

Indian Academy of Pediatrics (IAP)



GUIDELINES FOR PARENTS

Care of a Child with Intellectual Disability

Convener: Shruthi NM

Members: Ashwini A Marathe,
Dhananjay R Shah,
Jyoti Mishra

Reviewer: S Sitaraman



10 FAQs on CARE OF A CHILD WITH INTELLECTUAL DISABILITY

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Care of a Child with Intellectual Disability

Q1

How will I identify that my child is having intellectual disability, and what are the tests needed? How to assess the severity?

Intellectual disability (ID) (earlier known as “mental retardation”) refers to below average intelligence and limitations in performing daily lifeskills in children, with onset in early childhood years. The features of ID may appear as early as in infancy, or it may not be noticeable until a child starts schooling, and depends upon the severity level of the ID. Some common features are:

- Your child may lag behind other children of same age in mental development with or without associated lag in development. Your child may not be able to sit/walk/speak age appropriately.
- Your child may not be able to understand the simple instructions. Some kids may have difficulty in grasping complex instructions only.
- Your child may not be able to do certain tasks independently such as eating, dressing, bathing, and taking care of self, depending on severity level. He/she may lack sense of danger and self-safety.
- Your child may not be able to participate in games governed by rules and may have difficult peer relationships. He/she may have trouble solving problems and think logically.
- School-going children may have academic difficulties, memory impairment, learning difficulties, and behavioral/attention problems.

Intelligence quotient (IQ) and adaptive functioning (daily lifeskills) assessment with certain scales help in assessing the level of severity of ID. IQ score <70 is considered as ID. Following categories are known:

- *Mild*: IQ 50–69
- *Moderate*: IQ 35–49

- Severe: IQ 20–34
- Profound: IQ <20

However, only IQ scores may not be enough to assess functioning in real-life situations and practical tasks. Therefore, importance is given to degree of adaptive functioning while assessing the severity of ID.

Few other tests such as neuroimaging (MRI brain), urine and blood tests, electrophysiological studies (EEG), genetic tests, hearing and vision assessment, behavioral assessment, etc. may be needed for evaluating the *cause* of ID and managing the *comorbidities* associated.

Q2

What is IQ and adaptive functioning assessment? And how will it help in managing my child?

Intellectual disability (ID) has limitations in two major areas: (1) Intelligence and (2) Adaptive functioning. Intelligence refers to a child's ability to understand, learn, reason, judge, and solve problems. The intelligence is reflected through intelligence quotient (IQ), which is expressed in numbers and IQ <70 is considered as ID. Whereas, adaptive functioning refers to age-appropriate skills required for living a day-to-day life, such as taking care of self (eating, bathing, and dressing), communication, going out and live independently; and is assessed with special scores such as Vineland Social Maturity Scale (VSMS).

Assessment of these factors is important to know your child's ID category, which will guide the management of your child. It helps in planning the adaptive training, education of the child, vocational training, etc. A child with mild ID (educable) can go to school for basic education which will help them vocationally, learn practical life-skills, and become independent allowing them to function with minimal level of support. A child with moderate ID (trainable) can be trained and placed in sheltered jobs. Children with severe and profound ID (dependent) have limited developmental opportunities. A child with severe ID can perform their routine tasks with supervision and verbal/physical prompts and those with profound ID (totally dependent group) may need lifetime support for their living.

Assessment of severity (with respect to intelligence scores as well as adaptive functioning scores) is thus essential in order to provide individualized care and education, to seek benefits from the center and state sponsored welfare schemes, and for some legal purposes also (for one to stand trial in the court of law).

Q3

What are the other problems that my child will face as he grows up? What precautions should I take?

Your child may have other problems associated with ID. Identifying the underlying etiology can help to identify and predict many associated problems. These may vary according to the severity level of ID. Following are some of the problems that can be associated in ID children with varying severity:

- Epilepsy
- Attention deficits and hyperactivity
- Autistic phenotype (impaired communication and social behavior, stereotypies)
- Depression and anxiety disorders
- Cerebral palsy/motor or sensory impairments
- Hearing and vision impairments

Being watchful of the symptoms and availing medical care as early as possible can help in managing such issues. Treating the associated comorbid conditions is very essential in comprehensive care of children with ID.

Q4

Whom to consult for the guidance for the care of the child having intellectual disability?

A child with intellectual disability needs a multidisciplinary team for its management. At the center of the team is the “pediatric neurologist” or the “developmental pediatrician”, who will help in the diagnosis and assessment of the child, medical management of the child as well as planning and coordinating the services required for the child and the family. Diagnosing the cause of ID is of paramount importance and plays an important role in genetic counseling.

The child may also require the support from the multiple specialists (**Fig. 1**).

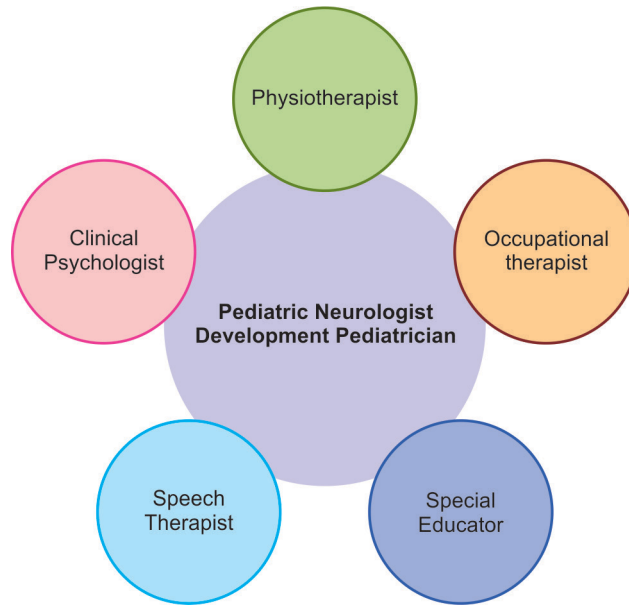


Fig. 1: A child with intellectual disability needs multidisciplinary specialists for its management.

All these faculties will work together and each child will be provided with an individualized comprehensive plan for the optimal development.

Q5

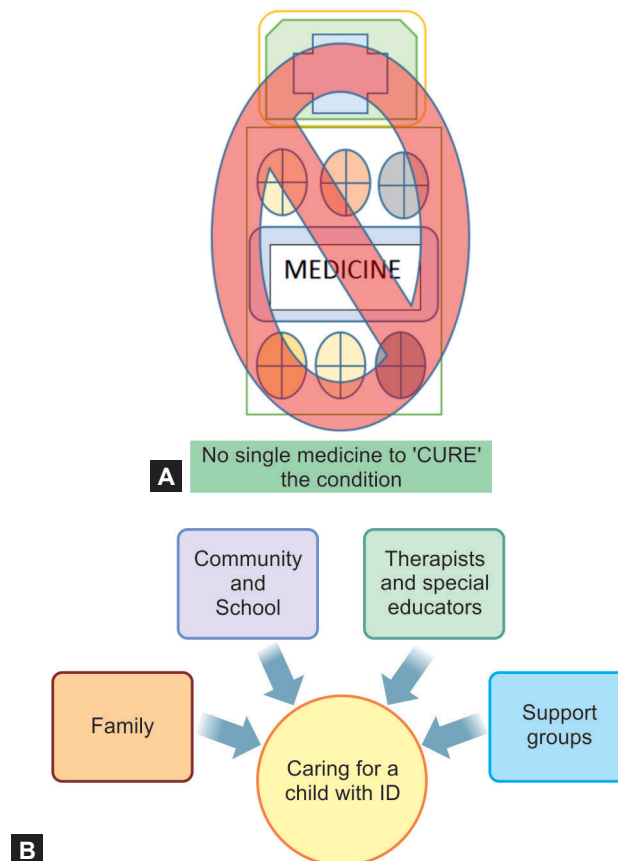
What are the treatment options (medicines, therapies, etc.)? Which will be helpful for my child? Will he improve and become normal with treatment?

Intellectual disability is not cured by medicines. However, maintaining good health and nutrition, starting therapies from an early age, family involvement, and community support help children to progress and achieve their best potential for personal independence and social responsibility. Based on each child's needs, the management options need to be individualized. These management options as a part of a multidisciplinary team may include the following (**Figs. 2A and B**):

- *Medical management:* To monitor the child's overall health and development, address specific medical issues, plan, and coordinate the therapies as per each child's needs.

- *Speech therapy*: To support the child's speech clarity and communication.
- *Physical therapy*: To support the child's physical and movement skills.
- *Occupational therapy*: To support the child's hand skills needed for eating, writing as well as basic daily-living skills.
- *Counseling*: To support the mental health of the child and family.
- *Social worker support*: To help in community participation and identify key resources to support the family.
- *Special educators and teachers*: To develop a comprehensive, individualized plan with all above for the child with family involvement.

Remember, ID is not a disease and cannot be cured, but it does not mean that the child cannot learn and develop. Be patient, be optimistic. Early diagnosis and ongoing interventions can improve adaptive functioning.



Figs. 2A and B: Medicines and caring for a child with intellectual disability (ID).

Q6

What can we do at home to nurture our child’s overall physical and mental wellness and progress? What can be done to help my child be self-sufficient in the society?

To nurture your child’s wellness and progress, along with medical care and therapies, it is also important to focus on participation in various activities at home, school, and community.

The best start is the supportive and caring family atmosphere, where you know your child best to emphasize his strengths and interests. Involve your child in household activities. Start with achievable activities that motivate and interest them. When teaching any task, break it down into smaller steps. Demonstrate or show pictures rather than only verbal directions (**Figs. 3A to C**). Give clear concrete instructions and assistance where necessary. Create opportunities for practice in different settings but avoid frustrating the child. Provide immediate praise for smallest effort or achievement. Know about what your child is learning in school, find ways to apply that at home. For example, if the teacher is teaching money, take your child shopping and help him count money.

To help your child be self-sufficient in the society, encourage independence from an early age. Help your child to learn daily care skills such as feeding, toileting, and grooming. Follow a routine with picture schedule for the same, if required. Gradually work on developing further independence skills for navigating in the community, and then transitioning into adulthood. Look for opportunities for community participation for your child such as in schools, recreational centers as well as for vocational or employment purposes. Also, continue to create awareness at all levels to reduce barriers to inclusion and participation.



Figs. 3A to C: Involvement of a child in household activities and the supportive and caring family atmosphere.

Q7

Can my child go to school? Should I send my child to regular school or special school? How will I secure my child's future?

Yes, your child can go to school, but whether he will require a regular school or a special school, it will depend on the severity of the intellectual impairment.

- Learning in the early years is most effective on "one-to-one basis" (**Fig. 4**). This has to be provided by the parents at home and the special educator at the school.



Fig. 4: Learning in the early years on "one-to-one basis".

- Child who needs individual support may find it difficult to benefit from a classroom-like situation, and hence needs to be integrated carefully.
- Most kids with moderate-to-severe level of disability will need special education methods throughout their lives.
- Availing the government policies and disability benefits can also help in securing the child's future.

What are the “government” policies for a child having intellectual disability? What is “disability” certification? And what are its benefits?

The government policies recognize that the “Persons with Disabilities” constitute a valuable human resource for the country and that most of such persons can lead a better quality of life, if given equal opportunities and effective access to rehabilitation measures. With this aim, the government has brought out the “National Policy for Persons with Disabilities” and has enacted three legislations for persons with disabilities, viz.

1. *Persons with Disability (Equal Opportunities, Protection of Rights, and Full Participation) Act, 1995*, which provides for education, employment, creation of barrier-free environment, social security, etc.
2. *National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disability Act, 1999* has provisions for legal guardianship of the four categories and creation of enabling environment for as much independent living as possible.
3. *Rehabilitation Council of India Act, 1992* deals with the development of manpower for providing rehabilitation services.

The Government of India has also notified guidelines for evaluation of the disabilities and procedure for certification. Disability benefits have been provided for persons with benchmark disabilities (disability >40%) and those with high support needs. Based on intelligence and adaptive functioning assessment the diagnosis and severity categorization of ID can be made.

Age at Certification

The minimum age for certification will be one (1) completed year. Children above 1 year and up to the age of 5 years shall be given a diagnosis as “Global Developmental Delay (GDD)” and for those above the age of 5 years shall be given a diagnosis of “Intellectual Disability”. The certification will be temporary for children <5 years and will be valid for maximum 3 years/5 years age (whichever is earlier). For children >5 years, the certificate will have to be renewed at the age of 5 years, 10 years, and 18 years and will mention the renewal age. The certificate issued at 18 years of age will be valid lifelong.

A person with a benchmark disability gets right for free education, reservations in government-aided higher educational institutions, reservations in jobs, self-employment, accessibility in public buildings, etc., travel concessions, income tax rebates. For more details, parents can visit www.disabilityaffairs.gov.in to know more about the Government Policies, Acts, Rules and Regulations, and benefits for person with disability.

Q9

Is there any organization working for these children and how to reach them?

In general, services are unevenly distributed and mainly focused in big cities and urban areas. A lot of nongovernment organizations (NGOs) and organizations are working for children with “Intellectual Disability” and making the world a better place for such children. There are now more than 1,500 such special schools for IDs and about 100 voluntary organizations, which provide the “Community Based Rehabilitation (CBR)” services with government support of up to 95% of the expenditure. Parents can reach to these organizations and can avail the given services for their children.

In addition, there are also certain State Government Institutions and District Disability Rehabilitation Centers (DDRC) providing rehabilitation services and various National Open Schools. Currently, there are >180 parents’ association forming an umbrella organization “Parivaar” (for more information caregivers can visit, www.parivaarnfpa.org). This group known as “The National Parents Association—Parivaar” aims to initiate, promote, or support rehabilitation services for persons with IDs and their families.

For detailed information, visit www.rehabcouncil.nic.in.

Q10

Can we plan for another child? What are the chances of recurrence in my next child? Does the child have this problem because of something that happened during pregnancy or is it because of us?

The most important thing to understand is that you are not to blame for your child’s intellectual disability.

A wide variety of biological and environmental conditions can cause intellectual disability. Some conditions are genetic/syndromic (e.g., Down syndrome/Fragile-X syndrome). Some are present before or at the time of conception, during pregnancy (e.g., those interfering with fetal brain development such as maternal drug/alcohol use, malnutrition, infection, etc.) and some during birth, or after birth (e.g., infections, trauma, perinatal hypoxia, certain inborn errors of metabolism). Even with recent advances in testing, a specific cause often cannot be identified in many children.

Hence, though it cannot be always said that there may be a recurrence in the next child, it would be advisable to consult your doctor before planning next pregnancy. Your doctor, with his knowledge of your child and family’s medical and psychosocial background, would be the best person to guide you about the risk of recurrence as well as prevention in next pregnancy.

Some simple but important general advice to lower the chances of any developmental difficulty in a baby would be taking folic acid before conception and in early pregnancy, getting all-needed vaccinations, especially against rubella before pregnancy, and ensuring optimum pregnancy and neonatal care.