Child Psychiatry: Disorders, Assessment and Management
Clinical Practice Guidelines on Intellectual Disability

Authors

M. Thomas Kishore, Ph.D., **Gautham Arunachal U.**, MD., Fellowship in Clinical Genetics, **Shekhar P. Seshadri**, MD.

1. Introduction

Mental retardation is a developmental disorder and is associated with significant limitations in intellectual functioning and adaptive behaviours. Currently, it is widely referred to as 'intellectual disability' and 'intellectual developmental disorders'. In India, the Rights of Persons with Disabilities Act (2016) has introduced the term 'intellectual disability' in place of 'mental retardation'. But, India being a signatory country to the World Health Organization (WHO), where the ICD-10 guidelines are adopted in the clinical practice, the term 'mental retardation' is still in clinical use.[a] Thus, both the terms, *intellectual disability* and *mental retardation*, are in use in India. Despite variation in the terminology and the differences in the criteria for diagnosis (e.g. ICD-10; DSM-5) and assessment of disability (as notified in the guidelines in January 2018, which are based on the RPD Act), it is commonly agreed that significant impairments in intellectual functioning and adaptive behaviour during the developmental period is the hallmark of the condition (see, table 1).

Insert table 1 here

It is estimated that nearly 2.5% of the global population will have low levels of intellectual functioning commensurate with ID. However, a wide variation in point prevalence of intellectual disability has been reported in India, from around 1/1000 to 32/1000, depending on the case definition, methodology, and population selected. An important point that can be noted in the literature is that prevalence rates vary depending on whether deficits in either intellectual functioning or adaptive behaviour or both are considered. Though ID is recognizable in infancy or early childhood, it is often difficult to accurately diagnose it before 5 years of age. Standardized measures of intellectual functioning, adaptive behaviours become more and more reliable and valid beyond this age. Hence global developmental delay (GDD), which often predicts future development of ID, is used as a surrogate marker in children between age group of 3 months to 5 years. Shevell et al. (2008) defined GDD as evidence of significant delay in two or more of the following developmental domains: gross/fine motor, speech/language, social/personal, cognition, and activities of daily living. But, not all cases of GDD may have cognitive deficits or end up as ID. Males are diagnosed with ID 30% more than females, especially in the milder ID range. However this difference seems to disappear when the ID is more severe. ID is also associated with high morbidity and extreme costs of care. ID can cause significant impact on the individual, families, health care system, and state.

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Foot notes:

[a] The WHO Working Group on the Classification of Intellectual Disabilities has recommended replacing the term 'mental retardation' with 'intellectual developmental disorders (IDD)' in ICD-11 (Salvador-Carulla et al., 2011).

1.1 Nature and needs of the condition:

Intellectual disability is a permanent condition therefore it creates special needs for both the individual and the family across the life span. The needs could be related to independent mobility, physical care, communication needs, modified curricula, aids and appliances, occupational and vocational opportunities; and medication if there are treatable, comorbid medical conditions. The special needs may necessitate support in varying degrees throughout the life span. Therefore, holistic programme should address the lifelong needs in a step by step fashion. For instance, when a child with ID is in preschool years, the needs may centre around self-care, socio-communication skills, school readiness skills but not so much about independent living or literacy. Similarly, for an adolescent with ID, the needs could be about education, prevocational training, and future independent living. As these examples indicate ID will imply multidisciplinary approach to intervention for optimum outcome.

1.2 Aetiolgical work up of ID:

Aetiology of ID/GDD is heterogeneous. Rigorous aetiological evaluation helps to address treatment options and to discuss expectations from the care givers including an understanding regarding prognosis (static versus progressive disease); to procure appropriate services; to guide service providers and implement necessary policies. It also helps in removing guilt and allaying ongoing recrimination in families. Another important utility of an aetiological evaluation is to estimate accurate recurrence risks and for definitive prenatal diagnosis in subsequent pregnancies.

The cause for ID and GDD can be non-genetic/environmental or genetic. Non-genetic causes like prenatal infections, substance use like alcohol during pregnancy, postnatal meningoencephalitis account for only one third of cases and the rest are of genetic origin. The flow chart here is a modified version of the 'Finnish approach'. This provides a means for systematic aetiological evaluation of ID. The common causes are also listed in the flow chart (See Figure 1).

Insert figure 1 here

This modification of the Finnish approach at the preliminary level reliably distinguishes probable genetic and non-genetic aetiologies in majority of cases. Most of the non-genetic causes produce ID which is usually static in nature and potentially amenable for training. Further the non-genetic causes in the subsequent pregnancies are either treatable or preventable especially the maternal factors like malnutrition, diabetes, teratogenic drugs and substance use. Finnish approach also paves way for further diagnostic genetic testing among those cases initially suspected to be of genetic aetiology. Genetic diagnosis is essential not only for accurate genetic counselling of recurrence risks and prenatal diagnosis but also for appropriate management. This is in the light of newer strategies of treatment made available through thorough understanding of pathophysiology of genetic disorders for several disorders. With the advances in the field of therapeutics, over 80 such disorders are potentially treatable and several other disorders have some form of management strategy.

These diseases if untreated can be progressive and lead to significant morbidity as well as mortality. Majority of such inherited cases can be accurately diagnosed, provided that advances in the field of genetic diagnostics are utilized.

1.3 Comorbidities

1.3.1 Medical comorbidities

Various medical comorbidities are often associated with ID. Depending on the aetiology varying degrees of both neurological and non-neurological comorbidities are encountered. Some are a consequence of ID itself. Few of the common medical comorbidities are the following: epilepsy, spasticity, dystonia, ataxia, visual impairment, hearing impairment, congenital heart disease, cleft lip and cleft palate, limb anomalies like CTEV, congenital dislocation of hip joint, renal malformations, failure to thrive with vitamin and mineral deficiencies, recurrent infections, feeding disorder and short stature.

The medical comorbidities can be significant barriers for training and developmental learning and require attention in overall management. One can anticipate almost certainly the possibilities of physical disorders based on the aetiology behind ID. With vast literature available on almost every one of the aetiologies, we can predict and screen for presence or absence of the co morbid medical disorders.

Epilepsy is a common comorbidity in nearly 15-30% individuals with ID. With increasing severity of ID the prevalence increases to around 50%. Similarly many electroclinical syndromes of Epilepsies like Early Infantile Epileptic Encephalopathies (EIEE) such as West syndrome and Ohtahara syndrome as well as other late onset syndromes like Lennox Gastaut syndrome are invariably associated with ID. Ongoing seizures especially if treatment refractory often leads to developmental arrest. Such a condition remains a barrier against training and thereby any hope of making developmental gains. Hence it is essential that these disorders need particular attention and rigorous management.

Another domain of neurological disorder that impairs motor development and locomotion is the impairment in pyramidal, extrapyramidal or cerebellar systems as well as combined. Spasticity, dystonia, tremors and ataxia often lead to impairment in motor development and there by successful locomotion. It is essential to differentiate the static or progressive forms of these disorders for appropriate counselling and management.

1.3.2 Behavioural and Psychiatric Problems

People with ID are 3 to 5 times at higher risk of any psychiatric disorder compared to the general population in ID at all ages, with a cumulative prevalence of around 40%. It is conceivable that, global cerebral functioning is affected by varying aetiologies causing ID which in turn can lead to variety of neuropsychiatric manifestations. Beside these neurobiological underpinnings, social discrimination, deprivation can also influence onset of psychiatric comorbidities in this group. Neuropsychiatric manifestations often commence insidiously with atypical presentation and are commonly written off as spectrum

manifestations of ID. Hence it is mostly under reported, misdiagnosed and undertreated. This pattern of 'diagnostic overshadowing and masking' is well documented. Limited choice in using structured diagnostic interviews is another barrier for accurate diagnosis of comorbid psychiatric condition. Eventually only symptomatic treatment is resorted to, which may not solve the entire problem.

Aetiology of ID can often provide clues to anticipate certain psychiatric comorbidity as certain behavioural phenotypes are frequently associated with some syndromes. Some Examples are severe self-injurious behaviour in Lesch Nyhan syndrome; skin picking and OCD in Prader Willi syndrome, autistic traits and hyperactivity in Fragile X syndrome; self-hugging stereotypy and trichotillomania in Smith Magenis syndrome; Schizophrenia like disorders in 22q11 deletion syndrome. In majority, unspecified behavioural disorders are very common.

2. Overview of Assessments and evaluation

Assessment is a process of collecting data for the purpose of making decisions. Assessment provides us with baseline information for intervention whereas the evaluation is the assessment of outcome of an intervention. In clinical practice therefore we need both assessment and evaluation methods. The purpose of the assessment is as following:

a. To identify the condition based on specific criteria and to establish that it is a clinical entity that requires appropriate mental health services and placement decisions.
b. To identify and treat etiological factors and risk factors for intellectual disability.
c. To identify the needs implicated by the condition and design a programme plan to reduce the disability impact.
d. To match the nature and needs of the conditions effectively with the best intervention methods available.
e. To evaluate the effectiveness of intervention.

The following key questions could be asked to guide assessment, intervention and outcome measure (for more details, please see appendix 2):

- What is the nature of the delay- specific or global?
- Is the delay associated with significant limitations in intellectual functioning and adaptive behahviour?
- Are there any comorbidities?
- Are there any treatable etiological conditions
- What are the areas of intervention?
- Where and how the intervention should be carried out?
- Where the individual should be placed for maximum help (or, what are the existing agencies/ services providers through which the interventions can be implemented)?
- How to evaluate the intervention outcome (or, what are the indices to stop intervening)?

3. Diagnosing ID and its comorbidities

Diagnostic process of ID is similar to any other behavioural and mental disorders but with subtle differences. The Diagnostic process involves history taking, observation including medical examination, intellectual and adaptive behavioural assessment, identification of comorbid psychiatric disorders and need-based laboratory investigations for other medical conditions. Therefore the diagnostic process encompasses several components that are as follows:

3.1: History Taking: The purpose of eliciting the history is to establish that there is an evidence for deficits in both intellectual functioning and adaptive behaviours that have an onset during the developmental period; and to note possible etiology of ID, identify comorbities and response to interventions, if any. Therefore it requires interviewing of key people including the index patient and behavioural observation of the patient. Key people could be parents, caregivers, service providers who know the birth and developmental history of the child.
A useful and comprehensive approach to assessment would include noting chief complaints in chronological order with mode of onset, duration and precipitating event followed by history of presenting illness and a detailed prenatal and perinatal history as a prelude. Developmental history in greater detail, particularly related to motor, language and communication, self-help skills, socio-emotional skills, cognition, and occupational skills/ leisure-time activities; medical comorbidities and its treatments; Psychiatric history including the details of onset, evolution and current status of behavioral and other psychopathological disturbances; and treatment history. This should be followed by a comprehensive family history including the three-generation pedigree, consanguinity, family background, current living arrangements, and details of potential stressors, coping and adaptation by the family.

3.2: Physical Examination: It must involve routine systemic examination, anthropometric assessment and observation of atypical morphological features suggestive of specific genetic disorders. Detailed physical examination helps to identify the aetiology in majority of cases, detect comorbid medical conditions and also helps in ordering appropriate investigations. Physical examination in cases with ID consists of three parts which are as follows:

3.2.1 *Anthropometry*: This provides indication towards nutritional status, underlying medical or genetic condition. The measures should include the following- Height (Length in case of neonates and infants), arm span, upper segment and lower segment lengths, sitting height, weight, head circumference, chest circumference, abdominal circumference, intercanthal and interpupillary distances and palm and foot lengths.

3.2.2 *Dysmorphology examination*: Dysmorphology is the observation, documentation and study of birth defects as well as syndromes. A thorough head-to-toe examination should be carried out to identify minor physical anomalies [MPAs], which provide clues towards

aetiological diagnosis especially the genetic disorders (see, Table 2). It requires keen observation and knowledge of normal versus abnormal morphology.

3.2.3 *Examination of major organ systems*: A systematic examination of all the organ systems to rule out multi organ involvement and co morbid medical conditions has to be performed for overall assessment and management. It is essential to be meticulous in observing and documenting the findings of physical examination as many of the MPAs can be easily missed. Hence it may be important to take photographs or videos after informed consenting to document and revise the original findings at a later date. Some of essential things to note are vision, hearing, locomotion [videos may help], and any major congenital anomalies. Presence of MPAs provides clues towards genetic versus non genetic aetiologies (see Table 2). Hence branding every child universally with cerebral palsy which is often due to a non-genetic cause with a static course can be avoided. Presence of four or more MPA's should alert the physician towards probable genetic cause.

Insert table 2 here

If MPAs are encountered in a child, such a case can be referred to a dysmorphologist/medical geneticist for further evaluation. The book Smith's Recognizable Patterns of Human Malformation is an excellent source for the list of syndromes and other related issues. Freely available series of articles titled, 'Elements of Morphology' in American Journal of Medical Genetics (2009) is yet another source for standard terminology and definitions of MPAs (see, https://onlinelibrary.wiley.com/toc/15524833/149A/1). Further, progressive multi organ dysfunction may be a clue towards a disorder of inborn error of metabolism which may be potentially treatable. Organ sytem examination is similar to any branch in medicine and readers are referred to standard books like Hutchison's clinical methods.

3.3. *Behavioural observation*: The purpose of behavioural observation is to corroborate the clinical history with regard to intellectual functioning and behavioural repertoire. Therefore, it should start with observation of general appearance, any oddities in behaviour, attention span, receptive and expressive speech abilities, social and interpersonal abilities. Socio-culturally appropriate stimuli could be presented to understand the level of general fund of knowledge, generic concepts, abstract thinking, reasoning and problem solving abilities that are not strictly dependent on academic learning. But, clinicians may use any standard format of general mental status examination for children to complement the behavioural observation.

3.4: Assessment of Intellectual Functioning and Adaptive Behaviour:

This step is to confirm the clinical diagnosis and identify the severity level of ID. Both ICD-10 and DSM-5 recognize the need for assessing the intellectual functioning with standardized tools that yield intelligence quotients (IQ). DSM-5 restricts the use of IQ to draw a cut-off of 65 - 75 (IQ 70 ± Standard Error of 5) for identifying ID. Conversely, ICD-10 advocates a IQ cut-off of 70 to identify ID and different IQ ranges for categorizing four severity levels such as, mild (IQ 50-69), moderate (IQ 35-49), severe (IQ 20-34) and profound (IQ less than 20).

The ICD-11 Working Group advocated that severity levels for IDD should rely on a clinical description of the characteristics of each subcategory, but the IQ score can be considered as one of the clinical descriptors that are important in determining the severity level. Therefore, till the time ICD-11 comes into force, the ICD-10 guidelines should be followed, which relies on IQ both for identifying the condition and ascertaining the severity levels of ID.

Clinicians may note that the choice of tests in the Indian context is limited notwithstanding the fact that the norms are in many cases are not revised (see, Appendix 1). This is a major concern given the evidence for Flynn effect, which refers to observed rise in IQ scores over time, resulting norms obsolescence. Therefore, the IQ scores should not be rigidly interpreted. When IQ tests are not applicable because of young age (e.g. children below 3 years) or associated sensory-motor issues and gross understimulation, standardized developmental scales (e.g. Developmental Screening Test; Developmental Assessment Scales for Indian Infants) can be used as applicable. The developmental tests yield 'developmental quotients (DQ)' which are interpreted the same way as IQ scores. With regard to the assessment of adaptive behaviour, Vineland Social Maturity Scale (VSMS) is the only standardize measure available in India at present. VSMS yields social quotient (SQ) and a profile of eight important domains of adaptive behaviour. If administration of VSMS is not possible for any reason, clinician can ask socio-culturally relevant questions to understand the level of adaptive behavioural functioning. If needed, DSM-5 list of specifiers for severity levels of ID could be referred to assess the adaptive behaviours till the time ICD-11 guidelines come up.

Wherever IQ and SQ indicate different severity levels of ID, decisions are taken in favour of SQ scores because the latter denotes the degree to which the index patient is able to meet the standards of culture-appropriate demands of daily life. Thus, SQ reflect the severity of ID better than IQ under ordinary circumstances. However, when assessment of the severity of ID by means of the usual procedures is rendered particularly difficult or impossible by associated sensory or physical impairments and severe behavioural disturbances, the condition should be identified as 'Other mental retardation'**.** If there is evidence of mental retardation, but insufficient information is available to assign the patient to one of the four categories or other mental retardation, it can be identified as 'unspecified mental retardation'. In case of 'Other mental retardation' and 'unspecified mental retardation', more information on developmental skill repertoire and periodical assessments of intellectual and adaptive behaviour is desirable to infer the current level of functioning and associated severity levels of ID. Test selection should be proper if the person has comorbid sensory-motor impairments. (see, Appendix 3). Lastly, it must be recognized that use of IQ and adaptive measures for clinical diagnosis is different from disability assessment and the latter has specific guidelines that must be strictly adhered to.

3. 5 Confirmation of ID diagnosis

Based on the information obtained through case history, observation and testing, ID could be coded into any of the six categories such as mild, moderate, severe, profound, other and unspecified mental retardation. ICD-10 has provision for using a fourth character to specify

the extent of the behavioural impairment, if this is not due to an associated disorder (e.g. F7x.0 to denote 'No, or minimal, impairment of behaviour') and an additional code from ICD-10 should be used if the cause is known (e.g. F72 severe mental retardation plus E00. [congenital iodine-deficiency syndrome]). Evidence for additional coding of etiological causes may come from laboratory findings.

3.6 Diagnosis of comorbid psychiatric disorder:

Any changes in behaviour compared to previous period, dip in overall functioning, and changes in vegetative functioning should be carefully recorded in each visit. If it is pervasive and indicative of a comorbid psychiatric disorder it has to be carefully considered. A timeline method would be helpful when in doubt. During clinical evaluation, a greater reliance on onset and chronological evolution of symptoms, intensity, frequency, context of occurrence of symptoms, precipitating and 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.

The behavioural observation will start from the moment the child enters the consultation room. Equal attention need to be paid to child's behaviors, parental reports, as well as to verbal interview in arriving at conclusions. If necessary, child and parents must be interviewed separately. Playroom observation and multiple baseline observations for a functional analysis (Antecedent-Behavior-Consequences or ABC analysis) of symptoms is sometimes required.

Clinicians may need to create child-friendly space with appropriate toys, picture books, art and craft material. The setting should be safe, well lit, and ventilated. It is preferable that depth-interview is conducted only after *developing rapport* with the child. The rapport could be developed by allowing the child to sit where he/she prefers to sit or move; asking about their age, likes and pet name; offering toys. It is important to *build partnership with parents from the outset,* which could be achieved by listening and valuing their opinions, and impressions, and efforts; and appreciating the parents for the right things they have done.

Depending on the language development and conversational skills, verbal interview can be conducted with simple, structured, clear and concrete questions. It is better to avoid leading questions. The examination may include the following:

- Basics: Behaviours suggesting sensory-motor impairments or physical health issues.
- Response to interview situation: Excited, fearful and tense, shy, inhibited, guarded, uncooperative, or defiant.
- Alertness: Over-aroused, withdrawn.
- Attachment to parents and response to separation: Clinging, wanting to be carried all the time, indifferent to separate on.

- Sociability: Social orientation, approachability, social responsiveness, eye-to-eye contact, reciprocal inyteractions, and awareness of social boundaries.
- Motor Activity level: Fidgetiness, restlessness, hyperactivity; lethargy
- Course of motor behaviors during interview or response to firm instructions: Quiet initially, but restless later on; 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.
- Speech, language & communication: Verbal/non-verbal comprehension and expression; vocabulary, articulation, and flow.
- Mood: Inhibited, excessively cheerful, whining and crying, irritable,
- Play behaviour: Type of activity, duration, themes, etc.
- Other inappropriate behaviors: Any excess behaviours that are inappropriate to the age and socio-cultural context.
- Impressions on current developmental attainment: Whether excess behaviours or skill deficits are typical of a known psychiatric or developmental disorder?
- Parent child interactions: Quality of engagement with child; communication patterns; degree and quality of control over the child; response to good and bad behaviours.

Standardized instruments such as Psychiatric Assessment Schedule for Adults with Developmental Disability, Reiss Screen for Maladaptive Behavior, Psychopathology Inventory For Mentally Retarded Adults, Developmental Behavior Checklist and Psychiatric Instrument for the Intellectually Disabled Adults can be utilized as per the need. But, rating scales should be used only to complement the clinical observations.

4. Laboratory investigations:

Often it is difficult to completely examine children with ID due to their inability to communicate or comprehend commands or due to their behavioural issues. Some of the malformations can be missed in spite of an exhaustive and careful examination. Malformations like atrial septal defect in early infancy, single kidney, holoprosencephaly, and mild hearing / visual impairment etc. can be missed during routine examination, which can be barriers for adequate management of ID. As highlighted in the earliesr sections, an array of aetiological factors can result in ID and at least some of them can be potentially treated. Hence a bunch of investigations are essential not only to identify the cause of ID but also to make sure the treatable causes have been investigated for (see, Table 3).

Insert table 3 here

Majority of Indian families do not possess medical insurance scheme. Hence clinician has to carefully consider the financial circumstances of the family, clinical hints, and treatability to order appropriate investigations. One should always consider the possibility of recurrence of the same disorder in the next pregnancy before an investigation is deemed unnecessary. This has to be discussed with the family and appropriate genetic counselling should be provided. Family can then chose to proceed or not to proceed with further investigations. MRI of brain

and screening of metabolic disorders is considered mandatory investigations in all cases of ID. American Academy of Neurology (web addresss) provides useful guidelines in this regard.

5. Psychosocial assessments:

Persons with ID will be at high risk for neglect and abuse. Therefore, risk assessment should be an integral part of comprehensive assessment plan in ID. Adaptive behaviour is always impaired in people with ID, but the deficits are less evident in environments where support systems are in place. Hence support systems available to the family and child must be reviewed. Therefore, psychosocial assessments are very important.

5.1 Assessment of family needs and functioning

Parents and families are the main source to implement the intervention plan in any condition that requires extensive long-term support. Specifically in the context of ID, studies indicate that their perceptions of the condition, disability impact, perceived support, stress and coping mechanisms are very important moderators of intervention. Therefore, clinicians may consider assessing these areas further. Need may be appropriate tools such as the following could be used for this purpose: GEM Questionnaire, Disability Impact Scale, Family Support Scale, Family Efficacy Scale, Family Needs Schedule (note: these scales are available in public domain at www.nimhindia.org/punblications); Family Interview for Stress and Coping in Mental Retardation (FISC-MR) for assessing stress and coping of the parents of children with ID.

5.2 Psychoeducational assessments:

With Universalization of elementary education and the Right to Education, many children with ID are in the mainstream as compared to a decade ago. Children both in the mainstream and in special school settings may need appropriate psychoeducational assessment. Tools such as the Grade Level Assessment Device and Functional Assessment Checklists for Programming (available at www.nimhindia.org/punblications) can be used for this purpose. Another grey area is assessment of 'school readiness skills' because there are no standardized measures. Often children diagnosed with GDD or young children with ID are referred to Mental Health Professionals for assessment of school readiness skills. In such a scenario, a clinical assessment could be carried out by focusing on the following: sensory-motor abilities, eye-hand coordination skills, activity-based attention span, receptive and expressive skills (but, not necessarily verbal communication); independent personal care, particularly toilet indication, drinking and eating; sitting tolerance and basic social skills such as eye contact, waiting for turn, following the authority, staying without primary caregivers, ability to engage in play. In addition to this any significant medical history (e.g. seizures, ADHD) which needs supervision of medication in the classroom should also be counted. A special note should be made if any aids and appliances are required to enhance to the functional abilities of the child (e.g. reading glasses, hearing aids, wheelchairs, specially adapted

furniture). Accordingly the assessment report must include appropriate recommendation for placement and intervention.

6. Disability Assessment

According to the Guidelines based on the Rights of Persons with Disabilities Act 2016 (Government of India, 2018, p. 94), disability assessment is done through three stages such as screening, diagnosis, disability calculation (see, Table 4). The minimum age for certification is one (01) completed year. Children above one year and up to the age of 5 years shall be given a certificate with a diagnosis of Global Developmental Delay (GDD). Children above the age of 5 years shall be given a diagnosis and certificate as Intellectual Disability. The Medical Superintendent or Chief Medical Officer or Civil Surgeon or any other equivalent authority as notified by the State Government shall be the head of the Medical Board. The Authority shall comprise of the following: (a) The Medical Superintendent or Chief Medical Officer or Civil Surgeon or any other equivalent authority as notified by the State Government; (b) Pediatrician or Pediatric Neurologist (where available)/ Psychiatrist or Physician (if age >18years); (c) Clinical or Rehabilitation Psychologist and (d) Psychiatrist. It is preferable that clinicians time to time refer to relevant source to be updated with the guidelines. Temporary certificate can be issued for children less than 5 years, which will be valid for maximum 3 years or 5 years age, whichever is earlier. For children more than 5 years, the certificate will mention when to renew. As per the Act the certificate will have to be renewed at age of 5 years, 10 years and 18 years. The certificate issued at 18 years age will be valid lifelong.

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7. Formulating a treatment plan.

The treatment plan need to address the issues related to the following five dimensions as indicated in a given case:

1. Severity of ID
2. Psychiatric Problems
3. Medical Conditions
4. Psychosocial adversities
5. Global functioning

Each of these five dimensions will have implications for biological, psychological and social intervention. Consider for example, a person with mild ID and ASD and seizures, with limited access to services and health care facilities in his community will have significant impairment in functioning as compared to a person with ID alone. In this example, the former will need appropriate medical, behavioural and psychosocial interventions to address all these issues.

Setting for intervention is an important factor. Unless there is an indication for careful monitoring of medication on daily basis or poor therapeutic outcome if the patient is anywhere other than in the institutional setting, individuals with ID are offered services in the community or on day-care basis. The idea is that the persons with ID should be in a least intrusive environment so that they can have maximum opportunities for learning and development in natural environment.

7.1 Medical interventions

Every attempt should be made to identify treatable causes of ID or at least potentially treatable symptoms such as hearing impairment, spasticity and so on. Some of the conditions which present with ID are nearly completely preventable or to some extent reversible with appropriate management, provided that it is treated early in the course. Examples of treatable disorders are listed in table-5 and such cases have to be referred to specialists accordingly for further management.

Insert table 5 here

It is also important to treat associated medical problems along with therapies aimed at altering the pathophysiology among children with ID. Specialists need to be consulted for appropriate management to obtain maximal benefits. Few examples are treatment of epilepsy with antiepileptic drugs, spasticity with antispasticity medications, hearing impairment with hearing aids and cochlear implantation, sleep problems with sedatives as well as sleep hygiene techniques and so on.

7.1.1 Genetic counselling

Genetic counselling is often deemed as a speciality in the current medical practice though it can be practised by all clinicians to varying degrees depending on their expertise. As two thirds of cases of ID have genetic aetiologies, genetic counselling becomes mandatory. The commonest situation is when genetic counselling is required in ID is when parents have one child with ID and would like to know the risk of recurrence and possibility of prenatal diagnosis. Genetic counselling not only provides accurate information on prognosis of disorders and recurrence risks but also helps in removing guilt and allaying ongoing recrimination in families.

7.1.2 Management of comorbid behavioural and psychiatric disorders

Nearly 20 to 80% of the ID population can have problem behaviours ranging from hyperactivity, temper tantrums, odd behaviours to aggression. Behavioural problems are potential reasons for stigma, segregation and caregiver's burden. Lack of occupation, limited developmental opportunities and communication abilities are major factors of problem behaviours. While problems behaviours can be a source or trigger for psychiatric problem and/or part of psychiatric disorder, they can also exist independently. In either case a thorough behavioural plan is required. Identification of the problem behaviours is the first step in management. Behaviours that lead to social exclusion, stigma; and those that interfere with learning should be given priority. Based on the hierarchy, target behaviours can be selected and functional analysis can be conducted to understand the antecedents and maintaining factors. Basic premise of the behaviour managment is that opportunities are created to facilitate positive behaviours that would otherwise serve the same function as the problem behaviours do (e.g. reinforcing any form of socially appropriate communication as a

substitute for temper tantrums secondary to verbal communication deficits). In principle the techniques should be least intrusive and culturally appropriate therefore the behaviour management plan can be implemented through the following three levels:

(i) Restructuring the environment to control the antecedents and provide ample opportunities for positive learning;
(ii) Differential reinforcement to strengthen the adaptive behaviours by providing opportunities for reinforcement of adaptive behaviours
(iii) Controlling inappropriate reinforcement of problem behaviours.

It is also important to recognize that all problem behaviours are not due to environmentally mediated, inappropriate reinforcement practices. Problem behaviours may be an atypical presentation of psychiatric comorbidity or an indicator of the onset of a psychiatric episode. In some cases, problem behaviours may be a manifestation of ineffective coping strategies to manage the psychiatric distress.

Psychiatric comorbidity not only presents itself more diffusely and atypically in these children it is often difficult to treat. Carefully studying behavioural profile may point to a particular psychiatric disorder. Management may need a muti-pronged approach usually involving pharmacological and psycho-social interventions. If there is no adequate information to establish a psychiatric diagnosis, psychosocial interventions should be attempted first.

As only a handful of medications have been licensed for use in children, often it is difficult to manage these disorders. This has to be discussed with parents in detail and their expectations should be handled regarding outcome of such a treatment. Very few large systematic controlled trials are available in ID group however open drug trials, case reports and expert reviews suggest the following:

- Begin with low dosage and increase it slowly.
- Adequate trial time should be allowed before deeming failure of a medication.
- Outcome to be monitored at multiple settings [home, school]
- Rationalize medications when multiple medications are being used and change one drug at a time.
- Paediatric dosing schedules and guideline should be followed.

There are few studies on medications in comorbid disorders in ID viz. methylphenidate in ADHD, or anti-psychotics for schizophrenia. Risperidone also is widely studied as symptomatic treatment for problematic behaviours such as stereotypes and aggression (see, Table 6). For further details in dosing and indications latest edition The Maudsley prescribing guidelines are a good source. Specific details on pharmacological management could also found in condition-specific Clinical Practice Guidelines of the Indian Psychiatric Society.

Insert table 6 here

7.2 ***Non-Pharmacological Management****.*

7.2.1 Child-centric interventions

The non-pharmacological intervention should be guided by life span and functional approaches. Accordingly the following general framework can be adapted in regular clinical practice:

- *Life span approach*: Life span approach is that it regards the developmental needs and the tasks that the individual must achieve at a particular stage to adapt to the environment. Accordingly, the skill training focuses on all important domains of adaptive behaviours such as conceptual, social, and practical skills that are considered important at a given developmental stage. Initial three years, the focus should be on acquiring sensory-motor skills, socio-communication skills, basic self-help skills and concepts. During 3-6 years of age the focus can be on school readiness skills and mastery of culturally-appropriate adaptive behaviours. During 6-18 years the focus should be on consolidation of academic and independent personal skills that can lead to future vocational training, employment and adult independent living.
- *Functional approach*: It is preferable that the tasks taught to the individual enable him or her to function well in everyday tasks. For example, there is no point in mastering the spelling of five exotic animals when the child does not even know where to use them as compared to mastering the sight words essential for daily functioning and community use (e.g. danger, exit, stop, own name, etc.). Irrespective of the age and socio-cultural context, each individual first needs training in self-care (toilet control, bathing, eating, dressing, grooming), motor skills (specially, eye-hand coordination skills), receptive and expressive language abilities, social skills and concepts in one set. Later, the children can be recommended for academics or functional academics finally leading to vocational training, gainful occupation and independent living skills. Throughout the programme health and safety skills should be strengthens.
- *Making provisions for additional disabilities*: Depending on additional disabilities, the child may need aids and appliances. For example, adapted furniture in cerebral palsy and hearing aids for hearing impairment.
- *Special focus on early intervention*: Early identification and intervention with children at risk for GDD or ID should be a top priority. It is also important to recognize that early intervention can start from pre-natal period in terms of identifying high-risk pregnancies, providing appropriate health care, and dealing with psychosocial adversities. Nonetheless, the post-natal early intervention plan should include accurate diagnosis of ID and comorbid conditions; identification of underlying aetiological processes and methods of treatment as applicable; and activities to facilitate sensory-motor integration, speech and language development, and socio-emotional development. The basis of early intervention is healthy bonding and attachment between mother and the child. Therefore, any stable caregiver can also be involved in early stimulation. In principle, early intervention progarmmes should aim at stabilizing the current developmental milestones and create opportunities for the development of future tasks. Play-based methods, culturally rooted good practices of early childcare should be strengthened. Material recommended for intervention should be easily available and culturally appropriate otherwise parents will be overwhelmed if they are not easily available. For more formal intervention, referrals can be to the

District Early Intervention Centres of the *Rashtriya Bala Swasthya Karyakram* and the *Anganwadi Centres* of the Integrated Child Development Services.

- *Referral and linkage*: Appropriate services can be obtained from programmes under the Sarva Shiksha Abhiyan, National Institute of Open Schooling, District Disability Rehabilitation Centres, Composite Rehabilitation Centres, National Institutes and local non-government agencies.[b] Wherever possible it is better to refer the individual to the agencies in their own locality to cut down the costs of rehabilitation. Therefore, a registry of local, regional and national agencies working in the area of developmental disabilities can be maintained for this purpose.

7.2.2 Family-centred interventions

- Parents and families should be given proper information regarding the nature, needs and management of ID and its comorbidities in simple language devoid of any technical terms. Need may be appropriate literature and specific web-based sources can be recommended for further reading. Siblings and other key family members can also be involved in the programme plan.
- Parents and families should be supported in finding right resources for health care, therapy, education, vocational and occupational needs.
- Ensure that parents and families are aware of the social provisions and importance of disability certificate for the child to avail the same.
- Emphasize on self-advocacy by creating awareness about various policies and provisions related to ID. If the person with is an adult, information regarding the guardianship and National Trust Act is a must.
- Making meaning of the condition and developing a sense of control are crucial for optimum functioning of families. Various methods such as individual counselling, group counselling, parent-training programmes, self-help groups can be used to achieve this.
- Each family is unique therefore the family support programmes must meet the needs of the family in the context of disability impact.
- Parents and primary caregivers must be routinely screened for stress-related disorders because there is ample evidence to suggest that a syndromal depression and anxiety is high among parents of children with ID.

In summary, intellectual disability is a developmental disorder that affects general intellectual functioning and adaptive behaviours. It has no definite cause, but multiple risk factors including genetic, biological and environmental factors. Depending on the severity of the condition and the underlying aetiological processes, ID can also present with comorbid conditions. It is important to identify the treatable conditions and treat the same. Special attention should be paid to psychiatric and behavioural disorders, which are common in ID and cause stigma, caregiver burden, need for medication and segregation. Since ID causes disability, appropriate measures should be taken to certify disability and guide the families for appropriate support systems including the social benefits.

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[b]More details of the Government schemes can be found at www.socialjustice.nic.in

Non-pharmacological intervention should focus on skill development leading to educational and vocational competencies so that the individual will acquire necessary capacities for future adult independent living. Depending on the stage of development, referral can be made to different service agencies starting from early intervention services under the RBSK and ICDS to educational provisions under the Sarva Shiksha Abhiyan to vocational training an guardianship under the National Trust. Parents and families should be involved along with the individual at all levels of decision making in order to promote self-advocacy.

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Table 1:
Terminology and conceptual issues related to intellectual disability among different diagnostic systems.

System	Term	Definition	Intellectual functioning	Adaptive behaviour	Developmental Period
ICD-10[a,1]	Mental retardation	It is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities.	Components are cognition, language, motor and social skills. An intelligence quotient of 70 is the cutoff. It categorizes ID into four severity levels that are based on IQ.	Not clearly defined. It is implied that assessment of adaptive behaviour is part of assessment of intellectual functioning	Not explicitly defined, but understood to consider it as 18 years.
DSM-5[b]	Intellectual Disability (Intellectual Developmental Disorder)	Intellectual Disability (Intellectual Developmental Disorder) is a disorder with onset during the developmental period that includes intellectual and adaptive functioning deficits in conceptual, social and practical	Components are reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience On standardized tests of	Deficits on Adaptive functioning results in failure to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support the deficits will affect one or	Defined as 18 yars.

		domains.	intelligence, score of 65-75 is considered to indicate intellectual disability; where the tests quotients have standard deviation of 15 and mean of 100 and standard error of 5.	more activities of daily life, such as communication, social participation, and independent living across multiple environments. Nomenclature of severity levels is same as it is in ICD-10, but the levels are decided based on the deficits only in adaptive functioning. DSM-5 have explained the adaptive behaviours in each of the three domains of intellectual functioning such as, conceptual, social and practical domains in reference to the severity level and age.	
Rights of Persons with Disabilities Act, 2016 [c]	Intellectual Disability	Intellectual disability, a condition characterized by significant limitation both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behaviour which covers a range of every day, social and practical skills	Like ICD-10, it has adopted the IQ cutoff of 7o for ID; and same terminology to denote severity levels, but with different cutoffs. The severity levels are based on the scores of the Vineland Social Maturity Scale (a standardized, normative measure adaptive behaviour scale)	Adaptive behaviour is not defined but is understood to cover a range of every day, social and practical skills. Scores on Vineland Social Maturity Scale (a standardized, normative measure adaptive behaviour scale) are considered to define severity of ID.	Not explicitly defined, but understood to consider it as 18 years.

			: Profound Disability = 0-20 (100%) Severe = 21-35 (90%) Moderate= 36-54 (75%) Mild = 55-69 (50%) Borderline = 70-84 (25% Note: Borderline disability is not a benchmark disability.		
1CD-11 Working Group on Intellectual Disability (2011). [d; 1]	Intellectual developmental disorders	A group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills.	The Working Group advocated continuing clinical severity levels of ICD-10, due to their current diagnostic and clinical utility . And, IQ score should be considered as one clinical descriptor among others also considered important in determining severity level.	Adaptive behaviour is not defined but implied that difficulties in adaptive behaviour will manifest in meeting the demands of daily life expected for one's age peers, cultural, and community environment. These difficulties include limitations in relevant conceptual, social, and practical skills.	Not explicitly defined, but understood to consider it as 18 years.

Source:

[a]World Health Organization (1992). ICD-10 Classification of Mental and Behavioural Disorders. Geneva: World Health Organization

[b]American Psychiatric Association (2013). Diagnostic and Statistical Manual of Mental Disorders, 5th ed. Arlington, VA: American Psychiatric Association.

[c]Government of India. Rights of Persons with Disabilities Act. New Delhi: Government of India, 2016.

[d]Salvador-Carulla L, Reed GM, Vaez-Azizi LM, Cooper S-A, Martinez-Leal R, Bertell M, et al. Intellectual developmental disorders: towards a new name, definition and framework for "mental retardation/intellectual disability" in ICD-11. World Psychiatry 2011; 10:175-180.

.Note:
[1]Need to refer to ICD-11 final guidelines as and when they become operational.

Figure 1: *Finnish Approach*

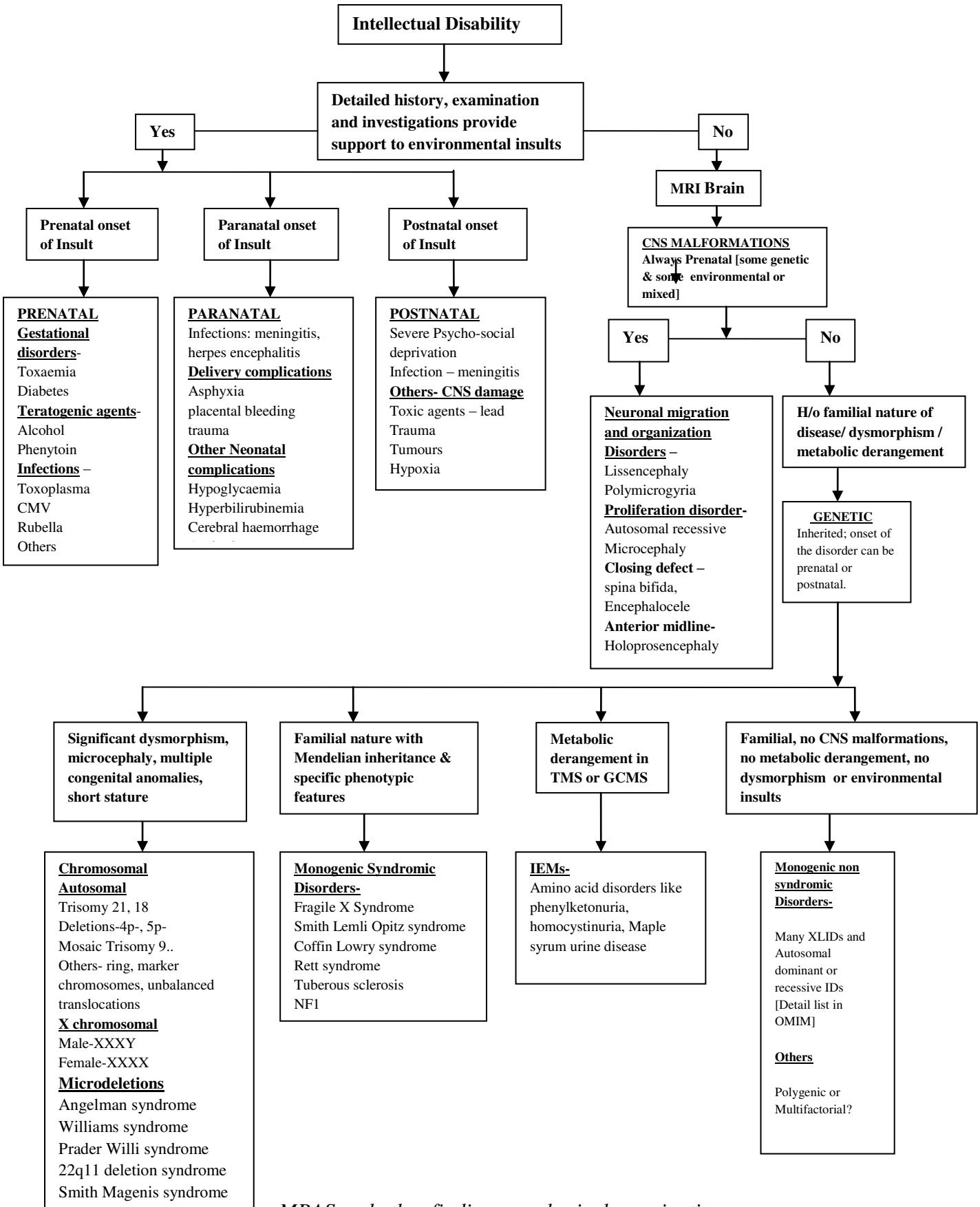

Table 2: *Some common MPAS and other findings on physical examination*

Scalp Hair:	Sparse, light colored, double whorl on scalp, easily breakable
Shape of skull:	Brachycephaly, scaphocephaly, trigonocephaly, oxycephaly, plagiocephaly
Facial appearance:	Coarse facies, elongated, triangular, small
Eyes and periorbital structures	Deeply set, prominent eyes, microphthalmia, upslanting / downslanting palpebral fissures, hypertelorism, epicanthal folds, strabismus, ptosis, bushy eyebrows, synophrys, microcornae, corneal clouding, cataracts, coloboma of iris, blue sclera, telangiectasia etc..
Ears:	Low set, small, large, malformed, anteverted, posteriorly rotated, pre-auricular tags, pits, cup-shaped etc..
Nose:	Depressed nasal bridge, short and stubby, beak shaped, bulbous tip, flaring or hypoplastic nostrils, anteverted nares etc..
Palate:	high arched, ridged palate, clefting, bifid uvula etc..
Chin:	Prominent, retrognathia, micrognathia etc..
Hands:	Broad hands, short hands, simian crease, Sidney line, spade shaped etc..
Fingers:	Clinodactyly, brachydactyly, syndactyly, camptodacyly, arachnodactyly, polydactyly, broad thumb etc..
Chest:	Pectus excavatum, pectus carinatum, nipple anomalies, gynaecomastia
Abdomen:	Protuberant, scaphoid, umbilical hernia, hepato-splenomegaly, inguinal hernia
Spine:	Kyphosis, scoliosis, spina bifida
External genitalia:	Micropenis, macro-orchidism, undescended testis, ambiguous genitalia, hypospadias, absent secondary sexual characteristics, shawl scrotum etc.
Skin:	Dry and coarse, café-au-lait spots, abnormal pigmentation, hemangioma, ichthyosis, absence of sweating
Feet:	Pes planus, pes cavus, valgus / varus anomaly, broad hallux, increased distance between 1st & 2nd toe.
Skeletal:	Exostoses, increase carrying angle, joint hypermobility

Table 3 : *Physical Investigations in ID.*

Test	**Examples of Conditions detected**

Brain imaging with MRI and MRS*	CNS malformations, , cerebral creatine deficiency, hypomyelinating and dysmyelinating disorders
Thyroid function test	Hypothyroidism
Advanced metabolic tests (Gas chromatographic Mass Spectroscopy(GCMS), tandem mass spectroscopy (TMS*)	Fatty acid oxidation disorders, Amino acid disorders, urea cycle disorders and organic acidurias
Enzyme studies	Tay-Sachs disease, Metachromatic, leukodystrophy, some NCLs, MPS
Urine screen for mucopolysaccharides and oligosaccharides	MPS and Oligosaccharidosis
Karyotyping	Down syndrome, large deletions, ring/marker chromosomes, translocations
FISH and MLPA	Prader Willi syndrome, William syndrome, Sub-telomeric deletions
Chromosomal Microarray	CNVs [many microdeletion duplication syndromes]
Next generation sequencing /Sanger sequencing	Monogenic disorders like Rett syndrome (MECP2 mutation), XLID, tuberous sclerosis, NF1
Repeat primed PCR	Fragile X syndrome
EEG	Epileptic encephalopathies such as West syndrome
Hearing evaluation (BAER)	Sensory-neural hearing impairment
Visual evaluation	Wilson disease, cataract, Optic atrophy, cortical blindness, refractive error
Blood group of child and parents	Rh iso-immunization
Immunologic tests (Ig M antibodies	TORCH infections [to be performed preferably with in 6 to 8 weeks of delivery]
Investigations for organ system functioning: ECHO Renal & Liver function tests with ultrasound abdomen	 Cardiac malformations Renal malformations, nephropathy, hepatosplenomegaly due to storage disorders

*Note: Mandatory investigations if obvious aetiologies [like Down syndrome, NF1] are not found clinically.

Table 4: *Disability certification process as per the guidelines based on RPWD Act.*

Screening	**Diagnosis**	**Disability calculation**

Many of the children with ID/GD are on follow-up with pediatricians as developmental delay. Hence, they can be assessed by pediatricians and screened for associated co-morbidities, viz. hearing/ vision/ locomotor impairments/ epilepsy. Then these children are referred for detailed assessment.	The screened children will be referred to Child/ clinical psychologists for Adaptive functioning and IQ testing. The tools that can be used for the same include Vineland Social Maturity Scale (VSMS) for the adaptive functioning; and Binet-Kamat Test (BKT)/ Malin's Intelligence Scale for Indian Children (MISIC) for IQ testing. Based on these the diagnosis of ID will be confirmed. Based on adaptive functioning assessment, severity scoring will be done and disability for ID charted.	The disability calculation will be done based on VSMS score. The following will be used for disability calculation: (i) VSMS score 0-20: Profound Disability-100% (ii) VSMS score 21-35: Severe Disability-90% (iii) VSMS score 36-54: Moderate Disability-75% (iv) VSMS score 55-69: Mild Disability-50% (v) VSMS score 70-84: Borderline Disability-25%

Table 5: *Summary of medical interventions*

Replacement of deficient molecules:	Thyroxine supplementation for hypothyroidism Enzyme replacement therapy for MPS Copper histidine for Menkes disease
Small molecule therapy:	Usually provided at high doses [beyond daily recommended doses] Tetrahydrobiopterin along with low phenylalanine diet for PKU Creatine monohydrate for CCDS Pyridoxine, B12 and folate for homocytinuria
Bone marrow transplantation:	For Alpha Mannosidosis and MPS 1
Pharmacotherapy:	Vigabatrin for Succinic semialdehyde dehydrogenase deficiencyy and tuberous sclerosis.
Special/modified diet:	For many organic acidurias and aminoacidopathies like PKU, Glutaric aciduria type 1, MSUD etc.
Chelation of excess metals:	Wilson disease and Manganese transporter deficiency

Table 6: *Summary of pharmacological treatment options.*

Symptom/Disorder	Medication found to	Dose[#]	Caution / Side

	be effective in children with ID		effects
Hyperactivity, ADHD	Methylphenidate (IR)	Start with 5-10mg, increments of 5-10mg per week, maximum up to 2.1mg/kg	Tics, Insomnia, anorexia (height and weight monitoring).
	Clonidine	0.1 to 0.5 mg/kg in 2 to 3 divided doses	Excess somnolence, hypotension (monitoring of BP required).
	Risperidone (especially in the presence of aggression and irritability)	0.5 – 2mg	Extrapyramidal symptoms, and somnolence.
Aggression, self-injurious behaviours and irritability	Risperidone	In general, dose in pediatric population is 0.5 – 2mg. Start with 0.25 mg per day for children < 20 kg weight and 0.5 mg per day for children > 20 kg weight*	
	Clonidine	0.1 to 0.5 mg/kg in 2 to 3 divided doses	Postural hypotension and excess somnolence.
Stereotypy and restricted repetitive behaviours and interests [RRBI]	Risperidone SSRIs especially fluoxetine for other RRBI (cochrane review 2013 showed no evidence of effectiveness and emerging evidence of harm).	Dosage as above Start with 2.5 mg per day up to 10mg per day. May be lower than usual doses used to treat depression in neurotypical children.	As above. Agitation, insomnia, anorexia, suicidal ideation.
Depression, obsessionality and anxiety.	SSRI	Fluoxetine 5-10 mg/day is the starting dose. Sertraline 25-50 mg daily. Effective dose is 50-100mg.	Higher risk for hypomania in ID children.
Sleep disturbance	Melatonin	1-10mg doses have been tried; usual starting dose in children is a 2mg single late evening dose	Epilepsy [no conclusive evidence]

	If insomnia is associated with hyperarousal, then Clonidine or Clonazepam.	Wide range of benzodiazepines like Clonazepam (0.25-0.5mg), Lorazepam (0.5 – 1mg) have been tried. Best titrated based on symptoms starting from lowest dose. However, less preferred due to paradoxical reactions.	Paradoxical heightened agitation, impulsivity and disinhibition. Excess somnolence

[#]Dose as used in non-ID children. There is uncertainty regarding optimal dose in ID population

* Doses used in autism, but limited literature regarding dose in ID.

Appendix 1: Scales of intellectual functioning and adaptive behaviour adapted or normed for Indian population.

Sl.No	Test	Indian Adaptation	Age	Content	Merits	Limitations
1.	Seguin Form Board*	Bharatraj (1971) Goel & Sen (1984); Revalidated by Venkatesan (1998)[1]	Reliable for 3 to 11 years old, but valid for all age groups of people with ID.	Performance test	It serves as a quick measure of general intelligence.	Validity is doubtful for children above 11 years of age as it becomes more a measure of visuo-motor speed than global intelligence.
2.	Binet-Kamat Test of intelligence*	Kamat (1967) adapted 1916 revision of Binet-Simon Test; Reappraised by Venkatesan (2002a)[2]	3 yr – adulthood	Age scale; Predominantly verbal	Balances verbal and performance items	Test items depend on formal education. Verbal items not available for vernacular languages other than Kannada and Marathi. Some items are completely redundant.
3.	Stanford-Binet Intelligence Scale	Kulshreshta (1971)	3 yr – adulthood	Age scale; Predominantly verbal	Balances verbal and performance items; and also offers a short scale. More suitable for Hindi speaking population	Did not include people with low intelligence in the sample.
4.	Malin's Intelligence Scale for Indian Children	Malin (1973) adapted the original scale of Wechsler's Intelligence Scale for Children	6 – 16 Yr	Has verbal and performance tests	It measures both verbal and performance intelligence	Some of the verbal scales depend on formal education.
5	Developmental Screening Test	Bharat Raj (1977)	0 – 15	Developmental tasks	It assesses global development.	DST is highly loaded with speech and language items hence not suitable for conditions such as, cerebral palsy, autism and speech and hearing impairment.

6	Vineland Social Maturity Scale	Malin (1968); expanded by Bharatraj (1992)	0 – 15	Culturally appropriate adaptive behavioural skills.	It gives a comprehensive profile of adaptive behaviour.	Needs revision in tune with the changing concepts of adaptive behaviour.
7	Progressive matrices a. Standard	Raven (2003); Indian norms are available (Deshpande et al., 2002)	11 yr to adults	Non – verbal	It covers the whole range of intellectual development trough form comparisons and analytical reasoning	Not suitable for illiterates and persons with low intelligence. It does not give IQ scores.
	b. Coloured	Raven (2003);	5 to 11 yr		It gives percentiles	Same as above.
8.	Gessel's Drawing Test*	Verma er al. (1972); Revalidated by Venkatesan (2002b)[3]	15 months to 8 yr.	Performance test	It is reliable screening test of mental developmental	It is not a valid test for the children who have not attended school or have no experience with a pencil or children with specific finger dexterity problem.
9.	Bhatais's Battery of Performance Test of Intelligence	Bhatia (1955)	11 yr and above	Performance test	Many subscales are indigenous	It measures IQ above 70 hence not suitable for suspected cases of ID.
10	Wechsler Intelligence Scale for Children - Fourth Edition (India)	Wechsler (2003)	6 – 16 years 11 months	Contains both verbal and performance scales	It has updated areas of assessment in accordance with the development of children in India.	Test administration takes 60-90 minutes.

Note:
The table is adapted from Arya, S., Kishore, M.T., Ranga, S., Bisht, J. Current Status of Intelligence testing in India: Perspectives on disabilities. NIMH News Letter, 2005; 18 (2&3), 19-23. ©NIEPID (formerly, NIMH), Secunderabad.

* Revalidation/reappraisal details could be found in Madhavaram, T.K. Intelligence Testing and its Implications for Disability Evaluation in Individuals with Mental Retardation. Psychol Stud 2011; 56(3):289–294. DOI 10.1007/s12646-011-0093-y

Appendix 2: Tests of development, adaptive behaviour and general intellectual functioning in comorbid conditions.

Appendix 2: *Key questions to aid assessment, intervention and treatment plan.*

Decision Area	Key questions to be answered
Diagnosis	• What precipitated the consultation? • Is there a delay in important areas of development such as motor; speech, language and communication; personal care/ self-help skills, cognition/learning and emotion? If yes, is it a global delay (i.e. delay in more than one important area of development)? Or, specific delay (i.e. deficit in only one area, for example, speech and communication deficits in case of hearing impairment)? • Does the global delay suggest significant impairments in intellectual functioning as is reflected in the adaptive functioning that is considered appropriate for the age and socio-cultural standards for personal independence and social responsibility? (Note: Asking key questions related the adaptive behaviour that reflect practical, conceptual and social skills is important; presenting questions based on the behavioural indicators given in DMS-5 [American Psychiatric Association, 2013; p.35-36] will be useful in this regard). • Are the deficits in intellectual functioning and adaptive behaviour appeared during the developmental period (i.e. before the age of 18 years)? • *Special circumstances*: Is there an evidence for significant impairments in intellectual functioning and adaptive behaviours but no reliable early developmental history as in case of children reported with sheltered homes, orphanages and adopted or those under foster care; or who do not have valid birth records or the caregiver does not have adequate information?
Comorbidities/ co-occurences	• Are there any identifiable comorbid conditions or co-occurrences? If yes, do they have specific implications for health care and other forms interventions? • Do the co-morbid conditions increase the severity of ID because of additional disability? And, do they denote 'multiple disabilities'? If yes, do they have specific implications for health care and other forms interventions?
Aetiology and risk factors	• Are there any treatable etiological conditions of ID? Or, are there any risk factors associates with the present condition or have the potential to aggravate the disability in future? Does it need further medical examination and laboratory investigations to confirm the screening results? If yes, specify them (For specific details, see the sub-section on medical comorbidities for possible etiological conditions, risk factors and essential laboratory investigations).
Nature and needs of the condition	• Given the developmental stage and the socio-cultural background of the individual with ID, what are the immediate needs of the child and family and other service providers? • What would be the impact on the child, family and the immediate environment if the needs are not met? • How does the current needs impact the future independent living

	of the individual with ID? • Does the person with ID requires any special assistance and adaptations to meet the identified needs? • What are the resources available at various levels (e.g. family, neighbourhood and community) to meet the identified needs?
Intervention Plan	• Is there a need for medication to treat associate medical conditions including psychiatric comorbidities? If yes, identify the condition and medical intervention. • Does the child require referrals for any therapies (e.g. speech, audiological, physiotherapy and occupational therapy, educational [supported/special/integrative]) to restore or enhance the functional abilities • Does the child need specific behavioural management plan for managing challenging behaviours? • If the evidence-based intervention plan including all or any of the above strategies is implemented, in what the quality of life of the person with ID will be better? • Is the intervention plan cost-effective? • Are there any significant side-effects or offshoot troubles of the intervention? • Will the intervention plan facilitate inclusion of the person with ID in the mainstream? • Knowledge, attitudes and perceptions of the caregivers with regard to the condition? What are the needs of the caregivers • Will the intervention plan help reduce the caregiver's burden?
Placement decisions	• Which is the best setting to deliver the targeted interventions (e.g. home, hospitals, vocational/rehabilitation centres; day-care or residential schools, *Anganwadi* centres and District Early Intervention Centres)? • If medical and therapeutic interventions are required, which is the best setting to obtain maximum positive outcome for the individual with ID- outpatient or inpatient? • Who are the people or agencies through which the intervention can be delivered? • Is the placement least intrusive that the persons with ID will continue to have normal developmental and learning opportunities and appropriate socio-cultural experiences? • Are all options for community integration are exhausted before considering segregation from the mainstream for any reason including safety, dignity, optimizing the potential, quality of life, and wellbeing?
Evaluating the outcome of intervention	• Are there any indicators other than the direct measures to suggest that the intervention is effective? • Is the positive therapeutic outcome observed in one setting is maintained or generalized to other settings?

Appendix 3: *Tests indicated in case of ID and comornid conditions.*

Type of disability	**Screening**	**Adaptive behaviour**	**Global intelligence scale (in the order as below)**
ID alone	DST	VSMS	BKT
ID and VI	DST	VSMS	• Prorate the IQ based on MISIC verbal scales. • BKT
ID and HI	GDT and SFB	VSMS	• Prorate the IQ based on MISIC performance scales. • BKT is not suitable becaue of high loading of verbal and language items.
ID and CP (or, locomotor disability)	DST and GDT	VSMS	• BKT; Profile analysis will help identify specific effect of motor deficits on test performance • Prorate the IQ based on MISIC verbal scales.

Note: DST = Developmental Screening Test; VSMS = Vineland Social Maturity Scale; GDT = Gessell's Drawing Test; SFB = Seguin Form Board; BKT = Binet-Kamat Test of Intelligence; MISIC= Malin's Intelligence Scales for Indian Children

Source: Kishore MT. Trends in intelligence testing of persons with mental retardation and its implication for certification of disability and service provisions. An unpublished study funded by the Indian C