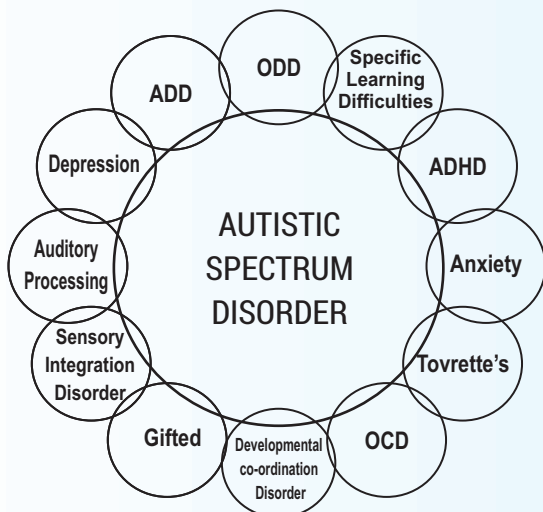


SPECIAL ISSUE: WORLD AUTISM DAY: 2<sup>nd</sup> APRIL 2019

## MESSAGE

World autism awareness day (WAAD) is remembered and celebrated by all of us on 2nd April every year. The UN General Assembly passed resolution no. 62/139 on 1st November 2007 and declared 2nd April as the World autism awareness day. Since then this day marks that the doctors and all concerned become more aware of the condition. It stipulates that organizations around the world will come together to diagnose, treat, manage, rehabilitate and research on autistic children. The day aims to put spotlight on the hurdles that children with autism and their caregivers face. The celebration therefore is aptly looked at as a commitment not with sympathy, but empathy and empowerment.

Pediatricians need to be highly aware of autism spectrum disorders which include multidimensional entities as listed under:



## Early detection :

The American Academy of Pediatrics recommends that all children be screened at their 9, 18, 24 and 30 month visits. WHO and UNICEF have stressed through various Lancet series 2013 and 2016 on early childhood development as an important domain of nurturing care along with health nutrition, child protection (security), early learning and responsive care giving. Thus at every visit of the baby for immunization or any illness developmental screening should be performed to detect autism.

In 2013, a revised version of diagnosis and statistical manual of mental disorders was released. It changed the classification of autism to -

- 1) Autistic disorder
- 2) Asperger's syndrome
- 3) Pervasive development disorder

A child who exhibits the following symptoms must be looked at minutely by Pediatricians and screened for autism.

- a) Making little or inconsistent eye contact.
- b) Tending not to look or listen to people.
- c) Rarely sharing enjoyment of objects or activities by pointing or showing things to others.
- d) Falling, not responding to name calling, being slow.
- e) Difficulty in conversation, not interested.
- f) Facial expression and movements not matching parental stimulation.
- g) Repetitive behaviours.
- h) Unusual voice tones.

All these should be considered in light of the actual age of the child and developmental age. Many may show developmental delay, some may not be intelligent or have learning difficulties.

Early diagnosis by a pediatrician and timely referral to physiotherapist, occupational therapist, ophthalmologist, ENT surgeon, neurologist, psychiatrist, psychologist, counsellor, special schooling and play therapist will go a long way in maximizing the potential in every child.

Let us pledge on this day (WAAD), the 2nd April, 2019 to give our best to a child with autism. My good wishes to all the activities.

**Dr. Phadke M. A.**

**Editor-in-Chief COMHAD New Letter, Sr. Adv. NHM, UNICEF,  
Former Vice Chancellor, MUHS, Former DMER, Govt. of Maharashtra.**



# GROWING UP....WITH AUTISM

**Dr. Jaya Shiwalkar**

**President AHA Nagpur, Pediatrician/Adolescent Psychologist**

Adolescence is a transitional period between childhood and adulthood. It is a period of rapid psycho social growth and beginning of independent thinking, along with strong emotional reactivity.

It is a stormy and challenging phase of life for any adolescence, but more so for children with autism when they enter into puberty.

How a person will experience this adolescent phase of life, is determined by....

- Genetic factors

- Hormonal levels

- Environment

IQ and level of autism

It is important for parents and caretakers to understand how brain is maturing at this age and how it affects the adolescent. Not only this ,but along with this ,there are hormonal changes which will lead to heightened emotionality and aggression. All these growing up changes need to be understood in reference to challenges of autism.

But adolescence is not only about problems and challenges. On the other hand ,it is an opportunity for the parents to use this phase of rapid development and maturity to incultate many important skills in the developing adolescents.

Some important pointers for the parents are.....

- \*As the brain is maturing 'it has tendency to master the activity, which the child is doing repeatedly. Thus engaging adolescent in positive /creative activities, he will get used to it.(It is called "pruning of brain)

- \*Maturing brain results in increased understanding, mental ability and learning skills, hence it is an opportunity to develop new skills.

- \*The frontal lobe of brain (front portion) is responsible for the development of various skills ,such as....

- Organization of the environment as well as self

- Time management

- Control of emotional urges

- Judgement

- Decision making and problem solving

It is important to understand that these skills are developed around 21 to 25 yrs of age. Hence parents have opportunity to provide various learning experiences till young adulthood.

- \*It is time ,when brain is maturing and it leads to increased creativity, expansion of vocabulary, better visuo - spatial skills as well as improved psychomotor status. Hence environmental stimulation and exposure to various developmental activities have a great role to play in adolescent with autism.

- \*This is, as well ,time for hormonal changes resulting in physical and psychological changes.

Physical changes start earlier in girls and little later in boys. We all are aware that accepting any change is challenging for the children with autism. Hence, even the bodily changes may not be easily acceptable to growing teenager. Menarche, means onset of monthly periods can disturb the growing girls ,while appearance of facial and genital hair can be disturbing to the growing boy. Preparing the special adolescent for these pubertal changes needs special training of parents, caretaker and teachers.

- \*The pubertal changes are associated with psycho social changes as well. These changes leads to attraction to opposite gender. These feelings and its expression can confuse the adolescent with autism. This confusion is because of inability of the teenager to comprehend the complex developmental changes, may be because of lack of reading, communication as well lack of peer interaction.

Thus ,we can say that, adolescent is an important developmental phase in life of individual with autism. It leads to lot of positive changes as well as many challenges as well.

Proper training of parents, caretakers and teachers is essential for smooth development in these special adolescent.

## WHY SPORTS CLUB STARTED AT PRAYAS??

**Kiran Binkar (Diwe)**

**M. Phil in Rehabilitation Psychology**

Principal, PRAYAS School & Sports Club for Children with Special Needs,

“Non - acceptance” of the children in the mainstream, especially when they are exposed to garden or other public places, the fear anguish and the pain of the parents cannot be expressed. Keeping this in mind a noble thought channelized Shri. Ritesh Diwe to start an exclusive sports club for these children. The mission which started with only two children is now flourishing with more than 45 to the count, and the students are still coming.

Children with Autism have difficulties in the area of communication, expression, social and sensory issues, to name some. The speech impairment is one of the main hurdles for behavioral issues of these children. Keeping all these in mind the Sports club was started, if not eradicate at least to control these behavioral issues to some extent through sports therapy. One of the major issues which made the mind set go for the Sports therapy was the children's restlessness, which is one of the main concern of the parents.

Like all human beings, children with special needs do have some desires. The need of being involved in day to day life. To achieve something a desired goal like any other human being is a thought of a special child, they also want to be successful like any other individual.

Being compassionate is not sufficient, Sports for Children with Autism Spectrum Disorder increases motor co – ordination, visuo – perceptual, and visuo – spatial ability. Sports help these children to work in team and lead the team, following all the protocols required in the game.

For Children with special needs sports help to co – ordinate with all sensory organs and make them goal focused. As said Sports is good for both body and mind, Sports for Children with autism help them with high and lows of life. Sports help these children to control their emotions, channelize the negative feelings in the positive way.

Sports helps to cover the area of hyperactivity, restlessness, aggression, stubbornness, and other behavioral issues and other behavioral issues very conveniently through Yoga, floor exercise and other specific exercise coordinated and designed with the help of expertise of these field along with Ritesh Sir's mission.

## GUIDELINES FOR EVALUATION AND ASSESSMENT OF AUTISM AND PROCEDURE FOR CERTIFICATION IN INDIA

**Dr Urmila Dahake**

**MD (Pediatrics), PG Diploma in Developmental Neurology,  
BA, MA in Counselling Psychology. Joint Secretary COMHAD UK.**

Autism has been recognized as one of the disabilities under Section 2 of the National Trust Act, 1999. The Ministry of Social Justice & Empowerment, Government of India has developed Guidelines for Assessment of Autism for the purposes of issuance of disability certificate in consultation with Union Ministry of Health and Family Welfare.

**Definition:** Autism Spectrum Disorder is a lifelong neurological condition typically appearing in the first three years of life that is marked by pervasive impairments in the areas of social skills and communication; often associated with hyper-or-hypo-reactivity to sensory input; unusual interest of stereotypical rituals, or behaviours; and may or may not be accompanied by intellectual impairment.

The recommendations for assessment and certification are as follows

- The INCLIN tools (INCLIN-ASD) shall be used for identification Autism cases.
- The Indian Scale of Assessment of Autism (ISAA) shall be used for the detailed assessment and assessing the extent of disability for persons with autism beyond 6 years of age.
- Certification of disability for persons with autism may be carried out by a Autism Certification Medical Board, duly constituted by the Central Government or the State Government, comprising of members from the following fields:
  1. Clinical Psychologist/Rehabilitation Psychologist
  2. Psychiatrist
  3. Pediatrician or General Physician as the case may be

Based on the identification of cases of Autism with INCLIN-ASD and ISAA tool, certificate of Autism is to be issued. The certificate would be valid for a period of 5 years for those whose disability is temporary and are below the age 18 years. For those who acquire permanent disability, the validity can be shown as "Permanent" in the certificate.

# DEALING WITH HIGH FUNCTIONING AUTISM

**Dr Shubhada Khirwadkar**  
**MD (Pediatrics), MA (Clinical Psychology)**  
**Tender Buds Counseling Centre, Nagpur.**

Autism, as a specific condition with significant difficulties in socialisation & communication which pose serious behaviour challenges has been well recognized for years. For a long time, however, only people with very severe symptoms were diagnosed with autism. Starting in the 1990s, milder forms were recognized, which were termed high-functioning autism and Asperger's syndrome, which share many of the same symptoms, which are milder in form & the patients are able to master well many skills of day to day living as well as function quite well in specific fields of interest.

In 2013, the American Psychiatric Association & later Diagnostic & Statistical Manual(DSM) grouped the autism-related disorders into one term: Autism Spectrum Disorder, or ASD.

Autism spectrum disorder (ASD) are thus developmental disorders that affects communication and behavior. & includes limited and repetitive patterns of behavior.

The term "spectrum" refers to the wide range of symptoms and severity. Although autism can be diagnosed at any age, it is said to be a "developmental disorder" because symptoms generally appear in the first two years of life. As the child grows, its performance in daily functioning & mastering specific skills show wide ranging outcomes.

Each child with autism spectrum disorder is likely to have a unique pattern of behavior and level of severity — from low functioning to high functioning. Most children with autism spectrum disorder have difficulty in learning, and have signs of lower than normal intelligence. However, other children with the disorder have normal to high intelligence, they learn quickly, yet have trouble communicating and applying what they know in everyday life and adjusting to social situations. Those who are high functioning too have a hard time with social interaction and communication. They don't naturally read social cues and might find it quite difficult to make friends. They can get so stressed by a social situation that they shut down. They don't make much eye contact or small talk.

However, many of them are able to develop sufficient skills in a particular field. It is now recognized through various studies of interventions in such children that their area of skills if recognized early & handled efficiently they can do well in life despite their impairments.

Diagnosis in these cases is complicated. Seventy-five percent of people with autism score at 70 or below on intelligence tests and are therefore determined to be intellectually challenged. The other 25 percent presumably have average to superior intelligence. Giftedness can mask the symptoms of autism, and autism can mask giftedness.

Further, gifted kids sometimes exhibit behaviors (like an obsession with facts, intense preoccupation with an area of interest, lack of interest in peers, etc.) that are characteristic of autism.

Kids with autism can develop such expertise in their particular intense interest that adults initially miss the fact that they aren't equally smart about navigating the social world.

Accurate evaluation is very important. Teasing out whether a child is gifted and talented, autistic, or both is crucial if we need to provide him with the correct supports and services. Concerned parents need to insist that children be assessed by professionals who are aware of the unique presentation and needs of both diagnoses. Life doesn't prepare most parents for a twice-exceptional child.

Here are a few tips for helping such a child succeed in school and in life; they could be useful for parents, caretakers & educators.

**Expansion of interests:** Being able to talk at least a little about many things is an important social skill. Like kids with only autism, the twice-exceptional children often have a special interest in a particular subject. So there may be kids who know everything there is to know about dinosaurs or the solar system!

Rather than forcing a broadening of interests, follow the child's lead. Let her be the expert and encourage her to teach you about it. Then branch out from the special interest to include other areas. For example: If the interest is wild life, it's not too big a leap to talk about what happened to the extinct animals and what we can learn from it as we confront global warming. The object is to expand her range of interests so she can talk with others about things that are of general interest.



**Peer relationships:** Sadly, the twice-exceptional child is particularly vulnerable to bullying. The social deficits of autism make them “odd” to others. They don’t look people in the eye. They miss social cues. They are obsessed with whatever they are obsessed about and aren’t interested in hearing what someone else might want to talk about. The child needs special, focused training in how to get along with others in his age group. He also needs the relief that comes from being with people like him. Look for other kids who have similar interests or who find your child a little odd but interesting and support those relationships.

**Sports:** Not only does the child who is twice-exceptional have difficulty in managing the social requirements of team sports, but he/ she may be physically uncoordinated and awkward. If that’s the case, participating in team sports only sets your child up for more teasing and the loss of self-esteem that comes with being unable to meet the team’s expectations. The answer is in individual sports. If interested, these kids can succeed in activities like hiking, camping and biking. Some do well in activities that are both individual and competitive (like the swim team or archery). The patient coaching and practice needed for mastery are worth it. Doing any activity well increases both self esteem and social options.

**Pretending:** Don’t be alarmed if the child isn’t interested in pretending. Many gifted children with autism aren’t interested in fiction or imaginary play. Their thought process tends to be more concrete and literal. Introduce imaginary play but don’t push it. The twice-exceptional child will be creative in other ways — like discovering a new and advanced approach to a science question.

**Transitions:** Processing speed is sometimes slower than one might expect in a gifted child. Although we live in a world where multi-tasking seems to come easily to average kids, the twice-exceptional child may find this particularly difficult. Once engaged with an idea or activity, these kids have difficulty shifting their focus to another one. Although all children respond well to being given a warning when they have to leave one thing to go to another, the twice-exceptional child needs it even more.

**Speaking and writing:** Many of these children have large verbal vocabularies. At times they present their ideas in an almost professorial tone. But these same kids often have difficulty expressing themselves in writing. It’s as if their minds can’t slow down enough to write out their thoughts in an orderly way. Sentences don’t get finished, for example. Words may get left out. In addition, the fine motor skills that are required for beautiful handwriting seem to be beyond them. Unfortunately, there are teachers who mistake sloppy writing for sloppy thinking. Tablets and laptops come to the rescue. The “cut and paste” function is made for these kids. What they produce can be read without an interpreter. Advocate use of electronics rather than manual handwriting for note taking and assignments.

Without help, twice-exceptional children are often misunderstood and isolated. It is up to adult helpers and parents to translate the world to such children and such children to the world. They have special gifts and special needs. With careful coaching and support, they can learn the skills to become connected to others and to be contributing members of their communities. Most importantly, they can be happy with who they are!

## BEHAVIORAL MANAGEMENT IN AUTISM SPECTRUM DISORDER

**Dr. Dinesh Saroj**

**Developmental Pediatrician, COMHAD Coordinator.**

**Introduction :** All the efforts made in the past to define Autism Spectrum Disorder, has consistently identified Social Communication and Behavioral peculiarities and deficits. The social deficits are often the most compelling while behavioral difficulties are not easy to characterize or describe. They might range from simply trivial deviations to even selfinjurious or devastating behavior.

**General Principles of Behavioral Management :** Behavioral treatment is considered to be the dominant treatment approach in the management of Autism Spectrum Disorder, the prime reason being lack of knowledge about the physiological correlates of Autism. As a result, we do not have any definitive preventive or medical treatment for this syndrome. The most important factor which substantiates importance of behavioral treatment is its ‘Effectiveness’ and ‘Replicability’. It does not depend upon knowledge of etiology of the disorder. It views Autism Spectrum Disorder as a spectrum comprising of Behavioral ‘Excesses’ or ‘Deficits’. Examples of Behavioral Excesses include Self stimulation,

Self-injury and Compulsion. Examples of Behavioral Deficits include Language deficits, Social deficits and Inappropriate attention. The aim of Behavioral therapy is to reinforce 'Wanted' behaviors and reduce 'Unwanted' behaviors by suggesting the Caregivers what they can do before, during, after, and between episodes of problem behaviors

Behavioral therapy is often based on **Applied Behavior Analysis (ABA)**, a widely accepted approach that tracks a child's progress in improving his or her skills.

#### **Following points work as guide in Behavioral therapy-**

**1. ABCs of Behavioral management :** Whenever confronted with behavioral issues in Autism Spectrum Disorder, clinician must try to find out the controlling variables. This is usually accomplished by observing the events immediately preceding the behavior (the Antecedents) & the events immediately following the behavior (the Consequences). This is referred to as 'ABC' (Antecedents, Behavior, and Consequences) pattern of behavior. It helps us know why a behavior occurred, & if and how a medication is affecting the frequency of a behavior.

**2. Engaging them in a favorite activity :** A relaxing activity can help in releasing energy thereby decrease in Aggression, Stereotypy, Off-task behavior, and improvements in on-task and motor behavior; thereby managing difficult behavior.

**3. Identify Effects of Environment :** Autistic children can be very sensitive to the subtle changes in their environment. In case of a sudden change in behavior, a recent change in the environment should be rule out & helped.

**4. Identifying Emotional issues :** Children with ASD face difficulty with abstract concepts such as emotions. They can be helped by employing ways to turn emotions into more 'concrete' concepts, eg by using stress scales, traffic light system, visual thermometer, or a scale of 1-5 to present emotions as colors or numbers. Social stories can also be a useful way of explaining how to manage a certain emotion.

**5. Protect them from getting Bullied :** Autistic child is more prone for being bullied. At the same time, they may find it difficult to understand if they are being bullied. This may lead to difficult behavior. Boosting their self-esteem by praising and engaging them in social groups are good ways to help these kids.

**6. Tackle impact of Social Situations :** Unfamiliar social situations, with their unwritten rules, can be daunting. Repeated and graded exposure to unfamiliar social situations can help kids overcome their difficult behavior.

**7. Help them during periods of Change And Transition :** Autistic children may find it difficult to cope with change, whether temporary or permanent. It's important to prepare the child in advance, for what the change is likely to involve.

**8. Give them 'Time out' :** In case of distress caused by environmental factors, Time Out / Space Out, usually in a familiar place like a bedroom, can have a calming effect.

**9. Support Effective Communication :** Speak clearly and precisely using short sentences and facilitate communication by using visual cues.

**10. Be Patient And Realistic :** Maintaining a diary may make it easier to record even a small, positive change. Choose two behaviors to focus at a time. Goals set should be realistic. Efforts should be persistent.

**11. Praise and Reward :** A verbal praise, sticker, a star chart, or five minutes with their favorite activity for not engaging in a problem behavior or for staying on task can act like a positive reinforcement & help to encourage a particular behavior or achieve a new coping strategy.

**12. First Then Boards :** The "first" is usually a picture of a non-preferred activity and the "then" is a picture of a preferred activity. The child must do the first before being able to do the second activity. It helps with both receptive and expressive communication.

#### **To conclude:**

1. Step 1: choose a behavior. Preferably one at a time...
2. Step 2: identify ABC of the behavior chosen. Maintain a diary of the difficult behavior for 1-2 weeks. ...
3. Step 3: make changes.

## INTERNATIONAL CONFERENCE OF COMHAD 2018, BENGALURU, KARNATAKA, INDIA

International Conference of COMHAD 2018, in association with Commonwealth Health Professions Alliance (CHPA), NIMHANS Bengaluru, Ramaiah Medical College Bengaluru, Indian Academy of Pediatrics Bengaluru, IAP Karnataka, UNICEF, DME, RGUHS, & India & Bangladesh Chapters of COMHAD, was held at the most famous “Silicon Valley & Garden City of India” Bengaluru, Karnataka, India, on 8th & 9th December 2018 at Ramaiah Medical College Auditorium, Bengaluru, Karnataka, India.

The theme of the conference was **“Transforming Comprehensive Disability Care in Children from Policy to Practice”**

The conference was inaugurated at the hands of Governor of Karnataka, Hon. Shri Vajubhai Rudabhai Vala. It was a very successful conference attended by about 800 delegates from every corner of the medical and social field working for the welfare of specially challenged children. The eminent International and National faculties actively participated as Faculties for Scientific Sessions held.

It was concluded that with more active selfless participation of policymakers and stakeholders along with medical fraternity, transforming comprehensive disability care in children from policy to practice is possible.





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## FORTHCOMING EVENT

### National Conference of COMHAD 2019

Date : 23<sup>rd</sup> & 24<sup>th</sup> Nov. 2019

Venue : Dr. D. Y. Patil Medical College, Kolhapur

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