



**Challenges faced
by children with
developmental
disabilities**

Paediatricians and parents not trained in screening indicators for neuro diverse children



Challenges faced by children
with intellectual disabilities



Nearly one in eight Indian children ages 2 through 9 might have a neurodevelopmental disorder

~ INCLIN Trust International, 2018



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The Challenge:

1. Many paediatricians are unable to identify early signs of neurodiversity in the child. They often attribute it to shyness, slow language development or isolation.
2. Screening clinics do not have therapists and counsellors who are sensitized to working with and helping parents and care givers.
3. The result is that diagnosis is often delayed till the ages of 4-5.



The need for a solution:

Studies have shown that intervention after the age of 4 can result in significant loss in language, cognition and adaptive behavior for the child. Early intervention drastically improves the quality of life and the child's ability to adapt to daily living requirements.

Best results for children with developmental disability can be achieved when the parents work collaboratively with the therapists.



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A large proportion of childhood disability can be prevented by good antenatal, perinatal and neonatal care, avoidance of consanguineous marriages, ensuring safe delivery and timely immunization and neonatal screening for metabolic disorders.

Pratibha Singhi , Department of Paediatrics, Chandigarh

In many cases, neurodevelopmental disorders could have been prevented if birth asphyxia had been prevented with sufficient supply of oxygen.

Dr. Rakesh Kumar Jain, Pediatric Neurologist
Fortis Memorial Research Institute ,Gurgaon

Parents approaching pediatricians

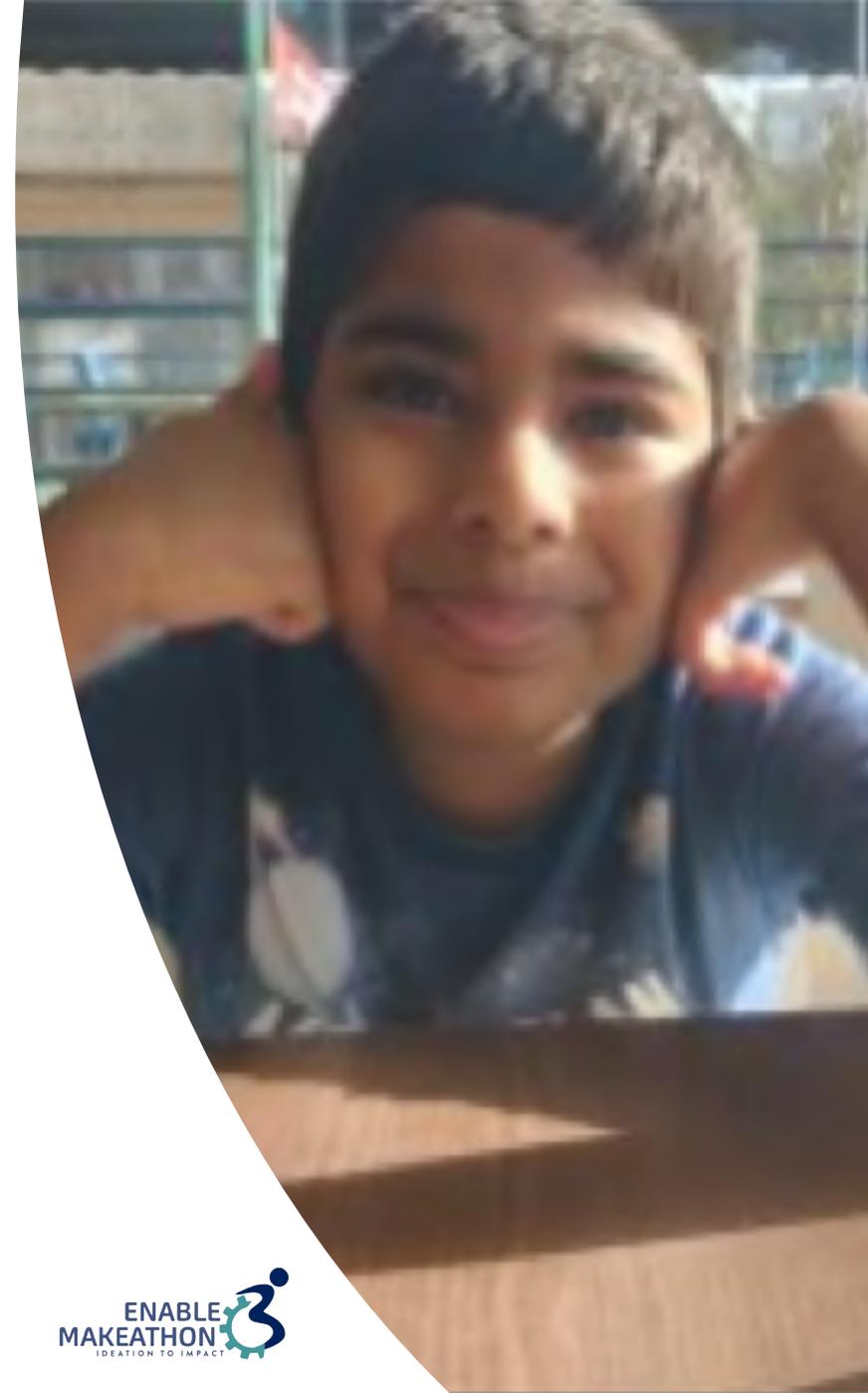
Studies show that there is on an average delay of 32 months between parents' first recognition of a problem and an eventual diagnosis.

Average age of diagnosis of ASD (Autism Spectrum Disorder) is often 4 years 10 months This is a valuable time and a window of opportunity for early intervention, which is lost by the child and the family. Paediatricians have an important role in minimizing this delay, as in majority of the cases, parents first approach the paediatrician with the problem.



This is Kartik...

Kartik is Radha's second child. In his early years, she noticed behavioral patterns in Kartik which were different from those exhibited by her elder child. She mostly attributed this to every child being different. Sometimes when she would get worried and consult her paediatrician, she was told that different children progress differently with respect to their language, cognition and social skills. Some are just more shy than the others. Kartik demonstrated repetitive behaviour, tendency for solitary play, insufficient eye contact and would not respond when his name was called out. His aunt who lived in France, pointed out that she had met children back home with similar repetitive behaviour and perhaps they may need to visit a special diagnostic clinic. That is when they visited the doctors at **Ummeed** and Kartik was diagnosed with autism at age 3.5.





“Lack of awareness in Doctors...

...Can be huge inhibitor in early diagnosis and timely consultation with a developmental paediatrician. Therapies work well when administered early and can substantially improve the quality of life, language and cognition of the child. Challenge in early diagnosis accentuate many fold for children with mild - moderate disabilities . Most often medical providers trivialize the disorder due to lack of training to offer caregivers evidence-based recommendations

Neurological disorders can often lead to other sensory issues such as delayed speech, low vision, etc. which the neurologists must be aware of and alert the parents for early signs and intervention. Lack of awareness amongst doctors can result in parents missing out on therapies and interventions which can assist the child.

Disability Expert



This is Aadi's story...

When Aadi turned 6 , the school called his parents to express concerns about his behaviour- he was bored, disruptive, fought with classmates and answered back to teachers. His parents had ourselves observed that he was easily frustrated with several incidents of hitting , crying , lying ... but he was a child and children are meant to behave not as adults . They told his teacher that maybe they are feeling this way because they are comparing him to his older sister who is very sincere and the head girl of the school.

Aadi was taken to a counsellor where he said :

“ I struggle to concentrate on things I don't like , meet expectations at home and at school, complete academic work, and communicate effectively with others. I feel terrible when I disappoint my teachers and parents but I can't help the way I feel”

“We believed that this was just a phase and attributed his aggression to him being little spoilt and his inability to follow routine and remembering instructions, to him being careless. We attributed it all to our busy careers and inability to devote time to him”.
“There were no pregnancy or birth problems , Aadi had received all his shots and was on no medication. Younger siblings are often spoilt and careless. We had no reason to suspect anything “

-Aadi's parents

It was only when Aadi turned 11 and academic difficulties, social skills problems, and strained relationships with family became totally unmanageable that they visited a psychiatrist and realized that their son had **Attention Deficit Hyper Disorder (ADHD)**.

“On delving deeper , we realized that even as a toddler he had shown clear signs - being overly fidgety - inability to sit still and concentrate etc but we missed these signs due to lack of awareness. School and Counsellor raised an alarm but could never direct us toward the real cause”

-Aadi's parents

Aadi has been now been prescribed Applied Behavior Analysis (ABA) Therapy which is meant to improve attention social skills, and academic performance.

It is difficult to understand why a therapy which is meant to bring you close to the real world is conducted behind the close doors of a therapy room. Ideally , the therapist should be accompanying Aadi to a playground , mall , school etc and provide therapy while he is being subjected to real world situations which he finds difficult to cope with”

Aadi's mother



“Though we felt something was not right when our child turned 18 months. We sought medical attention when our child was 2 years old, diagnosis of Autism happened only when he turned 6. We took way too long to traverse the journey across Denial – Denied Acceptance – Acceptance and lost crucial time in the process”.

-Parent of child with Autism

District Early Intervention Centres

In 2013, as a part of its National Children's Health Program, Government of India included neurodevelopmental disorders as one of the public health issues to be addressed, naming it as a national health concern for the first time. The government has opened District Early Intervention Centres (DEICs) in all districts of the nation in an effort to diagnose and treat these children. Resource constraint restricts the outreach and impact of DEICs. It should develop into a training centre for Anganwadi volunteers, teachers, expecting mothers etc. to enable increase in awareness



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With a paediatric population that constitutes nearly 40% of 1200 million people of India; the requirement of paediatric neurologist is huge. There are very few comprehensive Paediatric Neurology centers in India and hardly any in rural areas

~ **Special Educator , Inclusive School , Delhi NCR**

Need for pediatric neurologists

“Due to lack of resources , most therapy centers have young graduates working with the children . The milder the disability , the more inexperienced the staff who the child is paired up with. Parents feel very cheated when we have to pay so much for freshers , but they don't have a choice as there are hardly any resources available.”

“My child became completely silent when he turned 3”.

Doctors told me that he had “acquired” Autism after the MMR vaccine and put him on a naturopathy diet to cleanse his system but nothing changed. It was only when he turned 5 that on seeking further consultation we were told that autism develops in utero, well before a baby is born ,MMR vaccine does not cause Autism and no diet can “undo” it. The Myth about why my child became silent continues and no doctor has been able to answer it convincingly



Some possible solution ideas:

1. **Doctors need to be apprised of clear indicators which can indicate a developmental disability of the child.** This can be done through circulated material, apps, workshops to create awareness.
2. **New parents need to be provided early indicators which signal disability for their child,** when they leave the hospitals post-delivery. An application could be created with observational and behavioural checklist for parents.

Some possible solution ideas:

3. **Acute shortage of paediatric neurologists** in India necessitates training of medical officers and paediatricians at all levels to ensure early appropriate management of common neurological disorders in children.
4. With the new government mandate wherein 4% seats in schools are reserved for PwD, every school must have an early intervention centre and counselling and therapy services at a subsidized rate.

Helpful Readings

- Reference US National Library of Medicine, National Institute of Health
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5576710/>
- 1 IN 8 CHILDREN IN INDIA HAS NEURODEVELOPMENTAL DISABILITY, REPORT ESTIMATES(https://www.eurekalert.org/pub_releases/2018-07/p-epo071718.php)
- <https://www.kimt.com/content/national/489592611.html>
- <http://www.nams-india.in/anams/2014/50-3-4-91-107.pdf>

