

## **Autism is not a curse, Ignorance is**

“Your son has autism”, four words and suddenly the world around you changes. You don’t know, at first whether this is something good or bad. If bad, then, how bad? Most of us at first, ask, what is that?

I had not heard of autism even though I am a voracious reader. So, after assimilating and trying to make sense of what I had heard, followed a series of technical jargons: sensory disorders, delay in receptive and expressive language, occupational therapy, speech therapy etc... etc.

My attempt today is to explain in the simplest possible terms to a parent who has just heard about autism, what lies on the road ahead. I have to add that many professionals also need to understand autism. The journey here explained is mine, we all must have treaded this path but each experience believe me, when you ask parents would be unique as it is always said, “If you have seen one child with autism, then you have seen only ONE child with autism”.

First, the technical definition of autism.

Autism spectrum disorder (ASD) is the name for a group of developmental disorders. ASD includes a wide range, “a spectrum,” of symptoms, skills, and levels of disability.

People with ASD often have these characteristics:

Ongoing social problems that include difficulty communicating and interacting with others

- Repetitive behaviours as well as limited interests or activities
- Symptoms that typically are recognized in the first two years of life
- Symptoms that hurt the individual’s ability to function socially, at school or work, or other areas of life

(Definition courtesy: [www.nimh.nih.gov](http://www.nimh.nih.gov))

Put in a layman’s language a child with autism will have certain repetitive behaviours like spinning of objects, lining up of objects, flickering of fingers in front of their eyes, rocking their body and flipping of objects like a paper, straw or a scale or peculiar things like looking at things from the corner of their eyes.

Strange fixations like my son Kartik loves brands even before he could say mama, papa he could rattle of names like ICICI bank, HDFC, Indian Oil, Samsung etc. This started even before he turned three and continues even today when he has turned 15. Now the list has just diversified horizontally to pamphlets of all shops or more brands or actors, Alia Bhat & Deepika Padukone being his favourite.

Delay in speech and age-appropriate language would in fact be the key thing any parent would notice.

The most difficult part here is, we are constantly thinking and trying to come to terms with thoughts like, "where did we go wrong?", and the worst denial mode. In a denial mode parents and all relatives are consoling themselves with things like "it's just speech delay, very common", "your dad spoke late", "even normal children do this" and sometimes some professionals also join in with their bit "don't label the child" or "these are so mild symptoms he will be cured within six months".

Once there is a diagnosis of Autism Spectrum Disorder, it is like the opening of Pandora's Box you are being bombarded with information, treatments, therapy's from everywhere professionals, family members, friends etc. etc , but Pandora's Box also gave something else to humanity "Hope". Hope, that things would be better, things would get better and unfortunately or fortunately it is this, "hope" that is being exploited by some people or put to GOOD use by others. We as parents are completely at loss and at times do not know what to accept or reject. The worst part here is the child becomes the guinea pig for anything and everything.

So here is list of my experience as a therapist and parent on Autism. What parents of newly diagnosed or existing experienced parents can do:

1. Ignorance is no bliss, so read, question and seek answers.
2. Internet is a double edged sword, so clarify from other experienced parents and experts in the field whatever information you get.
3. Do not try any self-medication, it can have adverse effects.
4. Many parents ask me if my child will ever have a normal life?. People will call him retarded. It's tough I know, the journey from here on is never easy.

5. I respect the sentiments of parents who go for other forms of alternative treatments but kindly ask yourself, is it a placebo effect?
6. Think before you make your child a party to many fake claims which claim to cure autism completely.
7. Don't waste time running from pillar to post and trying new remedies. There are time tested therapies which have yielded excellent results, start therapy immediately.
8. There is no medicine that can CURE autism till date.
9. Early Intervention really makes a difference.
10. Early Intervention is a system of coordinated services that promotes the child's age-appropriate growth and development and supports families during the critical early years. This period is between 0- 6 years.
11. This is the period when the brain has high degree of plasticity. Skills and behaviours taught at this time are learnt faster and retained more.
12. Even after the age of six learning doesn't come to a standstill. In fact my 15 years old son Kartik surprises me every now and then with something new he picks up.
13. So intense intervention at this age leads to the maximum independence and skill enhancement.
14. Early Intervention is recommended because margin of window to be achieved is also small, which means that the numbers of skills to be covered are small. Remember each day your child is growing and a wait and watch approach will only increase this difference.
15. Occupational Therapy is one of the first therapies which a child should receive along with speech therapy.
16. The reason for above is Occupational Therapy works on the sensory integration of the child an indispensable factor in case of autism.
17. Many a times I have told parents who approach me that, "your senses are working completely in synchronisation. You are getting all the inputs from the environment to make you feel safe and secure. So, sitting from that position don't judge your child when he is anxious or agitated saying that the child is trying to be difficult or showing behaviours."
18. Also do not dismiss the symptoms you see as, "oh these are things which normal children also do".

19. So first come down to the child's level learn and understand what he / she is going through rather than trying to fix one behaviour after the other.
20. Speech does not come in isolation and since it is the most visible skill to a layman, many parents just end up doing speech therapy alone which does not yield the same results as when both speech and occupational the therapy are done together.
21. Learning to imitate a clapping action or pointing at the things is more important than saying A to Z at the age of two.
22. In other words an observant, independent and environmentally present child is a more important than rattling of ABC.. 's .
23. Any developmental delays are acceptable till one to one to two months after that take expert help.

Remember Autism is manageable, many children with autism join mainstream school, grow up as independent adults managing jobs and family, but they do not outgrow autism, early intervention, therapies , and persistent efforts help children and these adults to integrate with their peers and society, depending on the degree of autism, AND again with what I started.

Autism is not a curse ignorance is....