

What is Autism?

General Information and Frequently Asked Questions by Indian Parents

What is Autism?

This is by far the most frequently asked question. Briefly, it is a severely incapacitating life long developmental disorder that typically occurs in the first three years of life. It causes impairment or disturbance in three main areas: social skills, communicative (verbal as well as non-verbal) skills and in their repetitive and restricted behaviors. Autistic individuals may show abnormal responses to sensations. Any one or more of the senses may be affected. All these difficulties manifest themselves in behaviours i.e. abnormal ways of relating to people, objects and events in the environment.

Autism is known as a 'spectrum disorder,' because the severity of symptoms ranges from a mild learning and social disability to a severe impairment, with multiple problems and highly unusual behavior. The disorder may occur alone, or with accompanying problems such as mental retardation or seizures. Autism is not a rare disorder, being the third most common developmental disorder, *more common than Down's Syndrome*. Typically, about 20 in a population of 10,000 people will be autistic or have autistic symptoms. 80% of those affected by autism are boys. Autism is found throughout the world, in families of all economic, social, and racial backgrounds. Doctors, politicians, and rickshaw drivers alike all have autistic children.

What is a person with autism like?

A child with high functioning autism may have a normal or high I.Q., be able to attend a regular school and hold a job later in life. However, this person may have difficulty expressing himself and may not know how to mix with other people. Moderately and more seriously affected children with autism will vary tremendously. Some autistic children do not ever develop speech, while others may develop speech but still have difficulty using language to communicate. Often, there is an unusual speech pattern, such as echoing whatever is said to them, repeating a word over and over, reversing "you" and "I" when asking for something, and speaking only to express needs, rather than emotions.

A child with autism looks just like any other child, but has distinctive behaviour patterns. A child who is autistic may enjoy rocking or spinning either himself or other objects, and may be happy to repeat the same activity for a long period of time. At other times, the child may move very quickly from one activity to another, and may appear to be hyperactive. Many autistic children have

sensitivity to certain sounds or touch, and at other times, may appear not to hear anything at all. Autistic children may have very limited pretend play; they may not play appropriately with toys or may prefer to play with objects which are not toys. Autistic children may be able to do some things, like sing songs or recite rhymes very well, but may not be able to do things requiring social skills very well.

How is autism diagnosed?

There are no medical or genetic tests that can detect autism. These can only rule out other conditions. A diagnosis of autism requires a sensitive and experienced doctor to observe the child very carefully, ask the parents about the development of the child, and then objectively follow internationally recognized criteria for diagnosis. Onset may occur at birth, or a child may have a period of normal development followed by a deterioration of verbal and social skills around 1 1/2-2 1/2 years. Where onset is at birth, the disorder can be detected as early as a year. Autism may occur alongside conditions such as mental retardation and hyperactivity, but the autistic traits in the person are typically what require attention.

What is the cause of autism?

At this point in time we do not know what causes it. However, current research indicates that anything that can produce structural or functional damage to the central nervous system can also produce the condition of Autism. We know that certain viruses and known genetic conditions are associated with Autism. In addition, there are families that have more than one child with autism. At present, it is believed that about 10% of all cases can be accounted for genetically. It is difficult to tell parents why their child has autism since researchers believe the problem to be caused by different factors, and in most cases, the cause is never known. Autism is *not* caused by an unhappy home environment, both parents working, mental stress during the pregnancy, poor handling by the mother, an emotional trauma, or other psychological factors. You cannot cause a child to become autistic.

Can it be prevented? Can it be cured? What is the treatment?

At this point we do not know what causes Autism and so cannot fix (cure) what is wrong in the child's brain. Many therapies (medications, diets, etc.) are being tried but nothing is proven. Similarly, without knowing the cause of autism, there is no way to prevent it. At present, there is no cure for autism: there is no medication, no pills, no injections which can make the problem go away. The only

consistently effective treatment for autism is a structured training program; therefore, a combination of a good school and parent training is the best known treatment. *Autistic children can make significant progress if the intervention is appropriate and consistent.* Early intervention, before the child is five, is especially crucial to the child's progress. This is why an early and accurate diagnosis is so important. Autistic children grow to become autistic adults, and there is a particular need for meaningful outlets for social interaction and employment where possible.

How is it different from Mental Retardation?

When a person has M.R. there is a more or less even impairment in skills in all areas of development. Therefore, if an M.R. child of 8 years has a mental age of 5 then all his skills would be roughly around 5 years (i.e. motor, communication, social, self-help, cognition etc.). In Autism, there is an uneven skill development- in fact this is the hallmark of autism. In some areas the child may show age-appropriate skills; in some the skills may be below the developmental level; and then again there are people with Autism who possess exceptional skills i.e. beyond their age level.

Can the child ever live an independent life?

Autism is a spectrum disorder. Currently there is no reliable objective measure of how severe the Autism is in an individual child. Children with Autism have potential for building up their skills and they can be helped if they receive early, well-focused intervention. Depending on the child's individual skill profile and the appropriateness and intensity of intervention he or she receives, children with Autism can lead relatively independent lives.

What are the chances of her going to a regular school?

There are a number of autistic children who have integrated into regular schools. The chances depend on several factors. The most important is "What is the skill profile, how early diagnosis was received, and thereafter the kind of early intervention provided?" Most children with Autism have different learning styles from regular children and therefore teaching styles also need to be different. In some schools this is not understood and therefore children with Autism face difficulties; after Grades 4 or Grade 5 many have to drop out.

When and will my child ever speak?

A large member of autistic children (about 30-50%) do not use speech. It is very

difficult to say when and whether the child will ever speak. It is confirmed that there is no difficulty in their physical abilities that stops them from speaking. Some children who might have spoken as infants and then lost their speech may or may not get their speech back. Currently, it is unknown why some children develop speech and others do not. Experience with children with autism has shown that if the environment is accepting, and people are aware of the kind of speech they themselves need to use with the child, it can produce positive results.

Can Speech Therapy help?

Speech Therapy can help some children. It is absolutely essential for the speech therapist to understand Autism and also the individual child. Otherwise, the conventional methods of speech therapy help children with Autism very little, because as stated above, the inability to speak is not a physical problem. However, every child with autism can benefit from interventions that emphasize communication.

Why is he hyperactive?

Hyperactivity can have a medical reason. However, most children with Autism are restless because of an impairment of their imaginative and social skills. They cannot play with their toys and other children meaningfully and find it very difficult to occupy themselves. Often they eat a lot to keep themselves occupied. Hyperactivity can be reduced as the children are taught new skills and ways to keep themselves occupied.

What are chances of Autism in the next child born to us? Can we have a normal child?

About 10% of the cases of Autism can be accounted for genetically. If there is one child with Autism in the family, risks of having another child with autism is much higher than in the general population. So far, there is no reliable test to detect Autism in the foetus.

Why does he keep playing with his fingers/ rocking himself back and forth/ spinning around etc?

Children with Autism respond to sensations abnormally. They often have a condition known as sensory dysfunction this means either over or under stimulation in any one or more of the sensory modalities (hearing, sight, taste, touch, smell, balance). One theory is that these unusual mannerisms like flapping

and rocking etc. are natural responses or methods of coping with sensory difficulties. These behaviours may help them to relax.

Is there any hostel for such children?

Unlike some Western countries, in India there are few hostels for people with mental disabilities and ones exclusively for autistic individuals do not exist here. However, it is now increasingly accepted that during the early years of development, it is important for an autistic child to live and grow in a home environment. As the child grows up, he can be trained to live in a group home but it is very important for the autistic people living in such homes also to integrate with society in general and not just be abandoned in a home or hostel.

Can they get married and have regular children?

The essence of marriage is companionship. It is a union between two consenting adults and it involves adjustment and carrying on day to day responsibilities of life. It also involves an ability to plan the future etc. Before deciding to marry an autistic person, the following things need to be considered:

--The level of functioning of the person.

--That the partner understands the needs of, and that he or she knows everything about, the autistic spouse (if one of them is not autistic).

-- Financial status (employment, family support etc.)

However, since marriage is an issue of social commitment and companionship, by the very nature of the condition many able people with autism and their families choose not to marry.

Are people with Autism also mentally retarded?

It is very difficult for people with autism to take an IQ test because they may have certain skills but are not able to use them or exhibit them in a test. About 50% of people with autism are also mentally retarded, just the way that people with cerebral palsy or down's syndrome can have mental retardation. Autism can occur in association with other difficulties like Cerebral Palsy, Dyslexia, Downs Syndrome, Visual Impairment, and Seizure Disorder.

If a child has autism and mental retardation or any other condition which needs more attention, autism or mental retardation (or any other condition)?

If a person with autism also has Mental Retardation (or any other condition), his

training will need to primarily address his Autism. This is because autism is a condition that affects all aspects of a persons behavior and development. Our goal is to help the person become integrated into society and so it is important to focus on the development of social, communicative and adaptive skills. However, for a child with Cerebral Palsy for instance in addition to the above occupational therapy may also have to be provided. Similarly, for a child who also has Seizure Disorder or any other medical condition, appropriate treatment will be required.