability participation in Indian• labor markets; Recommend key interventions that could be pursued by the ILO in India•

India's transition to a knowledge-based economy requires a new generation of educated and skilled people. Its competitive edge will be determined by its people's ability to create, share, and use knowledge effectively. A knowledge economy requires India to develop workers – knowledge workers and knowledge technologists - who are flexible and analytical and who can be the driving force for innovation and growth. To achieve this India needs a flexible education system: basic education to provide the foundation for learning; secondary and tertiary education to develop core capabilities and core technical skills; and further means of achieving lifelong learning. The education system must be attuned to the new global environment by promoting creativity and improving the quality of education and training at all levels. Countries that have had the most rapid increases in educational attainment, as well as sustained economic growth, have upgraded education sequentially. In a globalized economy, a large pool of

skilled workers is indispensable for attracting foreign direct investment. Developing skilled workers enhances the efficiency and flexibility of the labor market; skills bottlenecks are reduced, skilled workers are more easily absorbed into the economy, and their job mobility is improved. It is crucial to invest in quality secondary and tertiary education and in vocational education and training (VET) if India's economy is to develop and remain competitive in world markets.

- **Definitions**

India's ability to deal with these changing realities is constrained as in few other places. While its population growth rate has declined over many years the labor force is still projected to grow by close to 2 percent or some 7 million or more a year over the next few years. Much of the economy and much of the population are still rooted in traditional activities and structures. Significant elements such as the cultural, social and political traditions of the country should, of course, be retained and education has a particular role to play in that. But other aspects should change if people are to move out of poverty. Over half of the labor force is still engaged in rural activities. Although there has been a significant movement away from iii agriculture this has still left most of the labor force, over 90 percent, working in the informal sector, much of it at low levels of productivity. For this majority group, access to secondary education and VET is crucial and for most of them secondary education and VET will be the last stage of their formal schooling. An effective school to work transition for these young people, made possible by higher quality secondary and tertiary education and VET, will improve their employment prospects and lifetime earnings.

- **Summary**

India has ratified the United Nations Convention on the Rights of persons with disability (UNCRPD) in 2007. Article 27 of UNCRPD "recognizes the right of persons with disability to work, on an equal basis with others; this includes the opportunity to gain a living by work freely chosen or accepted in the labour market and work environment that is open, inclusive and accessible to persons with disability". 15 Further, UNCRPD prohibits all forms of employment discrimination, promotes access to vocational training, promotes opportunities for self-employment, and calls for reasonable accommodation in the workplace. However, despite the fact that India has ratified the UNCRPD, young people still struggle to access decent work. Access to quality education, vocational training and employment are denied to millions of young persons with disability,

worldwide including India. 16 India has not ratified ILO Convention 159, which concerns Vocational Rehabilitation and Employment (Disabled Persons) Convention. This convention has been ratified by more than 80 countries. The Convention requests ratifying states to set out a policy on vocational rehabilitation and employment of disabled persons in the open labour market (integration of disabled in regular working environment). The Convention furthermore promotes equality of treatment between disabled and non-disabled workers, specifying the need for positive action, which would enable workers with disability many opportunities to be as productive as any other worker. This may require specific services for disabled workers, like adaptations in the work environment (access to workplace) or at the workplace of the individual worker. The Convention makes it mandatory to provide vocational rehabilitation and employment services for disabled workers in rural and remote areas, which is very relevant to the situation in India. 17 Several key pieces of legislation issued from 1980 onwards were (i) the Mental Health Act, 1987; (ii) the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (PwD Act); (iii) the Rehabilitation Council of India Act, 1992 and amended in 2000 (RCI Act); and (iv) the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (National Trust Act). The cornerstone of these is the PwD Act 1995 which heralded a new dawn in the lives of disabled people in India. For the first time in India, a separate law was formulated which talked about the multiple needs of disabled people. This Act helped disabled people to come together, forming advocacy groups to implement this law. Since the ratification of UNCRPD by India in 2007, there has been much discussion of the manner in which Indian laws must be modified to give effect to the obligations under the Convention. While the Ministry of Social Justice and Empowerment (MOSJE) has proposed 108 amendments to the PwD Act including 50 new provisions, the Disabled Rights Group (DRG) led by Javed Abidi has unequivocally stated that the PwD Act has served its time and that there is a need for a new law. Consultations on this issue at national and zonal levels have taken place. Advocate Kanchan Pamnani, who is blind herself, says that the old law will need more than 300 amendments to make it suitable to our times, and obviously it is better to frame a new one than make 300 changes in the old one.18

- **Revision**

Lack of daily living skills: Many persons with disability are not trained in basic living skills like

• maintaining personal hygiene, grooming, travelling, use of washrooms, personal safety, etc. Lack of self-esteem and confidence: Some persons with disability have low self-expectations

• about their ability to be employed and may not try to find employment. The social isolation of persons with disability restricts their access to social networks, especially of friends and family members that could help in finding them employment.In rural areas, persons with disability are ridiculed or get bullied. Sometime the parents also don't take them along for social gatherings, etc., due to the stigma. This reinforces their inferiority feeling and leads to low self – esteem. Overprotective parents: Many parents are very protective about their disabled children, which

• can be a hurdle for the child to become independent. Many persons with disability are dependant either on their parents, siblings and friends for small tasks, which makes it difficult for them to independently seek employment. Most of the time they are escorted by their parents/relatives, whereas companies stress they want persons with disability who are independent. Basic Skills: persons with disability may not have access to situations of regular social interaction,

• may have specific issues with communication (spellings for visually impaired do not get reinforced by "seeing", sentence construction for hearing impaired do not get reinforced by "listening" and so on leading to difficulties in training them for employment. Life Skills: This is an important employability skill to get the job. Among the persons with

• disability candidates skills like team building skills, time management, money management, are lacking or weak. Poor knowledge of English: Rural aspirants with reasonable qualifications have very poor

• knowledge in English. Sometimes they cannot even spell/write their village name in English. This is a big challenge to make them work ready in many service sector jobs, including data entry operator, where minimum English knowledge is necessary. Lack of access to skills and technology: Education and training are central to good and

• productive work for a reasonable income. But young persons with disabilities often lack access to formal education or to opportunities to develop their skills, particularly in the field of information technology. Rural disconnect from markets: There are many disabled youth who are not aware about the

• training/job opportunities available for them especially in the rural areas where disability is more acute. They are also not exposed much to the outer world and

are isolated in their own world. Technological changes especially new trends like online recruitment make it difficult for persons with disability to cope, many of whom have never worked with computers before.

- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

Points for Clarification

Unit 5: Documentation of assessment, Result interpretation & Report writing – Implications of assessment, Outcomes for Community living

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

- **Introduction**

This pack provides practical help and guidance to a nurse1 undertaking community health needs assessment. It provides information and advice on the stages of needs assessment, enabling the nurse to complete the process realistically within her/his everyday work. This pack does not assume any prior knowledge of the subject.

Community health needs assessment is a process that: describes the state of health of local people; enables the identification of the major risk factors and causes of ill health; and enables the identification of the actions needed to address these. A community health needs assessment is not a one-off activity but a developmental process that is added to and amended over time. It is not an end in itself but a way of using information to plan health care and public health programmes in the future. The steps of community health needs assessment are as

follows. Profiling the collection of relevant information that will inform the nurse about the state of health and health needs of the population; and analysis of this information to identify the major health issues. Deciding on priorities for action Planning public health and health care programmes to address the priority issues Implementing the planned activities Evaluation of health outcomes

Concepts and principles of health needs assessment Defining "health" and "need" This pack uses a holistic model of health, emphasizing the social, economic and cultural factors that affect health as well as individual behaviour. The concept of "need" used in this pack incorporates those needs felt and expressed by local people as well as those defined by professionals. It moves beyond the concept of demand and takes account of people's capacity to benefit from health care and public health programmes. Factors affecting health Health is affected by a number of factors: the physical environment in which people live, such as the quality of the air they breathe and the water they drink; the social environment – the level of social and emotional support people receive from friends and/or family; poverty, a significant factor worldwide, which shortens and reduces enjoyment of life; behaviour and lifestyle – for example, smoking causes lung cancer and coronary heart disease so a reduction in this behaviour will reduce the disease; and family genetics and individual biology – if you come from a healthy family you have a better chance of staying well. This pack will encourage the nurse to consider all these risk factors in relation to a community and make an assessment of their importance. Involving the community It is assumed that the nurse using this pack has responsibility for providing nursing services to a caseload of individual patients and a wider responsibility for improving the health of the community. The pack also assumes that the nurse wishes to work in partnership with local people and will be looking for ways to involve others in her/his work. Community needs assessment incorporates many of the principles of community development (Appendix 1), which has been defined as: "...a way of tackling a community's problems by using the energy and leadership of the people who live there".

- **Objectives**

If people feel involved in developing a local health plan they will be more committed to putting it into action. It is therefore important that all those who will be involved in using 3 the plan are also involved in the health needs assessment process. For the nurse this means collaborating with other professionals and the

local community. Nurses will also need to agree with their employers on the flexibility and autonomy to change their work patterns according to the needs identified through the community needs assessment process. The pack takes a user-friendly approach to community health needs assessment, guiding the beginner through the process. Section One outlines the type of information a nurse needs to think about when creating a profile of the community. Reasons are given for the inclusion of each piece of information. Section Two gives practical advice on how a nurse might find this information. Section Three helps the nurse to analyse and use the information, decide on priorities and create action plans. By working through the pack, the nurse will gain a basic knowledge of the health needs assessment process and will be able to begin this task within his/her own work setting.

- **Definitions**

Minority ethnic and religious groups can be marginalized within a community; a lack of awareness can result in a community health needs assessment that may not include the most vulnerable groups. Nurses need to be aware of the different ethnic and cultural groups within the community. Ethnic groups can be classified by racial origin, religion, colour or nationality. You may choose to use the national classification so that you can make comparisons with other areas. Different groups face different problems and require services that are sensitive to their cultural and linguistic background. This can be seen in diseases that are specific to one group such as sickle cell anaemia and thalassaemia. Religious groupings are useful to know, as they can have a powerful influence over people's lives and are often a source of community support and influence health behaviour. Ethnicity and cultural background have a significant impact on health, and individuals, whatever their ethnic background, are entitled to equal access to health care. Even if the numbers are small, nurses should take action to ensure equality of access to health care and health programmes that are culturally and linguistically appropriate. There may be one or many languages in use within the community, together with local or regional dialects. Language and literacy are essential for communicating health information and for accessing services. If literacy is a problem within the community, be sensitive to this and take account of it when deciding on methods of community participation. Knowledge of local minority languages is vital to ensure equity and to enable the whole community to become involved in the community health needs assessment process.

- **Summary**

Mortality data This generally describes patterns of death in relation to age, gender and cause of death. It is a basic measure of epidemiology – the study of disease in populations. Information is collected nationally, regionally and sometimes at local level, usually from death certificates. It indicates deaths from disease, accidents, suicides and homicides, and the general health of the population in terms of life expectancy (Appendix 2). Mortality rates work best for large populations; in small communities a little change can produce large statistical distortions. A problem in using mortality rates is that they depend on a shared understanding of cause of death and do not describe the health of the living. Morbidity data This is information on types of illness and disability, their incidence and prevalence. It can be taken from a wide range of sources including hospital records, infectious disease notifications and disability registers, sickness records, general medical practice, child health records, census material and other surveys. Information collected in this way should be treated with care, as it may be a measure of health service activity rather than true disease patterns. It is a reflection of illness and not health. Behaviour measures These are often used as indicators of health. Smoking is one of the best examples. This is an activity proven to cause ill health, so if a lot of people smoke it shows a large potential for illness in the population. Breastfeeding is considered the best of all infant feeding methods, so it is taken as an indication of good health. These measures should be treated carefully as they are about behaviour, yet are sometimes used as proxy measures for health. "Quality of life" measures These are a means of assessing physical health, functional ability and psychological wellbeing. The assessment scales are based primarily on an individual's own assessment. These have been developed mostly in North America and the United Kingdom to measure health outcomes based on people's perception of their health. The reliability and validity of these tools vary, but they are still useful in providing people-based measures of health. Examples include the Barthel Index, the Nottingham Health Profile and the Index of Activities of Daily Living.2 Use of service information This information can help build a picture of morbidity as it can describe the diseases that are being treated by the health services. It will cover both treatment, for example hospital admissions, and uptake of preventive services, such as immunization and screening programmes. Care may need to be taken, however, as some health problems may not yet have any services. In countries where access to services is limited through inadequate provision or an individual's ability to pay for treatment, this information will often be unreliable as an indicator of population health.

- **Revision**
- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

Points for Clarification

- References / Further Readings

Block 5: Assessment of Family Needs

Unit 1: Significance of psychosocial needs and its assessment in family

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

- **Introduction**

People the world over live at risk of disasters – both natural occurrences, such as weather disturbances, volcanic eruptions, earthquakes and tsunamis, and industrial or transportation accidents. As well, war, armed conflict and terrorism also widely threaten communities around the globe. Emergencies are situations in which the lives and welfare of people are at such a risk that extraordinary action must be mobilized to ensure their survival, protection and well-being.1 The physical consequences of an emergency situation are quite evident: death, disabilities, displacement and much pain. However, the psychosocial consequences are less obvious. While victims' immediate emotional responses to complex and social emergencies may be detectable, it is much more difficult to know the long-term effects of such events. Providing psychosocial support to communities and individuals helps them to cope with their emotions and restore well-being. There has been little argument that such support is critical in any society affected by a calamity, but there are concerns regarding its nature. Particularly where international organizations oversee the provision of services, the question often

arises: "Are we seeking to impose general, clinical or bio-medical frameworks rather than paying attention to local ways of healing and restoring well-being?" The assessment of the situation before, during and after a disaster or eruption of conflict is crucial in identifying and promoting local or culturally appropriate psychosocial responses that address the needs of children and their families in affected communities. The healing and rebuilding of individuals and families are necessary for the mending and reconstruction of the greater community. Given the noble task and the difficult challenge of addressing the psychosocial consequences of disasters, the essential principle is to encourage healing processes at all levels, fully involving the community in the assessment of a situation in affected areas and in the development of recommendations on psychosocial support empowers that whole community. Psychosocial self-help and mutual help – as it relates to children and their families – are the cornerstones of this handbook. The fundamental assumption in the development and eventual use of this book is the importance of close collaboration with local or community-based organizations in the assessment of the psychosocial well-being. Depending on the situation, this collaboration entails spending a great amount of time and energy in the field – with the affected people. This is a guidebook for any agency, organization or academic doing rehabilitation work and focuses on the assessment to be conducted when an emergency first hits or just after a major event in an armed conflict. In these situations, typically a responding agency or group organizes an assessment team of five to eight people who go to the affected area to determine the needs of survivors. This handbook speaks to those assessment teams that focus on the psychosocial as well as physical needs of children, their families and the communities. One of the more important points this handbook stresses is to avoid making children and communities run through the same assessment activities that different teams would hope to conduct. To respect this, coordination is needed among all groups seeking to make psychosocial assessments. If there is no leading response agency or body at first, groups concerned about psychosocial issues should as best as possible coordinate their efforts through a local partner in the affected community. This handbook does not spell out how to achieve that coordination but addresses the preparation needs of an assessment team and what an assessment should concentrate on, including sensitivities and issues to be aware of. This handbook also includes guiding principles and ethics to conducting a community- and child-centred psychosocial assessment. In addition to providing resources, this handbook has the following objectives: To be used as a tool for the assessment of the psychosocial well-being of♣ children and families in emergencies; To be used as a tool in developing recommendations and strategies that♣ are based on the psychosocial well-being framework; and To promote the principles, ethics and techniques that uphold the♣ participatory approach and that build on the resiliency of children, families and communities.

- **Objectives**

Identifying a community's strengths and resilience in times of emergencies, particularly as it relates to protecting children, is a complex challenge. An assessment team needs to adhere to certain principles and ethics that will guide the way team members relate with children and a community in every phase of the process and ensuing actions. These principles and ethics are anchored in the Universal Declaration of Human Rights and the United Nations Convention on the Rights of the Child. Past experiences in conducting psychosocial needs assessment and programming underscore the importance of: 1. Integration of psychosocial approaches to peace and development efforts (holistic approach) The processes and actions in assessments and follow-up programming should have an integrated approach to psychosocial well-being. This means recognizing that psychosocial interventions don't operate in a vacuum and that they need to be linked to individual and social quests for truth and justice. The rebuilding of communities destroyed by a calamity and reconnecting people to their sources of livelihood cannot be separated from the psychosocial recovery and healing process. The eventual goal of the assessment process and succeeding actions is to contribute to the community's pursuit of peace, social justice and respect for human rights. During the assessment process: q Ask the community to identify potential areas or issues needing immediate attention. q Ask for potential sources of conflict and tensions at the individual and social levels. q Ask the community about support needed to pursue peace and development. 2. Respect for cultural traditions (contextual approach) The assessment team should seek to be informed about the cultural traditions and practices of an affected community. Respect and appreciation of the differences and identifying the similarities between team members' culture(s) and the culture(s) of the affected community are essential in establishing and maintaining a connection with them. The key words here are "context", "culture" and "perspective". During the assessment process:

* Be aware of the ways to ask questions politely.

* Social hierarchies should be respected whenever possible but should not override the need to protect the confidentiality and privacy of individual participants.

* Codes of dress and ways of eating, whenever possible, should be respected.

The assessment team must ensure that the selection of participants, be they adults or children, and the processes and methods in the assessment process "serve to correct, not reinforce, patterns of exclusion".3 This requires attention to socio-economic barriers, including gender and age discrimination, and to the ethnic and religious differences in a given area. When gathering information on sensitive subjects, such as the effect of armed conflict or disasters on children, the assessment team must be aware of the potential harm it can do to the participants. The methods and activities, such as home visits and interviews, need to be carefully designed so as not to "re-activate emotional pain and grief and/or humiliate the participant in the eyes of others". Participants must be told that they can refuse to answer any question on any grounds without repercussion. In the event that a participant exhibits a negative emotional or psychological response to an interview or other type of assessment method, the assessment team has a duty to help find support for the participant.5 Prior to initiating the assessment, the team members should identify available support services within or near the community. The assessment team also has a duty to protect any child if they receive information of incidents likely to cause significant harm.

Consent from the community must be sought before embarking on an assessment mission. Where children are participants of an assessment process, the consent of the parent or adult guardian should be secured before any discussion begins with a child. The assessment team should first explain to the parent or adult guardian who they are, what the assessment is about, what information is being sought, what methods will be used, how the information collected will be used and the possible consequences of a child's participation. The adult must be allowed to ask any question he/she may have. Children must then be given the same information in age-appropriate language to determine if they are willing to participate. Where appropriate, the assessment team should then describe its objectives and purpose to the community or community leaders to ensure cooperation. The assessment team must stress to all parties, particularly to children, that declining to participate in the assessment is an option at any point of the process and will have no negative repercussions. This is an especially important point in situations of dependency, such as where displaced persons rely on relief aid for their survival.

- **Definitions**

The members of an assessment team are obliged to create and maintain an environment that prevents abuse and exploitation; and they have particular responsibilities to support, maintain and enforce this environment. Any form of

exploitation and abuse by members of an assessment team constitutes gross misconduct and is grounds for termination of a contract or agreement. The exchange of money, employment, goods or services for sex, including sexual favours or other forms of humiliating, degrading or exploitative behaviour, is prohibited. Sexual activity with children (persons younger than 18) is prohibited regardless of the local age of majority or age of consent. Members of an affected community most likely will want to know how their participation in the assessment will benefit them. Simply put, don't promise anything that cannot be delivered and deliver that which has been promised. Many people living in conflict areas or in evacuation centres are surviving in difficult and desperate conditions. From the outset, an assessment team must ensure that children, parents, families and the community understand what they will get out of the assessment mission. Though the members of the assessment team may hear some awful stories and may genuinely wish to help, do not promise that the assessment will improve their situation. The recommendations of the assessment might lead to assistance or policy changes, but, in reality, they may have no immediate impact, meaning that the lives of children and communities affected by armed conflict or disaster might not change at all.

- **Summary**

An assessment is an information-gathering process. In the period immediately following a disaster or a major event in an ongoing conflict, information is needed on the extent and magnitude of damage to lives, property and to the environment. For instance, information is needed on the number of people (children, women and men) affected, the groups needing special protection and infrastructure damage. Knowing what children have experienced leads to the identifying and recommending of survival, protection and information measures that are needed. An assessment seeks to know the impact of the experience of the disaster or conflict on the psychosocial well-being of children and their community. This includes looking at changes in and impact on the: Capacity of families and communities to protect children – Has the♣ experience of a calamity diminished or enhanced the capacity of parents, health workers, teachers, police, social workers and others (who interact with children) to protect children? Children's knowledge, life skills and participation – Is there accurate,♣ adequate, appropriate and accessible information to enable children to find ways to help themselves and others in their community? Attitudes, traditions, customs, behaviour, relations and practices – Has the♣ experience of conflict or disaster brought about attitudes or practices that facilitate recovery or bring more harm? For example, in responding to the disaster, were there practices that did not respect the community's customs, such as in the identification, handling and disposal of

bodies? Protective legislation and government commitment to enforcement – Are♣ the measures enacted in response to an emergency designed to protect children and uphold their rights? Are there any preventive measures? Resources for recovery, reintegration and wellness – Has the disaster♣ affected the resources of the community in its ability to recover? This includes assessing the impact on local coping and healing ways, mutual support groups in the community (such as women's or church groups) and basic care and support practices and services. An assessment is an enabling process. It should facilitate the community's appraisal of its needs, wants and values following a disaster. It also should facilitate the community members' understanding and interpretation of their situation so that they can make informed decisions for actions, in the short term and for the future. Hence, the assessment should be conducted in a participatory way. In other words, the assessment should: Be a collaborative exercise between adults (women and men) and children♣ (girls and boys) in the community and between the community and external agencies, from planning to implementation stages and to the dissemination and utilization of assessment findings and results; Emphasize varying degrees of participation among different types of♣ stakeholders, particularly children, depending on their capacity, availability and their desired quality and level of involvement; Be a process of individual and collective learning through which adults and♣ children become aware of their strengths and weaknesses, of the wider social realities in relation to their specific conditions, and of the actions they could take to improve their situation; Be a flexible process that is continuously evolving, adaptive and responsive♣ to the needs and circumstances of the emergency situation, the community and its people – as well as of the assessment team; and Be an empowering experience that leads children, families and communities♣ to feel greater commitment and ownership of the assessment process and findings and any actions that result from it. An assessment is for action. The key to doing an assessment is to create solutions and recommendations together. The community needs to find solutions to the problems that were identified and articulated during the assessment and to find ways to promote the psychosocial well-being of children and adults. It also needs to seek cooperation and coordination within the community and partnerships with external agencies.

- **Revision**
- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

Points for Clarification

- References / Further Readings

Unit 2: Assessment of parental needs and its implication in planning IFSP

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

• Introduction

The individualized family service planning process is used to develop and deliver appropriate early intervention services to an infant or toddler with significant delays and his or her family. Throughout the IFSP process, family members and service providers work as a team. The family's concerns and priorities guide the entire process. After all evaluation and assessment information has been gathered, the team develops IFSP outcome statements. Outcomes reflect what family members see as important for their child and themselves. The team then determines objectives, strategies, supports, and services necessary to support those IFSP outcomes. The team must take into consideration the child's and family's daily routines and the capacity of the family to meet their own child's unique needs. The objectives, strategies, supports, and services are committed to the document called the IFSP. The IFSP is an agreement between the family and the Birth to Three program.

- **Objectives**

Procedures for IFSP development, review, and evaluation (34 CFR sec. 303.342) are:

- A meeting to develop the initial IFSP must be held within 45 calendar days of the child's referral to the Birth to Three System (i.e. from the call to Child Development Infoline). An IFSP is completed only when a child is eligible for Birth to Three services.

- This meeting must be conducted in settings and at times that are convenient to the family. It most often occurs in the family's home.

- For families not proficient in English, the meeting must be in their native language or preferred mode of communication unless it is clearly not feasible to do so. This may involve use of an interpreter.

- Parents must be provided with written prior notice of the time and place of the meeting a reasonable amount of time before the meeting to ensure that they will be able to attend. Form 1-6 (Written Prior Notice) should be used for this purpose

- The IFSP must be reviewed at least every six months or more frequently if changes are needed or if the family requests a review. The purpose is to determine the degree of progress made toward achieving the outcomes and whether revision of the outcomes or services is necessary.

- According to IDEA Part C regulations, a meeting must be conducted at least annually to evaluate the IFSP for a child and family, and, as appropriate, to revise its provisions. This means anytime within the 12 months after the initial or previous evaluation of the IFSP. The results of any current assessments (completed within the past three months) conducted under § 303.321 and other information available from the ongoing assessment of the child's development in all five domains and the family concerns must be used in determining what services are needed and will be provided. This assessment does not need to be completed by a multidisciplinary team.

- A transition conference should be held for each child prior to exiting the Birth to Three System unless it is not possible. The following two situations determine who should attend:
    - For each child who may be eligible for preschool special education services (IDEA Part B), the service coordinator must convened a conference with the approval of the family that includes a representative from the school district. Form 3-8 Referral to LEA should be completed and sent to the school district prior to the meeting. The transition conference must be at least 90 days or, at the discretion of all parties, not more than nine months before the child's third birthday to ensure adequate time to plan and to carry out transition activities. Eligibility for preschool special education will not be determined during this meeting, please refer to the Transition procedure for more information.

    - For each child who is not being referred for preschool special education services (IDEA Part B), the service coordinator must convene a transition conference at least 90 days prior to the child's exit from the Birth to Three System (and as early as nine months prior to the third birthday. Reasonable efforts should be made, with the approval of the family, to invite participation from any community agency from whom the family is seeking services. If the program will be contacting these participants then a Release of Information Form 3-3 should be signed by the parent before sharing information and inviting others.

- If a family **meets the criteria to be responsible for a monthly family cost participation fee and** chooses to receive only those services available at no cost, an IFSP is written to reflect this decision (see "Completing the IFSP Form for a Child Receiving Services at No Cost" in this procedure). If, at a later date, a family chooses to begin receiving direct services, the IFSP must be revised to reflect this decision.

- Once a child is found to be eligible for Birth to Three services he or she remains eligible while enrolled in the Birth to Three System until they meet the exit criteria (see Exit procedure). This is true for children moving from an IFSP with services at no cost to an IFSP with direct services.

- **Definitions**

Connecticut General Statute 17a-248e(c) requires that the IFSP be developed in consultation with the child's primary health care provider who is licensed in Connecticut or a contiguous state. To meet this requirement, the service coordinator should obtain parental permission to contact the primary health care provider indicating that his or her input is requested for a patient's IFSP. The primary health care provider's input should be sought regarding services that will be recommended and whether there are any contra-indications warranted by the child's medical status. Following the IFSP meeting, the IFSP form must be sent to the primary health care provider (physician or advanced practice registered nurse) for review and signature before implementation of services. Use Form 3-6, the cover letter to the primary health care provider requesting his or her signature on the IFSP that indicates confirmation of the appropriateness of the diagnosis(es) as stated by the diagnostic (ICD-9 and or **ICD-10**) code(s) and the recommendations for the treatment services as they are written. This signature serves as a prescription for physical therapy and authorization for insurance billing. Since the IFSP is used to bill commercial insurance, the primary health care provider who signs the IFSP must meet the insurance plan's definition of primary health care provider. A faxed signature from the primary health care provider on the service page of the IFSP is acceptable.

Interim IFSP

Early intervention services may begin for a child who is eligible for Birth to Three services and the child's family prior to the completion of the multidisciplinary assessment under the following conditions:

A. Parental consent is obtained, and

B. An interim IFSP is developed that includes:

   1. the name of the service coordinator who will be responsible for the implementation of the interim IFSP and coordination with other agencies and persons, and
   2. the early intervention services that have been determined to be needed immediately by the child and the child's family.

C. The interim IFSP must be signed by the child's primary health care provider (faxed copy is permissible) before services may begin.

The multidisciplinary assessment (and review of the interim IFSP which then becomes the initial IFSP) still must be completed within 45 days from the child's date of referral to CDI.

- **Summary**

Completing the IFSP Form

The Connecticut IFSP was designed to be in compliance with IDEA 2004 and Sec. 303.344 of the IDEA regulations as amended in 2011. The Connecticut Birth to Three System's IFSP form was created to support the concept that the development of this plan is a process that begins with the first phone call to the system. Each section of the form helps to document the process. For more detailed information on the IFSP form page by page, see the *IFSP Handbook* at birth23.org/files/procedures/ifsphandbook.pdf

Completing the IFSP Form for a Child Receiving Services at No Cost

If a family of an eligible child meets the criteria for the Family Cost Participation fee (see Family Cost Participation Procedure) they may request to receive only those services that are available at no cost. IDEA Part C regulations require the following services must be provided at no cost to the family: evaluation, assessment (initial and annually), IFSP development and review, service coordination (including transition planning) and procedural safeguards.

When a family of a child eligible for Birth to Three services chooses to only receive those services available at no cost to the family the entire IFSP should be completed as it would be for any IFSP, reflecting information about the child and the family concerns as well as outcomes, transition plans and the team members who participated in the development of the plan. The outcome page must include strategies that reflect family and community resources since Birth to Three direct services will not be provided.

The service grid on Section 8 can be left blank or an annual assessment can be listed on the grid because this is the only Part C service that will be provided. Service coordination is already identified on the page and can be highlighted making sure the correct name and contact information is listed.

To help the family understand what will be happening as a result of this plan, it is recommended that the service coordinator attach an additional page (IFSP blank page can be used or the meeting notes section) to clarify what the family can expect when choosing only those services provided at no cost.

The parent still signs the IFSP indicating they have received their rights and are in agreement with the plan. If they give written permission to send a copy of the plan to the primary health care provider, the completed IFSP is sent, however the primary health care provider's signature is not required since no services are being provided.

The same process should be used when doing a periodic review or annual review of the IFSP for a family that will be receiving only those services provided at no cost as would be done with a family that is receiving direct services.

Periodic Review of the IFSP

To stay current with the child's and family's needs, the IFSP is reviewed at least every six months and more frequently if conditions warrant or the family requests such a review. Each time an IFSP is reviewed the clock starts again on the requirement that IFSPs be reviewed at least every six-months. The IFSP must be fully evaluated based on an updated assessment of the child in all areas of development within twelve months of the initial IFSP or the last full evaluation of the IFSP regardless of periodic review date(s).

The purpose of a periodic review is to determine the degree to which progress toward achieving the outcomes is being made and whether revisions to those outcomes, or services, or transition plan, or other information is necessary.

The review may be carried out at a meeting or by another means, such as a phone call, that is acceptable to the parents and other participants. (However, even if the review is by telephone, it does not eliminate the need for prior written notice or the team membership as specified in section 303.343 (b).)

Prior to the meeting or scheduled phone call, prior written notice must be provided to the family within a reasonable time to ensure that they will be able to attend. Use Form 1-6 (Prior Written Notice) for this purpose. An IFSP review may only be held without written prior notice if it is initiated by the parent rather than by the program.

Annual Meeting to Evaluate the IFSP

According to IDEA Part C regulations, a meeting must be conducted on at least an annual basis to evaluate the IFSP and revise its provisions as appropriate. This evaluation of the IFSP must be based on a recent assessment that addresses all five domains of development for the child. It does not need to be the result of a multidisciplinary assessment the child's primary interventionist, if qualified under the Birth to Three Personnel Standards to complete evaluations and assessments, can provide all of the assessment information, in collaboration with the family and other team members. The results of current outside evaluations, information from the curriculum assessment, and the family assessment should be used in determining the status of the outcomes and service needs..

The IFSP meeting arrangements must be made and prior written notice provided to the family using Form 1-6, Prior Written Notice.

Implementation of the IFSP

As soon as possible following the IFSP meeting, the service coordinator should send a full copy of the IFSP (with all referenced reports attached) to the parent and copies to everyone else the parent has listed on a signed release of information Form 3-3.

Programs must provide, arrange, or ensure access to the services described in the IFSP Section 8 following the meeting and after obtaining the required primary health care provider signature. Programs cannot provide or arrange for a service for which the parent has not given consent or for which consent has been withdrawn. All services scheduled to be provided at least monthly must begin no later than 45 days from the day that the parent signs the IFSP. The service coordinator should ensure uninterrupted implementation of an IFSP.

Indicating Start and End Dates on the IFSP

For an initial IFSP or for one with new services, the start date should reflect an estimate of when the primary health care provider's signature will be obtained. The date that the services will end is indicated on the line for that service under End Date. The IFSP is written for up to one year. The service end date should be listed as the date of the projected annual meeting to evaluate the IFSP or the day before the child's third birthday if that date comes first, unless services are expected to change sooner.

When services are scheduled to increase or decrease during the course of an IFSP use multiple lines on the service grid in Section 8 to record the projected changes. This example reflects a phased decrease of Physical Therapy services. The process would be reversed to reflect a phased increase in services.

What is Going to Happen	Delivered by: (Discipline responsible)	Location	How often	How Long	Start Date	End Date
Early intervention visit	Physical Therapist	Home	1 times a week	1 hour	3/3/14	6/3/14
Early intervention visit	Physical Therapist	Home	2 times a month	1 hour	6/4/14	3/3/15

When completing the IFSP at the annual review the start dates should begin again with the meeting date for ongoing services and the projected start date for any new or increased services. The physician's signature will need to be obtained before any new or increased services begin and the start date should reflect this projected date.

- **Revision**
- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

Points for Clarification

- References / Further Readings

Unit 3: Assessment of siblings and its implication in planning IFSP

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

- **Introduction**

The IFSP is a document that outlines the type of early intervention services your child will receive. A team of professionals- in conjunction with the child's family- develops the IFSP. Since you play an integral part in its development, it is important for you to understand the IFSP document and how your child will be assessed.

The major components of an IFSP include: A Cover Page that provides basic demographic information. A Levels of Development / Child Outcome Ratings Page that documents the results of the assessment and provides a picture of the child's current level of development in comparison to same-aged peers. A Functional Outcomes Page that outlines the goals established for the child. Family input is critical for this section of the IFSP to make sure

that the goals being established are consistent with family priorities and are delivered in the child's natural environment. The Authorized Service Plan Page is a detailed listing of the specific professional services that will be provided to the child including specifics on who, when, where and how often the services will occur. A Transition Page documents planning that has or will occur prior to changes in services. This is especially important when the child is nearing 3 years of age and begins the process of leaving early intervention services. An Implementation and Distribution Authorization Page verifies that legal safeguards and privacy rules have been followed. A Meeting Participants Page documents participants in the IFSP.

The assessment component of the IFSP will look at five areas of development:

- **Physical** - assesses fine and gross motor skills, how the child integrates with his/her environment, along with vision and hearing,
- **Cognitive** - assesses a child's thinking skills and how he or she processes information,
- **Communication** - assesses a child's receptive (understanding) and expressive (producing) language abilities,
- **Social/emotional** - assesses how a child interacts with other children, adults and his/her environment,
- **Adaptive** - assesses self-help skills like dressing and feeding.

The assessment of your child should stem from a multidisciplinary play-based evaluation.

A multidisciplinary assessment means that there should be a variety of professionals from different backgrounds assessing your child. Find out more on professionals in the field of early intervention.

A play-based evaluation means that your child will be observed while playing with other children and/or adults in a child-friendly environment.

- **Objectives**

- 12.1.1 An interim Individualized Family Service Plan (IFSP) may be needed pursuant to the Individuals with Disabilities Education Act regulations 34 CFR 303.310(c)(3) and 303.345 for children for whom the following has been determined:

- If there are exceptional circumstances that make it impossible to complete the evaluation and assessment within 45 days and the Service Coordinator has documented those circumstances in the child's EI record (for example, the child or parent has been hospitalized); or

- Obvious immediate needs were identified, even at the time of referral that would ensure the completion of evaluations/ assessments that will determine the child eligible for EI services (e.i. a physician recommends that a child with cerebral palsy begin receiving physical therapy for developmental issues as soon as possible). NOTE: In this case evaluations/assessments and eligibility determination must still occur and the initial IFSP must still be developed within the 45-day timeline.

- 12.1.2 An interim IFSP may not be used to extend the 45-day timeline unless 12.1.1 applies.

- 12.1.3 A physician's prescription must be obtained prior to direct service provision, routed to the appropriate service provider and a copy maintained in the CFC permanent record for each of the following EI services/service providers:

- Audiology and aural rehabilitation services provided by licensed Audiologists or licensed Speech-Language Pathologists;

- Occupational therapy services provided by licensed Occupational Therapists;

- Physical therapy services provided by licensed Physical Therapists; and

- Speech-language therapy services provided by licensed Speech-Language Pathologists.

- **Definitions**

- 12.2.1 The Service Coordinator shall determine whether an interim IFSP is needed pursuant to Individuals with Disabilities Education Act regulations 34 CFR 303.310(c)(3) and 303.345. If so, document the reason(s) the interim IFSP is needed in case notes. NOTE: An interim IFSP is not to be used to extend the 45-day timeline unless exceptional circumstances can be documented.

- 12.2.2 An interim IFSP can be implemented if there are exceptional circumstances that make it impossible to complete the evaluation and assessment within 45 days (i.e. child is ill). If exceptional circumstances have been determined:

- Document the exceptional circumstances that made it impossible to complete the evaluation and assessment within the 45-day timeframe;

- Develop and implement an interim IFSP to the extent appropriate and consistent with 303.345(a) and (b).

- 12.2.3 An interim IFSP can be developed if obvious immediate needs were identified even at the time of referral. NOTE: In this case eligibility must still be determined and the initial IFSP must be developed within the 45-day timeline.

- Document that obvious immediate needs were identified even at the time of referral. NOTE: An interim IFSP is not to be used to extend the 45-day timeline unless exceptional circumstances (see 12.1.1 above) can be documented; and

- Develop an interim IFSP to the extent appropriate and consistent with 303.345(a) and (b).

- 12.2.4 Within 303.345(a) and (b) states that an interim IFSP can be developed prior to evaluation and assessments if the following conditions are met:

- Parental consent is obtained;

- The interim IFSP includes the name of the Service Coordinator who will be responsible for implementation of the interim IFSP and coordination with other agencies and persons; and

- The interim IFSP includes the EI services that have been determined to be needed immediately by the child and the child's family.

- 12.2.5 Communicate with the family to arrange for a meeting time and location.

- 12.2.6 Provide reasonable prior written notice to the family and other participants of this meeting.

- 12.2.7 Assist the family in determining their ability to participate in the cost of services that are subject to fees.

- 12.2.8 Enter the interim IFSP dates in Cornerstone and complete the IFSP form with the child's parent/guardian and with input from the IFSP team members who recommended immediate services for the child and family.

- 12.2.9 Work with family to ensure that prescriptions for direct services are obtained prior to service provision as necessary.

- 12.2.10 Ensure that the services being discussed are appropriate to the needs of the child and/or family.

- 12.2.11 Facilitate the selection of available providers as described in Provider Selection and as required by applicable private insurance requirements. (NOTE: Private insurance may not be used for evaluation/assessment activities).

- 12.2.12 Generate authorizations for appropriate EI services using the Service Authorization screen in Cornerstone.

- 12.2.13 Arrange for the interim IFSP to be implemented.

- 12.2.14 Request service reports at the end of the interim IFSP period and monitor provision of services.

- 12.2.15 Maintain the child's permanent and electronic record during the interim IFSP period.

- 12.2.16 Ensure that evaluations/assessments are completed within the 45-day time frame unless the above applies and the evaluations/assessments could not be completed due to exceptional circumstances within the required 45-day time frame

12.3 Initial/Annual IFSP Development Policy

- 12.3.1 All IFSP meetings must be conducted as follows:

- In settings and at times that are convenient for the family; and

- In the native language of the family or other mode of communication used by the family unless it is clearly not feasible to do so.

- 12.3.2 Meeting arrangements must be made with, and written prior notice provided to, the family and other participants early enough before the meeting date to ensure that they will be able to attend.

- 12.3.3 All IFSP meetings must include the following participants:

- The parent or parents of the child;

- Other family members, as requested by the parent, if feasible to do so;

- An advocate or person outside of the family if the parent requests that the person participate;
- The service coordinator responsible for implementing the IFSP;
- The providers who completed the evaluations/assessments; and
- As appropriate, providers who will be providing early intervention services to the child/family (annual IFSP review meeting).
- 12.3.4 At the meeting to develop the IFSP the Service Coordinator shall:
- Coordinate and participate in the IFSP meeting;
- Ensure that the meeting is conducted in the parent's native language or other mode of communication, unless it is clearly not feasible to do so, or that an interpreter is present to interpret what is discussed;
- Seek a consensus by the multidisciplinary team regarding child outcomes. The IFSP team will measure each child's functioning as compared to same-age peers related to the following three outcomes:
- positive social-emotional skills, including social relationships;
- acquisition and use of knowledge of skills; and
- use of appropriate behaviors to meet needs.
- Seek a consensus by the multidisciplinary team regarding, functional outcomes, goals and objectives and an integrated plan to meet the outcomes, goals and objectives;
- If no consensus is reached, the Service Coordinator may establish a DHS-approved service plan (IFSP) that is consistent with DHS guidelines (EI policies/procedures) that will be reviewed by DHS designated experts (clinical technical assistance consultant(s) under contract by CFC offices);
- Provide the parents with prior written notice of the DHS proposed service plan IFSP. The parents may seek mediation or a due process hearing officer regarding other requested services; and

- Complete the Consent for Release of Information for Children With Identified Hearing Loss form and submit the form to the Illinois Department of Public Health (IDPH) Vision and Hearing Screening Program at the address identified on the form if the child meets any of the following criteria: 1) the child presented with an identified hearing loss during initial enrollment; 2) the child was referred from an IDPH Newborn Hearing Program with a confirmed hearing loss; 3) an identified hearing loss was confirmed after the initial IFSP meeting; or 4) the family of a child with an identified hearing loss chose not to accept EI services.

- 12.3.5 The IFSP is an important document. Those portions of the IFSP completed by hand must be legibly completed in ink.

- 12.3.6 The IFSP is a confidential document. Photocopies of the completed IFSP must be distributed to the family, providers and other individuals/agencies/physicians as soon as reasonably possible but no more than 15 business days after the completion of the IFSP meeting as directed by the parent's informed, signed consent on Section 7 of the IFSP (Implementation and Distribution Authorization). NOTE: AT and Transportation providers are not required to receive a copy of the IFSP.

- 12.3.7 The original signed IFSP is maintained in the child's permanent record housed at the CFC office.

- 12.3.8 All necessary services for each eligible child as agreed upon by the IFSP team, including the family, must be documented on the IFSP regardless of availability.

- 12.3.9 DHS shall not pay for services listed on the IFSP that DHS is not required to fund.

- 12.3.10 EI funding is the payor of last resort for IFSP services that DHS is required to fund.

- 12.3.11 A physician's prescription must be obtained prior to direct service provision, routed to the appropriate service provider and a copy maintained in the child's permanent record for each of the following EI services/service providers:

- audiology and aural rehabilitation services provided by licensed Audiologists or licensed Speech-Language Pathologists;

- occupational therapy services provided by licensed Occupational Therapists;

- physical therapy services provided by licensed Physical Therapists;

- speech-language therapy services provided by licensed Speech-Language Pathologists.

- 12.3.12 Decisions regarding services for each individual child are made by consensus of the IFSP team, including the parents. EI services should be based on a collaborative relationship between families and providers that emphasizes the family's role as central in EI activities. Frequency of developmental services should depend on the amount of time necessary for the family to incorporate new techniques into family routines and re-evaluation/assessment of the child's response to the developmental services.

- 12.3.13 The family is the primary interventionist and the primary foundation of their child's optimum development in all areas. In order for developmental services to be successful, it is essential for families to be involved in facilitating carryover to daily living activities. This means that the most important goal of the EI provider/family collaboration is to support the child's participation in the family and his/her functional/natural environment.

- 12.3.14 Intervention services should be considered as a means of achieving the functional outcomes that have been determined by the IFSP team. Specific strategies should be collaborative and interdisciplinary, avoiding unnecessary duplication of similar activities by multiple EI providers.

- 12.3.15 The inclusion of specific services in the intervention plan should never be based solely on the presence of a medical diagnosis or delay. Developmental services must be linked to specific developmental functional outcomes, regardless of the underlying cause of the developmental delay.

- 12.3.16 Acute rehabilitative therapy is not a developmentally based service, but is a medically based service that is provided by other resources outside the EI arena. Once the condition has become sub acute or chronic, EI services to treat the developmental delay(s) can and should be provided by the EI Program.

- 12.3.17 Evaluations, eligibility determination and IFSP development may occur on the same day if the following criteria apply.

- All required intake activity has been previously completed with the family, a review of existing records has occurred and the appropriate composition of the evaluation team has been determined. NOTE: See Intake and Eligibility Determination sections of this manual for steps that must be completed prior to the development of the IFSP.

- The family has been contacted and has agreed to the completion of evaluations, eligibility determination and the development of the IFSP on the same day. NOTE: A minimum of two disciplines is required to complete evaluations to determine initial eligibility and to re-determine eligibility on an annual basis. Arena or team evaluations may be used. However, the evaluators should be carefully selected to ensure that each evaluator is addressing an identified area of concern. Use developmental information obtained through the Referral and Intake processes to help determine the most appropriate composition of an evaluation team for each child.

- 12.3.18 If a family agrees to allow evaluations, eligibility determination and IFSP development to occur on the same day, the Waiver of Written Prior Notice form must be completed on that day in the presence of the family and the following information must be documented in writing:

- the evaluation team's determination regarding eligibility;

- the reason for the team's decision;

- the procedural safeguards available to the parent, including the right to refuse EI service; and

- the parent's consent to waive written notice of eligibility determination and written prior notice of the IFSP meeting. NOTE: Service Coordinators should carefully observe the family and ensure that they are adequately informed and emotionally prepared to proceed with the development of the IFSP. If the Service Coordinator feels that the parent(s) needs time to consider the evaluation findings or does not have sufficient support to proceed, the Service Coordinator should immediately stop the meeting and work with the family and providers to reconvene the team at a later date that is convenient to the family.

- Natural Environments - If it is determined that a specific service must be provided in a setting other than a natural environment, the IFSP team must complete the Natural Environments Worksheet to justify the decision to provide the service(s) in a non-natural environment.

- **Summary**

The Individualized Family Service Plan (IFSP) is the written agreement between the family and the local tiny-k program that documents a plan for services needed by eligible infants or toddlers between the ages of birth and age 3 and their families. Development of the IFSP is a dynamic process that involves a collaborative planning effort and partnership between the parents (and other identified family members or persons who know the infant or toddler and family) and the professionals who will deliver services and supports to the infant or toddler and family. It is intended as an ongoing process of planning and adjusting services for the changing developmental needs of the child and his or her family. The IFSP should be fully understood (i.e., be user- and reader-friendly) by the parents/family and professional team members. The IFSP process is family-centered and assists in empowering the family. Therefore, cultural values and beliefs should be sought and honored throughout the IFSP process. Partnerships in the development of the IFSP include active participation among all team members, including the parents/family members and professionals. The parents are key team players in providing information about their infant's or toddler's strengths and needs, as well as the family's strengths, resources, concerns, priorities, and preferences. However, it is the parents' choice to decide the extent of their role and level of activity in the development and implementation of the IFSP. It is the professional's role to fully explain the IFSP process so parents and other family members are empowered to choose their roles and levels of activity accordingly. Parents are responsible for the ultimate decision in determining whether they, their infant or toddler, or other family members accept or decline services. The contents of the IFSP must be fully explained to parents and their informed written consent must be obtained prior to the provision of services described in the IFSP. The family's signature on the IFSP indicates the family participated in the development of the IFSP. The family service coordinator initiates the IFSP process and takes responsibility for the development, implementation, review, and revision of the IFSP. Reasons for the Initial IFSP Process: 1) To summarize all information known regarding the infant's or toddler's strengths and needs and the family's strengths, concerns, priorities, preferences, and current resources 2) To review the family's identified routines, daily activities, and natural environments 3) To develop and refine outcomes the family has chosen (includes outcomes for both the infant or toddler and the family) 4) To develop strategies for meeting the identified outcomes 5) To determine appropriate services and supports that link to meeting the identified outcomes 6) To develop a written document that will guide the family, the family

service coordinator, and the other service providers 7) To determine the responsibilities of each team member 8) To determine how communication between the parent and other team members will be maintained 9) To determine where (natural environments), when, and how services and supports will be delivered to the infant or toddler and family I. Notice of the IFSP Meeting [34 CFR 303.342; § 303.421] The Prior Written Notice Form can be found at: http://www.ksits.org/download/Prior_Written_Notice.doc Meeting arrangements must be made with, and written notice of the meeting provided to, the family and other participants early enough before the IFSP meeting date to ensure they will be able to attend. In Kansas, providers give the family and other participants a 10-calendar-day written notice of the IFSP meeting. Parents have the right to waive this notice. Parents must be informed of their rights prior to the meeting, including the right to bring a family member or other individual who knows the infant or toddler and family and can contribute to preparing the IFSP. IFSP meetings must be conducted A. in settings and at times convenient to families, and B. in the native language of the family or other mode of communication used by the family, unless it is clearly not feasible to do so. If parents are unable to attend the scheduled IFSP meeting, the team will not meet. The reason for the cancellation of the meeting must be documented in the infant's or toddler's records. The IFSP meeting must be rescheduled as soon as possible and at a time mutually agreed upon by the parents and other team members. II. Timelines and IFSP Meetings [34 CFR 303.342(a)(b)(c); 303.20] A. The first IFSP meeting is held after the initial evaluation (including any assessments of the infant or toddler and family) and determination of eligibility. The initial IFSP meeting must be conducted within the 45-calendar-day time period from receipt of the referral for the initial evaluation. The meeting is to be scheduled at a mutually convenient time and place for the family and other participants. B. Periodic IFSP reviews for an infant or toddler and his or her family must be conducted every six months or more frequently if conditions warrant, or if the family requests a review. Quarterly reviews are encouraged. Reviews may be carried out at a face-to-face meeting or by another means acceptable to the parents and other participants (e.g,. Skype, phone). The intent of this review is to ensure the constantly changing developmental needs of the infant or toddler and priorities of the family are acknowledged and documented. The purposes of the periodic review are to: 1) review and revise the IFSP, as appropriate, 2) determine the degree to which progress toward achieving the outcomes is occurring,

- **Revision**

III. Participants in IFSP Meetings [34 CFR 303.343] A. Participants in the initial IFSP and annual review of the IFSP must include: 1) the parent or parents of the

infant or toddler, 2) the family service coordinator who has been working with the family or who has been designated by the local tiny-k program to be responsible for the implementation of the IFSP, 3) other family members as requested by the parent; 4) an advocate or other person outside of the family as requested by the parent, 5) the person or people directly involved in conducting the evaluations and assessments. If unable to attend, input from any of these individuals shall be provided through other means, including one of the following (a) Participating in a conference call (b) Having a knowledgeable authorized representative attend (c) Making pertinent records available at the meeting 6) as appropriate, the people who will be providing services to the infant or toddler, family, or both. B. Participants in the periodic review of the IFSP shall include 1) the parent or parents of the infant or toddler, 2) the family service coordinator, 3) other family members as requested by the parent

- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

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Points for Clarification

- References / Further Readings

Unit 4: Assessment of extended families needs and its implication in planning IFSP

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

• Introduction

For each infant or toddler with a disability who chooses to participate in the Infant Toddler Program, the lead agency must ensure the development, review, and implementation of an Individualized Family Service Plan (IFSP). The IFSP is developed by a multidisciplinary team, which includes the parent, and is done in compliance with state definition of evaluation and assessment, in a timely manner, and consistent with state and federal requirements. The IFSP is a written plan for providing early intervention services to an infant or toddler eligible for early intervention services and for the child's family. The plan is: • Based on the multidisciplinary evaluation and assessment of the child and information approved by the family or family assessment if the family wants to have such information included; Implemented as soon as possible once parental consent for the early intervention services in the IFSP is obtained; and • Developed in accordance with the IFSP procedures.

The Individualized Family Service Plan (IFSP) is a written plan outlining the provision of services for the eligible child and family. The IFSP must be developed jointly with the family and the appropriate qualified personnel and must be based on the multidisciplinary evaluation of the child and the resources, priorities, and concerns of the family. The IFSP outlines the services necessary to enhance the development of the child and the capacity of the family to meet the needs of the child. The Individuals with Disabilities Education Act (IDEA) and Idaho Code, Title 16, Chapter 1 require the development and implementation of an IFSP for every eligible child and family who chooses to participate in the Infant Toddler Program. A Service Coordinator is available to each family throughout the IFSP process and subsequent service delivery.

- **Objectives**

Terms related to an IFSP are defined in the following paragraphs. Documentation – Includes evidence that actions of implementation procedures have been carried out. Unless otherwise indicated; acceptable methods of documentation in a child's permanent record include physician orders and notes, copies of required forms and letters, staffing notes, evaluation narrative reports or protocols, nursing notes, or Continuing Service Reports (CSRs). Family Concerns – Areas family members identify as needs, issues, or problems they want to address as part of the IFSP process. Family Priorities – A family's desires and choices for how early intervention will be involved in family life. Family Resources – The strengths, abilities, and formal and informal supports that can be mobilized to meet family concerns, needs, or outcomes.

Family Strengths – Characteristics family members identify as contributing to the growth and development of the child and family. Among the areas of family life that many families identify as strengths are coping strategies, nurturing relationships, communication, religious or personal beliefs, family competence, and family/community interconnectedness. IFSP Team – Made up of family members and professionals who meet together to identify strengths and needs, develop and carry out Outcomes and strategies, and evaluate the effectiveness of the IFSP. Long Term Interruption – Includes items such as staff resignations, staff training, extended illness, maternity leave, extended family vacation or illness. ITP defines long term interruption as an interruption to early intervention services for greater than 90 days. Strategies – Planned strategies and resources used necessary to achieve a stated Outcome. Strategies include who will do what during which regular activities and routines, and where will it occur. Outcomes – Statements of changes a family wants to see for their child or themselves. Outcomes are identified and stated in the words of the family. Program

Graduation – Occurs when direct services are no longer indicated for a child following reevaluation by qualified service provider(s) and the child's team. Evaluation – The procedures used by qualified personnel to determine a child's initial and continuing eligibility. Assessment – The ongoing procedures used by qualified personnel to identify the child's unique strengths and needs and the early intervention services appropriate to meet those needs throughout the period of the child's eligibility.

- **Definitions**

The child's best interests must always be paramount in the case practice and service delivery of child and family services. The Best Interests Framework for Vulnerable Children and Youth (Department of Human Services, 2006) encapsulates that a child's experience of safety, stability and development must be viewed through the lens of their age and stage of life, gender and culture. The best interests principles in the CYFA (s. 10) provide the framework for intervention and place the child at the centre of all decisions and actions.

- **Summary**

An Individualized Family Service Plan (IFSP) is a working document produced collaboratively by program staff and family members that contains the agreed upon Early Intervention services for an eligible child and family. Based on a multidisciplinary eligibility evaluation and any completed assessments, the plan includes services necessary to enhance the development of an eligible child, and the capacity of the family to meet the child's needs. All certified Early Intervention programs use the current universal IFSP form approved by the Massachusetts Department of Public Health. It's important to have a plan in writing, which shows the work families and staff will do together. The IFSP is the written plan that lists services and supports to eligible children and families. The plan will include:

- Information about your child - including assessment results, your family's concerns, and your child's strengths.
- The outcomes (goals) you want to achieve for your child and family.

- Strategies and activities to reach those outcomes together .
- The services to be provided - how often, by whom, when, and where.
- The person who is your service coordinator. Your service coordinator will help you develop your plan, make sure it is followed, and explain your family rights and procedural safeguards.
- The steps to help you and your child in the transition from EI.

At Early Intervention, we believe that no one knows your child as well as you. You are a partner in developing the IFSP, and it is important for you to be part of the process.

You may want to think about some things as the process gets started:

- What are some of the things you and your child do everyday?
- What activities does your child enjoy doing? What activities are difficult for your child?
- What do you need to support you as a family?
- What are your hopes and dreams for your child?

- **Revision**
- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

Points for Clarification

- References / Further Readings

Unit 5: Assessment of family and community resources for inclusion and strengthening of family, documentation, recording and reporting

- **Introduction**
- **Objectives**
- **Definitions**
- **Summary**
- **Revision**
- **Assignment/Activity**
- **Points For Discussion And Clarification**
- References / Further Readings

• Introduction

The need to improve academic achievement among diverse student populations—notably African American, Latino, Native American, immigrant and language minority students, and students from poor families—is one of the most persistent and challenging issues that education faces. This research synthesis looks at the roles families can and do play in addressing that issue. The report also explores barriers to involvement for minority and low-income families, strategies used to address those barriers, and recommendations that local educational leaders can adapt to address their specific needs. This is one of a series of reports that examine family and community connections with schools. The reports are

intended to help local school, community, and family leaders obtain useful information derived from empirical research. The federal commitment to grounding educational strategies in rigorous scientific research—a commitment laid out in the No Child Left Behind Act and elsewhere—has led to close examination of the research base addressing a number of important educational topics. The primary audience for this synthesis is practitioner leaders—superintendents, principals, curriculum supervisors, lead teachers, family involvement staff, community leaders, and others who may be responsible for or interested in helping shape local policy or practice regarding school, family, and community connections. The report is organized so that, depending on their needs and interests, local leaders may quickly access practical information or explore the topic in depth. Secondary audiences for the report include local and state policymakers, program developers, professional development providers, and researchers. According to the dictionary, "diversity" means "difference." Given this definition, the critical question becomes, "Different from whom, or what?" In current educational discourse, the terms diverse and diversity most commonly refer to students who are different from what the literature describes as the "mainstream" of U.S. society, i.e., students who are not White, middle-class, native-born, and/or native English-speaking. As the word is commonly used, a diverse classroom or school population does not necessarily indicate a heterogeneous group of students. Rather, the term tends to be used for any group of students, however homogeneous, most of whose members do not reflect mainstream characteristics. Diversity often serves as a stand-in for other terms, such as "minority" or "disadvantaged"; it is sometimes used euphemistically, to mask or avoid issues (such as race) that are embedded in other terms. The literature on diversity includes a wide range of student and family characteristics and affiliations. From the universe of possibilities, this synthesis focuses specifically on three categories: race or ethnicity, culture (including language), and socioeconomic status. These three categories reflect the most common use of the term "diversity." For example, Hoffman (1997) notes that "almost every definition [of diversity] focuses on the experiences of minorities that have historically been ill-served by American education and socioeconomic structure" (p. 378). Moll (in a foreword to Paratore, Melzi, & Krol-Sinclair (1999), 1 specifically defines diversity in terms of "racial, cultural, or class differences" (p. x). Conceptual frameworks, research studies, and educational programs often span these three categories. The literature strongly suggests that issues related to race, culture, or class are among the biggest challenges for improving U.S. education, in terms of both numbers of students addressed and persistent challenges in effectively serving these populations. In his foreword, Moll states: The issue of how to address diversity in schools. . . promises to be the foremost educational issue well into the 21st century. In fact, in my estimation, educational researchers

who do not address issues of diversity in one form or another, especially in the United States, are at risk of their work becoming irrelevant. (p. x)

- **Objectives**

Parent, family, and community involvement in education correlates with higher academic performance and school improvement. When schools, parents, families, and communities work together to support learning, students tend to earn higher grades, attend school more regularly, stay in school longer, and enroll in higher level programs. Researchers cite parent-familycommunity involvement as a key to addressing the school dropout crisis1 and note that strong school-family-community partnerships foster higher educational aspirations and more motivated students.2 The evidence holds true for students at both the elementary and secondary level, regardless of the parent's education, family income, or background—and the research shows parent involvement affects minority students' academic achievement across all races.3 Supporting teaching and learning requires addressing students' social service needs, as well as their academic ones, and this broad-based support is essential to closing achievement gaps. The positive impact of connecting community resources with student needs is well documented.4 In fact, community support of the educational process is considered one of the characteristics common to high-performing schools.5

- **Definitions**

Parent, family, and community involvement means different things to different people. A research-based framework,6 developed by Joyce Epstein of Johns Hopkins University, describes six types of involvement— parenting, communicating, volunteering, learning at home, decision making, and collaborating with the community—that offer a broad range of school, family, and community activities that can engage all parties and help meet student needs. Successful school-parentcommunity partnerships are not stand-alone projects or add-on programs but are well integrated with the school's overall mission and goals. Research and fieldwork show that parent-school-partnerships improve schools, strengthen families, build community support, and increase student achievement and success.

- **Summary**

Although the research unequivocally affirms the positive and long-lasting effects of parent, family, and community involvement on student learning, this data is often overlooked in local, state, and national discussions about raising student achievement and closing achievement gaps. Education reform efforts that focus solely on classrooms and schools are leaving out critical factors essential for long-term success. What happens before and after school can be as important as what happens during the school day. Even the most promising reforms can be "reversed by family, negated by neighborhoods, and might well be subverted or minimized by what happens to children outside of school."8 While education is clearly an asset to the individual, it also benefits families and serves the common good. Education is a core value of our democratic society, and it is in everyone's self-interest to insure that all children receive a quality education. Our democracy, as well as our economy, depends on an educated citizenry and skilled workforce. Too many policymakers, community leaders, and even parents still view schools and student learning as the sole responsibility of educators. While educators take their professional responsibilities seriously, they also recognize that they cannot do it alone. They need and depend on the support from parents and community members. One dynamic too often observed is that parent involvement in education tends to decline as their children go up in grade, with a dramatic drop once students reach middle school.9 In fact, the lack of parental involvement is viewed by teachers, administrators, the public, and even parents of school-age children, as the single biggest problem facing our nation's schools.10 To promote student growth and school success at every grade and age, well thought out parent-communityschool partnerships, linked to school improvement goals, are needed in every community

- **Revision**

- **Assignment/Activity**

POINTS FOR DISCUSSIONS / CLARIFICATION

After going through the unit you may like to have further discussion on some points and clarification. Note down those points:-

Points for Discussion

Points for Clarification

- References / Further Readings

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RAJA BHOJ MARG (KOLAR ROAD), BHOPAL- 462016