Mental Retardation - Definition and Identification

Introduction

Mental retardation is defined as sub average intelligence. It is a generalized disorder appearing before adulthood, characterized by significantly impaired cognitive functioning and deficits in two or more adaptive behaviours. It has historically been defined as an Intelligence Quotient score under 70. Once focused almost entirely on cognition, the definition now includes both a component relating to mental functioning and one relating to individuals' functional skills in their environment. As a result, a person with a below-average intelligence quotient (BAIQ) may not be considered mentally retarded. Syndrome mental retardation is intellectual deficits associated with other medical and behavioural signs and symptoms. Non-syndrome mental retardation refers to intellectual deficits that appear without other abnormalities.

Mental retardation is not a disease. It's also not a type of mental illness, like depression. There is no cure for mental retardation. However, most children with mental retardation can learn to do many things. It just takes them more time and effort than other children.

Every child with mental retardation is able to learn, develop, and grow. With help, all children with mental retardation can live a satisfying life.

Definition

As formal definitions of mental retardation were developed during the first half of the 20th century, they tended to reflect the judgment of chronicity. The most important of these, and the one that continues to influence the defining of mental retardation, was authored by the psychologist Edgar Doll (1941). His pioneering definition included six elements that he considered essential to the concept of mental retardation:

- Social incompetence
- Due to mental sub-normality
- Developmentally arrested
- Obtained at maturity
- Is of constitutional origin
- Is essentially incurable

The first four of these elements have continued to be overtly central to the prevailing conceptualization of mental retardation.

Social incompetence associated with deficits in mental ability is a thread that runs from Doll's definition through subsequent definitions to the most current. The same is true for his emphasis on mental retardation as a disability that originates during the developmental period. The last two elements of Doll's definition, however, are not found as formal elements of contemporary definitions of mental retardation.

It has long been recognized that environmental variables also are important as causes of mental retardation. Much retardation, for example, is associated with the depriving effects of poverty.

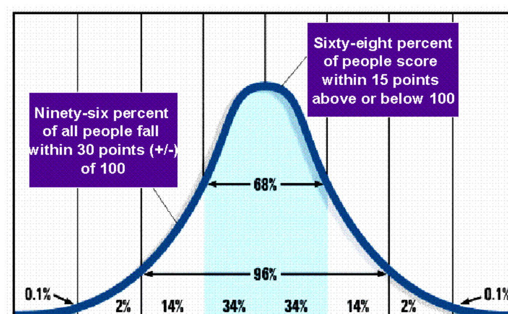
This recognition, however, is not operative in many community and school contexts where "true" retardation is still considered to be physiological in origin. Mental retardation is also no longer considered to be an ‘incurable’ condition in official definitions.

The goal of educational services for many students, in fact, is to help those students achieve a level of competence at which it would no longer be appropriate to describe them as having mental retardation. The attitude of incurability about children and adults with mental retardation has continued to be a reality, however, in the minds of many people.

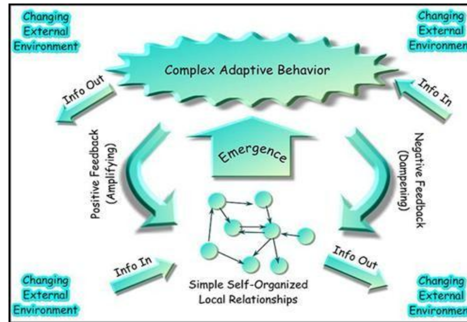
The legacy of Doll's conceptualization of mental retardation can be seen most clearly in definitions that have been developed during the second half of the 20th century by the American Association on Mental Retardation (AAMR). The definitions published by this professional organization have always included the criteria of low measured intelligence and deficits in social competence. They have also consistently described mental retardation as a developmental disability.

In 1959 the AAMR, at that time called the American Association on Mental Deficiency, published a definition of mental retardation that read as follows: Mental retardation refers to sub average general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behaviour. The definition was revised in 1961. That revision specified the meaning of the term sub average general intellectual functioning in a manner that was to have considerable impact on the field of mental retardation.

One standard deviation below the mean on an intelligence test was delineated as the point at which intellectual functioning should be considered sub-normal.



This specification meant that on an IQ test with a mean of 100 and a standard deviation of 15, any score below 85 would be diagnostic of mental retardation. If the total population was tested and classified on this basis, almost 16% would be diagnosed as having mental retardation. Even higher percentages would be expected to be found in subpopulations where minority status, language factors, or socioeconomic background depresses intelligence test scores. There were criticisms of the concept of adaptive behaviour as it appeared in the 1961 definition.



The argument was made that adaptive behaviour as it was presented in the definition was not actually functional for the diagnosis of mental retardation. In reality, it was argued, the determination of retardation continued to be based on intelligence tests and the idea that intelligence was not significantly 'associated' with adaptive behaviour in this process.

The 2010 Revision of the AAMR Definition

In 2010 AAMR was renamed as AAID (American Association on Intellectual Disability) and mental retardation was renamed as intellectual disability.

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

Intellectual functioning—also called intelligence—refers to general mental capacity, such as learning, reasoning, problem solving, and so on.

IQ TEST

IF A + B = 76

A - B = 38

A ÷ B = ...?

One criterion to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.

Standardized tests can also determine limitations in adaptive behaviour, which comprises three skill types:

• Conceptual skills—language and literacy; money, time, and number concepts; and self-direction

• Social skills—interpersonal skills, social responsibility, self- esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.

• Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

On the basis of such many-sided evaluations, professionals can determine whether an individual has an intellectual disability and can tailor a support plan for each individual.

But in defining and assessing intellectual disability, the American Association on

Intellectual and Developmental Disabilities (AAIDD) stresses that professionals must take additional factors into account, such as the community environment typical of the individual's peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave.

Indian Scenario

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.

Pre-Colonial India

Historically, over different periods of time and almost till the advent of the colonial rule in India, including the reigns of Muslim kings, the rulers exemplified as protectors, establishing charity homes to feed, clothe and care for the destitute persons with disabilities. The community with its governance through local elected bodies, the Panchayati system of those times, collected sufficient data on persons with disabilities for provision of services, though based on the philosophy of charity. With the establishment of the colonial rule in India, changes became noticeable on the type of care and management received by the persons with the influence from the West.

Pre-Independence

Changing Life Styles in India Changes in attitudes towards persons with disabilities also came to about with city life. The administrative authorities began showing interest in providing a formal education system for persons with disabilities, particularly for families which had taken up residences in the cities. Changes in the lifestyle of the persons with mental retardation were also noticed with their shifting from ‘community inclusive settings’ in which families rendered services to that of services provided in ‘asylums’, run by governmental or non-governmental agencies (Chennai, then Madras, Lunatic Asylum, 1841). It was at the Madras Lunatic Asylum, renamed the Institute of Mental Health, that persons with mental illness and those with mental retardation were segregated and given appropriate treatment. Special schools were started for those who could not meet the demands of the mainstream schools.

The first residential home for persons with mental retardation was established in Mumbai, then Bombay (Children Aid Society, Mankhurd, 1941) followed by the establishment of a special school in 1944. Subsequently, 11 more centres were established in other parts of India.

Post-Independent India–Current Scenario

Establishment of Special Schools

Article 41of the Constitution of India (1950) embodied in its clause the “Right to Free and Compulsory Education for All Children up to Age 14 years”. Many more schools for persons with mental retardation were established including an integrated school in Mumbai (Sushila Ben, 1955). Notwithstanding this obligatory clause on children’s mainstream education, more and more special schools were also being set up by nongovernmental organizations

(NGOs) in an attempt to meet the parents' demands. Indian Education Commission 1964-66 The Indian Education Commission, 1964-66 made a clear mention of the presence of only 27 schools for persons with mental retardation in the entire country at that time. In 1953, training teachers to teach persons with mental retardation was initiated in Mumbai by Mrs. Vakil. In 1971, special education to train persons with mental retardation was introduced in Chennai at the Bala Vihar Training School by Mrs. M. Clubwala Jadhav. In the same year, the Dilkush Special School was established in Mumbai initiating special teachers' training programs. The various Acts passed and the policies touching the lives of the disabled are dealt with in Chapter 11, Policies and Programmes.

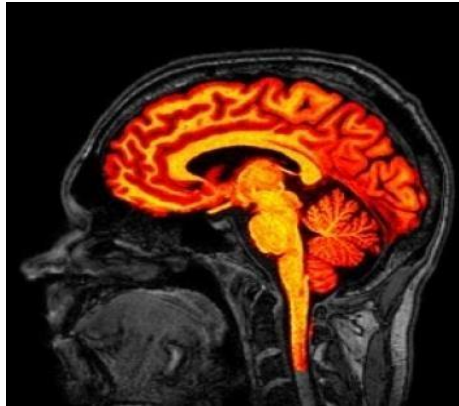
Internationally, the definition of mental retardation has moved away from a medical model to that of an educational model which is functional and support based and emphasizes the rights of the individual. According to the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, enacted in India, mental retardation means a "condition of arrested or incomplete development of mind of a person which is specially characterized by sub-normality of intelligence". Field workers, parents and professionals in India opine that this definition has scope for improvement.

To this date, a systematic enumeration of the number of persons with disabilities in the country has not been made, the reason being the large geographical area. Data on educational and other needs of pre-school, school going children, youth, adults and senior citizens is not available. Classification of Persons with Mental Retardation Based on the 1983 AAMR definition, the operational classification for persons with mental retardation is as follows: Educational Classification In the special education centres in India, the classroom classification in operation is as shown below:

Most of the classification systems define mental retardation with emphasis on significantly sub-average intellectual functioning of the individual (assessed by the standardized intelligence tests). In India, where a majority live in rural areas, engaged mostly with traditional, semi-skilled vocations, the adapted Indian intelligence tests have limitations in assessing the exact levels of intelligence due to lack of standardization on such population. No standard test has been so far developed suited to the Indian cultural milieu. Certification A disability certificate is issued by a Medical Board duly constituted by the Central and the State Governments.

The State Government will constitute a Medical Board consisting of at least three members out of which at least one may be a specialist in the concerned field. In need of correction in the certification process are: limited availability of the specialists in respective areas of disability, distance from the residence to the assessment and certification place, lack of guidelines on the standard test and the person to be used for assessment. No indigenously established behaviour norms are available.

Identification of Mental Retardation



With the implementation of the Persons with Disabilities Act (PWD), 1995 mental retardation 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.

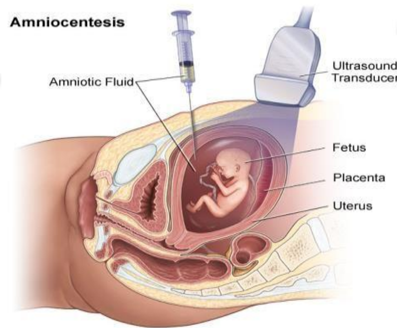
Early identification includes screening, early diagnosis and parent counselling. Information on early identification and prevention is also presented in Chapter 6 on 'Array of Services' and other chapters. Screening is a procedure for an initial identification of persons with mental retardation and for a follow up with assessment. Screening Procedure Many of the screening techniques collated by National Institute for the Mentally Handicapped (NIMH), Secunderabad, appeared in RCI: Status of Disability in India, 2000.

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:

Pre-natal Procedures - Blood tests for the pregnant mothers for any anaemic condition, diabetes, syphilis, Rh incompatibility and neural tube defects in the foetal stage.

- Ultrasonography (during pregnancy) is carried out in the second trimester of pregnancy to detect such disorders as neural tube defects, hydrocephaly, microcephaly, Hydrencephaly, 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



- 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

- Foetoscopy is done during second trimester of pregnancy in diagnosing certain physical anomalies, metabolic disorders or biochemical abnormalities
- Chorionic Villous Sampling where a biopsy of the chorionic villi is performed either trans-abdominally or vaginally. The sample is then subjected to karyotyping and enzyme determination.

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 neuro behavioural 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
- 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 haemorohage in the newborn
- Biochemical Tests in neonatal screening for identifying metabolic disorders
- 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 haemorhage, hydrocephalous and congenital anomalies like holoprosencephaly, a-genesis of corpus callosum, Arnold chiari malformations, congenital cysts and calcifications

- 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

Compared with other children, did the child have any serious delay in sitting, standing or walking? Does the child appear to have difficulty in hearing? Does the child have difficulty in seeing? When you tell the child to do something, does he seem to have problems in understanding what you are saying? Does the child sometime have weakness and/ or stiffness in the limbs and/or difficulty in walking or moving his arms? Does the child sometimes has fits, becomes rigid, or lose consciousness? Does the child have difficulty in learning to do things like other children of his age? Is the child not able to speak at all (Cannot make himself understood in words/say any recognizable words)? Is the child's speech in any way different from normal (Not clear enough to be understood by people other than his immediate family)? Compared to other children of the same age, does the child appear in any way backward, dull or slow? If an answer to any of the above items is 'Yes', then suspect mental retardation.

Other Screening Tools

Some of the other popularly used tools in India include

- Cooperative preschool inventory Caldwell
- Croydon Scales (Screening Checklist) (Wolfendale & Bryans)
- Denver Developmental Screening Test (Frankensberg, Dodds and Fandal)
- Early Childhood Assessment: A criterion referenced screening device (Schmaltz, Schramn and Wendt)
- AGS Early Screening Profiles (Harrison, et al.)
- Developmental Indicators for the Assessment of Learning-R (Mardell, et al.)
- Early Screening Inventory (Merisels, et al.)
- Brigance 'K' and 'T' Screen for Kindergarten and First Grade (Brigance). Indian Screening Tools
- Developmental Screening Test (DST) by Bharat Raj is a widely used screening tool by professionals. The NIMH schedules noted earlier are used for further referral
- Upanayan Early Intervention Programming System (1987)
- Functional Assessment Check List for Programming (FACP) 1991

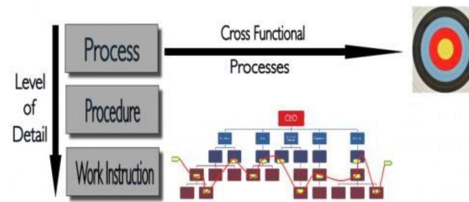
The revised Madras Developmental Programme System Behavioural Scale MDPS-A curriculum based assessment checklist (1975) is suitable for identification purposes.

Screening of Childhood Disabilities

A multi-centre study carried out in 1994 at NIMH revealed that about 50% of parents recognize the delayed development or mental retardation of their children below the age of 2 years while 35% of the parents recognized only after the age of 2 years. Screening Approach in the Community The screening approach in the community involves sorting out children who are at risk and the diagnostic evaluation of those identified in screening. Bio-chemical/Metabolic Screening in Persons with Mental Retardation is in use, but not available freely to the public. Selecting Appropriate Screening Measures For screening or an early detection program, appropriate screening measures must be selected. A screening device should meet the technical criteria of standardization, reliability, validity, and normative data.

The screening instrument should also be culturally appropriate, acceptable to the participants and cost effective. Screening tests must have established sensitivity and specificity to be valid.

Mental retardation, a condition characterized by some degree of intellectual impairment, has undoubtedly existed and been recognized since the emergence of human race. The incompetent individual, unable to meet the demands and expectations of society, has been described and discussed in both the oral and written histories of Romans, Medieval Europe, and all known contemporary societies. Though mental retardation is not an uncommon phenomenon, yet most people remain unmoved by it, unless they are directly or indirectly affected at the personal level in the context of family, friends or relatives. Hence little attention has been paid to it.



The phenomenon of mental retardation is not restricted to any one social class; as, it cuts across all socio-economic levels. In India, like in other developing countries, early detection of mental retardation has been achieved at the national level. In recent times, creation of awareness and education has facilitated the development of positive attitudes in the family and in the community. Learning environments and experiences that promote independence and inclusion in the community have now become mandatory. The Rehabilitation Council of India (RCI) has initiated early childhood special education towards the provision of comprehensive services in the prevention, intervention, care and management of children with mental retardation.