Clinical Practice Guidelines for the Diagnosis and Management of Children With Mental Retardation

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INTRODUCTION

Intelligence, which is highly evolved in human beings, is defined by Wechsler as 'the global capacity of the person and to deal effectively with his / her environment' (Wechsler 1939).[1] We make use of our cognitive or intellectual ability it to learn, understand, imagine, remember, think, adapt and modify our environments. Given this fact, it is no wonder that a diminished intellectual capability puts significant limitations on the person's functioning. Mental retardation (MR), the hallmark of which is diminished intellectual capability, is thus the most disabling of all disabilities with significant consequences for the individual themselves, their families. The societal responses to MR may make problems more complicated for these individuals. History is replete with instances of their neglect, abuse, and victimization. ***These lessons from the history have taught us that they must be treated with respect and dignity and their rights have to be recognized like any other human being.***

MR can be viewed from several perspectives: as an extreme of variation in individual abilities (psychometric), as a biomedical problem (consequence of disease or disorder affecting the brain) or as a condition that makes people face disadvantages in society (socio-cultural). Viewing mental retardation purely from any of these perspectives leads to severe limitations in our total understating and dealing with the problem. A balanced bio-psycho-social perspective is the best way to understand and deal with MR.

Though the guidelines described here pertain primarily to children, issues concerning adults are addressed wherever needed. In preparing these guidelines, search was made for available practice parameters, guidelines, reviews, and reports. In addition, search through Pubmed and other sources were made for relevant publications on from India and abroad. Some of the notable ones were AACAP practice parameters on mental retardation and comorbid mental disorders,[2] AAN practice parameter on evaluation of the child with global developmental delay, [3] review on psychopharmcotherapy in intellectual disability,[4] practitioner review on psychopharmacology in MR,[5] and 10 year review on MR,[6] and a WHO publication on MR.[7]

CONCEPT AND DEFINITION:

MR belongs to the class of developmental disabilities (DD). These are conditions in which one or more of human capabilities fail to develop adequately from childhood. Apart from MR, other DD's are specific delays in speech and language, in motor skills, in scholastic skills, and autistic spectrum disorders. Most of them are static encephalopathies, meaning that though they have some significant delay, they continue to improve with the passage of time, albeit as a slower rate. Most often, these conditions result from some or other form of damage or interference, either genetic or environmental, to smooth and orderly development of the brain or brain circuits. *However, there is a small sub-group of children who have progressive decline intellectual abilities (progressive encephalopathies or childhood onset degenerative disorders).*

Core concept of mental retardation has remained the same over the centuries, though has been worded differently at different times. Widely accepted definitions that are currently available stress on 3 dimensions: the intellectual (IQ less than 70), developmental (onset before 18 years of age) and thirdly the social (diminished ability to adapt to the daily demands of the normal social environment) criteria. The DSM IV, for instance defines MR as ' Significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgment of significantly sub-average

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intellectual functioning), with concurrent deficits or impairments in present adaptive functioning (i.e., the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety, and onset is before age 18 years.[8]

PREVALENCE

Prevalence of mental retardation in India is around 2% for mild mental retardation and 0.5% for severe mental retardation (defined as IQ less than 50).[9]. The major correlates are excess in males and rural areas. At least one-third of children attending Child Psychiatry OPD's or Child Guidance Clinics have MR.

CAUSES OF MR

Any disease or adverse influence that interferes with the smooth, orderly, and orchestrated development of the brain can result in MR. More than 500 causes for MR has been identified and the list is still growing .[10]] These adverse influences can be classified into prenatal, perinatal and postnatal causes depending on their timing. Table 1 lists these categories, types, and common examples. New causes such as sub-telomeric deletions and copy number variations (genomic disorders) have been discovered recently.

In India, Indian Council of Medical Research (ICMR) carried out a multi-centric study involving 1314 children with MR without an obvious environmental cause, and found that chromosomal anomalies were present in 23.7 per cent, metabolic defects in 5.0 per cent and an identifiable genetic syndrome in 11.6 per cent of the patients.[11]

Table 1: Etiologic classification of MR

CATEGORY	TYPE	EXAMPLES
Prenatal	Chromosomal disorders	Down syndrome, Klinefelter syndrome, Turner syndrome, Cri-du-chat syndrome, Prader Willi syndrome, Angelman syndrome, William syndrome
	Single gene disorders	**Inborn errors of metabolism:** Galactosemia, phenylketonuria, Mucopolysaccharidoses, Tay- Sachs disease, Lesch-Nyhan syndrome, Hypothyroidism, **Neuro-cutaneous:** Tuberous sclerosis, and neurofibromatosis **Brain malformations** such as autosomal recessive primary microcephaly, hydrocephalus **Others:** fragile X syndrome**,** Rett syndrome, Laurence Moon Bardet Biedl syndrome, Smith-Lemli-Opitz syndrome, Coffin Lowry syndrome
	Other conditions of uncertain genetic origin	Rubinstein Taybi syndrome De Lange syndrome
	Adverse maternal /environmental influences	**Deficiencies:** iodine deficiency, folate deficiency **Severe malnutrition in pregnancy** **Using substances:** alcohol (maternal alcohol syndrome), nicotine, and cocaine during early pregnancy **Exposure to other harmful chemicals**: pollutants, heavy metals, abortifacients, and teratogenic medications such as thalidomide, phenytoin and warfarin sodium in early pregnancy **Maternal infections:** rubella, syphillis, toxoplasmosis, cytomegalovirus, Herpes and HIV **Others:** excessive exposure to radiation, Rh iso-immunization

Perinatal	Third trimester	**Complications of pregnancy:** Ecclampsia **Maternal Diseases:** cardiac, renal, diabetes **Placental** dysfunction /deprivation of supply
	Labour	Severe prematurity, very low birth weight, hypoxic ischemic encephalopathy (birth asphyxia), Difficult and/or complicated delivery, Birth trauma
	Neonatal	Septicemia, severe jaundice, hypoglycemia
Postnatal		Brain infections: tuberculosis, Japanese encephalitis, and bacterial meningo-encephalitis
		Head injury
		Chronic lead exposure
		Severe and prolonged malnutrition
		Gross understimulation and experiential deprivation

COURSE OF MR

Intelligence is normally distributed in the population with a skew to the left and a hump in the lower ranges. This means that different clinical degrees of MR blend with each other imperceptibly. Also, there is a wide inter-individual and intra-individual variation in skill levels within each category. ICD-10 provides a general description of these categories.[12]

Clinicians tend to underestimate the future attainments of children who present with MR. Table 2 shows the adult attainments of children who present with different degrees of MR (summarized from several sources). From the table, it is clear that even children with moderate retardation are capable of acquiring a variety of skills and competencies, given right kind of inputs and opportunities. It is possible that a proportion of infants with mild developmental delay may turn out to normal intelligence in adulthood.[13]

Table 2: Adult attainments in different degrees of MR

DEGREE OF MR with IQ range as per ICD 10	ADULT ATTAINMENT
Mild (50-79)	Literacy ++ Self-help skills++ Good speech ++ Semi-skilled work +
Moderate (35-49)	Literacy + Self-help skills ++ Domestic speech+ Unskilled work with or without supervision +
Severe (20-34)	Assisted self-help skills+ Minimum speech+ Assisted household chores +
Profound (<20)	Speech+/- Self-help skills +/-

Note: ++ means definitely attainable: + means attainable: +/- means sometimes attainable;

CLINICAL PRESENTATION

Delayed milestones of development, poor ability to learn new things, poor speech and comprehension, poor self-help skills, and poor school performance, poor memory are the common presenting common complaints. Other reasons are for behavior problems such as restlessness, poor concentration, impulsivity, self-injurious behavior, or sleep / appetite disturbances. Recent onset behavior change in a child already having delay is another important presenting complaint, and needs careful evaluation. Sometimes parents bring them primarily for assessment of intellectual abilities, certification, etc.

ASSOCIATED (COMORBID) PSYCHIATRIC PROBLEMS

There is a vast body of literature suggests that MR at all ages is 3-5 times more frequently associated with psychiatric disorder than in general population, with a prevalence of around 40%.[14, 15]

Several studies from India have confirmed this excess prevalence, and also have reported on pattern of psychiatric comorbidity. [16-19]

There are many reasons for this excess prevalence:

(i) impairment in CNS development contributes not only to MR but also behavioral / emotional dysregulation,

(ii) associated problems such as seizures and speech problems makes them predisposed,

(iii) limited intellectual potential increases vulnerability to environmental influences and stresses, and

(iv) they are more likely to experience adverse conditions of upbringing such as understimulation, overprotection and inconsistent disciplining.

In a given child, any of these factors, either alone or in combination, may contribute to the development of psychiatric disorder.

Full range of psychiatric disorders has been described in children and adults with MR.[20,21]Both externalizing disorders such as oppositional defiant disorder and ADHD and internalizing disorders such as social anxiety and specific phobias are known to occur. Rates of ADHD in community samples of children with MR have been found to vary from 7% to 15%. Prevalence of schizophrenia in adults has been found to 3 times more common than in individuals with normal intelligence.[22] Affective disorders in all forms do occur in persons with mental retardation. Atypical presentations of bipolar disorders such as mixed episodes and rapid / continuous cycling have been more often reported.[23]

By and large, the same criteria that apply to individuals without MR are being followed for diagnosing comorbid disorders in MR, although there have been some attempts at developing alternate criteria.

Psychiatric disorders in persons with MR are commonly under-diagnosed or misdiagnosed. Several factors might be responsible:

- An erroneous belief that psychiatric disorders can't be diagnosed when there is MR is a common reason.
- ***diagnostic masking*** – manifestations of the disorder are modified or masked by the presence of MR, especially in more severe forms of MR.[24]
- clinicians may narrow their focus on only identifying disruptive behaviors and implement only symptomatic treatment, thereby neglecting to evaluate the global picture.
- ***"Diagnostic overshadowing"***, or the tendency to write-off symptoms as merely expressions of MR

and not psychiatric disorder will also lead to under-diagnosis.[25]

- Persons with MR may have difficulty responding to standard diagnostic interview questions.

It is desirable that clinicians attempt a formal diagnosis of psychiatric disorder rather than providing "behavior disorder" or "challenging behavior" label. Carefully studying behavioral profile may point to a particular psychiatric disorder.[26] However, a proportion of children presenting with behavioral problems such as aggression, impulsivity, irritability stereotypies and self-injurious behavior may defy classification and may get a label of behavior disorder NOS.

There has also been growing recognition that certain behavior patterns tend to be more often associated with specific etiologic syndromes (**behavioral phenotypes**).[27] Some Examples are severe self-injury in Lesch Nyhan syndrome, obesity and OCD in Prader Willi syndrome, PDD and ADHD in Fragile X syndrome, and psychotic disorders in velo-cardio-facial syndrome

Diagnosis of comorbid psychiatric disorder: *Recent onset changes in behavior, overall functioning, sleep and appetite patterns, often point towards a comorbid psychiatric disorder.* During clinical evaluation, a greater reliance on onset and chronological evolution of symptoms, intensity, frequency, context of occurrence of symptoms, precipitating & relieving factors elicited through careful interviewing of parents and caregivers will help in uncovering the psychopathology. School report is a valuable additional source of additional information. A period of behavioral observation rather than just traditional psychiatric interview will often help the clinician to decide on the presence and type of psychiatric disorder.

Recently, a few standardized instruments have been developed to screen for psychiatric and behavioral disorders such as Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD),[28] Reiss Screen for Maladaptive Behavior,[29] Psychopathology Inventory For Mentally Retarded Adults (PIMRA),[30] and Developmental Behavior Checklist (DBC).[31]

Table 3 lists common comorbid psychiatric disorders in children with MR.

TABLE 3: COMMON COMORBID PSYCHIATRIC DISORDERS IN CHILDREN WITH MR

- ADHD, ODD, CD restricted to home situation
- PDD, stereotyped movement disorder
- Anxiety and depressive disorders
- Disorders of sleeping & feeding
- Non-syndromal: restlessness, self-injurious behaviors, aggression, stereotypies, impulsivity, pica

ASSOCIATED PHYSICAL PROBLEMS

MR is often accompanied by medical disorders and disabilities, both neurological and non-neurological (Table 4). These will require attention in overall management. Structures of ectodermal origin, from which brain also develops, are more likely to be affected. Some conditions giving rise to MR are more commonly associated with certain disorder, for e.g., Down syndrome with congenital heart disease and Azheimer's dementia, congenital CMV infection with hearing impairment, kernicterus with dyskinetic CP, tuberous sclerosis with epilepsy, and Laurence Moon Bardet Biedl syndrome with retinitis pigmentosa. Seizure disorder has been reported in 15-30% of individuals with MR of all degrees.[32] This prevalence increases to around 50% of individuals with severe MR. Epileptic encephalopathies such as West syndrome and Lennox Gestaut syndrome are almost invariably associated with MR.

A small proportion of children with MR have multiple disabilities, for instance, a child with moderate MR, cerebral palsy and hearing impairment. Such children need extensive evaluation and intervention.

TABLE 4: MEDICAL DISORDERS AND DISABILITIES ASSOCIATED WITH MR
Seizure disorder
Cerebral palsy
Visual impairment
Hearing impairment
Congenital heart disease
Cleft lip and cleft palate
Orthopedic handicaps (CTEV, congenital dislocation of hip joint)
Vitamin and mineral deficiencies
Recurrent infections
Feeding skills disorder

CLINICAL EVALUATION IN MR

A thorough clinical evaluation is the basis for optimum management. There are a number of questions that the clinician needs to answer through a good clinical evaluation, as laid in Table 5. Attempts need be made not only to establish whether MR is present or not, but also to ascertain the degree, cause, associated problems, and family and psychosocial factors.

It is important to make efforts to identify the causative factors, for a number of reasons: some of them such as hypothyroidism are amenable for treatment; for genetic counseling purpose, and for prognostication. In addition, parents often want to know the cause even if it is not treatable, as it gives them a sense of cognitive control over the situation. They may also harbor some misconceptions about the causation, which can be addressed through counseling.

TABLE 5: CLINICAL QUESTIONS TO GUIDE EVALUATION
What precipitated the consultation
Is there significant developmental delay
Is it global (affecting all areas of development, viz., motor, cognitive, social, and language) or restricted (for instance only motor or speech)
How severe is the delay
What is the cause/s Is there a treatable cause
What is the recurrence risk
Are there associated medical problems
Are there associated behavioral or psychiatric problems
How much do parents know about the condition What are their expectations What are the difficulties faced by them
Are there any other issues
What and how to tell parents
The steps in clinical evaluation are depicted in Table 6, and described bewlow:

TABLE 6: DIMENSIONS OF CLINICAL EVALUATION IN MR
Detailed history
Thorough physical examination
Psychological testing
Physical investigations
Comprehensive diagnosis

HISTORICAL DETAILS :

A standard format for eliciting and recording the history is given below in Table 7. Information from Multiple sources - parents, other caregivers, previous consultation notes, school report, and from the child himself or herself whenever possible enhances the reliability of the information.

Table 7 : A scheme for history-taking in MR

- **Complaints** with duration, and evolution of current problems
- **Family history:** with 3 generation genetic diagram, family history of MR, epilepsy, other developmental problems, early deaths, etc, family background, current living arrangements, details stress, coping and adaptation by the family
- **Personal history:** pre-, peri-, and postnatal details, developmental milestones, & developmental course or trajectory (onset of delay, dates of acquisition of key milestones, delay in all areas or not, severity of delay, schooling history, and menstrual history)
- **Medical history:** seizures, feeding problems, recurrent infections, etc
- **Psychiatric history:** details of onset, evolution and current status of behavioral and other psychopathological disturbances
- **Treatment history:** past efforts by the family in seeking help, nature, and response to past treatment, and current medication
- **Current developmental attainments:** in motor, cognitive, language and social areas, parents' estimation of mental age of the child

PHYSICAL EXAMINATION :

Ideally a head-to-toe examination of all the organ systems needs to be carried out. Some of essential things to note are vision, hearing, locomotion, and any major congenital anomalies. Special attention should be paid to neurological examination. It is also desirable to systematically look for and document any minor congenital anomalies (MCA's) (Table 8). Presence of 4 or more MCA's is a pointer to a prenatal etiology.[13] This book (Smith's Recognizable Patterns of Human Malformation) is an excellent source for the list of syndromes and other related issues.

TABLE 8: SOME COMMON MCA'S AND OTHER FINDINGS ON PHYSICAL EXAMINATION

Facial appearance: typical facies (mongoloid, coarse), elongated, triangular

Height: short stature, tall stature, increased arm span, gigantism

Weight: obesity, emaciation

Head circumference: microcephaly, macrocephaly

Shape of skull: brachycephaly, scaphocephaly, trigonocephaly, oxycephaly, plagiocephaly

Ears: low set, small, large, malformed, protruding, lop, posteriorly rotated, pre-auricular tags, cup-shaped

Skin: dry and coarse, café-au-lait spots, abnormal pigmentation, hemangioma, ichthyosis, eczema, absence of sweating

Nose: depressed nasal bridge, short and stubby, beak shaped, bulbous tip, flaring or hypoplastic nostrils, anteverted nares,

Vision: amblyopia, refractive error, nyctalopia

Hearing: partial or complete loss

Neck: short, webbed, torticollis

Eyes: deeply set, proptosis, microphthalmia, upslanting / downslanting eyes, hypertelorism, epicanthal folds, strabismus, nystagmau, ptosis, bushy eyebrows, synophrys, microcornae, corneal clouding, K-F ring, cataracts, coloboma of iris, blue sclera, telangiectasia

Palate: high arched, shallow, clefting, bifid uvula

Hair: hirsutism, light colored, double whorl on scalp, easily breakable,

Other facial features: long / absent philtrum, midfacial hypoplasia, micrognathia, sloping forehead,

Hands: simian crease, Sidney line, spade shaped

Fingers: clinodactyly, camptodacyly, arachnodactyly, short little finger, syndactyly, polydactyly, broad thumb

Chest: pectus excavatum, pectus carinatum, nipple anomalies, gynaecomastia

Abdomen: protuberant, umbilical hernia, hepato-splenomegaly, inguinal hernia

Spine: kyphosis, scoliosis, spina bifida

External genitalia: hypogenitalism, macro-orchidism, undescended testis, ambiguous genitalia, hypospadias, absent secondary sexual charactersitcs, shawl scrotum

Feet: pes planus, pes cavus, valgus / varus anomaly, broad hallux, increased distance between 1st & 2nd toe

Skeletal: exostoses, increase carrying angle, joint hypermobilit

A number of syndromes can be diagnosed based on clinical features (table 9)

Table 9: common clinically recognizable syndrome encountered in india

Syndrome	Key features
Down syndrome	Typical facies, short stature, medial slanting of eyes, clinodactyly, simian crease, cup-shape ears
Fragile X syndrome	Elongated, triangular face, protruding /prominent ears, macro-orchidism in post-pubertal boys
Rett syndrome	Normal development till around 1 year of age in a girl child followed by plateauing and regression, loss of hand functions, mid-line hand stereotypies
De Lange syndrome	Hirsutism, long eye-lashes, synophrys, bushy eye brows, microcephaly,
Prader Willi syndrome	Obesity, hypogenitalism,
Tuberous sclerosis	Sebaceous adenomas, ash-leaf spots, shagreen patches, seizures
Congenital hypothyroidism	Lethargy, growth failure, coarse and dry skin, constipation, feeding problems, protuberant abdomen, bradycardia
Mucopolysaccharidoses	Typical facies, coarse skin, skeletal anomalies, macrocephaly
Homocystinuria	Marfanoid features,
Phenylketonuria	Light colored hair, abnormal smell of urine, microcephaly, seizures
Autosomal recessive microcephaly	Severe congenital microcephaly with only mild to moderate MR, no other anomalies
Rubinstein Taybi syndrome	Prominent beak-shaped nose, broad thumb and hallux

PSYCHIATRIC EXAMINATION AND BEHAVIORAL OBSERVATION:

This starts from the moment the child enters the consultation room. Equal attention need to be paid to behavioral observation, parental reports, as well as to verbal interview in arriving at conclusions. In other words this involves continuum of history-observation-interviewing / MSE. This calls for adequate clinical skills of observation, prioritization, flexibility in conducting the interview, communication, and adjusting the style and content of interviewing depending on the situation. If necessary, child and parents could be interviewed separately. Playroom observation and longer periods of observation for a functional analysis (Antecedent-Behavior-Consequences or ABC analysis) of symptoms is sometimes required. Table 10 provides a scheme for clinical interview and observation.

TABLE 10: AN APPROACH TO CLINICAL INTERVIEW IN MR

Setting for interview:

Toys, Books, Pictures, Paper, pencil
Couch, child friendly furniture
Safe from danger
Space to move around

Process of Interviewing

- *Building rapport*
  Make the kid and parents comfortable: child on mother's lap or in separate chair or to let the child move around
  Learn the pet name, get the exact age
  Be ready to get up from seat and move around to interact with the child to engage in some activity
  Offer toys, books, etc and quickly find out something the child is able to do; appreciate and comment on it to the parents
- *Build partnership with parents from the outset*
  Value their opinions, and impressions, and efforts;
  Appreciate parents for the right things they have done
- *Verbal interviewing: depends on language development and conversational skills:*
  Simple, structured, and brief;
  Use clear & concrete questions
  Avoid leading questions
  Use parents when necessary for interviewing
- *Clinical observation (common abnormalities in brackets)*
  Basics: Vision, hearing, locomotion, physical health
  Response to interview situation: (excited, fearful and tense, shy, inhibited, guarded, uncooperative, defiant)
  Alertness: (over-aroused, withdrawn)
  Attachment to parents and response to separation: (clinging, wanting to be carried all the time, indifferent to separaton)
  Sociability: check for Social orientation, approachability, Social responsiveness, ETE contact, reciprocity or response to overtures (solitary, withdrawn, poor ETEC, over-socialization)
  Motor Activity level: Fidgetiness, restlessness, hyperactivity; lethargy
  Course of motor behaviors during interview, response to firm instructions: (quiet initially, but later restless, unresponsive to firm instructions)
  Impulse control: (snatching, spilling, falling, bumping, climbing, interfering, temper tanrums; aggressive acts such as biting, throwing, beating, pulling hair, slapping)
  Attention, concentration: goal directedness, task completion, distractibility (short attention span, jumping from one activity to another, easily distracted)
  Speech, language & communication: check for verbal/non-verbal comprehension & Expression, vocabulary, articulation, and flow
  Mood: (inhibited, excessively cheerful, whining and crying, irritable,)
  Play behavior
  Other inappropriate behaviors: (stereotypies, Self-Injurious Behavior),
- Impressions on current developmental attainment:
  hand functions, self-help skills, use of objects, general information, capacity for new learning, rational thinking, pre-academic & academic skills

Parent child interactions
Quality of engagement with child
Communication patterns
Degree and quality of control over the child
Response to good and bad behaviors

Interaction between parents

INVESTIGATIONS

Given the fact that MR can result from a variety of insults to brain development, a range of physical investigations may be required to ascertain the cause of MR, as well as to delineate the associated problems such as hearing / visual impairment. Table 11 lists potentially useful investigations in MR.

In a given child, investigations have to be decided based on the clinical picture, the need for genetic counseling, treatability of the conditions likely to be detected, diagnostic yield of a given investigation, cost of investigation, economic status of the family, and the parents' need to know the cause. Ideally, investigations should be planned after a detailed discussion with parents about all these issues. American Academy of Neurology provides useful guidelines in this regard.[3]

TABLE 11: PHYSICAL INVESTIGATIONS IN MR

Test	Examples of Conditions detected
Urine screen for abnormal metabolites	Phenyketonuria, homocysteinuria, galactosemia, MPS
Thyroid function test	Hypothyroidism
Advanced metabolic tests (Gas chromatographic Mass Spectroscopyc (GCMS), tandem mass spectroscopy (TMS)	Wide range of neuro-metaboloic disorders such as fatty acid oxidation disorders, aminiacidopathies, urea cycle disorders and organic acidurias
Enzyme studies	Tay-Sach disease, meatachromatic leukodystrophy
Karyotyping	Down syndrome, other chromosomal disorders
FISH	Prader Willi syndrome, William syndrome, Sub-telomeric deletions
Molecular genetics	Fragile X syndrome (FMR1 mutation), Rett syndrome (MECP2 mutation),
Brain imaging	Tuberous sclerosis, lissencepahly,
EEG	Epileptic encephalopathies such as West syndrome
Hearing evaluation (BAER)	Sensory-neural hearing impairment
Visual evaluation	Wilson dis ease, cataract, Optic atrophy, cortical blindness, refractive error
Blood group of child and parents	Rh iso-immunization
Immunologic tests (Ig M antibodies)	TORCH infections

PSYCHOLOGICAL TESTING:

These are required for several reasons. It is especially useful in children who present with mild delays in development, sub-average or borderline intellectual functions or with learning difficulties (slow learners), when a systematic assessment of their different cognitive abilities helps in clarifying the diagnosis. Another important reason is for mapping out the child's assets and liabilities so that an individualized training program can be formulated. Estimating the IQ of the child is also commonly required for administrative reasons such as certification. Commonly used tests in India are Vineland Social Maturity Scale (VSMS), Binet Kamat Test (BKT), Malin's Intelligence Scale for Indian Children (MISIC), WISC, and Bhatia Battery. An Indian adaptation of Bailey's Scale for infants is also available (DASI). Checklists such as Portage checklist, BASIC MR from NIMH, Secunderabad, DDVP, Trivandrum Developmental Checklist are also useful for planning

targeted intervention.

Clinician has the task of synthesizing the information from historical data from many sources, examination and observation to arrive at a **comprehensive diagnosis.** A modified Rutter's multi-axial system for comprehensive diagnosis, as in Table 12 has been found to useful in MR, and helps in planning an individualized intervention plan.

TABLE 12 : A SCHEME FOR COMPREHENSIVE DIAGNOSIS IN MR (EXAMPLES IN BRACKETS)

I: Presence and degree of MR (mild MR)
II: Etiologic / syndromal diagnosis (fragile X syndrome)
III: Associated medical problems (epilepsy)
IV: Associated psychiatric problems (ADHD)
V: Family & psycho-social axis (poor awareness, high stress levels, overexpectation)

DIAGNOSIS AND DIFFERENTIAL DIAGNOSIS

- Moderate or severe MR at any age can be identified without much difficulty, based on elicitation of developmentalmilestones and current functioning in different areas.
- A useful technique to assign degree of MR is to make an estimate of mental age of the child based on the current abilities of the child, divide it by chronological age, and multiply by 100. This calls for a good understanding of developmental milestones by the clinician. Parents can often give a fairly accurate estimate of the child's mental age.
- Careful attention needs to be paid when there is milder forms of intellectual deficit before labeling the child as having MR. Diagnosis of MR should only be considered when there is significant, global delay or deficits in current developmental attainments in all areas of development. Standardized Psychological testing is desirable in this group of children
- The label of MR is better avoided in infants unless there is severe global delay or a DQ of less than 50.
- Other disorders and disabilities such as cerebral palsy without MR, pervasive developmental disorder without MR, specific leaning disability or specific delays in development of scholastic skills (dyslexia's), Specific delay of speech and language development, severe emotional disorder and visual and hearing impairment may be erroneously labeled as MR. Careful clinical evaluation especially focusing on the current abilities in different areas of development, viz., motor, cognitive, social and language, supplemented by psychological testing sorts out the diagnosis.

MANAGEMENT OF MR – PHILOSOPHIES AND APPROACHES

Over the last 2-3 decades, the following philosophies and approaches have emerged for the care of individuals with MR:

Normalization principle: the central notion of this principle is "to make available to persons with MR patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society".[34] It asserts their right to live with respect and dignity, exercise their choices, and the responsibility of the society to create a favorable environment for their development and well-being.

Home-based family care approach with parents as partners in care; this developed in contrast to the widespread institutionalization that was practiced in Western world. The focus, from this perspective, is to actively collaborate with families in building and providing services, to strengthen and empower parents so that these individuals can be provided optimum care at home.

Early detection and intervention: this applies to children who already have significant developmental delay, as well as to children who are at risk for developing MR (prematurity, low birth weight, neonatal hypoxic-

ischemic encephalopathy, neonatal hyperbilirubinemia, neonatal septicemia etc). Support for early intervention has come from a number of neurophysiological studies in animals, which have consistently demonstrated the vital role of experience and stimulation in sensory-motor, cognitive, and behavioral development and the adverse influences of experiential deprivation. The corresponding changes in the neuronal structure such as increased dendritic branching and inter-neuronal connections have been documented.[35]

Early intervention studies in humans have also demonstrated the efficacy of this approach in fostering development of babies with developmental delay.[36-38]

There have been several reports of early intervention in India, with some of them indicating positive results.[39-43]

The objectives of early intervention include (i) creating an optimal environment for best possible development of the child, (ii) to prevent the occurrence of secondary disabilities (reversible and preventable disturbances that result from sub-optimal care) and (ii) to equip parents with necessary skills and competencies to foster such development.

Children with developmental delay are prone for understimulation, thereby further impeding their process of development. Techniques of early intervention include sensory-motor stimulation, contingent-responsive stimulation, environmental enrichment, establishment of a mutually enjoyable and rewarding caregiver – infant interactions (parent-infant interaction intervention or transactional intervention), and behavior modification.[44]

Table 13 lists some of the common avoidable errors by clinicians when dealing with MR.

Table 13: Common errors by clinicians

Negative attitude and therapeutic nihilism towards MR ('nothing can be done')

Not treating the individuals with respect and dignity

Conveying implicitly or explicitly a sense of pessimism

Lack of adequate knowledge base

Cursory and incomplete evaluation

Missing or misdiagnosing comorbid psychiatric and medical conditions

Under-estimation of future attainments

Not providing treatment options

Giving false reassurances (he will be normal when he grows up)

SPECIFIC INTERVENTIONS IN MR

By its very nature, MR requires multi-sectoral (health, education, social welfare, community, legislation / policy making) and multidisciplinary (psychiatrists, other medical specialists, psychologists, social workers, speech pathologists, physio-occupational therapists, special educators, geneticists etc) approach to its management. Apart from their primary role as clinicians, psychiatrists also need to take initiative in becoming part of the networks, building networks, and even establishing services. Interaction, liaison and collaboration with other professionals such as psychologists, pediatricians, teachers, and rehabilitation professionals are very often required. For example, while referring a child to an NGO, which is providing service, the psychiatrist could write a referral note giving the details of clinical evaluation and the reason for referral.

Psychiatrists are often called on by Governmental Depts. (Disabled welfare, woman and child development etc) and NGO's to provide assistance, and guidance in their programs and related service / training activities. Psychiatrists also have a role in assisting the judiciary in different capacities. Psychiatrists could also play a role in advocacy for strengthening of the services.

RECOMMENDATIONS ON THE MANAGEMENT OF MR.

It is desirable to carry out the following interventions in the management of a child with MR. (These interventions are described in detail subsequently).

- Parent Counseling
- Treatment of the underlying disorder wherever possible
- Early intervention in children who are at risk and those who already have developmental delay
- Management comorbid psychiatric and medical problems
- Individualized training program for the child based on assets and liabilities in the child, family and environment
- Parent training for home-based management
- Referrals for special education, physio-occupational therapy, speech therapy, vocational training, and parent organizations
- Discussion about parental concerns such as social security, guardianship, menarche, marriage, etc and providing appropriate guidance
- Helping parents to access social welfare benefits etc
- Checking about the need for genetic counseling and offering appropriate help

Table 14: Overview of individual, family and community level interventions

- Individual
  - Medical interventions
  - Sensory-motor & cognitive stimulation
  - Speech and language therapy
  - Physiotherapy and occupational therapy
  - Self-help and social skills training
  - Education – inclusion in normal stream or special education
  - Pre-vocational training
  - Vocational training and job placement
- Family
  - Parent counseling: Alleviation of stress & enhancing coping & adaptation
  - Parent training for home based intervention
  - Family networking; Parent associations
    Helping families to access community and governmental resources and benefits
- Community
  Legislations, policies and programs
  Social security benefits to individuals and families

CBR program

Medical interventions

These are summarized in table 15. There is no evidence that Nootropics, or drugs that are supposed to enhance cognition are effective in MR. Hence, it is preferable to avoid prescribing this group of medication in MR.

Table 15: Medical interventions in MR

- Diagnosis and treatment of treatable underlying disorders
  - E.g., Hypothyroidism, PKU
- Diagnosis and treatment of comorbid medical & psychiatric problems

– E.g., Epilepsy, hearing impairment, ADHD, Undernutrition, feeding and sleeping problems

- Genetic counseling

Genetic counseling is highly skilled medical intervention, and often requires a close collaboration between clinicians, geneticists and other specialists. The commonest situation when genetic counseling is required in MR is when parents have one child with MR and would like to know the risk of recurrence. Experience of genetic counseling in India has been described in detail elsewhere.[45,46]

Management of comorbid psychiatric and behavioral disorders

This is an important area of intervention, given the fact that upto 40 % of children with MR have a diagnosable psychiatric disorder. Very often this proves to be a greater source of stress for families than MR per se. Also these children are likely to be rejected in social and educational settings. Management needs to be muti-modal, with both pharmacological and psycho-social interventions.

Pharmacotherpy : There have been a number of studies on the use of psychotropic medication in children and adults with MR, though majority of them tend to be open trials, case reports, or controlled studies with small samples. These studies have focused on utility of particular medications in discrete disorders (for instance, methylphenidate in ADHD, or atypical anti-psychotics for schizophrenia), or the efficacy of particular psychotropic agent in the symptomatic treatment for problematic or challenging behaviors (for instance risperidone for aggression, impulsivity and stereotypies).

The available data suggests that persons with MR respond to various psychotropic medications in ways similar to the typically developing population. For instance, there are several studies that have established the efficacy of methyphenidate in ADHD comorbid with MR at the dose of 0.3 to 0.6 mg / kg twice daily. However, rates of response tend to be poorer and the occurrence of side effects tends to be more frequent In view of this, lower initial doses, small increments while increasing the dose, and careful monitoring of response and adverse effects are required.[4,5] Studies have shown the efficacy of risperidone in aggression and stereotypies, clonidine in hyperactivity and impulsivity (especially in the presence of seizures as clonidine has no effect on seizure threshold,[47] and SSRI's in dysphoria, SIB and stereotypies.

Pharmacotherapy needs to be combined with psycho-social forms of treatment to obtain optimum and sustained improvement. These include parent counseling, parent training, behavior modification, skills training, and environmental changes. Individual counseling with appropriate modifications in language and approach could be attempted wherever it is necessary and feasible.[6]

It is common to see oppositional defiant behaviors, tantrums, and other disruptive behaviors in these children mainly as a learnt behavior in response to faulty parent child relationships and child-rearing practices. These can be effectively tackled through parent counseling, behavior modification, and parent management training.

In those with severe problems, a brief period of inpatient evaluation and management might be required.

Psycho-social management of MR

Individual interventions

This depends on the child's age, degree of MR, and the assets and liabilities in the child. In younger children, the focus is on sensory-motor / cognitive stimulation, physio-occupational therapy, and speech-language therapy. Table 16 lists some of the techniques and approaches to infant stimulation.

Table 16: some techniques early intervention and stimulation

Area	Approach / examples
Establish rewarding MII	Draw child's attention through eye-to-eye contact, touch, vocalization, facial movement, toys etc Introduce an activity and vary stimulus characteristics till child starts reciprocating by smile, motor activity, excitement, vocalization etc Notice these signals, respond back by animatedly repeating the activity and thereby establish interaction cycle Move to another interaction cycle later Integrate these cycles into daily routines such as bathing, and dressing,
Multi-sensory stimulation (covering all sensory modalities)	Touching, Tickling, stroking, gentle rubbing, gentle bouncing, gentle to-and-fro rocking with a tune, swinging, making purring sound on abdomen, gentle massaging Showing colorful cloth pieces, ribbons, balloons, toys; Playing tunes, hums, parallel vocalization, gentle clapping; sounds of bangles, bells, animals, talking, building simple conversation around daily routines Getting the child to experience different tastes and odors
Gross motor	Prone positioning, supported sitting, crawling, supported walking, passive and active range-of-motion exercises of all joints
Fine motor	Hand functions: grasping, reaching, holding, transferring, giving, pincer grasp, joining, pulling, pushing, beading
Early social	Imitating skills, pointing, joint attention, showing body parts Mother-infant games: peek-a-boo and its cultural variants, other culturally prevalent mother-infant games
Early Cognitive	Sorting, classifying, arranging, recognizing pictures, matching
Concept development	Size, shape, consistency, time, space (distance, direction etc), color

Older children require self-help / social skills training, education and pre-vocational training. Behavior modification techniques have been found to be extremely effective for training. Tables17 and 18 briefly describe the common techniques to build new skills and to eliminate inappropriate / excess behaviors.

Table 17: Behavior modification techniques for building new skills

Technique	Brief definition
Goal specification	Specified description of desired behavior to be learnt, based on current skills level and needs
Task analysis	Breaking activity into sequential steps; number of steps depends on child's learning capacity
Rewarding	Pleasant event following a given behavior; can be material (food) or social (praise, attention); should be immediate, consistent, appropriate and contingent
Modeling	Showing how, or demonstrating, so that the child imitate and learn
Shaping	Successive approximation to final task; teaching the simplified version of the total task and gradually increasing the complexity
Chaining	Breaking the task into small steps and teaching one after another
Back chaining	Teaching the last step first and then going backwards
Forward chaining	Teaching the first step first
Prompting	Assisting the child verbally or physically (hand over hand, gesturing, pointing) and gradually fading the assistance

Table 18: Behavior modification techniques for eliminating odd or problem behaviors

Technique	Brief description
Disregarding	Ignoring the behavior (as if it is not occurring at all) but continuing the attention to child
Ignoring	Ignoring both the child and behavior
Redirecting	Catching the child just as an odd behavior is beginning and guiding to child towards an appropriate behavior
Limit-setting	Clearly communicating what is acceptable and unacceptable behaviors to child and enforcing these
Blocking	Preventing the behavior from being completed (example aggression).
Gradual guidance	Waqiting for the child to stop resisting physically and thenm guiding towards completion
Time-out (from positive reinforcement)	Removal of attention and reinforcement contingent upon occurrence of a specified maladaptive / undesirable behavior
Differential reinforcement of other behavior	Noticing and rewarding the child while he or she shows desirable behavior or when undesirable behavior is absent (catching the child being good and praising)
Over-correction	Child has to not only restore but do something more to set right whatever damage or disturbance that has occurred as a result of undesirable behavior
Response cost	Withholding a privilege that child enjoys contingent upon the occurrence of undesirable behavior

Family-focused intervention in MR

In many ways, MR is as much a problem of the family as that of individuals with MR.. Keeping this in mind there has been a lot of emphasis in the recent decades in providing family-focused services and interventions. Major objectives of these interventions are (i) to alleviate stress and to enhance coping and empowerment in families (i) to equip parents with skills and competencies in training their affected child at home itself. It has been repeatedly demonstrated that parents can be effectively trained to implement developmental interventions at home itself.[48]

In India, several models and approaches have been attempted towards this goal of family empowerment.[49-52] Two essential components of family-focused interventions are parent counseling and parent training, which are described below.

Parent counseling

Parents face enormous stress in caring for their affected child. In the initial stages, they may go through the highly distressing and confusing emotions of Shock, disbelief, disappointment, anger, guilt, misery, helplessness, and worries about the future of the child. Later the nature of stress can span over several aspects of family life such as daily care demands, emotional distress (such as maternal depression), interpersonal difficulties (such as parental discord), financial problems and adverse social consequences (such as social isolation and stigmatization).[53,54]

Research also has shown that families make active efforts to cope with these stressors.[55] Table 19 lists some of the successful coping strategies adopted by families.

Table 19 : Effective coping strategies and resources by families

Adequate awareness, acceptance, and appropriate expectations

Favorable attitude and rearing practices

Believing that they can improve the child's functioning ("change agents")

Learning about the ways by which they can improve the child

Utilizing and Building social support

Finding about and accessing resources

Planning for things that are possible but "taking things as they come"

Taking pleasure in child's achievements, however small they are

Giving and receiving love from the child

Keeping their normal life intact,

Working together as a family to solve problems

Joining parent associations

Maintaining family health and harmony

Religious and moral belief

Successful coping and adaptation of families depends a lot on their initial encounters with the professionals.[56] Hence, psychiatrists need to pay careful attention while counseling parents. Table 20 lists some of the desirable counselor characteristics.

Table 20: Counselor characteristics

- Genuine concern for individual with MR and their families
- Ability to generate hope and optimism
- Sufficient basic knowledge about various aspects of MR
- Non-judgmental attitude

  Skills of listening, exploring, communicating
- Dynamism or action orientation – showing things, rather than just talking
- Sensitivity and perceptiveness to counseling processes – to shifts and changes in parents' feelings, thinking patterns, and responses
- Good working relationship with other professionals and agencies
- Recognition of one's own limitations and being honest

The different stages in parent counseling, the tasks for the counselor, and approaches have been described elsewhere,[57] and summarized in table 21. In brief, parent counseling needs to focus on disclosing the diagnosis in a psychologically proper, understandable manner, supporting parents by allowing ventilation, providing factual information at a rate that families can understand, clearing any misconceptions they may have about the condition, instilling realistic hope, giving practical solutions to enhance coping, discussing management options, making appropriate referrals, and equipping them with at least some skills for home-based training of the child. It is common to come across maladaptive rearing practices in these families in the form of understimulation, overprotection, and inconsistent disciplining. These, when present, also need to be adequately tackled though counseling.

Group approaches for parent counseling and training have laso been described in India, with encouraging results.[52,58,59] These are meant for educating, orienting, providing emotional support for parents and caregivers especially in the initial phases of contact, and training. Innovative variations of this basic theme such as parent workshops and caregiver-training workshops have also been practiced.

Table 21: Steps in parent counseling

stage	Methods / approaches
Develop working relationship	Treat them with dignity Get to know them well Show genuine interest and adequate time Empathize with their problems Appreciate their efforts
Explore	Family situation Physical and mental health of family members Reactions, stressors, awareness, attitudes etc Social support
Provide meaningful information	Nature of the problem Clear misconceptions Nature of interventions that work - *changing parents' mindset from Medical model to developmental model* Available resources
Provide emotional support	Allow ventilation Reassure and provide realistic hope
Enhance coping	Give practical suggestions about day-to-day management and dealing with stressful situations Identify and correct and maladaptive parenting such as overprotection, rejection, and inconsistent disciplining
Impart training skills	Skills transfer for home-based training program – stimulation, self-kelp skills training, etc

Table 22 lays down some of the messages that are to be communicated to parents during counseling

Table 22: some messages to parents during counseling

Look at abilities rather than deficits in the child (what the child is able to do and what can be taught, rather than what he or she is not able to do)
Notice successes and praise them, however small these may be.
Try to learn the techniques of training and practice them.
Remember that they are slow in learning but they can still be taught with patience, persistence, and the correct approach.
Find out about services that are available and utilize them.
There is no need to feel ashamed about having a retarded child.
There is no need to blame oneself or other family members for the child' s condition.
Do not overprotect the child; encourage them as far as possible to stand on their own feet.
Do not waste money unnecessarily on dubious treatments, which have not been proven.
Make contact with other parents and join parent organizations for mutual support
Keep the normal life intact, and work together as a family to solve problems
Do not cut off your relationships with relatives and friends; keep your social life intact
Try to arrange daily routines such that everybody gets some time off from the child

Parent training:

Studies from abroad have shown that parents can effectively learn the techniques of intervention and training and practice them at home to the betterment of their affected children.[48,60]

A number of studies from India also have demonstrated the efficacy of parent training for home-based intervention.[39,58,61] Several packages of intervention have also been developed based on developmental, transactional and behavioral models.[51,52,62] The techniques of training parents include instructions, demonstrations, educational materials, videos and manuals. Such materials developed at NIMH, Secunderabad, and Portage Guide to Early Intervention are quite useful towards this end.

Life Cycle Issues in MR

Different stages in the life of an individual with MR throws up different challenges to families, that needs to be adequately dealt with. Table 23 summarizes these life-cycle issues. Psychiatrists can help parents to address these issues in the best manner possible.

Table 23: Life cycle issues in MR

Stage	Issues and concerns
Infancy	Survival, accepting the condition, medical investigations & care
Later childhood	Schooling decisions, tackling social responses, behavior problems, playmates
Adolescence	Sexuality, menstruation
Adulthood	Vocation, marriage, offspring, parenthood, guardianship, social security

PREVENTION OF MR

The levels of prevention as recommended by WHO provides a good framework to conceptualize prevention (table 24). It is estimated that around 25% to 30 % of MR is potentially preventable by public health measures such as improving the nutritional status, access to basic medical facilities, and good pre- and perinatal care.

In the recent years, there has been enormous advancesa in field of prenatal diagnosis of conditions leading to MR. Some examples are non-invasive 'triple test' screening for Down syndrome, and advanced techniques of chorionic villus biopsy for chromosomal and metabolic disorders, in addition to well-established techniques of ultrasonogram (such as nuchal thickmess measurement at 11-14 weeks of gestation) and genetic amniocentesis. Highly advanced technique of pre-implantation genetic diagnosis has now become available in a few centers across the world.

Table 24: Levels of prevention in MR

LEVEL	APPROACH	EXAMPLE OF STEPS
PRIMARY PREVENTION (preventing the occurrence of retardation)	**Health promotion**	Health education, especially for adolescent girls
		Improvement of nutritional Status in community
		Optimum health care facilities
		Improvements in pre, peri and postnatal care
	Specific protection	Universal iodization of salt
		Rubella immunization for women before pregnancy
		Folic acid administration in early pregnancy
		Prevention of teratogen exposure (e.g., teratogenic drugs, substance abuse, toxins, irradiation and abortifacients
		Prenatal ultrasonographic screening for certain congenital malformations and syndromes
		Genetic counseling & prenatal diagnosis
		Detection and care for high-risk pregnancies
		Prevention of Rh iso-immunization
		Universal immunization for children
SECONDARY PREVENTION (halting disease progression)	**Early diagnosis and treatment**	Neonatal screening for treatable disorders (hypothyroidism, phenynlketonuria, galactosemia, homocysteinuria, congenital hydrocephalus)
		Intervention with 'at risk' babies
		Early detection and intervention of developmental delay
TERTIARY PREVENTION (preventing complications and maximization of functions)	**Disability limitation and rehabilitation**	Stimulation, training, and education, and vocational opportunities
		Mainstreaming / integration
		Support for families
		Parental self-help groups

SOCIAL AND COMMUNITY LEVEL INTERVENTIONS IN MR

In India, there have a number of developments in this important area of intervention. These have been describes in Appendix 1.

CONCLUSION

An informed, competent, and empathetic psychiatrist, who can blend both scientific and humanistic approaches, can make all the difference to individuals with MR and their families. Such individuals and families remain grateful forever for the care that they receive.

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Appendix 1

SOCIAL AND COMMUNITY LEVEL INTERVENTIONS IN MR

LEGISLATIONS

Government of India has enacted 2 important legislations that concern MR, as below.

Persons with Disabilities Act: Enacted in 1995, this Act envisages mandatory support for prevention, early detection, education, employment and other facilities and social security benefits for the welfare of persons with disabilities in general and mental retardation in particular. In addition, this Act provides for affirmative action and non-discrimination of persons with disabilities to achieve the ultimate goal of equalization of opportunities for these individuals. In keeping with this Act, the central government and several states in India have begun providing many social security measures like disability pension, family pension, scholarships for special education, travel concession, income-tax relief and special insurance policies. *The percentage of disability in MR has been specified by a Gazette notification of Govt of India(dated June 13 2001) as follows: mild MR: 50 %, Moderate MR: 75 %, Severe MR: 90 %, and profound MR: 100 %.*

National Trust for welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilitites Act 1999: This is a recent positive development in India. The spirit behind this Act is to enable and empower these individuals to live as independenetly and as fully as possible within the community and to actively involve the parents of individual with MR and voluntary organizations in setting up and running a variety of services and facilities with governmental funding. It is hoped that the implementation of this act will be the answer to an important concern of parents, viz., *'what will happen to our child after we are no more'*. Another important aspect of this Act is that it has provisions for parents to obtain Guardianship (either partial or complete) for their adult offspring's with MR,

OTHER GOVERNMENTAL POLICIES AND PROGRAMS

Recently, Ministry of Social Justice and Empowerment has come out with **National Policy on Disability**. In addition, there are a number of programs of Central Govt such as District Disability Rehabilitation Centers (DDRC's), Sarva Shiksha Abhiyan, Integrated Education for the Disabled (IED), National Program for Rehabilitation of Persons with Disabilities (NPRPD), and National Handicapped Finance Development Corporation that are providing services in different sectors.

National Institute for the Mentally Handicapped (NIMH, Secunderabad): Established in 1984, this apex Governmental institution has been active in human resource development, development of models of care, undertaking research, and documentation. It has numerous and very popular publications and videos on early stimulation, education, training, and rehabilitation meant for a variety of professionals and parents, which can be procured at a very reasonable price. NIMH also has published a very useful Directory of services all over

India. It has many regional centers offering a variety of services.

Sarva Shiksha Abhiyan, a recently introduced program of Govt of India, follows the principle of inclusion education and aims at 'zero rejection' policy, and plans to cover children with disabilities of any kind and of any severity aged 6-14 years. There is provision for training resource teachers who can provide extra educational inputs in the school or home setting.

Respite and residential care facilities: the idea of respite care, viz., and institutional care for short durations of time to help families tide over periods of crisis is catching up in India. Though, as a policy, permanent institutionalization cannot be encouraged, there are a small proportion of individuals who either cannot be cared for at home for a number of reasons, or because they do not have a family; they may require institutionalization.

NGO SECTOR

NGO sector has played a pioneering role in building services, especially the special educational facilities, and community based rehabilitation (CBR) Programs.

Another recent positive development is the formation of **Parent Associations**. There are now more than 100 parent associations in India and there is also a federation of parent associations (Parivaar NFPA) which has been very active in advocacy, influencing policy development, and developing services.

Â· Mental retardation etiology, manifestation, assessment, management and. prevention. Â· Specific learning disabilities Â· Psychopharmacology in children Â· Psychosocial management issues with children. Â· Adult outcome of child psychiatric disorders. 15. Â· Liaison with teachers, schools, child care institutions. Â· Recognition of Disability and its alleviation among children and. adolescents. (I) Extra-mural activitiesÂ The candidate should refer to the NBE Guidelines for preparation and submission of Thesis Protocol before the writing phase commences. The minimum writing requirements are that the language should be clear, concise, precise and consistent without excessive adjectives or adverbs and long sentences. There should not be any redundancy in the presentation. â€œClinical practice guidelines are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.â€(Institute of Medicine, 1990). Issued by third-party organizations, and not NCCIH, these guidelines define the role of specific diagnostic and treatment modalities in the diagnosis and management of patients.Â Travelersâ€™ Health: Clinician Resources (CDC). Allergy and Immunology. Guidelines for the Diagnosis and Management of Asthma (NHLBI). Diagnosis and Management of Food Allergy (Journal of Allergy and Clinical Immunology) [165KB PDF]. Allergic Rhinitis and Its Impact on Asthma (ARIA) Guidelines: 2010 Revision (Journal of Allergy and Clinical Immunology).