

**B. Ed. Spl. Ed. (M. R. / H. I. / V. I)-
ODL Programme**

AREA - C

**C-12 : ASSESSMENT AND IDENTIFICATION OF
NEEDS [MENTAL RETARDATION/
INTELLECTUAL DISABILITY]**



**A COLLABORATIVE PROGRAMME OF
NETAJI SUBHAS OPEN UNIVERSITY
AND
REHABILITATION COUNCIL OF INDIA**



AREA - C ● DISABILITY SPECIALISATION COURSES

COURSE CODE - C-12 M. R./I. D.

ASSESSMENT AND IDENTIFICATION OF NEEDS

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Dr. Ashit Baran Aich
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Netaji Subhas Open University

From the Vice-Chancellor's Desk

Dear Students, from this Academic Session (2015-17) the Curriculum and Course Structure of B. Ed.- Special Education have been thoroughly revised as per the stipulations which featured in the Memorandum of Understanding (MoU) between the Rehabilitation Council of India (RCI) and the National Council for Teacher Education (NCTE). The newly designed course structure and syllabus is comprehensive and futuristic has, therefore, been contextualized and adopted by NSOU from the present academic session, following the directives of the aforesaid national statutory authorities.

Consequent upon the introduction of new syllabus the revision of Self Instructional Material (SIM) becomes imperative. The new syllabus was circulated by RCI for introduction in the month of June, 2015 while the new session begins in the month of July. So the difficulties of preparing the SIMs within such a short time can easily be understood. However, the School of Education of NSOU took up the challenge and put the best minds together in preparing SIM without compromising the standard and quality of such an academic package. It required many rigorous steps before printing and circulation of the entire academic package to our dear learners. Every intervening step was meticulously and methodically followed for ensuring quality in such a time bound manner.

The SIMs are prepared by eminent subject experts and edited by the senior members of the faculty specializing in the discipline concerned. Printing of the SIMs has been done with utmost care and attention. Students are the primary beneficiaries of these materials so developed. Therefore, you must go through the contents seriously and take your queries, if any, to the Counselors during Personal Contact Programs (PCPs) for clarifications. In comparison to F2F mode, the onus is on the learners in the ODL mode. So please change your mind accordingly and shrug off your old mindset of teacher dependence and spoon feeding habits immediately.

I would further urge you to go for other Open Educational Resources (OERs) - available on websites, for better understanding and gaining comprehensive mastery over the subject. From this year NSOU is also providing ICT enabled support services to the students enrolled under this University. So, in addition to the printed SIMs, the e-contents are also provided to the students to facilitate the usage and ensure more flexibility at the user end. The other ICT based support systems will be there for the benefit of the learners.

So please make the most of it and do your best in the examinations. However, any suggestion or constructive criticism regarding the SIMs and its improvement is welcome. I must acknowledge the contribution of all the content writers, editors and background minds at the SoE, NSOU for their respective efforts, expertise and hard work in producing the SIMs within a very short time.



Professor (Dr.) Subha Sankar Sarkar
Vice-Chancellor, NSOU

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**C-12 : ASSESSMENT AND IDENTIFICATION OF
NEEDS [MENTAL RETARDATION/
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**Netaji Subhas Open
University**

**AREA - C
C-12 : ASSESSMENT AND
IDENTIFICATION OF NEEDS**

C-12 □ Assessment and Identification of Needs

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Unit - 1 □ Intellectual Disability—Nature and Needs

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1.1 Introduction

Intellectual Disability (ID), once called Mental Retardation, is characterized by below-average intelligence or mental ability and a lack of skills necessary for day-to-day living. People with intellectual disabilities can and do learn new skills, but they learn them more slowly. There are varying degrees of intellectual disability. Intellectual disability has limitations in two areas. These areas are *Intellectual functioning*. Also known as IQ, this refers to a person's ability to learn, reason, make decisions, and solve problems. *Adaptive behaviors*. These are skills necessary for day-to-day life, such as being able to communicate effectively, interact with others, and take care of oneself. Historically, the person affected by Intellectual disability have experienced varied treatment ranging from abandoning them to providing them equal opportunities like non-disabled persons. The definitions have undergone changes based on the trend of the day. The various definitions also will be discussed.

The word "Etiology means causation. Knowledge of the causative factors of intellectual disability is important. Intellectual disability can be caused by any condition that impairs development of the brain before birth, during birth or in the childhood

years. Several hundred causes have been discovered, but in about one- third of the people affected, the cause remains unknown.

There are varying degrees of intellectual disability, depending on the extent of damage to the brain in the individuals. Here we will see how they are classified based on certain yard sticks .Medical classification, go by causes/etiology, psychological classification are made based on IQ. The educational goes by potentials of the persons with intellectual disabilities.

With the implementation of the Persons with Disabilities Act (PWD), 1995 intellectual disabilities has been recognized as a disability with an identity of its own. Earlier, data on mental retardation had been clubbed with data on mental illness. It is only in the recent years that early identification of persons with mental retardation has become possible. Systematic thinking on screening and identification emerged consequent to the National Policy on Education (NPE), 1986, even though working groups had been set up even as early as 1981 during the International Year of the Disabled Persons (IYDP) by the then Ministry of Welfare. Early identification includes screening, early diagnosis and parent counseling.

1.2 Objectives

After studying this unit you will be able to:

- Narrate the historical perspective of Intellectual Disability
- Understand definition as they evolved
- Define mental retardation
- Understand the causes and prevention of MR
- Explain the classification of MR.
- Understand different screening methods.
- Understand needs of PWDS.

1.3 Historical perspective of Intellectual Disability (ID)

History of Intellectual Disability

Identification of persons with mental retardation and affording them care and management for their disabilities is not a new concept in India. The concept had been translated into practice over several centuries as a community participative

culture. The status of disability in India, particularly in the provision of education and employment for persons with mental retardation, as a matter of need and above all, as a matter of right, has had its recognition only in recent times, almost after the enactment of the Persons with Disabilities Act(PWD), 1995. As years passed by "the right to live received recognition and importance. However they were considered as menace to the society 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 hours total care.

History of intellectual disability in India

- As early as the Ramayana period (around 5000BC) we have a reference to intellectual disability. Queen kaikayi's maid Mantara was dull witted and thus easily duped. The concept of problems was mentioned first in Atharva veda.
- A much older system of philosophy the Sankya, contain 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 behavior has always been hard, but are more readily recognizable " childish mind" model for intellectual disability appeared in a riddle of the Upanishads compiled perhaps in 500BC.
- A careful study of the ancient Indian literature reveals that there have been a few references to persons with intellectual disability. In the mythology of patanjali, we read that patanjali had to teach Goudapathaga, who was a dull headed persons.
- The Patanjali yoga sutras 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 intellectual disability and discusses the different types and classification.
- Clear reference to persons with intellectual disability can be traced in the Sangam literature (200BC-200AD) by Eryanar 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 viz, Vasusakti, Ugrasakti and Anekasakti, who were greater fools or “supreme block-head”. This folly caused their father's courtier Vishnu Sharma to devise the world's first special education text Panchatantra, around the 1st century Be. Basham remarks "Never was a school text book better written"
- Ancient Hindu, Buddhist and Sanskrit text 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 might end up with more time at school than the clever ones.
- Arthasatra mentions treatment and care given to people with disabilities at mattas (monasteries) and in the time of Ashoka, at the hospital at Pataliputra.Sinhalese asylums for people with disabilities were set up by the century in what is now SriLanka.

History of special Education in western countries:

Introduction from Ancient times to 1200AD

The subject of mental retardation has been neglected in ancient writings but there is enough evidence in historical records to show it existed. The causes were then as now congenital, chromosomal, inter uterine damage, premature or protracted birth, or infections and accidents in infancy and childhood. Infant mortality was high and most children with Downs Syndrome, cerebral palsy or other disability where there was a weakened resistance to infection would have succumbed early to pulmonary infections, heart defects and gastroenteritis.

However, some would have survived, like children who had a mental disability but no physical impairments. At a time when most people lived by agriculture, herding sheep and goats, or fishing, and reading and writing were unnecessary, moderate intellectual disability would not have been important. People with disabilities, whether physical or mental disabilities were treated in different ways according to

where they lived. Some parts of the Talmud advocated disability as a holy state and a means of getting to heaven and similar sentiments were expressed towards those who helped disabled people. At the heart of Jewish law was the idea that every human being newborn or adult, deformed or healthy, slave or free was made in the image of God. Abortion and infanticide were condemned while pagan religions sanctioned, condoned and encouraged the killing of malformed or sick infants.

Plato stated that pregnant women over the age of forty years should have an abortion and Aristotle recommended both infanticide and abortion if there was a risk of a deformed child. He supported a law to ensure the compulsory exposure of all malformed babies who were abandoned with their ankles pinned together. The birth of a retarded child was interpreted by the Greeks as a punishment inflicted on its parents by the gods. Rearing a sick or disabled child was economically burdensome and unprofitable.

In Sparta, racial homogeneity was prized. Citizens had to be physically strong and mentally able. There was a legal requirement to abandon deformed and sickly infants. Babies were left to perish on a mountainside or thrown into a chasm. If the disability was not obvious at birth, but the child was later found to be an "idiot" the child would be abandoned. And left to fend for itself, Meanwhile the Celts had a much more enlightened attitude. The social order was based on community, democracy and individual rights. Each clan or tribe occupied its own territory, and this was divided into three sections. The clan leader and his family had one section, another was set aside for the use of the poor, sick and disabled and the largest section was common ground for the whole tribe. Members working their own plots paid taxes which were used for the upkeep of the community and to support the poor, the sick and the aged. The Celts had hostels, orphanages and hospitals. Ancient Celtic laws show there was a well-developed medical service and that each individual tribe was responsible for caring for the sick, the wounded and those with mental handicaps. The Celts covered territory from Ireland to Hungary, from Sweden to Spain.

Early Roman law gave power to the father to have absolute rights over his children. He could expose any female infant or a child of either sex who was deformed or disabled. Soranus a physician in the 1ST and 2nd centuries AD wrote the earliest known treatise on gynecology and in it he had a chapter entitled How to recognize the Newborn that is worth rearing. He gave a quite scientific and detailed analysis of the various medical examinations which should take place.

Some mentally retarded people would have received asylum in sanctuaries as

did other groups in the ancient world. However feeble minded and mentally disabled people had their political rights curtailed and would not have been granted Greek or Roman citizenship.

As Christianity spread, a far more compassionate view was taken of people with disabilities of any kind. Charity towards people with disabilities and illnesses was preached and the Church set up orphanages for abandoned children in the 3rd and 4th centuries and the earliest hospital was founded by St Fabiola in Rome in 399 AD. St Nicholas, the Bishop of Myra showed particular compassion towards mentally retarded children and urged giving them tender care.

In the Islamic world from the seventh century, feebleminded people were treated with respect. There was a belief that their minds were in heaven while their body moved around amongst ordinary mortals. Of all people we would think of as mentally disabled were thought to have any disability, but rather to be special individuals who were favoured by Heaven.

Little was known about the causes of mental handicap, and medicine was based on "humours" and a close link between the body, mind and soul. Europe was still in the Dark Ages of science and medicine but in the Islamic world Avicenna (980-1037) wrote a textbook the Canon of medicine in which he mentioned hydrocephalus, meningitis and other mental disorders. He recognized and defined various levels of intellectual functioning and knew that brain injury could affect memory and speech. There were mental hospitals in Cairo and Baghdad in the 11th and 12th centuries. Ibn Al-Baitar also wrote about mental disabilities during the first half of the thirteenth century.

From the time of the end of the Roman Empire in Europe until the late middle ages, life remained very rural. By 1066 England had a population of less than one million. The majority lived in villages and hamlets surrounded by forests and marshes. Agriculture was the main occupation and the most powerful people were those who owned the most land. In a rural society literacy and intellectual ability were not important and every member of the family would have taken part in the daily grind of fetching water and fire-wood, ploughing the fields, or feeding the animals. Disabled people would have relied on relatives for their care but with poverty, malnutrition, poor hygiene and a feudal system life would have been hard. However city life was beginning again and St Bartholomew's hospital was founded in 1142 in London. In Prussia we have a record from the 12th century which said that mentally afflicted people were put in prison. As the medieval period continued, the population gradually increased and life became more sophisticated as more people moved into towns and

the generation of wealth meant that new phenomena such as urban beggars, some of them disabled became an issue and the importance of landed wealth led to the first law defining a distinction between mentally ill people and mentally disabled people.

The Mediaeval period 1200-1450

Children with mental disabilities could be born to anyone rich or poor. Medieval society was based on the preserving and transfer of landed wealth. If the heir to property were mentally disabled, the King wanted to make sure that he was protected during his life time (or her lifetime) and that the property then went to the rightful successor.

During the second half of the 13th century a law was passed. It distinguished between "natural fools", people who were mentally disabled from birth and those who had a mental illness and might recover or have periods of lucidity. The King used to "contract out" care of mentally disabled people to private individuals. In fact often private individuals would tell the king about a mentally disabled person so that they might get custody it was a private but monitored guardianship. They would pay the King a lump sum called a fine and annual rents and they would enjoy the revenue from the land and provide the person with the necessities of life until they died and the land passed to their heirs For a mentally ill person, especially one who had periods of lucidity they had to be kept at the economic level suited to his rank and the guardian could not have the surplus revenues. If f they recovered the guardian no longer looked after the estate.

A record of an Examination of Emma de Beston in Cambridge 1383.exists.Emma was asked whence she came, said she didn't know. She knew there were seven days in the week but could not name them. She said she had had 3 husbands but couldn't name one. She was asked how many shillings there were in 40 pence. She did not know. Asked if she would take 40 silver groats or 40 pence she said they were the same value. They found she was not of sound mind having neither sense nor memory nor sufficient intelligence to manage herself her lands and her goods. By inspection she had the face and countenance of an idiot .Because of this 80% of cases coming to the court described the heir as a fool rather than a madman because the guardian got more revenue from a fool. When the law was changed in the 16th century the number of people described as mentally disabled coming before Courts of Wards dropped to 30% in 1640.There was no dramatic decline in mental handicap. It is simply that when it was no longer advantageous to the guardian to have custody of someone who was disabled rather than mad, more people were recognized as mentally

ill rather than mentally disabled.

Another document from the thirteenth century clearly distinguishes mentally ill from mentally disabled people. It stated that "women, serfs, people under 21, open lepers, idiots, attorneys, lunatics, deaf-mutes, those excommunicated by a bishop and criminal persons" were all barred from becoming judges.

In 1376 in Hamburg mentally retarded persons were confined to a tower in the city walls called the idiots cage. In Gheel in Belgium there was a saints shrine said to cure the mentally ill and afflicted. Many mentally handicapped and mentally ill people went there. Eventually an adult care scheme grew up where families fostered people with mental handicaps. This is still going on.

Renaissance, Reformation and Beyond 1450-1800

Many paintings of the Renaissance, show infants and children with Downs Syndrome depicted as cherubs and the infant Jesus. Various explanation have been put forward. Some have said that people with mental or physical disabilities were all part of Gods order blessed infants of their good God, and had a special place alongside popes, bishops, king's noblemen and knights. People believed they would gain the favor of God by giving help and compassion to them.

If this were true, it would have been a golden age where handicapped people were not only socially accepted but taken as models of divine and saintly beings. Unfortunately this theory is not entirely true. During the sixteenth and seventeenth century there are two views of disabled people ,either related to Satan or innocents unstained by normal and sinful human characteristics.

In 1480, a book about witches. The Mallus Malificorum was published and read widely .In some areas where there was great superstition, women who gave birth to a disabled child were sometimes killed or exiled. They believed that a baby with a deformity or mental handicap was not the baby that was born to its mother but a replacement left by fairies and demons. This view was adapted from pagan folklore and Christianized explanations of the story were that the parents were guilty of some wickedness, or that the parents loved the child more than they loved God or that the mother had been seduced by the devil. Superstition held that a disabled, or deformed child was bad luck a curse divine retribution or that disability indicated possession by the devil or was the outcome of evil-doing.

During the Middle Ages and into the 16th century people with physical defects, like hunchbacks or dwarfs, and people with simple minds were often kept as court

jesters and fools. There is a tradition that Tycho Brahe(1546-160 1) the astronomer had as a close companion an imbecile to whose mutterings the astronomer listened to as divine revelations.

Mentally disabled people would have been cared by many members of the family but if the breadwinner died, or the family fell on hard times they could claim relief from the parish. 17th and 18th century parish records mention people with learning disabilities describing them as idiot, stupid, innocent, witless. Different phrases like crazy or mad were used for mentally ill people. If the primary care died then person could be the legal obligation of parish .and be looked after by the Parish nurse or other parishioners. Sometimes they would receive a clothing allowance.

Bethlem or Bedlam Hospital was transferred to the City of London. In 1598 a committee appointed to inspect Bethlem found it " so loathsomely and filthy kept, not fit for any man to come into the said howse." there was an attitude that people who placed lunatics or idiots in Bedlam ought to pay for their upkeep. It was now felt that families who couldn't look after the mentally disabled person themselves should pay towards their upkeep and care elsewhere. Sometimes the mentally handicapped person was cared for in his own lodgings by a servant the beginning of private lunatic asylums.

In early 16th century the majority of hospitals were almshouses and leper houses which did not provide medical care. During the seventeenth century hospitals providing care for the sick increased in number during the eighteenth century, specialist hospitals especially lying in hospitals became more common as did institutions into which the mad were detained since madness was not seen as a medical problem, these institutions were refuges rather than hospitals in the modern sense. 1615 in a legal dictionary, "an exposition of certain difficult and obscure terms States "Idiot is he that is a fool natural from birth and know not how to account or number 20 pence nor cannot name his father or mother nor of what age himself is or such like easy and common matters so that it appears that he has no manner or understanding or reason nor government of himself whether it is for his profit or disproof." In the 1650 's the managers of Bedlam tried to make a distinction between the curable mad and "those dangerous to be abroad" who should be in a hospital and harmless idiots who should not befit would be necessary to certify those who were lunatic .A subcommittee was set up to identify and eject those who were idiots and not lunatic. Bedlam was rebuilt in 1676.

Segregation, Incarceration and Eugenics 1800-1945

The period from 1800- 1945 has been in many ways one of the worst for people

with mental handicaps and disabilities. Industrialization and scientific theories led to them being shut away from society and the legacy of prejudice is still with us today. This was also the period during which thousands of disabled people became the victims of mass murder by the Nazis.

There were five categories of mental illness: melancholia or delirium, mania with delirium, mania without delirium, and dementia. - The fifth was, idiotism or the obliteration of the intellectual faculties. He described a defective perception and recognition of objects, partial and total abolition of the intellectual and active faculties, This disorder may originate in a variety of causes such as excessive or enervating pleasures, the abuse of spirituous liquors, violent blows on the head, deeply impressed terror, profound sorrow, intensive study, tumors of the cavity of the cranium, apoplexy, excessive use of the lancet in the treatment of active mania.

The greatest number of idiots are either destitute of speech or are confined to the utterance of some inarticulate sounds. To be an idiot is almost levelled with an automaton to be deprived of speech or to Seguin a pupil of Itard founded in Paris the first school for idiots in 1837 .In 1846 the first private school for mental defectives in England was opened in Bath. In 1847 Park House in High gate opened by a philanthropist Andrew Reed and this had an annexed at Colchester which later became the Royal Eastern Counties hospital and newly built model asylum at Earl's wood which opened in 1855. It had 500 beds which set the pattern for many similar institutions and these 19th century hospitals lasted well into second half of the twentieth century. Retain that power merely of pronouncing inarticulate sounds, to be obedient only to the instructions one and sometimes to be insensible even to that to be incapable of feeling, attending to or gratifying without assistance their appetite for food, to remain motionless in the same place and position for several days together without discovering one single expression either of thought or expression. To be at other times subject to certain furious and evanescent outbursts of passion.

Such are the characteristics of idiotism. Hence attention to their physical wants and comforts is the utmost that can be devised for these unfortunate beings ... education would not be appropriate owing to the natural indolence and stupidity of idiots they might be engaged in a manual occupation suited to their capacities.

In 1867 the Idiots Act was passed. It was decided that "harmless paupers of the chronic or imbecile class should not be the responsibility of the workhouse, which was their only refuge. Instead they should be seIn the 1860's the first large scale institution was built in order to incarcerate and segregate people then known as idiots

and the insane in Large numbers. Its chief physician was Down who was the first person to accurately describe the syndrome which bears his name The theories of Dr. Down.

He believed that people with Downs Syndrome were a throwback to a more primitive racial type. He was impressed by the oriental appearance of their eyes and thought his patients looked like Mongolians whom he apparently believed to be primitive. Down may have thought that different ethnic races represented different evolutionary stages in man which meant that people with "mongolism" were throwbacks or representatives of arrested development at some earlier evolutionary stage. At this time there was a belief that the British race was superior to all others, a view we now know to be racist. Mental handicap appeared in all social classes the wealthy Victorians in Britain began to make residential provision for their own affected relatives and this provision was later extended to include the other social classes. In England small schools for the so called idiots began to open and pre occupation with education included those with disabilities. Unfortunately this only interested a minority and as industrialization gained momentum there was little room for the weak and incapable. The workhouses became full of social rejects. Until 1870 the majority of children in the UK received no formal education. Education was provided by voluntary bodies, the church and private fee paying schools. Most "mentally defective" children were confined to workhouses and institutions. Asylums were set up and "educable idiots and imbeciles" there received training and formal teaching. The Forster education act of 1870 established school boards to provide elementary education in those areas where there were insufficient places in voluntary schools.

National Curriculum

Elementary classes were large. Instruction was based on the "official code" with rote learning and memory tests. Teachers were paid by results. Some children were not able to learn in this environment. The 1899 Elementary Education (defective and epileptic children act) applied to children who "by reason of mental or physical defect are incapable of receiving benefit from the instruction in ordinary schools but are not incapable by reason of such defect of receiving benefit from instruction in special classes or schools. There was considerable reluctance however to set up such schools and by 1908 only 133 out of 327 education authorities were using their powers.

In 1914 the power to provide education for mentally defective children became a duty and in 1918 for physically disabled children. These special schools and

private institutions were often run as charities supported by voluntary subscriptions. The main purpose was to provide training and discipline so that the disabled inmates became less of a public burden and didn't end up as beggars or living on poor law handouts or becoming a public nuisance. While the institutions were providing asylum(refuge) their inmates were expected to help run them. It was felt a healthy body encouraged a healthy mind and Satan made work for idle hands. Physical training and work therapy were encouraged. Social training including simple tasks like mending and cookery was given and instruction in whatever primary subjects could be learned such as telling the time and classes in Speech. They were not hospitals but therapeutic communities did not to care for the "helpless".

In Ireland in the Late 19th and early 20th century religious orders began to take over country mansions, build residential centers, or take over disused sanatoriums Isolated by physical barriers spacious grounds, walls, busy roads. Nuns and monks intention to provide a high quality of devoted care for "children of God" emphasizing their role as protectors of a rejected population, these religious communities drew upon their own traditions of separation from the outside world. They catered for a wide geographical area.

By the end of the 19th century the enthusiasm for education had given way to demands for the permanent segregation from the rest of society. Eugenics was based on a wrong interpretation of Darwin's theories of natural selection. Focusing on hereditary nature of defects it led to wholesale incarceration... Disabled people became segregated into institutions there was no welcome for disabled people in the community. The National Assistance Act of 1911 introduced the first welfare benefits.

A Royal commission on the feeble minded estimated that there were 150,000 "mental defectives "in England and Wales. The care of the mentally handicapped was passing from educationalists to the medical profession who were thought to be able to provide answers to the problem. The government came under pressure to do something for mentally handicapped people... This pressure came from two opposing schools expressing compassion on one hand and fear on the other. The Mental Deficiency Act of 1913 laid on local authorities the duty of providing care for certain cases of mental deficiency .This was done partly by Guardianship paying for accommodation in certain voluntary institutions providing new premises.

Inclusion, Civil Rights and a better life 1945-2000

The 1944 education act introduced Compulsory Secondary Education. It also

introduced the 11 plus segregating children into secondary modern and grammar schools and subdividing children with impairments into 11 categories including educationally sub normal ,maladjusted and those with speech defects as well as blind, deaf and delicate. Seriously disabled children had to be educated in special schools more and more special schools were opened in the 50s 60s and 70s.

In 1948 with the introduction of the National Health Service in Great Britain many institutions were nationalized and became hospitals .This led to more emphasis on the more helpless patients and on those with disturbed behavior being admitted to these hospitals to the exclusion of those only requiring accommodation and simple supervision. The National Assistance Act of 1948 imposed a duty on Local Authorities to arrange for the welfare of disabled persons. These include people who are "deaf, blind, dumb, and other persons who are permanently handicapped by illness, injury or congenital deformity or who are suffering from a mental disorder" Mental disorder covered both mental illness and mental handicap.

In the 1950's and 60's it was recognized that environment plays an important part in the development of social and mental ability and in 1970 under the Education (Handicapped Children) Act the 70,000 children who had been considered uneducable under the terms of the 1913 MDA act got the right to education under a new category of "educationally sub normal-severe "and 400 new special schools were formed out of the old junior training centers.

The Disabled Persons employment act of 1959 says a local authority must make provision for sheltered employment, training and assistance in finding work for registered disabled people.

The chronically sick and disabled persons Act of 1970 put a duty on local authorities to provide services for disabled people such as practical assistance in the home, help with getting TV, radio, library and other recreational facilities, help with travelling to services arranged or approved by the local authority, assistance with adaptations to the home for greater safety or comfort, holidays, meals at home and elsewhere and help with getting a telephone training.

But attitudes change very slowly and a leaflet from as late as 1973 published by the then National Society for Mentally Handicapped children states:

"When informed by their doctor that their child is affected with mongolism and warned that it may show some mental backwardness, parents often imagine the worst and think that their child will never walk or talk. Although a few Mongol children are as handicapped as this and they can live at home when young, they will

probably later need permanent hospital care. Due to their slow intellectual growth most Mongols are precluded from making satisfactory progress in formal education of the type provided by Local education authorities. However they benefit from the less formal type of education which they receive at the special centers provided by the local Department of Health although these are not always yet available in the more sparsely populated areas of Britain.

In addition to the two already mentioned there is a third considerably smaller group of children with mongolism who are even less backward and develop intellectually from a half to two thirds the rate of an average child. Many of this group can profit from formal education, particularly when given in the smaller classes with specially trained teachers in schools for the educationally subnormal"

From a leaflet published by the National Society for Mentally Handicapped Children entitled The Child with Mongolism (under which is the strap line 80 to 90 per cent can learn to do simple tasks) Printed in 1973.In 1981 at the time of the trial where Dr. Leonard Arthur was accused of murdering a baby with Downs syndrome such children were described as "walking time bombs of disease and infection" In a different trial concerning Alexandra another baby with Downs Syndrome she was described as "an unfortunate pathetic creature", " a helpless and mindless Mongol"

The Disabled Persons Act 1986 put a duty on local authorities to assess people for services. The 1981 education act and the 1989 Children Act, have helped to improve services for children. The 1993 Community Care Act took services away from Long stay hospitals and placed them in the community but without extra cash. The 1993 Education Act and the new Labour legislation are trying to increase choice for children to attend mainstream schools and the Disability Discrimination Act of 1995 hopes to ensure that disabled people have equal civil rights in some areas. It makes it against the law to run a service or provide goods and facilities in a way which makes it impossible or unreasonably difficult for a disabled person to use the service or goods. It is against the law to refuse to serve someone who is disabled. People will have to provide equipment or other helpful items to make it easier for disabled people to use their service. People will have to remove physical obstructions or provide other ways of letting disabled people use their services. The government is able to set minimum standards for new public transport vehicles and for new homes and buildings. The Community Care (direct payments act) 1996 gave local authorities the power to make cash payments known as direct payments to community care users for the purchase of their own support .However, the new code of practice

on Special Educational Needs and the education section of the disability discrimination act have both been weakened by pressure from people who see inclusion as expensive.

In conclusion, how does life for an "intellectually impaired" person in 2000 compare with that of a "natural fool" in 1 000 AD? Their standard of living is much better. Almost everyone in Britain today lives more comfortably than the King lived in Norman times-they have flush toilets, gas and electricity, good transport, a variety of food whatever the season and 24 hour a day entertainment from TV. They have much better health care and education and a welfare system to protect them from starvation and destitution. However the legacy of segregation is still with us today. Many people coming into the community in the 80's and 90's have lived for more than 50 years in a mental handicap hospital. Many children are still educated in special school, and those in mainstream encounter prejudice and ignorance and a mindset of league tables while adults are still catered for in specialist day centers and residential homes.

Nevertheless, public attitudes are slowly changing, the Disability Discrimination Act and legislation on inclusion though not going far enough recognize that people with learning disabilities have equal rights and their opportunities for education and employment are much better than 50 years ago. Let us hope that during the 21 st century the harm done in the 19th and early 20th centuries by eugenics can be put in the past and that just as the 20th century brought about civil rights for women and former slaves, the 21 st century can bring about equal rights and opportunities for people with learning disabilities.

1.4 Definition of Intellectual Disability—International and Indian perspective

1.4.1 Definitions as per ICD10

ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO). It contains codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases.

"A condition of arrested or incomplete development of the mind, which is

especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition.

1.4.2 American Association on Intellectual and Developmental Disabilities (AAIDD)

Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

KEY CONCEPTS

- I. DISABILITY
- II INTELLECTUAL
- III. ADAPTIVE BEHAVIOUR
- IV. AGE OF ONSET



DISABILITY

A disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

(WHO, 1976)

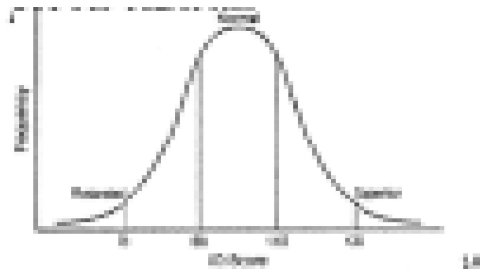
Disability is an umbrella term, covering

- Impairment
- Activity Limitations
- Participation Restriction

INTELLECTUAL FUNCTIONING

Intelligence refers to general mental capability, such as learning, reasoning, problem solving and so on.

Limitations in intellectual functioning refers as an IQ test score is approx.



ADAPTIVE BEHAVIOUR

Adaptive Behaviour represents the *conceptual, social* and *practical skills* that are learned and performed by people in their everyday lives.

- **Conceptual skills-** Language and Literacy, money, time, number
- **Social skills-** interpersonal skills, social responsibility, safety, follows rules, avoids victimization.
- **Practical skills-** ADL, occupational, travel, using telephone.

AGE of ONSET

There is evidence of disability during the developmental period—before the *age of 18*.



ADDITIONAL CONSIDERATIONS

- **Community Environment**
- **Peer Group**
- **Cultural Differences**
- **Linguistic Diversity**



1.4.3 World Health Organisation (WHO)

A condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Retardation can occur with or without any other mental or physical condition.

Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.

Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society.

The use of the term intellectual disability in the context of the WHO initiative “**Better health, better lives**” includes children with autism who have intellectual impairments. It also encompasses children who have been placed in institutions because of perceived disabilities or family rejection and who consequently acquire developmental delays and psychological problems.

1.4.4 PwD 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.

1.4.5 RPD bill(proposed)

THE RIGHTS OF PERSONS WITH DISABILITIES BILL, 2014

A **BILL** to give effect to the United Nations Convention on the Rights of Persons with Disabilities and for matters connected therewith or incidental thereto. WHEREAS the United Nations General Assembly adopted its Convention on the Rights of Persons with Disabilities on the 13th day of December, 2006; AND WHEREAS the aforesaid Convention lays down the following principles for empowerment of persons with disabilities,- (a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (b) non-discrimination; (c) full and effective participation and inclusion in society; (d) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;(e) equality of opportunity; (f) accessibility; (g) equality between men and women; (h) respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities; AND WHEREAS India is a signatory to the said Convention; AND WHEREAS India ratified the said Convention on the 1 st day of October, 2007; AND WHEREAS it is considered necessary to implement the Convention aforesaid.

1.4.6 Diagnostic and Statistical Manual of Mental Disorder IV (DSM IV)

DSM is the manual used by clinicians and researchers to diagnose and classify mental disorders.

“Mental retardation is defined as significantly sub average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skills areas i.e communication, self-care, home living, social/interpersonal skills, use of academic skills, work, leisure, health and safety with an onset before the age of 18 years.”

1.4.7 Diagnostic and Statistical Manual V (DSM V)

The diagnosis of intellectual disability (intellectual developmental disorder) is revised from the DSM-IV diagnosis of mental retardation. The significant changes address what the disorder is called, its impact on a person’s functioning, and criteria improvements to encourage more comprehensive patient assessment.

Intellectual Disability (Intellectual Developmental Disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains.

Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:

The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.

The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.

The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.

Unit 1.5 □ Etiology, Causes & Prevention

1.5.1 Prenatal Hazards

Infections

The most common prenatal infections associated with intellectual disability are rubella, toxoplasmosis syphilis and cytomegalovirus. These infectious diseases are responsible for a small percentage of the population of intellectuality disabled persons.

Congenital rubella

This disease in new borns is caused by a virus that infects the pregnant woman during the first placental and then to fetal infection. The embryological timing of the viral insult is crucial as the fetus is especially vulnerable during the first 3 months of pregnancy. The symptoms are varied and unpredictable; rubella pregnancies may lead to spontaneous abortion to still birth to live birth with one or more abnormalities or to a perfectly normal child.

Congenital Rubella is wholly preventable through a vaccine. The vaccination of children is of special concern because they often spread the viral infection to previously unexposed mothers. Vaccination of prospective mothers is also recommended.

Congenital cytomegalovirus

This is the most common of fetal infections and is found in about 1 percent of all new borns. Fortunately about 95 percent of affected infants are asymptomatic. Neonatal death is common and about 75 percent of survivors show neurological abnormality, blindness, deafness, spastic quadriplegia, or hypotonia, and variable degrees of intellectual disability.

Congenital Toxoplasmosis

This is a protozoan infection that like rubella is typically non injurious to the pregnant woman but devastating to the fetus also as in rubella Fetal vulnerability is largely confined to the first of month of prenatal life and neurological lesions and brain calcification characterize the congenital form of the disease. The acutely ill new born usually dies in the first month of life and the great majority of survivors possess complete or partial blindness and psycho-motor disturbances. Treatment of the new born consists of chemotherapy which is designed to arrest the infectious process.

Maternal Fetal blood incompatibilities

Intellectual disability may occur when the mother acquires what is in effect an allergic reaction to her new born baby blood. Rh disease is the well-known example of the phenomenon. ABO blood group incompatibility is also a potential though lesser cause of fetal central nervous system damage.

Rh - incompatibility

It occurs when mother and fetus have different Rh blood group factors. The Rh factor is an autosomal hereditary trait, Rh positive is dominant to Rh- negative. The maternal - fetal incompatibility arises only when an Rh negative mother bears a child of an Rh positive father. Where the father is homogenous, all of the children would be Rh-positive and potentially vulnerable the remainder, offspring shall be Rh-negative like the mother.

Although the precondition to the Rh disease is an Rh-negative mother and an Rh-positive fetus problems arise only, if there has been some previous mixing of fetal and maternal blood. If this has Rh-positive blood will have responded to the baby's foreign blood by producing antibodies that have the capability of destroying fetal blood cells. Such antibody effects are more likely to be found in later born children but fortunately only about 10 per cent of vulnerable mothers react. Sensitization of the Rh negative mother to Rh positive blood usually occurs at child birth when some mixing of maternal and fetal blood into the maternal circulation or after an abortion. Following sensitization of the mother she begins to produce antibodies. If this occurs during the first pregnancy there are usually no ill effects on the fetus. But if during succeeding pregnancies mixing recurs an enhanced maternal store of antibodies can destroy red blood cells, causing fetal anemia and setting the stage for possible post natal damage to the brain. It is the latter that has implications for intellectual disability.

Folic Acid Deficiency

Neural Tube defects are birth defects that occur in the brain or spinal cord. Spina-bifida is the most common NTD. Babies born with the NTD anencephaly can be still born or die soon after birth. Women, who take the vitamin -B and folic acid is also helpful in preventing NTD. These foods include peas corn dried beans, white and whole wheat bread, fortified breakfast cereals and orange juice. The folic acid can be destroyed if these foods are over cooked.

Drugs alcohol and tobacco

There are some 20 drugs that are known to produce adverse fetal effects so called teratogens. In the late 1950s and early 1960s we became aware of thalidomide, in the 1960s with the flourishing of hard drugs; we were alerted to the chromosomal breakage in connections with LSD and to fetal heart lungs skeleton, and central nervous system associated with the maternal use of amphetamines. an anti-nauseant used during pregnancy and a cause of limb malformations. In the 1960s it was found in drug-addicted. In the 1970s and 1980s, attention has been called to the adverse effects on the fetus of alcohol and tobacco during pregnancy.

Narcotic Addiction

The use of heroin and methadone throughout pregnancy appears to have two fetal effects. Babies tend to be similar and about 80 percent are born addicted. Addiction is seen in the appearance of withdrawal symptoms within 4 days after birth. In order of frequency, they involve the central nervous system looseness, in coordination of sucking and swallowing and seizures the gastrointestinal system and the autonomic nervous system.

Marijuana

The effect of marijuana smoking during pregnancy is unclear. Women who use marijuana during pregnancy are at greater risk for babies with low birth weight, shorter gestation periods and major malformations.

Alcohol

The most commonly abused drug alcohol has been clearly tied to fetal abnormalities including intellectual disability. The clinical picture in the neonate has been termed the fetal alcohol syndrome. Its symptoms are retarded physical development, microcephaly, micrognathia microphthalmia, cardiac defects and intellectual disability. Although there is no direct evidence of an adverse effect of maternal tobacco smoking during pregnancy on later mental development, research indicates increased pregnancy risks that could be associated with neurological abnormality and cognitive impairment.

The initial study on the effects of cigarette smoking during pregnancy found an increased risk of pre-maturity in the newborn. Numerous studies reveal that birth weights are reduced in proportion to the number of cigarettes smoked. There is now evidence that maternal smoking related increase in several complications of pregnancy bleeding, abrupture of the membrane.

Other teratogenic Drugs

Drugs used for medical purposes may also damage the fetus. Reference was made earlier to thalidomide. Quinine can cause deafness, and anticonvulsant drugs can produce abnormalities. The so-called fetal hydantoin syndrome occurs in about 10 percent of the offspring of epileptic women and like the fetal alcohol syndrome includes growth impairment at both the physical and intellectual levels.

During pregnancy the mother must avoid smoking, taking alcohol, harmful medications poses some risks of lung disorders in neonates and drugs for giving birth to a healthy child.

Radiation

The teratogenic effects of radiation have long been known. Early studies found that women who were receiving therapeutic pelvic irradiation for cancer during early pregnancy have an increased risk of having children with microcephaly and intellectual disability. The same clinical picture was seen in pregnant woman exposed to first trimester, can be harmful. Since most of our radiation exposure is through medical treatment, prevention of these problems requires careful use of X-ray in pregnancy and throughout the child bearing years.

Chronic Maternal Health problems

A series of maternal infectious disorders, high blood pressure affects the circulation to the uterus and may either interfere. But there are also some non-infectious and chronic health problems that can threaten the health of the fetus.

Hypertension

In hypertensive disorders, high blood pressure affects the circulation to the uterus and may either interfere with the development of a normal placenta or cause it to undergo degenerative change. In either case the fetus is deprived of adequate blood supply either causing in utero death or impairing general growth and development. Hypertensive disease is a particular problem in the last trimester of pregnancy and is a major cause of maternal death and fetal loss.

Diabetes mellitus

The diabetic mother whether the diabetes is chronic or gestational in nature also creates fetal risks. She is much more susceptible to hypertension and to its potential placental circulatory problems. Diabetic women also tend to bear babies who are very large and yet have physiologically immature lungs. Their large size and immaturity can lead to problems to brain damage.

1.5.2 Perinatal Hazards

In terms of health, the first 28 days of life are the most important period in childhood. This is the time of greatest infant mortality but it is also a period during which sub-lethal damage from perinatal events is frequent. Brain injury suffered during labor, delivery or during the neonatal period cause a large proportion of neurological problems which later manifest themselves as cerebral palsy, deafness and/or intellectual disability.

Pre-maturity

It is one of the important factors associated with either neonatal mortality or chronic brain injury, abnormalities of birth weight and gestational age. The premature infant has been traditionally defined as either born before 38 weeks or having birth weight of less than 2500 grams. About 7-10 percent of births are premature but its frequency varies with the sex of the child and with race and socioeconomic status of the mother. The health problems of the premature neonate tend to be proportional to the degree of pre maturity. There are two primary causes of prematurity :- impairment of potential for normal growth associated with chromosomal abnormalities, exposure to toxins intrauterine infection and restriction of a normal potential due to such factors as multiple pregnancies or placental vascular disease as in diabetics or hypertension.

Asphyxia

While the roles of perinatal asphyxia and physical trauma as causes of brain damage have probably been exaggerated in the past, these hazards are still important. Asphyxia is a leading cause of death in very small infants, those with birth weights of 1000 grams. On the other hand, the healthy newborn is said to be remarkably resistant to it if there is no prior brain damage. If there has been no evidence, however prolonged perinatal asphyxia can produce either brain damage or death. Common causes are pre-mature separation of the placenta, prolapse of the umbilical cord, difficult labor, depression of the respiratory center due to excessive anesthesia and obstruction of the respiratory airway.

Physical Trauma

Physical trauma during the birth process can result in traumatic vascular injury. While it has been greatly reduced by modern obstetric procedures, it still occurs particularly in connection with prematurity or difficult labor. Massive brain

hemorrhage is usually fatal, but small intra-cerebral hemorrhages can lead to motor abnormalities, seizures and intellectual disability.

Herpes infections

This is a viral infection of the geriatric that is occurring with increasing frequency in pregnant women. Following initial infection the virus is generally dormant within the maternal tissue until reactivated by a variety of stimuli and resulting in renewed infection. The herpes virus is generally contagious. It is transmitted from mother to infant during childbirth where about half of the newborns are affected. When the maternal infection is recognized close to the time of birth delivery may be by cesarean section. Because of the neonate's immature immunological system, spread of the infection is common, and results in death or serious consequences in about 80 percent of cases.

1.5.3 Postnatal Hazards

Post-natal biological factors causing intellectual disability consist of infectious diseases, which affect the brain, cerebro-vascular accidents (most often from head injury), brain tumors, poisons, environmental toxins and severe dietary protein deficiency.

Infectious Diseases

There are two kinds of infections that can result in permanent neurological problems and intellectual disability - encephalitis and meningitis. Encephalitis is inflammation of the brain, and meningitis is inflammation of the three membranes that line the brain, the meninges.

Encephalitis

Inflammation of the brain leads to injury to nerve cells (neurons). This may result from an initial invasion of the brain by an infectious agent (primary encephalitis) or following the infection of another organ (secondary encephalitis). The major sources of primary encephalitis are the viruses of mumps, herpes simplex, and infectious mononucleosis. Mumps virus is the most common and can produce death or such permanent neurological deficits as intellectual disability, cerebral palsy and seizures. Among the secondary encephalitis, the most common is measles encephalitis, but it can also be associated with whooping cough. Measles encephalitis is a very rare complication of ordinary measles.

The course of the disease is unpredictable, with about 20 percent suffering permanent damage.

Meningitis

In meningitis, there is infection of the meninges with consequent inflammation and symptoms of increased intracranial pressure (fever, bulging of fontanelles, projectile vomiting, alternating periods of drowsiness and irritability). In serious infections associated with high fever, one sees convulsions, stupor or coma. With the development of antibiotics and other drugs, there has been a major reduction in mortality rate in the most serious of the meningitis, bacterial meningitis, but a sizable proportion of children affected in the first year of life are still left with crippling neuromuscular problems, hearing and visual impairments, seizures and cognitive deficits.

Cerebral Trauma

Among children, accidental injuries are the greatest threat to life. About 40 percent of all trauma cases in children involve head injuries. Most injuries to the head are simple concussions or mild contusions, and there is usually complete recovery without complications. The head injuries that are more serious are those that involve intracranial bleeding. Bleeding between the outermost membrane covering the brain (and spinal cord), the dural matter, and the brain itself, subdural hematoma, can result in cerebral atrophy and neurological deficit. Fortunately, neither organic dementia nor intellectual deficit, as such, is a common outcome of cerebral trauma. The main symptoms are enuresis, disturbance of sleep patterns, episodically aggressive behavior, and decline in school achievement.

High percentage of injuries occurs in children who are tired, hungry or playing in unsupervised or unsafe areas. Risk is high when illness or emotional tension is there in the family.

Poisons and Environmental Toxins

In the earlier section on pre-natal factors, reference was made to the potentially adverse environment to which a fetus might be exposed through maternal use of drugs. There are also some post-natal dangers to the brain associated with drug use. Glue sniffing has been linked to brain damage, and barbiturate abuse has been related to impairment in cognitive functioning. The most important of the toxic dangers, however, are lead and mercury.

Lead Poisoning

Lead encephalitis is a complication of lead poisoning. It usually results from prolonged ingestion by the infant or young child of flaking leaded paint, the kind found in dilapidated housing. Daily consumption of only a few small chips for 3 months can produce lead poisoning. Most cases of acute lead encephalitis occur in children ages 1 - 3 years, of whom about 5 per cent die and 50 per cent sustain permanent brain damage.

Mercury Poisoning

Dramatic evidence of the toxic effects of some metals has also been shown for mercury. Accidental consumption of mercury may cause serious neurological problems involving memory, skin sensation, vision, gait, and emotional stability, cerebral palsy and intellectual impairment. In addition to these effects, mercury consumption by pregnant women may lead to pre-natal damage.

Malnutrition

One of the most perplexing questions in intellectual disability has been the effect of malnutrition on mental development. It is estimated that at least half of the children in developing countries are moderately or severely undernourished - with basic caloric deprivation as the primary problem. Research efforts to relate malnutrition specifically to intellectual impairment have been continually confounded by the fact that malnutrition usually does not occur alone but rather in combination with other biological and psychological hazards to normal mental development. For example, infectious diseases may be the most important cause of malnutrition. The malnourished child has limited resistance to infection, and the infection itself aggravates nutritional stress by elevating calorie requirements.

A study by the National Sample Survey, Government of India, has revealed that among the children, 31 per 1000 in the rural area and 9 per 1000 in the urban area are developmentally disabled. Malnutrition is one of the major causes responsible for higher number of developmentally disabled children in the rural India. This includes malnutrition of pregnant women, infants and young children.

All women require good nutrition during pregnancy, especially adolescent girls whose own bodies are still growing. Nutritious meals consisting of items from the five major food groups eaten each day help the fetus grow. These food groups include: vegetables; fruits; breads, cereals and rice; milk, yogurt and cheese; and

meat, poultry, fish, dry beans, eggs and nuts. Since foods within each group vary somewhat in nutrition content, pregnant women should vary their choices within each group. A woman should consume about 300 extra calories a day when pregnant. Adequate drinking of water helps the body digest food and absorb essential nutrients.

By eating a well-balanced diet, most women can get a good supply of vitamins and minerals needed for pregnancy. However, most doctors will prescribe a pre-natal multivitamin supplement to ensure the pregnant woman receives sufficient iron, calcium, folic acid and other needed nutrients.

Poor nutrition and unbalanced diets during pregnancy can cause low birth weight or pre-mature births. Infants who service these conditions are more likely to have intellectual disability, cerebral palsy, epilepsy and respiratory disease.

1.5.4 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 up to 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 at Various Levels

The old dictum "prevention is better than cure" is also applicable to intellectual disability. More knowledge on the causes of intellectual disability helps its prevention. Three levels of prevention of intellectual disability have been described. The levels of prevention are:

- Primary prevention
- Secondary prevention
- Tertiary prevention

1.5.4.1 Primary Prevention

Primary prevention focuses on the developing fetus. The objective is to reduce the number of children born intellectually disabled or with conditions that could lead

to intellectual disability. One of the important strategy can be to provide good teaching to a pregnant woman regarding dangers of drugs, alcohol and smoking. Genetic counseling for couple~ whose children are at risk is another. Research is essential to find:g causes and possible treatments for conditions that can lead to intellectual disability. The effects of rubella, for example, have been largely eliminated through antibody screening and immunization programme.

1.5.4.2 Secondary Prevention

The objective of secondary prevention is to identify and change environmental conditions that could lead to intellectual disability. By screening newborns for PKU, we can begin treatment and prevent intellectual disability. By eliminating sources of lead, we can reduce brain damage from lead poisoning. by providing youngsters from disadvantaged homes with strong preschool programmes, we can begin to counteract the elements that can cause intellectual disability due to environmental factors.

1.5.4.3 Tertiary Prevention

Tertiary prevention focuses on arranging the educational and social environment so people who are born with or who develop intellectual disability can achieve their maximam potential and highest quality of life. Early intervention programmes—start with youngsters who seem to be at risk for intellectual disability at an early age and try to sharpen their perceptual abilities, encourage the use of expressive language, and give practice in classification and reasoning. Some programmes urge parents to continue and extend these activities at home. All attempt to strengthen the thinking processes of young children who are delayed in development, and all succeed to a degree.

For prevention of intellectual disability, one must study the causes carefully and take appropriate preventive measures during pre-natal, peri-natal and post-natal period. Possible preventive measures have been suggested along with specific causes.

Steps for Prevention at different Stages of Development

Each developmental stage requires adequate attention to prevent mental retardation. For each stage the required preventive measures are described in a sequential manner.

1.5.4.4 Prenatal Prevention

Inadequate pre-natal care has been linked to pre-maturity and low birth weight, which is in turn linked to mental retardation. Pre-natal 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 very start of the pregnancy.

The Pregnant woman is advised:

- i. To go for regular anti-natal checkups for early detection of abnormalities, illnesses and infections so that prompt treatment and a good management plan for delivery can be provided.
- ii. To maintain good nutrition status: Poor nutrition for both the baby and the mother is linked with 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 mental retardation. Therefore, anti-natal 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 requirement 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 anemia 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), pre-natal 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
 - alphafoeto 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 injection of tetanus toxoid (TT) to avoid the tetanus infection during delivery and immediate post-natal. It also gives immunity of the fetus and the new born child as the maternal antibodies pass to the fetus via the placenta.

1.5.4.5 Natal and Perinatal Prevention

A trained person should conduct delivery under hygienic conditions. Unnecessary meddling of the fetus 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 placenta and control of the uterine bleeding after the delivery of the baby. Mother should be allowed to rest for few hours immediately after delivery. The following suggestions are to be followed:

- Good peri-natal care is an important factor in prevention of mental retardation.
- Pregnant woman should be advised to get delivery conducted by trained personnel at home under hygienic conditions or at a health center.
- 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 peri-natal 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 of and should have a long-term follow up for early detection of handicapping conditions and delays in development.

1.5.4.6 Postnatal Prevention

Neonatal screening: Some of the conditions of mental retardation like PKU and Hypothyroidism 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 should be counseled regarding mode of inheritance and recurrence risks in avoiding 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 at high risk for mental retardation such as pre-maturity, low birth weight, birth asphyxia, 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 handicap 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 Poliomyelitis and Rubella can be prevented by active immunization programmes. Immunization confers protection against the specific viral and bacterial infections.

To prevent the negative effects of Rh-incompatibility an injection of Rh-immunoglobulin (Rh-IG) must be given to susceptible pregnant women within 72 hours after each delivery, abortion or miscarriage.

Early identification and appropriate treatment of infections lessens the complications. 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.

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 retardation. However the following steps should be followed.

- 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 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.
- Use of alcohol, drugs and teratogens is 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 should ensure good nutrition and health to birth the mother and the child.

Family planning: The best age 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 family size should be restricted and children should be properly spaced.

Dissemination of the information: The information regarding prevention of mental retardation should be disseminated to the general public and the various professionals involved creating awareness. Research is needed to frame further developmental strategies for facilitating progress in prevention of mental retardation and developmental delays.

Unit 1.6 □ Classification of persons with Intellectual Disability

Classification of Intellectual disability

1.6.1 Psychological classification

A psychologist measures the intelligence quotient through psychological testing to make a psychological classification of an individual. The intelligence quotient of a person can be calculated by the given equation:

$$I.Q = MA/CA \times 100$$

I.Q = Intelligence quotient-Actual intellectual ability of a person

MA= Mental retardation-Mental age of the person as per test finding.

CA= Chronological Age -Actual age of a person.

Based on the 1980 APA definition, the operational classification for persons with mental retardation is as follows:

Level of Retardation	IQ Range
Mild Mental Retardation	50-BELOW 70
Moderate Mental Retardation	35-49
Severe Mental Retardation	20-34
Profound Mental Retardation	BELOW 20

1.6.2 Medical classification

Mental Retardation has been characterized according to medical symptoms and factors. It can be classified based on the following causes and symptoms-

1. Infection and Intoxication
2. Mental and physical problems
3. Metabolism and nutrition
4. Mental diseases
5. Unknown factors from birth
6. Genetic disorders
7. Diseases during pregnancy

8. Psychosis
9. Environmental factors
10. Other factors

**For more details on medical classification refer to unit 1 (1.3)

1.6.3 Educational classification

In the special education centers in India, the (9assroom ~ssification in operation is as shown below:

. Pre-Primary level - Chronological ages - Mental ages	3 - 6 years Up to 5 years
Primary level - Chronological ages - Mental ages	7 - 10 years 5 - 7 years
Secondary level - Chronological ages - Mental ages	10 - 14 years 7 - 9 years
Pre- Vocational level Chronological ages 14 - 16 years - Mental ages	15-below 18 years 8 + years

Classification by Educational Expectations :-

Terminology	IQ range	Educational expectation
Educable	IQ 50 to 70	Second to fifth grade achievement III 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	IQ 20 to 49	Learning primarily in the areas of self-help, very limited achievement in areas considered academic

Custodial	IQ Below20	Social adjustment usually limited to home an closely surrounding area.
		Occupational performance primari in sheltered workshop or an institutional setting.
		Usually unable to achieve even sufficient skills to care for basic needs.
		Will usually require nearly total care an supervision for duration of lifetime

1.6.4 Based on intensity of needed supports

Intermittent	Limited	Extensive	Pervasive
Supports on a needed basis characterized by episodic nature, person not always needing the support (s) or short term supports needed during life span transitions (e.g. Jobless or an acute medical crisis) intermittent support may be high or low intensity when required.	An intensity of supports characterized by consistency over time, time limited but not of an intermittent nature, may require fewer staff members and less cost than more intense levels of supports (E.g. Time limited employment training or transitional supports provided during the school to adult period.	Supports characterized regular involvement (e.g. Daily) In at least some environments (such as work or home) and not time limited (e.g. Long term support and long term home living support)	Supports characterized by their constancy and high intensity, provided to cross environments, Potential life sustaining nature pervasive supports typically involve more staff members and instructiveness than do expensive or time limited supports.

1.6.5 ICF

INTRODUCING THE ICF

The International Classification of Functioning, Disability and Health (ICF) are a framework for describing and organizing information on functioning and disability. It provides a standard language and a conceptual basis for the definition and measurement of health and disability.

The ICF was approved for use by the World Health Assembly in 2001, after

extensive testing across the world involving people with disabilities and people from a range of relevant disciplines. A companion classification for children and youth (ICF-CY) was published in 2007.

The ICF integrates the major models of disability. It recognizes the role of environmental factors in the creation of disability, as well as the relevance of associated health conditions and their effects.

This overview provides a brief introduction to the ICF — its structure, contents, purposes and applications.

Aims

The ICF is a multipurpose classification system designed to serve various disciplines and sectors — for example in education and transportation as well as in health and community services — and across different countries and cultures.

The aims of the ICF (WHO 2001:5) are to :

- provide a scientific basis for understanding and studying health and health-related states, outcomes, determinants, and changes in health status and functioning;
- establish a common language for describing health and health-related states in order to improve communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities;
- permit comparison of data across countries, health care disciplines, services and time; and
- provide a systematic coding scheme for health information systems.

The ICF 'has been accepted as one of the United Nations social classifications ... and... provides an appropriate instrument for the implementation of stated international human rights mandates as well as national legislation' (WHO 2001:5-6). Hence, the ICF provides a valuable framework for monitoring aspects of the UN

Convention on the Rights of Persons with Disabilities (UN 2006), as well as for national and international policy formulation.

Underlying principles

Four general principles guided the development of the ICF and are essential to its application.

Universality. A classification of functioning and disability should be applicable to all people irrespective of health condition and in all physical, social and cultural contexts. The ICF achieves this and acknowledges that anyone can experience some disability. It concerns everyone's functioning and disability, and was not designed, nor should be used, to label persons with disabilities as a separate social group.

Parity and etiological neutrality. In classifying functioning and disability, there is not an explicit or implicit distinction between different health conditions, whether 'mental' or 'physical'. In other words, disability is not differentiated by etiology. By shifting the focus from health condition to functioning, it places all health conditions on an equal footing, allowing them to be compared using a common metric. Further, it clarifies that we cannot infer participation in everyday life from diagnosis alone.

Neutrality. Domain definitions are worded in neutral language, wherever possible, so that the classification can be used to record both the positive and negative aspects of functioning and disability.

Environmental Influence. The IeF includes environmental factors in recognition of the important role of environment in people's functioning. These factors range from physical factors (such as climate, terrain or building design) to social factors (such as attitudes, institutions, and laws). Interaction with environmental factors is an essential aspect of the scientific understanding of 'functioning and disability'.

THE ICF MODEL

In the ICF, functioning and disability are multi-dimensional concepts, relating to:

- The body functions and structures of people, and impairments thereof (functioning at the level of the body);
- The activities of people (functioning at the level of the individual) and the activity limitations they experience;
- The participation or involvement of people in all areas of life, and the participation restrictions they experience (functioning of a person as a member of society); and
- The environmental factors which affect these experiences (and whether these factors are facilitators or barriers).

The ICF conceptualizes a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors. It is a bio psychosocial model of disability, based on an integration of the social and medical models of disability.

Ethical use

Every scientific tool can be misused, and the ICF is no exception. For all uses of ICF--clinical, research, epidemiological, health and social policy-it is essential that information gathered and analysed must respect the inherent value and autonomy of the individuals from whom the information is gathered. Standard rules about informed consent apply, but more importantly people with disabilities must participate in all aspects of the use of ICF and the application of the data produced.

Full participation and transparency of use are most important in the social applications of ICF and, in particular, with the anticipated use of IeF for the development of indicators for monitoring the implementation of the UN Convention on the Rights of Persons with Disabilities. This important human rights document-which embodies precisely the same conceptual refinement of functioning and disability as the ICF-is our moral compass towards the development of social policy and political change needed to achieve the full participation of persons with disabilities. The ethical application of ICF seeks to support and further this mandate for the future.

Unit 1.7 □ Screening, Identification, Characteristics and Needs of PWD

1.7.1 Early Identification and Screening

Screening is a procedure for an initial identification of persons with mental retardation and for a follow up with assessment.

Screening Procedure

Many of the screening techniques collected National Institute for the Mentally Handicapped (NIMH), Secunderaba, appeared in RCI.

A more systematic process and procedure has been the pooling of a battery of tests on clinical investigations by the NIMH, for identification and screening of persons with mental retardation. They include pre-natal, neonatal and post-natal diagnostic procedures:

i) Pre-natal Procedures

A number of prenatal testing procedures such as testing of maternal serum AFP, multiple marker screening, chorionic villous sampling, amniocentesis, and ultrasound and fetoscopy are available to detect the disorders of the fetus. On the basis of the results of screening appropriate corrective steps to prevent intellectual disability should be taken on the advice of a qualified physician. The following screening should be done.

- Blood tests for the pregnant mother
- Hemoglobin levels (Hb %) to detect anemia.
- Blood glucose levels to detect diabetes.
- Blood VDRL to detect syphilis.
- Blood group and Rh typing for blood group incompatibilities.
- Blood antibody titers to detect neural tube defects in the foetus.
- Alpha foeto-proteins to detect neural tube defects in the foetus.

ii) Ultrasonography(during pregnancy)

Many types of foetal pathology including those associated with intellectual impairment later one can be identified during the second trimester of pregnancy to detect such disorders as - neural tube defects, abnormal child.

iii) Maternal serum AFP (Alpha-fetoprotein)

Maternal Serum AFP (Alpha-fetoprotein) screening test is used to detect spina-bifida, Down syndrome and other disorders. It is specially targeted to women under age 35. The test, which measures the amount of alpha-fetoprotein from fetal urine, takes place at 16-18 weeks of pregnancy. A sample of the mother's blood is taken and analyzed for certain chemicals that, together with her age, will determine the individual risk of having down syndrome child, spina-bifida and other disorders. Those found to have an increased risk would be offered an amniocentesis. Results of AFP test take only one weekend the test is safe for both the mother and fetus.

iv) Multiple Marker Screening

Multiple marker screening measures alpha (AFP) and human chorionic gonadotropin (UE3). It enhances the effectiveness of screening for neural tube defects, trisomy 21, trisomy 18. It is done by a blood test that is offered to women between the 15 and 20 week of pregnancy.

v) Fetoscopy

Fetoscopy is done during second trimester of pregnancy in diagnosing certain physical anomalies, metabolic disorders or biochemical abnormalities. A viewing instrument is inserted into the womb. It is also used to take blood samples.

vi) Chorionic Villous Sampling where a biopsy of the chorionic villi is performed either transabdominally or vaginally. The sample is then subjected to karyotyping and enzyme determination hydrocephaly, microcephaly, hydrancephaly, holoprosencephaly, prosencephaly 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.

vii) Aminocentesis

Aminocentesis is indicated in cases of foetal chromosomal aberration, congenital metabolic errors and open, neural tube defects, severe Rh incompatibility and also in cases of advanced maternal age with previous birth history of an abnormal child. Aminocentesis is a Procedure for purposes of early identification and primary prevention for many genetic abnormalities.

Neonatal and Post-natal Screening and Diagnostic Procedure

Blood and urine examinations are conducted in the neonatal period in all suspected cases and with a previous history of mental retardation in the family. Cretinism is

another condition which can be diagnosed in the neonatal period and necessary treatment given.

- Apgar Score at one minute after delivery is an index of asphyxia and the need for assisted ventilation.
- Urine screening for metabolic errors - PKU (Phenyle Ketoneuria)
- Blood biochemistry tests for cretinism, rickets, jaundice.
- Blood antibody titres to detect infections.
- Chromosomal analysis for Down Syndrome, deletion of syndromes.
- Neonatal neurobehavioural assessments.
- EEG electroencephalogram for seizure disorder.
- Screening for visual impairments (visual acuity, fundus examination, retinoscopy).
- Screening for hearing impairments(Tympanogram, BERA.)
- Ultra sonogram.
- CT scan (computerized tomography).
- MRI (Magnetic Resonance Imaging) for intra-cranial pathology and structural abnormalities.

APGAR Score

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

SI no	Sign	Points		
		0	1	2
1	A-Appearance (colour)	Blue, Pale	Body pink extremities blue	Completely pink
2	P-pulse rate (Heart rate)	Absent	Below 100	Over 100
3	G-Gravity (muscles tone of extremities)	Limp	Little motion	Active motion
4	A-Activity (Response to catheter)	No response	Grimace	Cough or sneeze
5	R - Respiratory effort	Absent	Slow irregular	Good crying

● **Ultra Sound Examination :** 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 haemorrhage in the newborn.

Biochemical Tests in neonatal screening

● Biochemical Tests in neonatal screening for identifying metabolic disorders. 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 the intellectual disability in the family.

● **Electro Encephalography (EEG):** EEG is useful not only in epilepsy, but in many other cases of mental retardation and organic brain lesions. In certain cases it also helps in localization of lesions and the severity of a cerebral damage. Incidence of abnormal EEGs is higher in cases of mental retardation associated with epilepsy, encephalitis, severe degree of mental retardation and brain damage sustained before birth or during birth or in the early period of infancy.

● **Computerised Tomography (CT):** There are many abnormalities which can be detected by CT scan of the CNS such as, anoxia of tissue, intracranial haemorrhage, hydrocephalus and congenital anomalies like holoprosencephaly, agenesis of corpus callosum, Arnold chiari malformations, congenital cysts, calcifications, etc.

● **Magnetic Resonance Imaging (MRI):** This screening helps in identifying a large number of persons with suspected disability in a limited time period.

Screening Tools

The NIMH has developed quick Screening Schedule I (Below 3 years) and Screening Schedule II (3 to 6 years) shown in Table 1.

Table 1: Screening Schedule I (Below 3 years)

Sl No	Child's Progress	Normal Development	Delayed Development. If not achieved by the period
1	Responds to name / Voice	1-3 months	4 th month
2	Smiles at others	1-4 months	6 th month
3	Holds head steady	2-6 months	6 month
4	Sits without support	5-10 months	12 month

5	Stands without support	9-14 months	18 th month
6	Walks well	10-20months	20 th 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	A voids simple hazards	3-4 years	4th year
12	Has fits	Yes	NO
13	Has physical disability-what?	Yes	NO

If the child is found to be delayed in anyone of the items given from 1-11 and if he has fits or physical disability then suspect intellectual disability.

Table II : Screening Schedule II (3 to 6 years)

SI no	Item		
1	Compare with other children.did the child have any serious delay in sittYng-: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 has weakness and/or stiffness in the limbs and/or difficulty in walking and 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 of his age?	Yes	No
8	Is the child not able to speak at all?	Yes	No
9	Is the child's speech in any way different from normal?	Yes	No
10	Compared to other children of his age, does the child appear any way backward, dull or slow?	Yes	No

If any of the above items is answered "Yes", then suspect intellectual disability.

Table III: Screening Schedule III (7 years and above)

SI no	item		
1	Compared with other children, did the child have any serious delay in sitting, standing 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 not clear?	Yes	No
5	Does the child have difficulty in expressing without being asked what the child had seen/heard?		
6	Does the child have weakness and/or stiffness in the limbs and/or difficulty in walking and moving his arms?	Yes	No
7	Does the child sometimes have fits, becomes rigid, or lose consciousness?	Yes	No
8	Compared to other children of his age, does the child appear any way backward, dull or slow?	Yes	No

If any of the above items is answered "Yes", then suspect intellectual disability.

1.7.2 Characteristics of Intellectual Disability

Intellectual disability occurs before age 18, and is characterized by delayed development in intellectual functioning and adaptive behavior. The intellectual disability may vary from mild to profound. Adaptive behavior includes skills that people learn so that they can function in their everyday lives. This delayed development is reflected in low performance across academic and other skill areas, as well as significantly lower scores on measures of intelligence and adaptive behavior, when compared with students who are not identified with intellectual disabilities. A score of approximately 70 or below in an intelligence test is considered to be "below average" intellectual functioning. Students with intellectual disabilities have a measured IQ that is lower than 98% of the school-age population. A standardized test of adaptive behavior is used to determine if the child has deficits in conceptual, social, and practical skills that are significantly below average.

Attention and Concentration

- Difficulty focusing and maintaining attention on academic tasks.
- Short, but intense attention span; tasks will either bore or hold attention of student for long periods of time; student can seem off task.
- Easily distracted by even a minimal level of noise.
- Disorganization accompanied by snap decisions; often loses things; careless errors.
- Difficulty juggling multiple task demands or abrupt change in direction.
- Distorted sense of time; unaware how long it will take to do something.
- Get tired or overloaded quickly; need frequent breaks when studying.
- Hyperactivity and excessive movements may accompany the inability to focus.

Memory

- Cannot quickly retrieve names from memory
- Difficulty memorizing strings of numbers or letters
- Frequently lose or forget things

- Often will forget basic information such as the year, their age, friends' names, or names of places.

Oral Language

- Difficulty with sequencing when telling a story
- Difficulty with oral directions
- Difficulty pronouncing words
- Difficulty expressing ideas orally, even when they seem to understand
- Difficulty comprehending while reading aloud
- Unable to concentrate on and to comprehend spoken language when presented rapidly, which causes great difficulty in taking class notes.

Language Skills

- Difficulties associated with short-term memory, syntax, and auditory discrimination
- Decoding and encoding difficulties
- Difficulty reading aloud; slow in oral performance
- Difficulty producing comprehensible responses
- spelling difficulties

Social Skills

- Difficulties in interpreting social cues that may result in lowered self-esteem or cause students to have trouble meeting people or working cooperatively with others.
- Unable to distinguish subtle changes in tone of voice.
- Difficulty in recognizing the difference between sincere and sarcastic comments.

Categories of mild, moderate, severe and profound levels of intellectual disability are defined on the basis of IQ scores.

Mild Intellectual Disability

A mild intellectual disability is defined as an IQ between 50 and 70.

- Can independently participate in most leisure activities within their communities

- May have important relationships with the people in their life
- May struggle in certain social situations
- May marry and raise a family with support
- May have a job suited to their skills
- May live and travel independently with support
- May need help to handle money and to plan and organize their daily routine
- May learn to read and write in appropriate educational setting
- Likely to develop reading, writing, and math skills at a basic level

Moderate Intellectual Disability

A moderate intellectual disability is defined as an IQ between 35 and 50.

- Will have important relationships with the people in their life
- May learn to navigate their community and travel with support
- Will have difficulty planning trips and handling money independently
- Will recognize environmental print (e.g. signs, logos, sight words) in daily life
- Will need visual prompts such as daily schedules and pictures of routines
- Will need support in their daily lives
- May display independence in certain daily living activities, such as dressing and bathing

Severe or Profound Intellectual Disability

A severe intellectual disability is defined as an IQ between 20 and 35. A profound intellectual disability is defined as an IQ below 20.

- have important relationships with the people in their life
- May have little or no speech and will rely on gestures, facial expressions, and body language to communicate needs or feelings
- Will require functional communication systems (e.g. low or high tech augmentative communication devices) in order to express their wants and needs
- Will need visual prompts such as daily schedules and pictures of routines

- Will require extensive support with daily living activities throughout their life.

1.7.3 Needs of PwID

People have different abilities and develop at different rates. Some people find learning new skills or information difficult. This could be because they have an intellectual disability. A person has an intellectual disability if they have both the following before they are 18 years of age:

An IQ below 70 (average IQ is 100) Significant difficulty with daily living skills including looking after themselves, communicating and taking part in activities with others.

Intellectual disability can be mild, moderate or severe and factors such as personality, coping strategies and the presence of other disabilities (motor, social or sensory) will influence a person's requirement for support with daily living.

Needs depend on individual factors

Arbitrary categories of mild, moderate, severe and profound levels of intellectual disability are defined on the basis of IQ scores. These levels give some guide to the level of support someone might need but the way a person functions in their life also depends on other factors including:

- Personality,
- Coping skills,
- Other disabilities - for example, physical, social or sensory,
- The amount of support offered by family, friends and the community,
- What is demanded of them in different situations.

People with a mild intellectual disability

A mild intellectual disability is defined as an IQ between 50 and 70. Generally speaking, a person with a mild intellectual disability:

- participates in and contributes to their families and their communities,
- has important relationships in his/her life,
- works in either open or supported employment,

- may live and travel independently but will need support and help to handle money and to plan and organize their daily life,
- may marry and raise children with the support of family, friends and the service system,
- May learn to read and write.

People with a moderate intellectual disability

A moderate intellectual disability is defined as an IQ between 35 and 50. Generally speaking, a person with a moderate intellectual disability:

- has important relationships in his/her life,
- enjoys a range of activities with their families,
- friends and acquaintances,
- understands daily schedules or future events if provided with pictorial visual prompts such as daily timetables and pictures,
- makes choices about what s/he would like to do, eat, drink etc.
- may learn to recognize some words in context, such as common signs including 'Ladies', 'Gents' and 'Exit',
- may develop independence in personal care,
- will need lifelong support in the planning and organisation of their lives and activities.

People with a severe or profound intellectual disability

A severe or profound intellectual disability is defined as an IQ below 35. Generally speaking, a person with a severe or profound intellectual disability:

- recognizes familiar people and may have strong relationships with key people in their lives,
- has little or no speech and relies on gestures, facial expression and body language to communicate,
- Requires lifelong help with personal care tasks, communication and accessing and participating in community facilities, services and activities.

Remember

A person with an intellectual disability may need assistance with daily living skills such as self-care, communication and community access and participation. Categories of mild, moderate, severe and profound levels of intellectual disability are arbitrarily defined on the basis of IQ score and factors such as personality, presence of other disabilities and social support also play important roles in how the person functions in his/her daily life you're not sure whether a person is able to understand you, assume they and then monitor their understanding and adjust your language communication style accordingly. Always demonstrate respect for person and communicate in ways that acknowledge the age of the person and the value of their contribution.

1.8 Check Your Progress

1. Define Intellectual disability.

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2. Briefly describe intellectual disability in your own word.

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3. Describe historical perspective of intellectual disability.

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4. What is the biological basis intellectual disability ?

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5. How do you classify the etiological factors of intellectual disability?

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6. What are the influencing factors before conception?

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7. Enlist the prenatal causes of intellectual disability?

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8. Enlist the post natal causes of intellectual disability?

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9. What is prevention?how do you classify prevention?

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10. What are the prevention strategies for intellectual?

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11. Write classification of intellectual disability.

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12. Write psychological Classification.

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13. Write educational classification.

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14. Discuss about ICF.

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15. What is screening?

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16. Describe two medical screening procedures.

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16. Name any two Screening tools.

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17. Describe characteristics of [persons with intellectual disability.

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18. Explain the needs of PWID.

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1.9 Let Us Sum Up

In this unit, we have seen the historic perspectives of the concept of intellectual disability... Intellectual disability is mistaken for mental illness or varied social perceptions ranging from devil to godchild. In early centuries, they were killed or abandon, 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 Aveyron". Later various acts for the disabled persons came about and normalization processes were initiated.

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

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