

Autistic Spectrum Disorders

A Guide for Paediatricians in India

ACTION FOR AUTISM



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Merry Barua

Tamara C. Daley

AAHAN
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by Merry Barua and Tamara C Daley, 2008

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FOREWORD

Autism is a complex brain condition that presents at around age two with a core set of symptoms that include unusual ways of relating to people, of language developments and delay, and repetitive or stereotyped behaviors. The symptoms change over the life of the child, and into adulthood, with some symptoms falling away and others emerging, but they are found in all cultures and, based on what we know about autism in history, across time as well. Although autism, first described in the United States by Leo Kanner in 1943, was initially used to designate only the most severe cases, autism today is really a spectrum that includes a range of different levels of functioning, from individuals with profound mental retardation and little or no speech or communication, to more verbal, functionally able children, many of whom are being educated in mainstream environments. Autism is as common in India as it is elsewhere in the world, and makes no distinction between rich and poor, and numerous studies have disproven the long-standing assumption that autism is a 'Western' condition. Current epidemiological studies carried out worldwide indicate that at least 1 child in every 150 newborns has an autistic spectrum disorder. This makes autism the third most common developmental disorder, affecting upwards of fifty lakhs of people in India, more common than Down's syndrome, spina bifida, or cancer in paediatric populations. The majority of children with autism in India have not received a diagnosis or any intervention.

Although autism is not curable, its symptoms can be addressed with appropriate interventions and many children with autism can be educated and integrated into community life. Effective strategies can only be employed if the true nature of a condition is known. Although the characteristics of autism are generally evident in the first few years of life, the condition can go undetected or misdiagnosed for many years (most commonly as mental retardation, hyperactivity, ADHD, extreme shyness, poor upbringing, etc). Without accurate early diagnosis children with autistic spectrum disorders can be condemned to a life of inadequate provision, their special needs not tackled and their future lives devalued.

Research proves that the earlier an accurate diagnosis is made the better it is for the child, the family and those around them. Neuroscientists know that a child's brain is

most capable of change and adaptation in the first several years of life, so interventions to improve the intellectual, social, and emotional abilities of autistic children need to be employed as early as possible. The need for early identification is made more urgent by the accumulating evidence that intensive early intervention in optimal educational settings results in improved outcomes in most young children with autism, including speech in 75% or more and significant increases in rates of developmental progress and intellectual performance. Early intervention also ensures that difficult behaviors do not become entrenched in the child. Apart from delivery of appropriate intervention strategies to the child, early diagnosis also enables provisions for family supports and reduction of family stress. Since all autistic children become autistic adults, an investment in early diagnosis and intervention is an investment in the future.

But for a child to ever reach the point of diagnosis there needs to be better awareness and understanding of autism. The first point of ongoing medical contact for most children are paediatricians, hence awareness efforts in many countries including the United States and the United Kingdom are focused on paediatricians. Likewise in 1998, Action For Autism (AFA) launched a two-year nationwide project with paediatricians entitled 'Improving Awareness Among Medical Professionals and Facilitation of Services and Rehabilitation for Newly Diagnosed,' with support from the Rajiv Gandhi Foundation. We believe that as a result of the project, the number of children in India receiving an early and appropriate diagnosis improved significantly. The number of children brought to AFA for referral or diagnosis increased dramatically, many of them referred to us by paediatricians contacted during the project.

Ten years later, while there is a far greater awareness of autism in the medical community now, Action For Autism is often approached for information on specific issues related to autism. As part of AFA's ongoing efforts to ensure that many more children with autism are identified and diagnosed, and referred to services, at an early age, AFA has undertaken a second project with a key focus on the over 15,000 paediatricians registered in India. The proposal is guided by the understanding that increasing rates of diagnosis is meaningless, if not paired with practical strategies for maintaining or increasing awareness and information that paediatricians can share with families after diagnosis. This handbook has been prepared to address the latter.

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INTRODUCTION

Awareness of autism has grown tremendously since it was first described by Dr. Leo Kanner in 1943. Despite many gains that have been made in more accurately understanding and describing the causes, course and treatment of the disorder, many myths and misconceptions about autism still prevail. In many countries of the world, most of the public—as well as many professionals—are still unaware of how it affects people, and how to best work with individuals with autism. These may include those in the medical, educational, and vocational fields.

From among all the many professionals who come into contact with children, paediatricians are in the unique position to provide an early diagnosis of autism, since they are frequently the first point of professional contact for a parent. Despite their busy schedule, paediatricians are also in the best position to provide more than just a diagnosis of autism, and paediatricians in India have increasingly expressed interest in how to best direct parents about what to do next. In addition to some information on identifying features of autism, these pages carry answers to some of the questions paediatricians are commonly asked by parents, as well as some basic information on services and therapies available within India.

We hope this information will prove useful in the ongoing effort to increase awareness of autism among the medical community in India.

SECTION I:

FREQUENTLY ASKED QUESTIONS

Basic Information

1. What is autism?

As most professionals are aware, autism is a complex developmental condition that typically manifests in the first three years of life, and often is evident much earlier. It causes impairment, or differences from accepted typical development, in three main areas: social understanding, communication, and imagination – more specifically in social imagination. Individuals with autism may show unusual responses to sensations. Any one or more of the senses may be affected. All these difficulties can be evident in their behaviour, and people with autism may therefore have non-typical ways of relating to people, objects and events in their environment.

Many researchers believe that differences in cognitive processes, including executive function, and sensory processing can cause discomfort, frustration and anxiety. These feelings may also be expressed in a variety of unexpected ways, such as withdrawal, engaging in unusual repetitive behaviours, and, in extreme situations, through aggression and/or self-injury.

Autism affects individuals across a continuum. This is what makes autism often hard to understand. One child with autism may not speak at all, while another child might speak using complete sentences and may even have a flair for languages. One child may not play with toys at all, another might play with blocks and puzzles, and yet another may appear somewhat typical in play activities; all three children can have autism. Just as the definition of autism has ‘evolved’ over the past thirty years, researchers are continually examining different subtypes and groups of children in the hope of earlier diagnosis. As noted above, the variability in presentation is extremely wide. Currently, there is no reliable and objective measure of how severe autism is in an individual child,



although some professionals may use terms such as ‘just a little autistic,’ ‘mildly autistic’ and ‘severely autistic.’

2. What is the difference between the ‘Pervasive Development Disorder’ and autism?

According to the Diagnostic and Statistical Manual Fourth Edition (DSM-IV), Pervasive Developmental Disorders (PDD) is the umbrella term that refers to a group of conditions, which includes Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified. The diagnosis Pervasive Developmental Disorder Not Otherwise Specified or PDD-NOS is used when the full criteria for one of the four disorders within the Pervasive Developmental Disorders are not met, for example, if a child has an unusual presentation due to late age of onset, or symptoms that fall below the threshold for clinical impairment. The term autism is used to refer to Autistic Disorder within the PDDs.

Increasingly the broader ‘Autistic Spectrum Disorders’ (ASDs) is being used to include Autistic Disorder, PDD-NOS, Asperger’s Disorder, as a heterogeneous group of neuro-behavioural syndromes characterised by impairments in basic social relationship, communication and social imagination, and often rigid patterns of behaviour. The term ‘spectrum’ implies a range, from a child who experiences more mild impairments in the areas of language, social understanding and behaviour to a severe impairment, which can include comorbid conditions such as mental retardation. In recent years, Semantic Pragmatic Disorder is also being viewed by some as part of the Autistic Spectrum.

3. How common is autism?

There have as yet been no epidemiological studies of autism conducted in India, or in any comparable region of the world in order to provide a definitive estimate of either prevalence or incidence. Most estimates are based on population, and there has been

little evidence of variation based on geographic region (although this is an emerging field). Thus, while there are no studies from India, the numbers are likely to be similar. Autism is one of the most common developmental disabilities and current estimates of the prevalence of autism are 1 in 250. This would suggest that there are approximately 4 million individuals with an Autistic Spectrum Disorder in India. Of course, the actual incidence is not known. Eighty per cent of those with autism are males.

4. Is autism on the rise?

The number of people receiving a diagnosis of autism is definitely on the rise in India. Does that mean that more people are autistic today? Or is it due to better diagnosis? Perhaps both.

Shifting diagnostic criteria are certainly an important factor contributing to the increase in diagnoses of autism, on both 'ends' of the spectrum. Many children who have mental retardation in addition to autism may in the past have only received a diagnosis of mental retardation. For many years in India, physicians may not have seen an advantage in providing a differential diagnosis when the treatment would be the same, and when awareness of autism in India was so low. On the other end of the spectrum, many children with good communication skills may have been diagnosed with schizophrenia, ADHD, or completely missed altogether and simply considered to be 'unusual' children. Now, more and more of these children receive autism as a primary diagnosis.

Environmental factors have been cited as a cause of the rise in autism. While environmental factors may not 'cause' autism, they could be acting as a trigger, and just as there are increasing numbers of other conditions with an environmental component, so might it be with autism.

There is no doubt that greater awareness of autism in India among medical professionals has played a role in the increase of children diagnosed as autistic. Following an awareness campaign among paediatricians conducted by Action for Autism and the Rajiv Gandhi Foundation between 1999-2001, there appeared to be a sharp increase in the

number of diagnosis that followed and a drop in the mean age for diagnosis. In addition, the increased attention to the disorder by the popular media has reached both parents and professionals, Even with this increased awareness, the number of individuals receiving a diagnosis in India is still far behind that in higher income countries. And, within India, there are fewer children being diagnosed in rural areas as compared to those in urban areas of India.

5. When does autism appear?

In general, there seem to be two patterns of development and onset for children with autism. In some children, development appears to be unusual in some respect right from birth. Often, parents observe that their children do not babble, produce words and use gestures such as pointing with the expected frequency. In other children, development appears near normal through 12-18 months. These children interact with adults in the environment, use some speech to communicate, and show an interest in their social surroundings, though they may be a little behind their age. Then, at around 18 months of age, the difference in their abilities becomes evident. In some cases, an event in their environment seems to trigger a loss in the acquired skills such as speech and interaction. From what we have observed, whether a child has early onset autism or later onset autism does not appear to have bearing on future development and learning. However, research in this area is ongoing.

6. Are all children with autism ‘aloof and withdrawn’?

For many years it was believed that individuals with autism were not interested in human contact. As stated in an earlier section, autism is a spectrum condition. That means that autism manifests as an entire range of abilities, difficulties, and functioning levels. Therefore we find some children with autism who are so aloof that it requires a great deal of effort to get a response. There are others who may not initiate contact but are quite willing to comply with overtures and demands. At the other end of the spectrum

there are individuals who greatly enjoy and initiate social interaction, including hugging their parents and other shows of affection. Many children who are extremely aloof and withdrawn, when provided with a nurturing learning environment, over time move to become socially more active and connected.

The word 'autism,' as we are aware, has come from the Greek word 'autos' meaning 'self'. When the term 'autism' was first used to describe the condition we now know as ASD, autism was thought to manifest as severe withdrawal. Now with growing understanding of the condition we know that that interpretation is inaccurate. The term 'autism' is used throughout the world to name the condition just as the term diabetes is used to describe a particular condition. However, some organisations in India have coined Indian terms for autism of which the literal meanings are 'unreachable', 'lost', 'withdrawn' etc, thereby perpetuating an antiquated and erroneous belief of the autistic condition.

7. Are people with autism also mentally retarded? How is autism different from mental retardation?

The most common co-occurring condition with autism is mental retardation (MR). When a person has MR there is a more or less even impairment in skills in all areas of development. Therefore, if a child with MR of eight years has a mental age of two, then all his skills would be roughly around two years (i.e. motor, communication, social, self-help, cognition). 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, while in some areas the skills may be below the developmental level. As noted before, there are people with autism who possess exceptional skills much beyond their age level.

It is erroneous to say that the IQ of people with autism cannot be tested at all, but an accurate assessment does require a clinician who is very familiar with autism. It can be 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. For instance a test that is language based or relies on social understanding will not accurately gauge the cognitive



abilities of a child with autism. Earlier it was estimated at around 80% of children with autism have mental retardation just the way that people with cerebral palsy or Down syndrome can have mental retardation. Greater understanding of the condition now suggests that perhaps the number is closer to 50%.

8. If a child has both autism and mental retardation (or any other condition), which needs more attention: autism or the 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 impacts all aspects of a person's development and often learning. Our goal is to help the person be included in society: so while society has to make accommodations to include the person with autism; the person with autism also requires help to focus on the development of social, communication and adaptive skills. However, in addition, for a child who also has Seizure Disorder or any other medical condition, appropriate pharmacological treatment may be required.

One exception may be that if, along with autism, a child is profoundly mentally retarded with severe developmental delays, then the intervention may in some cases more resemble that for someone with profound mental retardation rather than for autism.

9. What other conditions commonly occur with autism?

The most common comorbid condition is believed to be mental retardation. A small percentage of people with autism may have Fragile X syndrome or Tuberous sclerosis. A third of all children with a diagnosis of autism will be at risk for seizure disorder. Autism can occur in association with other difficulties like Cerebral Palsy, Learning Disabilities, and Visual Impairment. For many years, researchers thought that autism could not co-occur with Downs Syndrome, but recent data has shown otherwise.

Many youngsters with autism appear to have sensory difficulties with unusual responses to sensory stimuli, difficulties with proprioception, and motor clumsiness. In addition, many children and adults with autism may experience anxiety disorders. Anxiety may become particularly heightened as children approach adolescence. At this time, difficulty in forming friendships and negotiating the social world may lead to depression in some people with autism. Just because a person with autism has difficulty forming appropriate relationships, it does not mean that they are immune to the pain that comes from social rejection and isolation.

10. How is autism different from schizophrenia?

Autism and schizophrenia are two distinct disorders. Years before Kanner used the term autism, Eugene Bleuler used it to describe a symptom of schizophrenia among individuals who seemed disengaged with their surroundings. Until the 1970's, schizophrenia was the only disorder used by the American Psychiatric Association that included the word 'autistic,' and therefore, many individuals with autism received a diagnosis of schizophrenia. This misdiagnosis may have also occurred because of some overlap in symptoms. However, by the 1980 edition of the DSM-III, autism and schizophrenia were clearly distinguished as two distinct disorders. Decades of careful research has continued to highlight the difference between the two disorders—not least of all the fact that schizophrenia in childhood is extremely rare, while early onset of symptoms is a hallmark of autism.

11. Why are children with autism sometimes hyperactive?

Parents of children with autism often note that their child seems hyperactive and 'constantly on the move.' Many children with autism may be restless because of an impairment of their imaginative and social skills. Because they do not know how to play with their toys and with other children meaningfully, they find it very difficult to occupy themselves. Hyperactivity may be reduced as the child is taught new skills and ways to keep himself occupied. It is important to understand that a child who does not know



how to play with toys and otherwise occupy himself, as a non-autistic child would – and therefore runs ‘aimlessly’ around the house, is not necessarily being ‘hyperactive’. He is simply trying to occupy himself the best way he can.

There is some evidence that food additives can contribute to hyperactive behaviour, and children with autism may be unusually sensitive to some of these substances. Children with autism are sometimes observed, for example, to benefit from a gluten-free, casein-free diet. Some people recommend a diet that cuts down on junk food and caffeine—which present in soft drinks, coffee, tea and chocolate—as a way to bring down hyperactivity. There may also be some connection between hyperactivity and refined sugar, but the relationship is much more uncertain than often stated. Hyperactivity can also have a medical reason. However, for many children with autism, it may more likely result from an inability to keep himself or herself occupied.

12. Why do children with autism play with their fingers/rock back and forth/ spin around?

Children with autism often respond to sensations in unusual ways. They often have a sensory dysfunction and therefore an over or under stimulation in any one or more of the sensory modalities (hearing, sight, taste, touch, smell, and balance). These unusual mannerisms like flapping and rocking are natural responses or methods of coping with sensory difficulties. These behaviours may help a person with autism to relax. In addition, since they are not always able to occupy themselves in more typical ways, such as playing with toys or looking at a picture book, children with autism resort to rocking and flapping, which gives them sensory pleasure and also serves as a way of occupying themselves.

Diagnosis

13. How is autism diagnosed?

Autism is a syndrome composed of a number of behavioural characteristics. In making a diagnosis, the physician has to observe the child's behaviours, as well as interview the parents to obtain a detailed developmental history from birth through time of the interview.

In some countries, diagnosis is carried out by a team of a developmental paediatrician, psychiatrist, neurologist, among others. In India, with the large numbers of cases that physicians have to deal with, as well as the dearth of such physicians in many places, usually a single professional is involved in making the diagnosis. This could include a clinical psychologist, speech therapist, special educator or other professional who deal with children with autism on a regular basis.

Several screening instruments have been developed to quickly gather information about a child's social and communicative development. A partial list of these include the Checklist for Autism in Toddlers (CHAT), the modified Checklist for Autism in Toddlers (M-CHAT), the Screening Tool for Autism in Two-Year-Olds (STAT), and the Social Communication Questionnaire (SCQ) for children 4 years of age and older. The CHAT and M-CHAT appear in Section II. For research purposes, other diagnostic tools may sometimes be used, such as the ADOS-G and the ADI-R.

Anyone providing a diagnosis of autism has to be aware that receiving a diagnosis is an extremely sensitive time for the parent. In many cases, a parent will have already begun to suspect that something was different about their child. Still, the decision to seek professional consultation is never made lightly. Professionals have to be sensitive and careful to avoid statements that make parents feel their child's behaviour is so clearly aberrant that the professional can 'see it a mile away'. In addition diagnosis should not be provided solely on the basis of parent report.



14. What are some common characteristics of children with autism?

As noted above, diagnosis is typically based on observation of the child and through parent interview. There are no absolute markers of the disorder and no single behaviour or characteristic that is absolutely required in order to apply a diagnosis. However, there are certain behaviours and features that tend to be more common. The following are a list of some behaviours to observe in the child being assessed, and to formulate questions on, in reviewing the diagnostic criteria.

The child with autism may:

- Prefer to be alone; appear unaware of other people's existence
- Not respond to name and may on occasion appear to be deaf
- Appear to avoid gaze or show unusual eye contact
- Not reach out in anticipation of being picked up
- Not seek comforting even when hurt or ill
- Not smile in response to parents face or smile
- Have difficulty in mixing and playing with other children
- Not point to share or indicate interest, or not share in others interests
- Not point to ask for something
- Not try to attract attention to his/her own activity
- Not look at a toy across room when adult points at it
- Not look at things adult looking at
- Have difficulty taking turns in turn-taking games or activities
- Not imitate adults' actions
- Not pretend to play house, talk on phone
- Have unusual or repetitive play, lack or have limited pretend play
- Have extreme unusual fears or have poor awareness of danger or not show fear
- Show delay or lack of language development or loss of early acquired language

- Rarely or not use gestures to communicate
- Lead adult by the arm to have needs met, or use adult hand as an object
- Reverse pronouns
- Echo words or phrases
- Have difficulty in initiating and sustaining conversation
- Enjoy rotating or spinning object, or lining up objects, twirl twigs, flap paper
- Be occupied with parts of objects like knobs, switches, wheels
- Show apparent insensitivity to pain
- Like sameness in everyday routines; may show resistance to change in routines or surroundings
- Display repetitive actions and ask repetitive questions
- Not cuddle or stiffen when hugged or cuddled
- Display unusual behaviour or body movement such as spinning, hand flapping, head banging, or rocking
- Show extreme distress for no apparent reason
- Appear unaware of distress in others
- Display good rote memory for nursery rhymes, commercial jingles, irrelevant facts

15. What is the significance of early diagnosis?

A correct and early diagnosis of autism is so crucial because scientific research has demonstrated that children who receive intensive intervention in a highly structured program by the age of 18-36 months have a greatly improved prognosis. According to The Council for Exceptional Children, a national U.S. organization:

Early intervention has been shown to result in the child: (a) needing fewer special education and other habilitative services later in life; (b) being retained in grade less often; and (c) in some cases being indistinguishable from (non autistic) classmates years after intervention.

In India, there is no system of screening that ‘catches’ all young children with a developmental delay or disorder. Parents must rely on referrals from their paediatricians, psychiatrists, and psychologists, on word of mouth, and through newspaper articles or television broadcasts. By the time families of autistic children become aware that there is a national organization specifically to deal with their needs, valuable time has often been wasted. Thus, the role of the paediatrician in providing an early diagnosis of autism is critical.

Some parents may become discouraged if they have not received an early diagnosis or have delayed the start of intervention. It is therefore important that while informing parents that early intervention is important, to also inform that intervention can be effective at any age.

16. Is there always value in providing a diagnosis?

Many paediatricians in India work in areas where there are no special schools or facilities for children with any disability, let alone children with autism. Some paediatricians see families who have no resources to send their children to a special school, may have themselves received no education, or who doctors question whether they will be able to ‘understand’ a diagnosis of autism. In these cases, is there value in providing a diagnosis?

We believe that even in these circumstances, it is appropriate—and important—for a diagnosis of autism to be provided. The reasons are numerous: increased diagnosis can encourage the establishment of special schools and services (if there is demand, there will be supply); parents do not need to be literate to be instructed on appropriate forms of intervention for their child; even where no services are available, parents can attend training in autism in other locations; future epidemiological surveys may look to recorded diagnoses as a source of information; and lastly, parents, regardless of their literacy or economic level, deserve and have a right to a correct and accurate diagnosis for their child.

Cause of Autism

17. What causes autism?

At the current time, the exact causes of autism remain elusive, but researchers increasingly believe that both genetics and environment play a role. There is compelling evidence for multiple interacting genetic factors; several candidate genes have been located, with over twenty gene clusters under examination. Research has shown that among identical twins, if one child has autism, then the other will be affected about 75% of the time. Among non-identical twins, if one child has autism, then the other has it about 3% of the time.

Genetic factors do not explain all cases of autism, and there are a host of other hypothesized causes. These include prenatal risk factors such as teratogens, pesticides, and maternal antibodies; some perinatal and obstetric conditions; and a range of postnatal factors, such as gastrointestinal or immune system abnormalities, allergies, and exposure of children to drugs, vaccines, infection, certain foods, or heavy metals. As discussed in the following section, there has been intense media attention on the possible causative role of the Measles-Mumps-Rubella (MMR) vaccine, and in particular, the preservative Thimerosal as well as on mercury poisoning; however, the evidence to date does not conclusively show a causative association between any of these factors and autism.

In short, it is difficult to tell why any individual child has autism and in most cases, it will never be known. Researchers from all over the world are devoting considerable time and energy into finding the answer to this critical question. As a paediatrician, it is important to convey to parents that, regardless of the cause of their child's condition, the treatment options are generally the same. In addition, it is important to note that several outdated theories about the cause of autism have been thoroughly refuted. Autism is not a mental illness. Children with autism are not unruly kids who choose not to behave. Autism is not caused by bad parenting. Furthermore, no known psychological factors in the development of the child have been shown to cause autism.



It is important to stress the last since in India there is still a belief that autism is caused by 'bad parents' – parents who do not pay attention to their children, parents who fight among themselves, working mothers, absentee fathers, and so on. This of course is not correct. While poor parenting can affect upbringing in any child, including non-autistic 'normal' children as well as autistic children, it does not cause the condition.

18. Is there a connection between autism and the MMR Vaccine?

As noted above, there is a belief among many parents that their child's autism is caused by mercury in vaccines, particularly in the MMR shots. Many parents first begin noticing symptoms in their children around 18 months, which is also the age that the MMR vaccine is commonly administered. A small study conducted in 1998 originated much of the controversy. Although the paper itself concluded that 'we did not prove an association between measles, mumps, and rubella vaccine and the syndrome described,' this association was implied and became extremely widespread. The co-authors of this paper have refuted a connection between MMR and autism, and numerous peer-reviewed studies have also failed to find an association between autism and the MMR vaccine. In addition, many children who have not received the MMR shot have received a diagnosis of autism. And, by 2002 in the U.S., only 2% of the vaccines on the shelves had any mercury, yet autism continues to occur in approximately 1 in 166 children. While these data may be accepted in the medical community, paediatricians should be aware that this evidence may not be reassuring to parents who are trying to decide whether to vaccinate a child and who are aware of compelling anecdotal evidence about the MMR-autism link.

Of all topics related to autism, the MMR-autism controversy in particular has been fuelled by media attention and a proliferation of internet sites on the subject, leading many parents now to refuse to vaccinate their children and also creating a whole slate of interventions to undo the 'damage' caused by the vaccine.

19. Can a person become autistic because of working parents or neglect?

Similar to other myths about autism, many early researchers attributed autism to parental behaviours. However, this psychogenic theory on the origin of autism has been fully discredited for nearly thirty years. Simply put, it is not possible to make a child autistic through parenting. Autism is a neurological condition and has no psychological basis. Disagreements between parents, conflict in the extended family, working mothers, poor parenting, and other factors may certainly affect the progress of a child just as they do the progress of a non-autistic child, but they do not cause autism. There is nothing a parent or caregiver can do to cause the disorder to occur.



Course of Autism

20. Will a child with autism actually learn, and is it worth the effort involved?

Yes. A number of factors may impact on how well a child may respond to a treatment programme, including how severely a child is affected, the child's age at the time of diagnosis and initial intervention, and the quality of intervention received. With appropriate intervention and teaching all children on the spectrum can show significant progress—even children with severe delays and the presence of exceptionally unusual behaviours. There are no children for whom treatment is 'not worth the effort.' At the same time, there is currently no reliable measure to determine how severely a child may or may not be affected and no way to predict or make a generalization about how any individual child will grow and progress.

21. Will a child with autism regress?

In general, regression that is associated with autism may not be a true regression but in fact, is one pattern of onset that is sometimes seen. Autism manifests within the first three years of life. In some children the symptoms are evident from the first months of life. In others, the child shows some social interaction, says a few words, and appears to 'play' in more typical ways, though these developments are usually not age appropriate; and then around 18 months something appears to trigger a full manifestation of the symptoms of autism. This late onset autism may appear as a regression. Another time that a regression may seem to occur is during periods of stress and transition. For example, more functionally able children such as children with Asperger Syndrome, appear to do quite well until they reach middle school, when the social pressures of coping with a mainstream classroom triggers difficulties in the child's behaviour which might manifest as a regression. Some children with autism appear to regress for a period during adolescence which is a stressful phase for most children. Lastly, children or adults with autism who experience seizures may experience a regression in some areas

as a result of the damage caused by the seizure; this is related to the comorbid seizure disorder rather than to autism specifically.

22. Will a non-verbal child with autism start speaking, and when?

A large number of children with autism (about 30-50%) do not use speech in a meaningful way. It is very difficult to say whether and when any given child will speak. Except in unusual cases, there is no physical impairment that keeps children 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 meaningful language 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. In addition, current intervention techniques focusing on the teaching of communication through speech or alternative and augmentative modes of communication such as pictures, signs, alphabet boards, and other communication tools; and using the child's wants and needs; can show quite remarkable results, particularly with very young children.

23. What is a child with autism like as a grown up? Can they lead an independent life?

A child with autism grows up into an adult with autism. However, the range of outcomes is very wide. As children with ASD grow, appropriate teaching can support their social understanding and use of communication; people with autism can continue to progress throughout their adulthood. There have been claims that some children have recovered. This perhaps implies that they are almost indistinguishable from other people in society, although long-term studies indicate that the great majority of people with autism continue to experience the features associated with autism throughout their lives.

As adults some individuals live independently, others live in semi-independent residences, and many will require supported living environments. Some individuals are employed, many of them in jobs that do not require high levels of social understanding. A



few marry and have children. However, many individuals—despite being functionally very able—will have difficulty finding and keeping jobs. They may also find conforming to social norms very stressful and continue to need support in developing coping strategies. Adults with autism are at above average risk of developing mental health problems, especially depression.

It seems safe to say that, while many adults with autism require sheltered workplaces and fully supported living arrangements, there will also be individuals such as Temple Grandin, Wendy Lawson, and Stephen Shore—adults with autism who lead independent lives and serve as active spokespersons for persons with autism. In fact, a number of such adults are actively involved in the autism movement in India already.

24. Can adults with autism marry 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, and the ability to plan for the future. 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 (e.g. employment and family support)

A few autistic adults do get married. Some marry other autistic adults, and some marry non-autistic partners. Like all marriages, some are happily married and some are not. Some of these couples have children—with and without autism. However, since marriage requires negotiating social and interpersonal relationships, the very nature of the condition leads many able people with autism not to marry.

In India since marriages often are arranged, it is important to keep in mind that when arranging a marriage for an individual with autism, the partner is made aware of the

condition. An open and honest marriage will have greater possibility of success than one based on misrepresentation and untruth.

25. Is there a cure for autism?

At this point, there is no known cure for autism. While we understand that there are differences in the brain that are related to autism, we cannot 'fix' or change these differences in a way that may be called curing autism. When a parent becomes aware that there is no cure for autism, this information can be both confusing and discouraging. However, it is important to realize that the prognosis for children with autism today is very different from that even twenty years ago. Our understanding and knowledge about what management strategies are most effective with autistic children has increased tremendously over the past two decades, and a child diagnosed with autism today will receive different interventions and beginning at an earlier age than was possible many years ago. This means each child's chances for learning and development are greater today than earlier.

Although there is no cure for autism, there are many people or groups around the world who promote various treatments that claim to cure children with autism. Parents of recently diagnosed children with autism are naturally susceptible to such claims. Hard-nosed educational intervention requires hours of one-on-one painstaking work with the child, and progress occurs incrementally. In comparison, miracle cures, whether consisting of something ingested, injected, or involving a procedure that seems like a 'medical treatment' - have an obvious appeal for parents. It may be impossible for a physician to understand the allure of this promise for a parent. One approach to responding to questions about such treatments is to encourage parents to be cautious of individuals trying to exploit their vulnerability, and to continue other forms of intervention. Some parents may feel obligated to try a miracle cure but will return to educational intervention when it does not work.

Paediatricians should also be aware of a growing movement among cognitively able people with autism, who oppose the idea of finding a cure for the disorder. It may be



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valuable for professionals to be acquainted with this perspective in order to better understand the complexity of living with autism.

Treatment and Interventions

26. What are some of the treatments for autism?

There are now dozens of different interventions and treatments that are used with children with autism. This does not mean, of course, that all of them are valid. The most effective treatment for all children with autism is an appropriate educational training program that is tailored to the child's specific needs. The earlier intervention is started, the more promising the outcome. Just as each child on the autistic spectrum differs in his or her presentation of autism, intervention methodologies have to be individualised to meet the needs of individual learning styles rather than chronological or mental age, or severity of autism.

In most cases a primary intervention is selected, and other appropriate therapies are added or incorporated as required. Most interventions for young children with autism in particular are based on the principles of behaviour analysis; some programs focus more on antecedents of behaviour while others focus more on on the consequences of behaviour.

In their search for therapies and treatment options, it will help parents to have some information on the better known methodologies.

Applied Behaviour Analysis (ABA), Verbal Behaviour Analysis (VB), Lovaas. Pivotal Response Training

ABA is the process of applying interventions based upon the principles of learning theory to improve socially significant behaviours. These include social skills, communication, and adaptive living skills such as gross and fine motor skills, and academics. ABA methods are used to support persons with autism: to increase behaviours, to teach new skills, to maintain behaviours, to generalize or to transfer behaviour from one situation or response to another. VB or VBA uses behavioural principles to focus on the teaching of communication along with other socially



significant behaviours. The Lovaas Method derives its name from O. Ivar Lovaas, a psychologist who gained recognition from the 1987 publication of a study he conducted with children with autism from which he concluded that early intensive behavioural intervention offered much hope for improving outcomes of children with autism. The Lovaas Method is derived from but not to be confused with the broader field of ABA. Pivotal Response Training is a naturalistic intervention model derived from the principles of ABA to focus on 'pivotal behaviors,' such as motivation and self-management, rather than targeting individual behaviors one at a time.

TEACCH (Treatment and Education of Autistic and related Communication-handicapped Children)

The TEACCH approach makes use of several techniques in various combinations and includes a focus on the person with autism, understanding autism, adopting appropriate adaptations, and development of a program building on existing skills, emerging capabilities, and the individual person's unique needs. Structured teaching is an important priority based on TEACCH research and experience that structure fits the 'culture of autism.' Addressing behavioural antecedents by organizing the physical environment, developing schedules and work systems, making expectations clear, explicit, and visual have been effective ways of developing skills and allowing people with autism to use these skills independently.

Augmentative and Alternative Communication (AAC)

AAC refers to ways other than speech that is used to accompany or augment the spoken word to help the person with autism understand spoken information. There is a mistaken belief that the use of AACs will prevent the child with autism from ever developing speech. The contrary is actually true: the use of other modes has often been found to facilitate the development of speech. AACs can be signs, electronic communication tools, pictures, cards and objects. Picture Exchange Communication System (PECS) is one such visually based way to help communication in people with autism.

Other treatment methods that parents may ask a paediatrician about or which a paediatrician may encounter include but are not limited to:

- Auditory Integration Training (AIT)
- Chelation
- Diet modification and nutritional interventions (including Vitamin B-12, gluten and casein free diets, and Super Nu Thera)
- Doman Delacato
- Facilitated Communication
- Greenspan/Floortime
- Higashi Daily Life Therapy
- Hyperbaric Oxygen Therapy (HBOT)
- Option Therapy/Son-Rise
- Rapid Prompting/HALO
- Relationship Development Intervention
- SCERTS® Model
- Sensory Integration Therapy
- Secretin
- Speech therapy
- Social Stories
- The Miller Method

There are other therapies available which while they may not address core areas of communication and social understanding, appear to help by creating an overall sense of well being, such as yoga, animal therapy, music therapy, art therapy, and so on. Lastly, many Indian families try Ayurvedic and Homeopathic treatments, and a number of centres and doctors in India have begun to advertise their services specifically as it relates to autism.

27. What are the goals for treatment?

In the broadest sense, every individual with or without disability has an equal right to live as participating members of their community. Treatment ultimately aims to reach this goal and allow an individual to achieve his or her full potential. Since each individual on the spectrum has different presenting features, strengths and difficulties, the specific goal of treatment will vary from child to child, as well as for the same child at different stages of his or her development.

For every person with autism, a treatment programme should aim to enhance the person's independence and give more opportunity for personal choice and freedom in the community. To achieve this, it is vital to develop functional daily living skills at the earliest possible age. This could range from feeding and dressing oneself, to learning to cross a street safely, to make a simple purchase, to ask for assistance when needed, or to simply respond with an "I don't know," when asked a question to which the autistic individual does not have the answer. These seemingly simple but critical skills may be difficult even for those with average intelligence levels.

Treatment for autism generally takes into consideration the core deficits of autism in the areas of social behaviour and communication. Woven into the individual's treatment program are ways of helping them better understand the nuances of social interactions and improving their own interpersonal skills. And, whether verbal or nonverbal, improving communication skills are a central focus of treatment. Most educational programs provide educational support in the area of academics, but the nature of this support should be based on the specific child. Clearly, teaching functional math skills may be more realistic for one child while another may be more than capable of complex higher skills.

Treatment should aim at helping an individual lead as 'inclusive' a life as possible. To achieve this, the core areas of impairment need to be targeted through specialized programmes developed over years of research, training and adaptation to the Indian context. Having said this, parents have to be advised to stay away from any treatments that suggest that they are somehow responsible for their child's autism.

28. Can children with autism go to a ‘normal’ school?

In short: yes, it is possible. Many children with autism in India attend regular schools. From accounts from such children we know that children with autism often face difficulties in regular educational settings because of their very distinct learning needs. These needs may arise from their uneven profiles of skills and deficits, difficulties in processing of information, difficulties in generalization, and their unusual behaviours. All of these have important implications for educational practices.

Teaching methods have to take into account these different learning styles. Where this is understood, children with autism without cognitive impairment have been successfully included into mainstream classrooms. Where this is not understood children may encounter difficulties and have to drop out, often after Grade 4 or Grade 5. Children who have coped fairly well until that point may find that the increased workload and expectations create an unmanageable level of stress.

Regular schools vary in their willingness to accept children with autism and work with them to meet their needs. Some parents choose not to convey this information to the school, for fear of being asked to leave. Often, it seems that a school is more willing to take a child with global developmental delay who is slower in learning but otherwise ‘fits’ into the class, but has reservations about a child with autism who displays ‘odd’ mannerisms and behaviours despite high intellectual ability.

When an appropriate arrangement can be negotiated, and with the help of a supportive teacher or school staff, the child with autism can have a very positive experience in a mainstream school and gain much both academically and socially. More importantly, the non-autistic children gain as much if not more in terms of developing more sensitive and all rounded personalities with a greater awareness of human diversity.

29. What kind of school is best for a child with autism to attend?

In an ideal world, all children with autism as well as other special needs would attend the same schools as more typically developing children, learning and playing side by



side. However, the reality is that most schools in India are not ready to accept children who are 'different' and this includes children with autism. Therefore, though the range of educational placements is extremely varied, the availability at this point in time is limited. This includes schools specifically for children with autism, schools that are attended by children with autism, mental retardation, cerebral palsy, as well as other disorders, mainstream or 'normal' schools that have separate learning centres, or schools that practice total inclusion. Which school the child attends will depend on both, the individual child, as well as the services that the child can access.

The decision of where a child with autism should educate has to be based on the skills and needs of the individual student, as well as the needs of the parent. As noted above, some children can work effectively and benefit from regular education programs, while others will need special classrooms for part or all of the day where the physical environment, curriculum, and personnel can be organized and manipulated to reflect individual needs. For a child to be mainstreamed in a regular school, the deciding factor must be the environment of the school. The child with autism will benefit from an environment that is inclusive and that which makes accommodations for his particular needs.

In every case, a parent is advised to consider all the factors involved before making a decision. It may be ill-advised to suggest that a child seek attendance at an autism-specific centre when it would mean a financial hardship or unmanageable commute for the parent and family. Parents should be able to freely visit schools and observe all the activities that occur in order to inform their decision about which school is best for their child's specific needs.

30. Are there any schools for children with autism in India?

Currently autism specific supports and services in India are extremely limited. The good news is that they are growing at a steady though slow pace. The numbers of professionals who are trained to provide children with the training and education that they need continue to be grossly insufficient. Though well-trained professionals: special educators,

speech language pathologists, occupational and sensory therapists, in collaboration with parents are considered the best persons to provide training; because of the dearth of professionals and services parents are increasingly taking the onus of training themselves and teaching their children, often with a significant degree of success.

Despite this difficult situation, a number of schools have started up in the last few years. These include schools that specialize in working with children with autism and schools that have children with a range of disabilities. Many of these provide good programming and intervention. In addition, a small but increasing number of mainstream schools across the country are including children with autism in their classrooms.

For a list of existing facilities see Section V.

31. Are there any hostels for children with autism?

A generation ago, residential institutions were the primary mode of care for children and adults in some Western countries. In India, too, there was a belief that children with different needs should be sent off to residential institutions to ‘spare’ the family the ‘agony’ of bringing up a disabled child. However, with the change in perceptions and growing acceptance of human differences, and the recognition of the importance of parental involvement, it is now increasingly accepted that it is important for the child with autism 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 persons with autism living in such homes also to integrate with society in general and not just be abandoned in a home or hostel. In India there are few hostels for people with mental disabilities and ones addressing specific needs of individuals with autism do not exist. Therefore, this is somewhat of a non-issue for families.



32. Can speech therapy help children with autism?

Speech therapy can help some children through the use of oral-motor activities. It is absolutely essential for the speech therapist to understand Autism and also the individual child. Otherwise, the conventional methods of speech therapy currently prevalent in India today help children with autism very little, because as stated above, the inability to speak is not a physical problem. Many children with autism have speech but do not use the speech for communication. However, every child with autism can benefit from interventions that emphasize communication. A speech therapist who is sensitive to the needs of the autistic child and who has good understanding of the use of behaviour modification techniques and their use with children with autism can contribute effectively. In addition, a good speech language pathologist can help the functioningly able child with difficulties of sentence structure, grammar, and the social use of language.

33. Will special diets or medication help children with autism?

Diets and medication may help in treating the symptoms of autism in some individuals. Some children with autism are believed to have intolerance to gluten and/or casein. Parents sometimes put their child on a diet free of gluten and/or casein in a systematic manner in order to firstly, assess whether the diet is indeed helping their child, and secondly, based on the result discontinue or continue the diet. Reports of changes range from no impact at all to better sleep patterns, less 'crankiness' and improved dietary habits. Taking children off processed foods, aerated drinks, foods with high sugar content, as already stated, appears to help children be more calm and manageable, according to some parent reports.

Some studies indicate that children with autism respond well to risperidone. The U.S. Food and Drug Administration approved Risperdal to treat irritability; the drug is also sometimes used to treat aggression, self-injury and temper tantrums. Risperdal is considered an atypical antipsychotic drug. A study by Stigler et al (2004) found another atypical antipsychotic drug called Abilify or Aripiprazole to be effective for reducing aggression, agitation and self-injury in a small group of children with autism.

Antipsychotic drugs are never the first line of intervention for a person with autism, and in general, their use in India has exceeded what is observed for children with autism elsewhere in the world. A medication trial with a child with autism has to be undertaken with caution, and parents have to be aware that diets and medications provide symptomatic relief—they do not address core areas of impairment seen in autism. In addition, parents have to be aware that drugs have a range of side effects, and that the positive impact on behaviour outweigh side effects.



Working with Parents

34. How do parents typically react to a diagnosis of autism?

While the diagnosis of autism is not completely unexpected, a diagnosis of autism can be very upsetting due to the nature of the disorder, coupled with the fact that there are only a handful of professionals who understand the disorder to its fullest extent. Parents' immediate reactions are sometimes similar to those seen following bereavement: an initial phase of shock and disbelief. Understandably, parents find it difficult to assimilate new information during this stage and may need to discuss difficulties again at a later date to grasp them fully. The early shock and numbness may be followed by a period of denial – the mind's way of keeping anxiety and stress at bay. Unfortunately, it also leads to parents minimizing the seriousness of the condition and fantasizing that somehow their child will be magically cured.

The next phase of the reaction is often full of feelings of anger at the seeming injustice of the tragedy. This may turn into guilt (we must have done something wrong), to sadness and despair (how will we cope?). Finally, however, parents come to accept the situation, form a realistic picture of their child's strengths and difficulties and begin focussing on practical ways of coping. They learn for instance that the child's unusual behaviour is because the child does not understand the world the same way that others do but that they can learn and progress with help.

Other factors also affect the way parents react to the diagnosis, for e.g., the apparent severity of the condition, the degree of any accompanying mental handicap, psychological resilience of each parent and the amount of support available from family, friends and professionals. Depending on individual circumstances, parents may show extreme reactions or unresolved emotions. This may, at its worst, manifest in feelings of pessimism, worthlessness, as well as physiological disturbances. If this happens, counseling and parent support groups can be useful.

35. When a couple has a child with autism, will the next child also have autism? Can they have a non-autistic child?

Because autism has a strong genetic component, the chance of a family having a second child with autism is elevated as compared to the general population. One estimate suggests that parents who have a child with an ASD have a 2% – 8% chance of having a second child who is also affected; another often-cited estimate is that families with one autistic child have a one in 20 chance of having a second child with the disorder. The specific chance for any given family cannot be reliably determined, since there are also cases of autism that are likely caused by non-genetic factors. A couple with an autistic child can also have a typically-developing second child who does not have autism.

36. Who can the parent contact after diagnosis?

Newly diagnosed parents would be advised to contact their nearest autism organisation, as well as schools and services in their area. Because of the dearth of services, many schools may have long waiting lists. However, some of them also run outreach and after-school programs for children who cannot be accommodated in the school. Some also run good trainings that parents could attend, particularly trainings in behaviour modification.

The numbers of schools and organisations are steadily increasing. By the time this goes into print, a few more organisations may have come into existence. Parents can refer to the Action for Autism Website at http://www.autism-india.org/afa_otherlinks.html for a current list of organizations and resources.

Finally, parents can be encouraged to contact any local parent support group, or if they have Internet access, they can meet parents both in person and around the world through a number of listserves, some of which are specific to autism and Indian families. Meeting other families with children with autism helps parents deal with their sense of loss, of guilt, and become proactive in learning how to help their child. A parent who is well-educated about autism is the best support that a child can have.



37. What are some of the books and materials that would help newly-diagnosed parents?

There are literally thousands of books that have been written on different aspects of autism. These include books written by people with autism. Some of these are excellent first books for parents to read.

- Children with Autism: A Parent's Guide edited by Michael Powers is one of the best first books that a parent could read.
- Emergence: Labelled Autistic by Temple Grandin who has autism is book that helps parents have a deeper understanding of their child's condition.
- Let Me Hear Your Voice by Catherine Maurice, and Son Rise by Barry Neil Kauffman are both parent accounts that gives parents a positive outlook on their child's diagnosis.
- The Mariposa School Employee Training Manual which can be downloaded free off the internet (www.MariposaSchool.org), is a great how-to book.
- Asperger's: What Does It Mean to Me? by Catherine Faherty & Gary B. Mesibov is a resource to help children with autism spectrum disorders understand their strengths, personalities, unique challenges, and increase their self-awareness.
- The Curious Incident of the Dog in the Night-time by Mark Haddon is a work of fiction featuring an individual with autism and is an excellent book to gain an insight into the world of Asperger Syndrome.

Of course, there are also thousands of pages of information about autism available on the Web. Most parents with access to a computer will immediately and readily find these sources. As with all information on the Web, some of it is reliable and useful and some of it requires greater scrutiny and filtering. For parents in India, there is an extensive amount of information specific to services and the status of autism in India available at the Action for Autism Website www.autism-india.org. Action for Autism also has material on autism in different Indian languages and has a regular section of the journal Autism Network written in Hindi available for free at the AFA Website.

For the busy paediatrician, the Indian Academy of Paediatrics has published a handbook entitled Understanding of Autism, edited by Dr. Shabina Ahmed.

SECTION II:

DIAGNOSTIC CRITERIA AND TOOLS

Screening Tools for ASD

The diagnostic criteria on the following pages will be familiar to many paediatricians in India. In addition, we have reprinted the CHAT and M-CHAT, two screening instruments that are available at no cost.

Other screening tools include:

Autism Spectrum Screening Questionnaire (ASSQ)

by Stephen Ehlers, Ph.D., Christopher Gillberg, Ph.D., Lorna Wing, Ph.D. (Published in 1999 in the Journal of Autism and Developmental Disorders, 29,129-141)
(for children 7-16)

Social Communication Questionnaire (SCQ)

by Catherine Lord, Ph.D., Sir Michael Rutter, Ph.D., et al.
(for children 4 and older)

Australian Scale for Asperger Syndrome (ASAS)

by Michelle Garnett, M. Clinical Psychology, Anthony Attwood, Ph.D.
(for children 5 and older)

Available at: <http://www.udel.edu/bkirby/asperger/aspergerscaleAttwood.html>

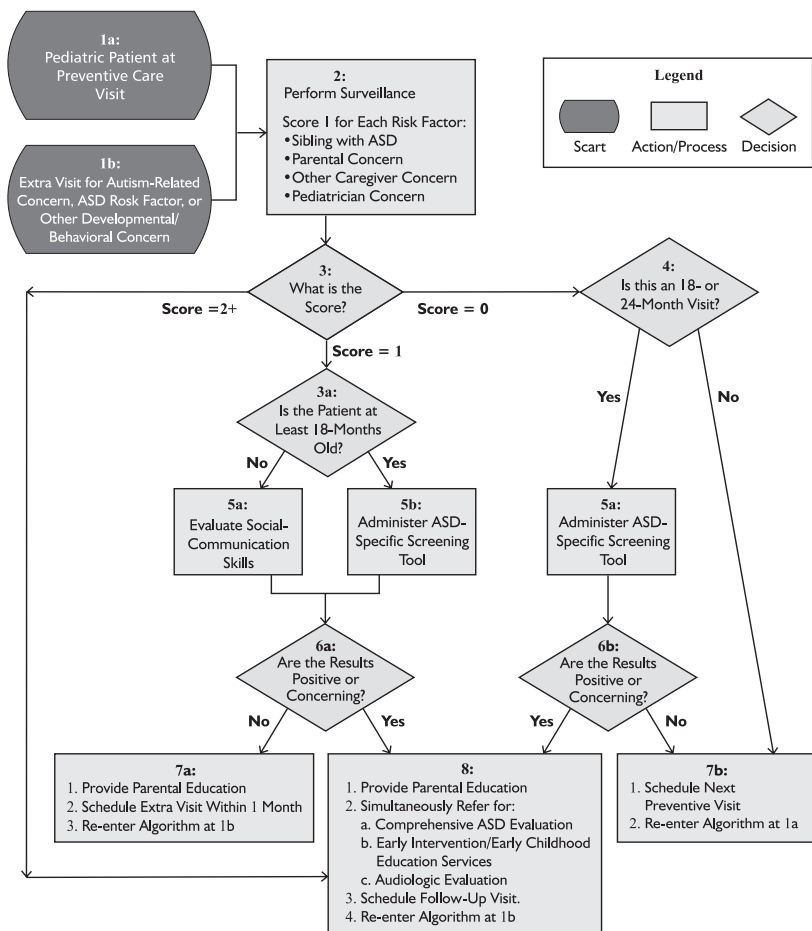
Screening Algorithm from American Academy of Pediatrics

The algorithm on the following page appeared in the journal Pediatrics as a model for surveillance and screening of Autism Spectrum Disorders. In India, the process may be somewhat different. For example, children do not regularly see a paediatrician at 18 and 24 months, so Step 4 may occur at different times. And, currently, children in India are



not regularly referred for audiologic evaluations. However, this model can be adapted as paediatricians in India see fitting. The important features of this algorithm are that children are screened early, and that specific ASD tools are used to further evaluate childrens' behavior and functioning.

SURVEILLANCE AND SCREENING ALGORITHM: AUTISM SPECTRUM DISORDERS (ASDs)



Reprinted from Pediatrics, November 2007. Identification and Evaluation of Children With Autism Spectrum Disorders. www.pediatrics.org Copyright©2007 by the American Academy of Pediatrics.

Diagnostic Criteria from DSM-IV American Psychiatric Association

- 299.00 Autistic Disorder

A. A total of at least six (or more) items from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3).

(1) Qualitative impairment in social interaction, as manifested by at least two of the following:

- (a) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
- (b) failure to develop peer relationships appropriate to developmental level
- (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest)
- (d) lack of social or emotional reciprocity

(2) Qualitative abnormalities in communication as manifested by at least one of the following:

- (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
- (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- (c) stereotyped and repetitive use of language or idiosyncratic language
- (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

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(3) Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

- (a) encompassing preoccupation with one or more stereotyped patterns of interest that is abnormal either in intensity or focus
- (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
- (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
- (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

- (1) Social interaction
- (2) Language as used in social communication, or
- (3) Symbolic or imaginative play

The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic Criteria from International Classification of Diseases (ICD-10)

F84.0 Childhood autism

A pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of 3 years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The disorder occurs in boys three to four times more often than in girls.

Diagnostic guidelines

Usually there is no prior period of unequivocally normal development but, if there is, abnormalities become apparent before the age of 3 years. There are always qualitative impairments in reciprocal social interaction. These take the form of an inadequate appreciation of socio-emotional cues, as shown by a lack of responses to other people's emotions and/or a lack of modulation of behaviour according to social context; poor use of social signals and a weak integration of social, emotional, and communicative behaviours; and, especially, a lack of socio-emotional reciprocity. Similarly, qualitative impairments in communications are universal. These take the form of a lack of social usage of whatever language skills are present; impairment in make-believe and social imitative play; poor synchrony and lack of reciprocity in conversational interchange; poor flexibility in language expression and a relative lack of creativity and fantasy in thought processes; lack of emotional response to other people's verbal and nonverbal overtures; impaired use of variations in cadence or emphasis to reflect communicative modulation; and a similar lack of accompanying gesture to provide emphasis or aid meaning in spoken communication.

The condition is also characterized by restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. These take the form of a tendency to impose rigidity and routine on a wide range of aspects of day-to-day functioning; this usually applies to novel activities as well as to familiar habits and play patterns. In early childhood



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particularly, there may be specific attachment to unusual, typically non-soft objects. The children may insist on the performance of particular routines in rituals of a nonfunctional character; there may be stereotyped preoccupations with interests such as dates, routes or timetables; often there are motor stereotypies; a specific interest in nonfunctional elements of objects (such as their smell or feel) is common; and there may be a resistance to changes in routine or in details of the personal environment (such as the movement of ornaments or furniture in the family home).

In addition to these specific diagnostic features, it is frequent for children with autism to show a range of other nonspecific problems such as fear/phobias, sleeping and eating disturbances, temper tantrums, and aggression. Self-injury (e.g. by wrist-biting) is fairly common, especially when there is associated severe mental retardation. Most individuals with autism lack spontaneity, initiative, and creativity in the organization of their leisure time and have difficulty applying conceptualizations in decision-making in work (even when the tasks themselves are well within their capacity). The specific manifestation of deficits characteristic of autism change as the children grow older, but the deficits continue into and through adult life with a broadly similar pattern of problems in socialization, communication, and interest patterns. Developmental abnormalities must have been present in the first 3 years for the diagnosis to be made, but the syndrome can be diagnosed in all age groups.

All levels of IQ can occur in association with autism, but there is significant mental retardation in some three-quarters of cases.

Includes:

- autistic disorder
- infantile autism
- infantile psychosis
- Kanner's syndrome

Differential diagnosis

Apart from the other varieties of pervasive developmental disorder it is important to consider: specific developmental disorder of receptive language (F80.2) with secondary socio-emotional problems; reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70 - F79) with some associated emotional/behavioural disorder; schizophrenia (F20.-) of unusually early onset; and Rett's syndrome (F84.2).

Excludes:

- autistic psychopathy (F84.5)



Checklist for Autism in Toddlers (CHAT)

The Checklist for Autism in Toddlers is a screening tool to be used by GP's during the 18 month developmental checkup.

Section A - Ask Parent:

Yes or No?

- 1) Does your child enjoy being swung, bounced on your knee, etc?
- 2) Does your child take an interest in other children?
- 3) Does your child like climbing on things, such as up stairs?
- 4) Does your child enjoy playing peek-a-boo/hide-and-seek?
- *5) Does your child ever pretend, for example, to make a cup of tea using a toy cup and teapot, or pretend other things?
- 6) Does your child ever use his/her index finger to point, to ask for something?
- *7) Does your child ever use his/her index finger to point, to indicate interest in something?
- 8) Can your child play properly with small toys (e.g. cars or bricks) without just mouthing, fiddling, or dropping them?
- 9) Does your child ever bring objects over to you, to show you something?

Section B - GP's observation

Yes or No?

- i) During the appointment, has the child made eye contact with you?
- *ii) Get child's attention, then point across the room at an interesting object and say "Oh look! There's a (name a toy)!" Watch child's face. Does the child look across to see what you are pointing at?

NOTE - to record yes on this item, ensure the child has not simply looked at your hand, but has actually looked at the object you are pointing at.

*iii) Get the child's attention, then give child a miniature toy cup and teapot and say "Can you make a cup of tea?" Does the child pretend to pour out the tea, drink it etc?

NOTE - if you can elicit an example of pretending in some other game, score a yes on this item

*iv) Say to the child "Where's the light?" or "Show me the light". Does the child point with his/her index finger at the light?

NOTE - Repeat this with "Where's the teddy?" or some other unreachable object, if child does not understand the word 'light'. To record yes on this item, the child must have looked up at your face around the time of pointing.

v) Can the child build a tower of bricks? (If so, how many?) (Number of bricks...)

* Indicates critical question most indicative of autistic characteristics



Modified Checklist for Autism in Toddlers (M-CHAT)

from: <http://www2.gsu.edu/~wwwpsy/faculty/M-CHAT.pdf>

The Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999) is available for free download for clinical, research, and educational purposes. There are two authorized websites: the MCHAT and supplemental materials can be downloaded from www.firstsigns.org or from Dr. Robins' website, at <http://www2.gsu.edu/~wwwpsy/faculty/robins.htm>.

Instructions for Use

The M-CHAT is validated for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). The M-CHAT can be administered and scored as part of a well-child check-up, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT was to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk for ASD will be diagnosed with ASD. To address this, we have developed a structured follow-up interview for use in conjunction with the M-CHAT. Users should be aware that even with the follow-up questions, a significant number of the children who fail the M-CHAT will not be diagnosed with an ASD; however, these children are at risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who fails the screening.

The M-CHAT can be scored in less than two minutes. Scoring instructions can be downloaded from <http://www2.gsu.edu/~wwwpsy/faculty/robins.htm> or www.firstsigns.org. The authors have developed a scoring template, which is available on these Websites; when printed on an overhead transparency and laid over the completed M-CHAT, it facilitates scoring. Please note that minor differences in printers may cause your scoring template not to line up exactly with the printed M-CHAT. Children who fail more than 3 items total or 2 critical items (particularly if these scores remain elevated after the follow-up interview) should be referred for diagnostic evaluation by a specialist

trained to evaluate ASD in very young children. In addition, children for whom there are physician, parent, or other professional's concerns about ASD should be referred for evaluation, given that it is unlikely for any screening instrument to have 100% sensitivity.

M-CHAT

Please fill out the following about how your child usually is. Please try to answer every question. If the behaviour is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1.	Does your child enjoy being swung, bounced on your knee, etc.?	Yes	No
2.	Does your child take an interest in other children?	Yes	No
3.	Does your child like climbing on things, such as up stairs?	Yes	No
4.	Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes	No
5.	Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?	Yes	No
6.	Does your child ever use his/her index finger to point, to ask for something?	Yes	No
7.	Does your child ever use his/her index finger to point, to indicate interest in something?	Yes	No
8.	Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them?	Yes	No
9.	Does your child ever bring objects over to you (parent) to show you something?	Yes	No
10.	Does your child look you in the eye for more than a second or two?	Yes	No
11.	Does your child ever seem oversensitive to noise? (e.g., plugging ears)	Yes	No



Autistic Spectrum Disorders

12.	Does your child smile in response to your face or your smile?	Yes	No
13.	Does your child imitate you? (e.g., you make a face-will your child imitate it?)	Yes	No
14.	Does your child respond to his/her name when you call?	Yes	No
15.	If you point at a toy across the room, does your child look at it?	Yes	No
16.	Does your child walk?	Yes	No
17.	Does your child look at things you are looking at?	Yes	No
18.	Does your child make unusual finger movements near his/ her face?	Yes	No
19.	Does your child try to attract your attention to his/her own activity?	Yes	No
20.	Have you ever wondered if your child is deaf?	Yes	No
21.	Does your child understand what people say?	Yes	No
22.	Does your child sometimes stare at nothing or wander with no purpose?	Yes	No
23.	Does your child look at your face to check your reaction when faced with something unfamiliar?	Yes	No

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SECTION III: **RESOURCES IN INDIA**

Please note that these lists are not comprehensive. Each year, additional schools that serve the needs of children with autism open, and others may close. For the most updated list, please see 'Other Links' section of the Action For Autism. Website at www.autism-india.org.

Autism Organizations in India (In alphabetical order)

Action For Autism (AFA)

The National Centre for Autism

Pocket 7 & 8

Jasola Vihar

New Delhi-110025

Tel: 011- 65347422, 40540991/92

Email: actionforautism@gmail.com

Web: <http://www.autism-india.org>

Assam Autism Foundation

5 Dinesh Ojha Path, Rajgarh

Guwahati 781005

Mob: 09864027292/14608

Email: autismassam@sify.com

Web: <http://www.aaf.org.in/>

Autism Society of Hyderabad

1-2-593/26A, Near Bala Saibaba Temple

Gagan Mahal Hyderabad- 500029

Mob: 09848513192

Email: autismsociety.hyderabad@gmail.com



Autistic Spectrum Disorders

Autism Society of India

60 Vittal Mallya Road
Bangalore- 560001
Tel: 080-23225279
Email: autismsociety@gmail.com
Website: www.autismsocietyofindia.org

Autism Society West Bengal

22 Anjuman Ara Begum Row
Kolkata-700033
Tel: 033- 64571576, 24730706
Email: autismsocietywb@gmail.com

Creating Connections

10/4 Block B
6 Sunny Park
Kolkata-700019
Mob: 09830941233, 09810225923
Email: shaneelm@gmail.com

Forum For Autism

2nd floor, Block A, Jeshtaram Baug
Dr.Ambedkar Rd, Dadar
Mumbai- 400014
Email: forumforautism@hotmail.com
Web: <http://www.geocities.com/Autismawareness>

Institute for Remedial Intervention Services

8-2-616/B/2/D, Road No: 11
Banjara Hills
Hyderabad- 500034
Web: <http://www.autismindia.com>

Parents Network for Autism

C-213, Patel Park
Nirala Nagar
Lucknow- 226020
Tel: 0522-2786508

Parents Association for Autistic Children (PAAC)

Plot No. 779, Defence Colony
Sainikpuri
Secunderabad-500094
Tel: 040- 27110749
Email: paac2004autism@yahoo.com

Sopan

A-4 Silver Arch, Ramnagar
Borivali (W), Mumbai- 400092
Tel: 022-28064443, 28864183
Email:sopantrust@rediffmail.com
Web: <http://www.sopan.org>

Ummeed Child Development Center

Ground Floor, Mantri Pride
1-B, 1/62, N.M. Joshi Marg
Subhash Nagar
Near Chinchpokli Station
Lower Parel, Mumbai- 400011
Tel: 022- 65528310/ 64054, 23002006/1144
Email: ummeed@vsnl.net
Web: <http://www.ummeed.org>



Schools and Other Services for Children with Autism In India (In alphabetical order)

Academy for Severe Handicaps and Autism (ASHA)

S-123 Kirloskar Colony
3rd Stage 4th Block
Basveswarnagar
Bangalore- 560 079
Tel: 080-23225279
Fax: 080- 22258103
Email: info@ashaforautism.com
Web: <http://www.ashaforautism.com/>

Adhaar Workskills Training for Adolescents and Adults

The National Centre for Autism
Pkt 7 & 8 Jasola Vihar
New Delhi- 110025
Tel: 011- 65347422, 40540991/2
Email: actionforautism@gmail.com
Web: <http://www.autism-india.org>

Asha Ka Jharna

Harlalka Kothi
Nawalgarh- 333042
Tel: 01594-222930/223094
Email: sudeepgo@rediffmail.com

Ashiana

Nityanand Marg Municipal School
Sahar Road, Andheri East
Mumbai
Tel: 022-26845062, 26125742
Email: ashiana_institute@hotmail.com

Autism Centre

c/o Prasanna Hospital
Deccan Gymkhana
Pune- 411004
Tel: 020-25652246
Email: info@prasannaautism.org
Web: <http://www.prasannaautism.org>

Centre for Autism Therapy, Counseling and Help (CATCH)

26, Madhusudan Nagar
Unit 4 Bhubanswar- 751001
Mob: 09937004040
Email: jenareeta@hotmail.com
Web: <http://www.catchindia.org>

Child Development Center at the Hinduja Hospital

Rm no-2310, 2nd floor, OPD bldg
P.D. Hinduja Hospital
Mahim
Mumbai- 400016
Tel: 022- 24451515 ext- 8258/8259, 2447258/59
Fax: 022- 24445907
Email: vrajeshudani@yahoo.co.in

Communication DEALL

47 Hutchins Road II Cross
Sarvajna Nagara (Cooke's Town)
Bangalore- 560084
Tel: 080- 25800826
Email: info@communicationdeall.org
Web: <http://www.communicationdeall.org>



Dakshinya Special Education Centre & School for Autism

A 32/250, Old Siddharth Nagar
Road no. 10, Behind Aadarsha Vidyalaya
Goregaon (W)
Mumbai- 400062
Mob: 09819023790

Darpan

3759/2, Kundan Nagar
Near Gurudwara Model Town Extn.
Model Town
Ludhiana- 141002
Mob: 09417160463

Development Centre for Children with Autism

1143 Sri Siddartha Campus
Srinagar Colony
Hyderabad- 500073
Tel: 040- 23732285
Email: eadara_raj@yahoo.co.in

Disha Charitable Trust

319-320, Race Course Towers Gotri Road
Vadodara-390007
Tel: 0265-2325250
Fax: 0265-2300059
Email: dishatrust@iqara.net
Web: <http://www.disha.org/>

Dikshan

22 Anjuman Ara Begum Row
Kolkata- 700033
Tel: 033- 24730706, 24170860
Email: indrani_basu55@yahoo.co.in

DEC

C/o Spastics Society of Karnataka
31, 5th Cross, Off 5th Main
Indira Nagar
1st Stage
Bangalore- 560038

Diuli Daycare Centre cum Preschool

841/1, Alto Porvorim
Goa- 403521
Tel: 0832- 2414916

Inspiration

AG1 123D
Vikaspuri
New Delhi-110018
Tel: 011-25611861, 25412463

Jyot Special School

Kutarkar Residency
Near multipurpose school
Borda, Margao
Goa- 403601
Tel: 0832- 2765097



Autistic Spectrum Disorders

Khushi

A/1, Raj Mahal Apartments
Service Road, Jogeshwari (East)
Next to BMC garden
Mumbai- 400060
Mob: 09819561468, 09820592543
Email: reena.singh@khushi.net.in
Web: <http://www.khushi.net.in>

Muskan

Special Education Centre for Autism
M.S. 39, Sec-D (Near Puraniya Chauraha)
Aliganj, Lucknow
Tel: 0522-2334811
Mob: 09794904682

Open Door

The National Centre for Autism
Pkt 7 & 8, Jasola Vihar
New Delhi- 110025
Tel: 011- 65347422, 40540991/2
Email: actionforautism@gmail.com
Web: http://www.autism-india.org/afa_opendoor.htm

Pathways

Sunita S. Lele
14, Pooja, Pandurang Colony
Pune- 411038
Maharashtra

Pradip Centre for Autism

Dr. Mallika Banerjee
Flat No: 4, Lakeview Cooperative Housing Society
P-203/B, Block B
Kolkata- 700089
Tel: 033-25341832/25748503 (office), 25340891 (d)
Email: mallib@hotmail.com

Priyanj Special School

239/1905 Motilal Nagar no 1
Achyut Behre Marg
Near Ganesh Mandir, Road no 4
Goregaon (west)
Mumbai- 400104
Tel: 022-28753880
Mob: 09821098325
Email: priyanj_school@yahoo.co.in

Rajkumari Amrit Kaur Child Study Centre

Department of Child Development
Lady Irwin College
Sikandra Road
New Delhi- 110001
Tel: 011- 23719859, 23318850
Email: rakcsc_lic@yahoo.com
Web: www.ladyirwin.edu.in

Rakshna

No 4, Rajaji Street
Gandhi Nagar
Madhurai- 625020



Autistic Spectrum Disorders

SAI

173, Ramkrishna, 2nd floor
10th Road, Khar West
Mumbai- 400052
Tel: 022-26007267
Email: kamini108@rediffmail.com

SAI-Apoorva Center for Autism

c/o Lions Club of Sarakki
21st mn, 1st Cross, JP Nagar Phase 2
Bangalore- 560078
Tel: 080-65710445
Mob: 09243195154
Email: apoorva.autism@gmail.com
Web: <http://www.saiautismcenter.org>

SAIRAM Autism

c/o Jai Vakeel School
Sewri Hills, Sewri Road
Mumbai- 400033
Tel: 022-24701129, 24702285

Samarpan

M.G. Road Municipal School
Third Floor, M.G. Road
Near Kesarkar Garden
Vile Parle (E)
Mumbai- 400057
Tel: 022- 26336537, 56043998
Email:samarpan_asd@rediffmail.com

Sambhav

School for Autism
28, Kasturba Nagar
Rani Sati, Nirman Nagar
Ajmer Road, Jaipur
Mob: 09309374871
Email: aartitiwari_7feb@yahoo.com

Sankalp Learning Centre

Q-9, New No. 41
6th. Avenue
Chennai- 600040
Tel: 044- 42113947
Email: sulata.sankalp@airtelbroadband.in

Sawera

Dr B.R. Ambedkar Centre
Guru Ravidas Mandir Complex
Opp. New Railway Station
Sector 2, Naya Nangal
Ropar- 140124
Tel: 01887-221574
Mob: 09417043267
Email: sawera_chd@hotmail.com

School of Hope

CPWD Complex
Near Chinmay School
Vasant Vihar
New Delhi- 110057
Tel: 011- 26143853, 26151572
Email: tamana@mantramail.com



Smt. Radhabai Jamnadas Thakkar Autistic Centre

Shree Manav Seva Sangh

255-257, Sion Road, Sion (West)

Mumbai- 400022

Tel: 022- 24092266, 24015561, 24077350/27

Email: smss@bom8.vsnl.com

Web: www.shreemanavseva.org

St. Mary's School, Aasmaan

Sector-19, Dwarka

New Delhi- 110075

Tel: 011- 28042487

Email: stmarysschooldwarka@rediff.com

Sunshine Centre for Autism

280, 6th Cross

Domlur Layout

Bangalore-560071

Tel: 080- 65360892

Email: sunshineautism@vsnl.net

Swabhimaan Trust

Plot No: 218 & 301, Palkalai Nagar,

Palavakkam, Chennai-600041

Tel: 044- 24511670

Email: ism_chhc@hotmail.com

Web: www.autismchennai.in

The Ashish Centre

F-3, First Floor
(Opp. Ramila Maidan)
Vikaspuri
New Delhi- 110048
Email: mail@ashishindia.org
Web: <http://www.ashishindia.org/>

Vatsalya Special School

R-756 Old Rajinder Nagar
New Delhi
Tel: 011- 25862824

We Can Trust

School and Resource Centre
4/ 370, South First Main Road
Kapaleeswarar Nagar
Neelangarai
Chennai- 600041
Tel: 044- 55461010



SECTION IV: OTHER USEFUL WEBSITES

National Organizations

Action for Autism (India)	www.autism-india.org
National Autistic Society (UK)	www.nas.org.uk
Autism Society of America (US)	www.autism-society.org
Autism Research Institute (ARI)	www.autism.com
Autism Speaks	www.autismspeaks.org
List of organisations worldwide	www.autism-india.org/worldorgs.html

Some Selected Treatment Approaches

Applied Behavioural Analysis (ABA)	www.abainternational.org/ http://rsaffran.tripod.com/faq.html#top
TEACCH	www.teacch.com/
Greenspan/Floortime/DIR	www.stanleygreenspan.com/ www.floortime.org/
Option/Son-Rise	www.autismtreatmentcenter.org/
PECS	www.pecs.com/
Relationship Development Intervention (RDI)	www.rdiconnect.com/
HANDLE	www.handle.org/
The Miller Method	www.millermethod.org/

Training Manual on Verbal Behaviour (<http://www.mariposaschool.org/materials.html>)

The Mariposa School has available a free, downloadable guide to implementing Verbal Behaviour. The manual includes over twenty topics, including increasing vocal productions; dealing with behaviors before they happen; teaching the child to use words instead of tantrums; teaching the child to ask and answer questions; teaching the child to understand the use of abstract language; building sentences and building emerging social skills.

First Signs and ASD Video Glossary (<http://www.firstsigns.org/>)

First Signs is a Website designed to educate parents, healthcare providers, early childhood educators, and other professionals in order to improve screening and referral practices and to lower the age at which young children are identified with autism and other developmental disorders. The First Signs site provides information on a range of issues, including the ASD Video Glossary– a Web-based tool that contains over a hundred video clips and is available free of charge. This tool can be extremely useful for both professionals and parents to better become acquainted with the subtle differences between typical and delayed development in young children and spot the early red flags for ASD.



SECTION V:

ABOUT ACTION FOR AUTISM

Clinical Services and Assessments

Action for Autism (AFA) offers several types of clinical services geared toward families who can attend programmes on a regular basis, and for those who for whatever reason, can only visit the centre on a fortnightly basis or less – for example, those who live in far-flung areas of Delhi or in other parts of the country. All programmes start with an initial assessment of the child. Based on the child’s strengths, behaviours, learning patterns, and training and the teaching methods best suited to him/her, a plan is made keeping in mind the child’s current needs as well as the parents immediate concerns.

(a) Diagnostic Assessments

Screening and diagnostic assessments are made following detailed observations of and interactions with the child, as well as comprehensive interviews with the family members. AFA has a full-time clinical psychologist who uses internationally standardised diagnostic criteria (DSM 4 TR) and a variety of standardised screening / diagnostic instruments including Checklist for Autism in Toddlers – Modified (M-CHAT), Childhood Autism Rating Scale (CARS) and Autism Diagnostic Observation Schedule (ADOS). Determining related disorders and differentiating ASD from other disorders is part of this process. The parents are provided with information on autism and services necessary to start intervention.

(b) Functional Assessments

Autism is hallmarked by an uneven skill profile. Functional assessments provide detailed insight into the current level of performance of the child in various skill areas including motor & speech development, imitation skills, cognitive development, academic skills and activities of daily living. The assessment is made over multiple sessions through a series of direct work sessions with the child, observation and discussion with the family. Individualized Education Programs (IEP) are prepared on the basis of functional assessments.

(c) Occupational and Sensory Assessment

A detailed assessment is made by filling up a sensory profile questionnaire which addresses all the sensory systems in depth. Along with this a comprehensive evaluation of the child is also done using observation and feedback from parents. The assessment provides a base for all subsequent interventions for the child.

Intervention Programmes

AFA does not view autism or disability as a tragic condition, but rather as a different way of being. AFA adheres to a philosophy of loving and accepting without judgments; acceptance of the child's personhood and the use of a highly individualized, structured program with each child. Through its various intervention programmes, AFA offers an eclectic mix of behaviour based methods and structured teaching. Elements of TEACCH, Applied behaviour Analysis (ABA), Verbal Behaviour Analysis (VBA), various forms of Assisted and Augmentative Communication (AAC) including Picture Exchange Communication Systems (PECS) are a part of the methods used.

(a) Parent Child Early Intervention Programme

The programme runs over a ten to twelve week period and starts each January, July and October. A group of approximately 15 to 20 parents (mothers, fathers or grandparents) daily train together (with their children), under the guidance of experienced, trained therapists. The programme seeks to maximize the benefits of the time that a parent spends with his/her child, teaching focused one-on-one intervention tailored individually to each child and taking into account the child's strengths, emerging skills and weakest skill areas. The programme also prepares children to join school setups and learn in a group through the activities done in group teaching sessions. More importantly the programme gives parents the tool to understand their child and the child's autism. Children as young as 18 months flagged for autism during their screening have been a part of this programme.



(b) The Open Door Day School

This laboratory school, begun in March 1994 has gained recognition as a model school for children with autism in India, and serves a unique dual purpose. As with any quality institution, the pupils and their families receive direct benefit and an improved quality of life. Just as important, the school is used to test, modify, and adapt training techniques gathered from around the world to the Indian context. In a controlled setting, new techniques are tested before being referred as an effective technique to parents and professionals in other parts of India.

Currently, the Day School has seven sections in which about 60 children aged 3 – 18 are placed depending on their needs and abilities. The Junior Section puts an emphasis on building basic interaction skills, pre-reading and writing skills and concept building. Concepts are taught in one-on-one sessions, while group activities are used to develop social skills. Alongside, the child's abilities to work independently and interpret instructions in a general environment are developed and strengthened. Gradually, the children learn independent work behaviours that enable them to learn vocational skills. Children, who are ready, move on to mainstream classrooms. The school combines group activities and one-on-one teaching, as well as music therapy, computer and sensory integration. In addition to building upon academic skills, all therapies and strategies focus on developing communication and social skills as well.

(c) Adhaar Work Skills Training Centre

Adhaar provides a specialized and supportive environment for people with autism aged 18 onwards to learn skills that enable them to work in a vocational setting. The focus is on developing and strengthening functional communication, interpersonal skills, and also building awareness of current affairs, independent living skills such as shopping and cooking, training in vocational areas such as weaving, block printing and bag making and developing leisure skills.

(d) On the Job Training Programme for Work Behaviours

Functionally more able young adults with autism often have difficulties in

understanding and coping with the dynamics of a work environment and may require additional assistance with these matters in order to find and keep a job.. To facilitate the learning of skills needed in natural work environments, AFA provides an opportunity to train on the job with us. Depending on the functional skills of the young adult, he /she is assigned a job profile. AFA simulates work settings to provide intense training in relevant work skills. The programme also focuses on aspects such as building upon punctuality, regularity and maintaining consistency; coping with unpredictable changes in routines and structures and developing interpersonal skills with colleagues.

(e) Educational Intervention Programme

On a regular ongoing basis, a special educator works one-on-one with the child one or more times a week as determined by the parents. Parents are encouraged to observe the sessions. Each session is followed by a discussion with the parent / family member who accompanies the child and observes the session. The discussion covers the session, the child's general progress and other queries so that the work can be continued at home. This programme is attended by children in mainstream schools needing support, children preparing for mainstream schooling, children in special needs setup requiring additional support, children who are being home schooled, and children who are not receiving any other special education inputs.

(f) Bubble: Social Skills Training Programme

Children functionally more able and based in mainstream schools may find it difficult to follow group instructions, comply with daily routines of classrooms like taking out notebooks, copying from the blackboard, sitting during transitions, waiting for their turn in classroom activities, asking for help and even giving answers to questions they may know. To address these and many such difficulties commonly faced by children with autism in mainstream schools, the programme replicates classroom situations through fun activities and builds upon social skills necessary to interact with peers and adults. The children work in small groups on a weekly basis with special educators and prepare to work more effectively within their daily school activities.



(g) Handwriting Programme

Difficulties in sensory processing, sensory awareness and/or perceptual skills and lack of motivation are common reasons that usually lead to difficulties in writing problems among children with autism. The premise for the handwriting program is combining sensory activities with direct instructions. A group of 4 - 5 children along with their parents participate in activities related to developing prewriting & writing skills under the guidance of a special educator and an occupational therapist.

(h) Inclusive Hobby Classes

The mandate of AFA is to create an inclusive environment where people with autism can live and work as fully participating members of their community. To move to this vision it is important that those who have special needs and are different from the norm are enabled to participate in society along with those who are what society terms 'normal'. Proximity and exposure leads to awareness and understanding and eventually acceptance. A variety of strategies have been used to bring inclusion beyond the classroom and enhance inclusive learning: through sports, through social events, and so on. AFA has introduced a series of intervention for children with autism to build upon leisure time skills in close proximity of children developing typically. The first of this initiative is Pottery Training.

Pottery includes activities ideal for addressing tactile and motor issues in addition to creativity. Clay work requires and strengthens various hands functions like grasp, pinch, hold, release, and rolling of palm which are also required in daily living activities. The children attend weekly classes in small groups under the guidance of a trained special educator and a potter in a truly inclusive setup.

(i) The Centre-based Programme for Home Management

Programmes for Home Management are schedules and plans designed by the parent and an AFA therapist together. Tailored to each family's individual needs, the therapists provide structure for daily routines and activities that the family carries out with the child at home. The plan is implemented at home and the family returns for an

update at predetermined intervals of a fortnight or more. The programme also gives families an opportunity to discuss for solutions to vexing issues of behaviours and learning of daily living skills.

(j) Extended Home Programme for Out Station Families

Outstation families often visit AFA and receive an intensive programme of observation, counselling, work sessions with the child, feedback and discussion with special educators, clinical psychologists, and sensory integration therapists. Depending on their duration of stay and where families so require, assessments and curriculum planning may also be carried out. Because the characteristics and behaviors of people with autism vary so widely, the individualized nature of these programs is particularly crucial, and parents are encouraged to stay in touch with AFA to make modifications and implement additional skills. Families from throughout India and abroad have received this service.

(k) Occupational and Sensory Intervention

The programme is available for all children with autism where sensory issues interfere with learning and daily functioning. Areas of intervention include providing an individualized sensory diet, activities to develop life skills and hand functions and providing training and home based programmes for parents. Sessions conducted by a trained Occupational Therapist are usually a combination of table top and sensory activities. Short term intensive sensory packages are also available.

Additional Family Support Services

(a) Afternoon Respite Care

AFA organises a daily after-school afternoon respite care for families where both parents are working or have an emergency to deal with. Students enrolled in the programme are engaged in a series of activities designed to build upon daily living skills, creativity and group interactions.

(b) Weekend Respite Care

For parents working on Saturdays, families in crisis or to simply give parents time to catch a movie or complete their shopping, AFA offers weekend respite where children and young adults with autism spend a day away from their parents and with their buddies. The programme focuses to train the students in daily living skills through activities like helping prepare lunch, and cleaning up while doing fun things such as going out for short outings, lunch to a restaurant. Preparations are underway to organise an overnight respite.

(c) Family Counselling

Family counselling soon after receiving a diagnosis and during critical phases such as approaching adolescence can greatly broaden the parents' options of how to most benefit their child, and can improve their ability to take positive, long term decisions by providing an opportunity to sort out factual information from misinformation. Counselling is provided to family members to deal with issues related to the pressures and stress of parenting a child with autism, parenting the sibling of a child with autism, living in a nuclear or joint family, second child issues, or any other concerns families may have. Appropriate coping strategies are discussed and developed with inputs from psychologists and medical professionals. Parents also receive referrals to schools and services elsewhere.

Trainings

(a) Workshops & Lectures

For over a decade, AFA has conducted practical and interactive training workshops for parents and professionals on various aspects of autism. AFA also coordinates with professionals from throughout the world to present on different topics. Just a few of these topics include: RDI, behavior modification, TEACCH, developing Individualized Education Plans, verbal behavior, AAC strategies, neurologic behavior aspects of the PDDs, and sexual concerns among individuals with autism. In addition members of AFA regularly present training workshops these have been in cities throughout India,

and in Bangladesh, Nepal, Pakistan, Dubai, and the United Arab Emirates. AFA works in close partnership with organisations in different regions in country. AFA has also helped several individuals and organisations set up clinical services to cater to families and children with autism in their region.

(b) Diploma in Special Education (Autistic Spectrum Disorder)

Children with autism benefit most from teachers with a comprehensive understanding of autism and autism-specific techniques. AFA offers a course recognised by the Rehabilitation Council of India (RCI) to train special educators in autism. Through extensive exposure in practical hands-on training and lectures, trainees learn to be comfortable with the principles and practices of different methods for working with persons with autism. Along with knowledge about autism and special education, the trainees gain knowledge of behaviour modification, social development, language development, and family counseling. Successful candidates receive placements in leading schools and special needs organizations, and many have been absorbed within AFA.

Ahaan: AFA Publication Division

(a) The Autism Network, AFA Journal

While journals about autism are available from the U.S., U.K., Australia and other developed countries, these publications are often not relevant to families in India, where services, education, health and legal issues are vastly different. In publication since 1994, the Autism Network is an invaluable source of information for those who deal with autism in India by bridging the gap between what occurs elsewhere in the world with here in India. The focus is on dealing with autism in our own cultural context while simultaneously including information from around the globe. The journal aims to bring parents and professionals of different regions and backgrounds together to share their own experiences and knowledge.

(b) Training Manuals

A few manuals and training materials for parents and professionals have been published and many more are currently being written. Reprints of the same are available in English and other Indian languages.

Resource Library and Information Service

At present, there is an extreme dearth of information available about autism in India. Because of the prohibitive cost of autism books, the majority of families are not able to obtain all the information they would like. AFA obtains the most current and relevant Indian and international books and journals and makes them available to those interested. The AFA library currently hosts several hundred titles of autism-related books and academic journals. In addition, the library maintains files on autism-related topics, conference proceedings and newsletters from abroad, historical information, and popular media articles on autism. The library also has a facility for parents and professionals to watch educational videos on various aspects of autism.

Research

AFA has a longstanding commitment to research in the field of autism. We strongly believe that research is the key to understand both the phenomenology and treatment of people with autism and build upon the existing services. With its vast network of families throughout South Asia and connections to families throughout the world, AFA has been pleased to participate in many collaborative research projects, as well as provide support to visiting scholars from India and abroad. AFA is also a training ground for budding professionals. Various students of social work, psychology, and special education from leading universities in India and other parts of the world intern at AFA.

Ailaan: AFA Department of Advocacy

(a) Awareness Raising

Increasing awareness of a lesser-known disorder such as autism is necessary for doctors to make accurate diagnosis and for society to begin to integrate autistic individuals into the mainstream. AFA has undertaken various projects to promote awareness and understanding about autism among parents and professionals as well as the general public. From 1998 to 2001, AFA mailed brief information sheets on autism to pediatricians, psychologists and psychiatrists in order to sensitise them to the symptoms of autism. A follow up study is currently in the process. AFA continues to raise awareness among the general public through popular media articles, and a variety of fun events such as walks, music concerts, dance performances, dinners, art show and carnivals. AFA also has available an awareness film on autism for South Asia, entitled 'Autism: An Indian Perspective.'

(b) Government Lobbying

Government recognition of autism in India is an ongoing campaign of AFA. In October of 1996, AFA led a delegation of parents of autistic children from throughout India to meet the then Ministry of Welfare and lobby for inclusion of autism in the National Legislation. In February of 1997, AFA subsequently met with the Joint Secretary of Welfare, the Minister of State for Health and Family Welfare, the Lieutenant Governor of Delhi and numerous other officials. AFA has been successful in having autism included in The National Trust Act. Lobbying will continue until appropriate legal reforms for people with autism and related disabilities have been achieved.

(c) Networking

AFA actively seeks partnerships with other non-governmental organizations and persons interested in autism both within India and abroad. These relationships help share experiences and ensure that support is provided to as many families as possible. To facilitate this process, AFA established a Federation of Indian Autism Organisations to represent the various schools and parent support groups all over the



country. Members of AFA have attended conferences in Scotland, the U.S., Denmark, U.K. and the Philippines, and have active collaboration with organisations in several countries. AFA also represents South Asia in the World Autism Organisation (WAO), based in Europe. AFA has formalized sister school relationship with Heartspring Worldwide Center for Children in Wichita, Kansas and Autism ACTION in Chicago. These partnerships offer the opportunity for additional support through cultural and informational exchange between the staff and the teachers. Within India, AFA participates in the activities of organisations dealing with mental and physical disabilities to help foster relationships with regional groups.

ACTION FOR AUTISM



Pocket 7 & 8, Jasola Vihar, New Delhi - 110025
Tel: 6534 7422, 4054 0991/92

E-mail: actionforautism@gmail.com
Website: <http://www.autism-india.org>