

## **CLINICAL PRACTICE GUIDELINES FOR AUTISM SPECTRUM DISORDERS**

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**CLINICAL PRACTICE GUIDELINES 2019 (Version 1.1)**  
**AUTISM**

*These guidelines have been framed after an amalgamation of expert guidelines across the globe, and existing practices in India, as outlined by experts in the field. Due to lack of systematic research in the field of autism in India, the evidence of the said practices is not documented, which becomes a limitation of these guidelines. The good part is that India has an indigenous tool for assessment, which has been recommended by the Government of India, which we have attached as an appendix.*

Autism has till date always been viewed as an illness from the medical model, and hunt for a ‘cure’ has been the norm. With increase in awareness and available therapies, the focus shifted to disability and inclusion. However, as more autistic individuals express themselves and their needs, the focus now has shifted from the medical model to the social model of neurodiversity, thereby implying that autism is actually a variant of normal human development and human diversity. The next decade will probably see how best the two paradigms can be aligned to destigmatize and integrate autistic individuals into society at large.

Keeping the above in mind, the 5th edition of Diagnostic and Statistical Manual of Mental Disorders (DSM 5) shifted from grouping the disorders as separate diagnoses under the umbrella of PDDs to conceptualizing them as all members of the broader category of known as Autism Spectrum Disorder (ASD). The number of core domain deficits was reduced to two (social communication and repetitive behavior). ASD would now be diagnosed when a patient demonstrated at least three symptoms in the domain of social communication and at least two symptoms of restricted interests/repetitive behaviors; including an added behavior of hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment.

**Table 1: DSM-IV-TR vs DSM-5**

<b>DSM-IV-TR</b>	<b>DSM-5</b>
3 symptom categories	2 categories
6 diagnostic items endorsed in the 'social impairment' category	Three diagnostic items endorsed in the 'social communication and social interaction' category
Specifies onset prior to age 3	Specifies early development
Includes Rett's, Childhood Disintegrative Disorder, Asperger's Syndrome, PDD-NOS	Sub-types eliminated Includes parameters for designating severity

### **Major Changes to the DSM-5, Autism Diagnostic Criteria**

- Category name changed from Pervasive Developmental Disorders to Autism Spectrum Disorders
- Inclusion of sensory differences in criteria
- Recommendation to identify “specifiers” to better understand the individual needs of each child with ASD (cognitive and language ability, level of supports needed, co-occurring medical and mental health conditions, catatonia)
- Inclusion of co-occurring mental health disorders (e.g., attention-deficit/hyperactivity disorder)

The International Classification of Diseases-10<sup>th</sup> version(ICD-10), still used the term Pervasive Developmental Disorder. What is interesting is that the proposed changes in ICD-11 have not only changed the nosology to Autism Spectrum Disorder, but have also included intellectual development and functional language, which is closer to the clinical picture, and also is in keeping with the concept of neurodiversity.

At a glance, when we compare these classificatory systems, below are the changes we can see.

**Table 2: Change in the classification of Autism**

<b>Pervasive Developmental Disorders</b>		<b>Autism Spectrum Disorders</b>	
<b>DSM-IV (1994-2000)</b>	<b>ICD-10 (1996-till date)</b>	<b>DSM-5 (2013-till date)</b>	<b>ICD 11(2019 onwards)</b>
<b>DSM-IV-TR (2000-2013)</b>			
299.00 Autistic Disorder	F84.0 Childhood Autism	299.00 Autism Spectrum Disorder	6A02 Autism spectrum disorder
299.80 Asperger's Disorder	F84.5 Asperger Syndrome		6A02.0 Autism spectrum disorder without disorder of intellectual development and with mild or no impairment of functional language
299.80 Pervasive Developmental Disorder - not otherwise specified (including Atypical Autism) — PDD-NOS	F84.1 Atypical Autism		6A02.1 Autism spectrum disorder with disorder of intellectual development and with mild or no impairment of functional language
299.80 Rett's Disorder	F84.8 Other pervasive developmental disorders		6A02.2 Autism spectrum disorder without disorder of intellectual development and with impaired functional language
299.10 Childhood Disintegrative Disorder	F84.9 Pervasive developmental disorders, unspecified		6A02.3 Autism spectrum disorder with disorder of intellectual development and with impaired functional language
	F84.4 Overactive disorder associated with mental retardation and stereotyped movements		6A02.4 Autism spectrum disorder without disorder of intellectual development and with absence of functional language
	F84.2 Rett's Syndrome		6A02.5 Autism spectrum disorder with disorder of intellectual development and with absence of functional language
	F84.3 Childhood Disintegrative Disorder		6A02.Y Other specified autism spectrum disorder

Thus with the above inclusions, the numbers are bound to increase. The latest statistics state that the prevalence of autism spectrum disorders (ASD), is now estimated at 1 in 68 , more in males, (Centre for Disease Control National Center on Birth Defects and Developmental Disabilities, USA, 2014), which is alarming rise from 1:500 less than a decade ago. The

possible reason for this is increase in the number of CNV and gene variations. Multiple genes seem to be involved. These genes are responsible for synaptic plasticity, synaptic scaffolding proteins, receptors, cell adhesion molecules or proteins that are involved in chromatin remodeling, transcription, protein synthesis or degradation, or actin cytoskeleton dynamics. Eg. Genes for neuroligins, SHANKs, CNTNAP2, FMR1 to name a few.

On analysis of neuronal growth and pathways cortico-striato-thalamo-cortical (CSTC) circuits (for repetitive behaviours), Ventral Tegmental Area (VTA) connectivity to Nucleus Accumbens (NAcc) (for social interaction), and Amygdala to Ventral Hippocampal connectivity (for social interactions), are areas of active interest and study. The validity of the same, and the translation into structural diagnostic neuro-imaging is yet to be established, and hence limits the use of the same.

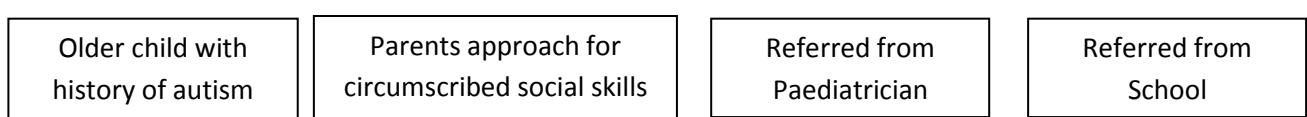
Similarly, functional neuropathology reveals excessive synapses due to a slow pruning process. However, diagnostic modalities to ascertain the same are yet awaited.

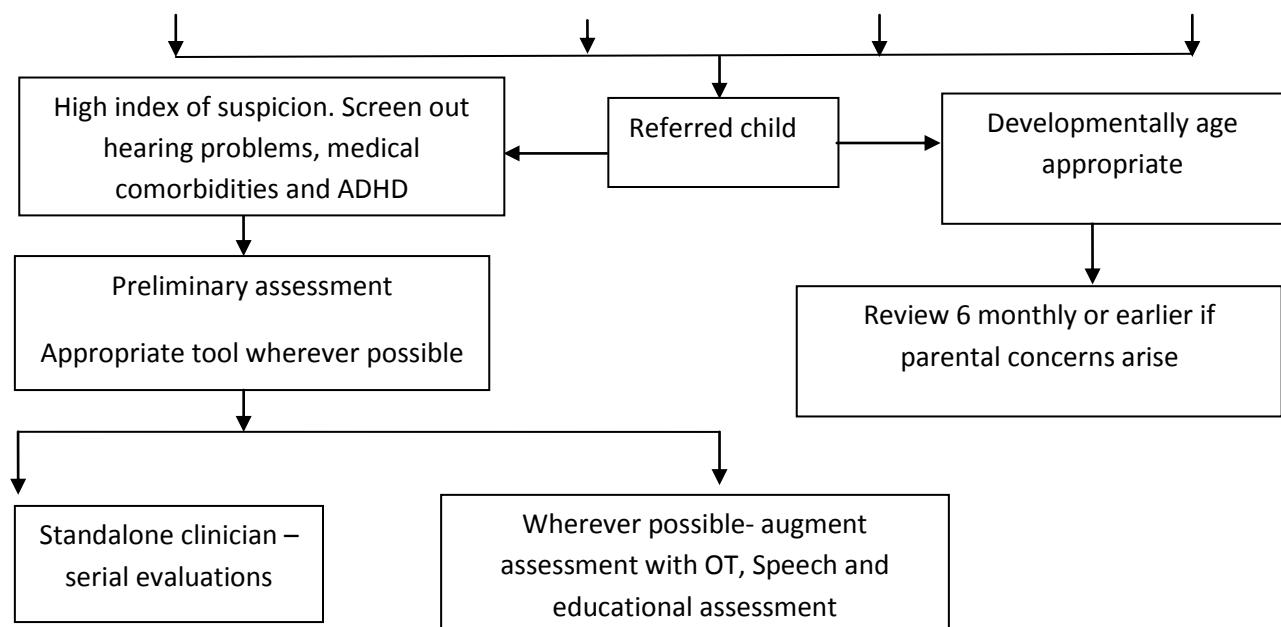
### **PROCESS OF ASSESSMENT**

Autism being a complex disorder, the assessment should as far as possible be done by multidisciplinary team who besides the psychiatrist should include a psychologist, a special educator, an occupational therapist and an audiologist and speech therapist. In the western world, educational psychologists in school settings double up for assessment of cognition and curricular level too. Also, it is good to keep the child's paediatrician in the loop, to ensure that any physical co-morbidites are handled effectively too.

Beyond longitudinal changes in ASD symptoms, the assessment of co-occurring physical and mental health conditions, is essential to providing quality care. Clinicians must actively ask about signs and symptoms of these conditions. Rule-out other conditions (e.g., hearing impairment), evaluate for co-morbid conditions (e.g., seizures) and search for underlying etiology (e.g., genetic syndrome). A medical history (birth, current health, family history), physical exam (growth, dysmorphic features, neuro, skin evaluation) and audiological evaluation, genetic testing (chromosomes, fragile X, microarray) and other optional investigations like EEG, brain imaging, metabolic testing, as appropriate might be useful depending on the nature of the case. The above approach, helps to delineate essential versus complex autism, when it comes to overall management and prognosis, as well as gives us a base on which to approach and psycho-educate the parents.

**Fig. 1. Approach to assessment of autism**





The Ministry of Social Justice and Empowerment (Department of Empowerment of Disabilities) released the INCLEN Tool for assessment of Autism Spectrum Disorder on 25<sup>th</sup> April, 2016 to be uniformly followed for assessment of autism in India. Inbuilt in the tool, is a scale called Indian Scale for Assessment of Autism, which not only gives cut off scores, but also severity indices and percentage disability, which helps certify(detailed later) and is in keeping with the new Rights of Persons with Disability(RPWD) Act.

The American Academy of Pediatrics (AAP) recommends that all children be screened for developmental delays and disabilities during regular well-child doctor visits viz. at 9 months, 18 months, 24 or 30 months. AACAP(American Association for Child and Adolescent Psychiatry) recommends ASD surveillance at all developmental & psychiatric assessments of children, ASD specific screening (e.g., M-CHAT) at 18 and 24 month visits or when surveillance raises concern. If the screening indicates significant ASD symptomatology, a thorough diagnostic evaluation is essential. Evaluation should include multi-disciplinary assessment with the clinician coordinating it. Diagnostic instruments commonly used: ADOS, ADI DISCO. The use of such instruments only supplement, but not replace informed clinical judgement. Early screening, however is recommended in order to intervene early.

**Table 3. Early Symptomatic Biomarkers for Detection of Autism**

Category	Symptoms
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Developmental Markers	<ul style="list-style-type: none"> <li><input type="checkbox"/> Developmental delays</li> <li><input type="checkbox"/> Typical development are orienting to name, looking at the faces of others, joint attention, affect sharing, and imitation<sup>1</sup></li> <li><input type="checkbox"/> Speech regression<sup>2</sup></li> <li><input type="checkbox"/> Poor visual tracking<sup>2</sup></li> <li><input type="checkbox"/> Repetitive activities<sup>2</sup></li> <li><input type="checkbox"/> Delay or certain oddities associated with toilet indication, squatting and related habits<sup>2</sup></li> </ul>
Behavioral Markers <sup>3,4</sup>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Stands on tiptoe</li> <li><input type="checkbox"/> Kicks a ball</li> <li><input type="checkbox"/> Begins to run</li> <li><input type="checkbox"/> Walks up and down stairs holding on</li> <li><input type="checkbox"/> Climbs onto and down from furniture without help</li> <li><input type="checkbox"/> Throws ball overhand</li> <li><input type="checkbox"/> Makes or copies straight lines and circles</li> <li><input type="checkbox"/> Lack of stranger anxiety<sup>1</sup></li> <li><input type="checkbox"/> Limited social responsiveness<sup>1</sup></li> </ul>
Cognitive Markers <sup>3,4</sup>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Finds things even when hidden under two or three covers</li> <li><input type="checkbox"/> Begins to sort shapes and colors</li> <li><input type="checkbox"/> Completes sentences and rhymes in familiar books</li> <li><input type="checkbox"/> Plays simple make-believe games</li> <li><input type="checkbox"/> Builds towers of four or more blocks</li> <li><input type="checkbox"/> Might use one hand more than the other</li> <li><input type="checkbox"/> Follows two-step instructions such as “Pick up your shoes and put them in the closet”</li> <li><input type="checkbox"/> Names items in a picture book such as a cat, bird, or dog</li> </ul>
Body Movements/ Motor Development Related Markers <sup>5</sup>	<ul style="list-style-type: none"> <li><input type="checkbox"/> Repetitive actions or posturing of the body, arms, hands, or fingers (including hand flapping, finger flicking, and atypical arm and foot movements during walking)</li> </ul>

**Table 4. M-CHAT R Scoring**

1	If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2	Have you ever wondered if your child might be deaf?	Yes	No
3	Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4	Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)	Yes	No
5	Does your child make unusual finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6	Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Yes	No
7	Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8	Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Yes	No
9	Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10	Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11	When you smile at your child, does he or she smile back at you?	Yes	No
12	Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13	Does your child walk?	Yes	No
14	Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15	Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16	If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17	Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say “look” or “watch me”?)	Yes	No
18	Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”?)	Yes	No
19	If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
20	Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)		

The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-

CHAT-R is 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 will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive

### **Scoring Algorithm**

For all items except 2, 5, and 12, the response “NO” indicates ASD risk; for items 2, 5, and 12, “YES” indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

**LOW-RISK**: Total Score is 0-2; if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.

**MEDIUM-RISK**: Total Score is 3-7; Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.

**HIGH-RISK**: Total Score is 8-20; It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

For assessment, the common tools used are screening tools and diagnostic tools.

#### **A) Screening Tools:**

Screening tools are designed to help identify children who might have developmental delays. It can be specific to a disorder (for example, autism) or an area (for example, cognitive development, language, or gross motor skills), or they may be general, encompassing multiple areas of concern. Screening tools do not provide conclusive evidence of developmental delays and do not result in diagnoses. A positive screening result should be followed by a thorough assessment. Screening tools do not provide in-depth information about an area of development

#### **B) Diagnostic Tools:**

Many diagnostic tools are available to assess ASD in young children, but no single tool should be used as the basis for diagnosis. Diagnostic tools usually rely on two main sources of information--the parents’ or caregivers’ descriptions of their child’s development; and a professional’s observation of the child’s behaviour. In some cases, the primary care provider might choose to refer the child and family to a specialist for further assessment and diagnosis. Such specialists include child psychiatrists, geneticists, neurodevelopmental pediatricians, and early intervention programs that provide assessment services.

Scale	Uses	Age Range	Method of	Scale
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			<b>Administration</b>	<b>Characteristics</b>
<b>ABC</b>	Screening	Children	Parent Rated	57 items, scale 1-4
<b>CARS 2</b>	Screening	Children	Clinician Rated	15 items, scale 1-4
<b>M-CHAT</b>	Screening	Toddlers	Parent Rated	23 items, yes/no
<b>CAST</b>	Screening	4-11 Years	Parent Rated	37 items, yes/no
<b>ASDS</b>	Screening	5-18 Years		50 items, yes/no
<b>ASDI</b>	Screening	Child/adult	Interview + Clinician Rated	50 items, yes/no
<b>ISAA</b>	Diagnostic	2-9 years	Parent interview	40 items, scale 1-5
<b>ADI</b>	Diagnostic	Child/adult	Interview + Clinician Rated	
<b>DISCO</b>	Diagnostic	Child/adult	Interview + Clinician Rated	
<b>ADOS</b>	Diagnostic	Child/adult	Semi-structured Interactive Session	

**Table 5: Summary of Selected Assessment Instruments for Autism Spectrum Disorder**

ABC: Autism Behavior Checklist, CARS: Childhood Autism Rating Scale, M-CHAT: Modified Checklist for Autism in Toddlers, CAST: The Childhood Asperger's Syndrome Test, ASDS: Asperger Syndrome Diagnostic Scale, ASDI: Acute Stress Disorder Structured Interview, ADI: Autism Diagnostic Interview, DISCO: Diagnostic Interview for Social and Communication Disorders, ADOS: Autism Diagnostic Observation Schedule.

Alternatively, information can be obtained from caregivers about the child's ASD symptoms using questionnaires. The two most commonly used are the Social Responsiveness Scale (SRS, SRS-2) and the Social Communication Questionnaire (SCQ).

### Additional Elements of ASD Assessment

In accordance with DSM-5 specifiers, some features related to ASD require additional assessment, including the presence of cognitive or language impairment (or both). Abilities in these areas can range from severely impaired to advanced. The presence of developmental delays or co-occurring diagnoses, such as Attention Deficit and Hyperactivity Disorder (ADHD), in addition to ASD symptoms may add complexity to the diagnostic assessment process. Given these complexities, cognitive and language assessments and consideration of comorbid emotional and behavioral disorders are recommended for all patients with ASD.

ADHD particularly becomes a very important co-morbidity and confounding factor with ASD. Prevalence of ADHD symptoms in individuals with a primary clinical diagnosis of ASD has been reported to be between 13 and 50 % in the general population. When in doubt, the

symptoms can be treated and a diagnosis can be made later. This particularly holds true for those who have high functioning autism (previously Asperger's) and hyperactivity.

Similarly, it is difficult to differentiate between intellectual disability and ASD at times, and the comorbidity is very high, around 30-45%. Besides, there are hardly any tests which can accurately assess cognitive ability and intellect in autism. Hence, whenever in doubt, a period of serial evaluation and observation helps in reaching the final diagnosis. The Autism Spectrum Disorders-Comorbidity for Adults (ASD-Ca), 84 item scale designed to look at comorbid psychopathology in adults with as an Intellectual Disability

### **Differential Diagnosis**

Most of the time, inputs from members of the multi-disciplinary team will help lead to the diagnosis of autism. However at times it becomes difficult to differentiate autism from other conditions. Hence the following are important to keep in mind while assessing the individual.

**Table 6: Differential Diagnosis of ASD**

<b>Core Feature of ASD(Clinical)</b>	<b>Possible Differentials</b>	
	<b>DSM 5</b>	<b>ICD 10</b>
<b>Difficulty in language/communication</b>	Language disorder	Expressive language disorder Mixed receptive-expressive language disorder
	Speech sound disorder	Phonological disorder
	Social (pragmatic) communication disorder	Social (pragmatic) communication disorder
	Selective mutism	Selective mutism
<b>Difficulties in social interaction</b>	Attention-deficit/hyperactivity disorder	Attention-deficit/hyperactivity disorder
	Anxiety disorders, particularly social anxiety disorder	Social phobia
	Major depressive disorder	Major depressive disorder
	Personality disorders	Personality disorders
<b>Restricted and/or repetitive behaviours</b>	Stereotypic movement disorder	Stereotypic movement disorder
	Obsessive compulsive disorder	Obsessive compulsive disorder
	Tic disorders, including Tourette syndrome	Tic disorders, including Tourette syndrome
<b>Difficulties in multiple domains</b>	Intellectual disabilities Global developmental delay	Intellectual disabilities
	Reactive attachment disorder	Reactive attachment disorder
	Childhood onset Schizophrenia	Childhood onset Schizophrenia

	Traumatic brain injury	Traumatic brain injury
	Neurobehavioural Disorder Associated with Prenatal Alcohol Exposure	Fetal alcohol syndrome
	Genetic or Metabolic Syndromes	

A differential diagnosis for specific core domains becomes easier to approach, rather than trying to establish a differential for the disorder as a whole. This helps avoid both over-diagnosis and under-diagnosis.

### **Approach to treatment**

Just as the ideal assessment for autism is multi-disciplinary, so too, approach to treatment involves a multi-sensory, multi-disciplinary approach. Early intervention should be the aim to yield the best outcome and results.

Despite advances in early diagnosis and intervention, efficacious reversal of core autistic symptoms is still not accomplished, to date.

Treatments include a range of behavioral, psychosocial, educational, medical, and complementary approaches. The options vary by age and developmental status.

Chronic management is often required to maximize functional independence and quality of life by minimizing core deficits in social skills and communication, facilitating development and learning, promoting socialization, reducing maladaptive behaviors and educating and supporting families.

The treatments can be broadly divided into the following:

#### **A] NON-PHARMACOLOGICAL TREATMENTS**

These form the mainstay of approaches towards autism. These may be divided into:

##### **a) Structured educational and behavioural interventions:**

###### **i. Early Stage Denver Model(ESDM):**

This aims to accelerate children's development in all domains; intervention targets derived from assessment of developmental skills; stresses social-communicative development, interpersonal engagement, imitation-based interpersonal development, and social attention and motivation

###### **i. Applied Behavioural Analysis(ABA):**

ABA is probably the most widely used intervention for children as well as adults with autism. It focuses on improving specific behaviors initially using discrete trials to teach

simple skills, then progressing to more complex skills and complex behaviours. It is helpful in a wide variety of skills viz. social skills, communication, reading, and academics as well as adaptive learning skills, such as fine motor dexterity, hygiene, grooming, domestic capabilities, punctuality, and job competence. ABA is effective for children and adults with psychological disorders in a variety of settings, including schools, workplaces, homes, and clinics. It has also been shown that consistent ABA can significantly improve behaviors and skills and decrease the need for special services. Ideally more than 20 hours per week, under the age of 4 is recommended. ABA also helps in minimizing negative behaviours. In autistic adults, ABA can help with memory, relationships and cognitive strength.

ii. SCERTS:

This is an educational model which uses practices from other approaches including ABA, TEACCH, Floortime and RDI. The SCERTS Model differs most notably from the focus of ABA, by promoting child-initiated communication in everyday activities. SCERTS is most concerned with helping children with autism to achieve progress, which is defined as the ability to learn and spontaneously apply functional and relevant skills in a variety of settings and with a variety of partners.

The acronym SCERTS refers to the focus on:

SC: Social Communication - Development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults.

ER: Emotional Regulation - Development of the ability to maintain a well-regulated emotional state to cope with everyday stress, and to be most available for learning and interacting.

TS: Transactional Support - Development and implementation of supports to help partners respond to the child's needs and interests, modify and adapt the environment, and provide tools to enhance learning (e.g., picture communication, written schedules, and sensory supports).

Specific plans are also developed to provide educational and emotional support to families, and to foster teamwork among professionals.

b) Developmental interventions:

These include therapies that focus on building emotional relationships, fostering social communication and building social skills. Most commonly practiced are:

DIR/Floortime-Developmental, Individual Difference, Relationship Based and

RDI-Relationship Development Intervention

c) Interventions for Communication:

Use of communication modalities such as sign language, communication boards, visual supports, Picture Exchange Communication System(PECS), use of social stories, and social skills training. The latter three are more commonly used strategies, with some degree of effectiveness.

The Picture Exchange Communication System, or PECS, allows people with minimal or no verbal abilities to communicate using pictures. An individual using PECS is taught to approach another person and give them a picture of a desired item in exchange for that item. This thus forms a means of communication. A child or adult with autism can use PECS to communicate a request, a thought, or anything that can reasonably be displayed or symbolized on a picture card. PECS works well in the home or in the classroom.

A Social Story accurately describes a context, skill, achievement, or concept according to specific defining criteria. These criteria guide the author to ensure an overall patient and supportive quality, a format, “voice”, content, and learning experience that is descriptive, meaningful, and physically, socially, and emotionally safe for the child, adolescent, or adult with autism. For more advanced communication or older children, social articles may be used.

The core of autism is the lack of social skills and inability to understand social nuances and graces. Social skills training provides a graded, step wise approach to train a child in the simplest of socially expected behaviour, in order to facilitate friendships in the real world, which become a challenge for a person with autism.

d) Educational assistance:

Structural educational approach with explicit teaching and formulation of individualized education plans is important for every child with autism.

TEACHH: Treatment and education of Autistic and related Communication-handicapped Children . It involves an array of teaching or treatment principles and strategies based on the learning characteristics of individuals with ASD, including strengths in visual information processing, and difficulties with social communication, attention, and executive function. Structured TEACCHing is not a curriculum, but instead is a framework to support achievement of educational and therapeutic goals. This framework includes:

1. Physical organization
2. Individualized schedules
3. Work (Activity) systems
4. Visual structure of materials in tasks and activities

The goal of Structured TEACCHing is to promote meaningful engagement in activities, flexibility, independence, and self-efficacy.

e) Sensory Integration:

Occupational therapists use sensory integration therapy to help a child with autism play like other children. Sensory integration therapy involves placing a child in a room specifically designed to stimulate and challenge all of the senses. Sensory integration therapy is based on the assumption that the child is either over- or understimulated by the environment. Therefore, the aim of sensory integration therapy is to improve the ability of the brain to process sensory information so the child will function more adaptively in his/her daily activities.

f) Others:

Some evidence of CBT for anxiety and anger management in the high functioning youth with ASD

Animal assisted therapy, particularly use of trained dogs, has been gaining increasing popularity. The premise that a non-verbal bond with the animal, can facilitate release of oxytocin, and thereby improve social skills and bonding, as well as build empathy; forms the basis of this therapy.

**Table 7: Overview of Non-pharmacological approaches for ASD**

Type of Therapy	Target age	Evidence for Effectiveness	Therapeutic goals
<u>Home Based</u>  ESDM(Parent based) joint attention, parent-child interaction, social interaction etc.	Young children	Insufficient or low	Supplements other interventions at home and provides strategies in the comfort zone of the child. It aims at improving overall skills in a real life setting

<u>ABA Based</u>			
Early intensive behavioural intervention	Young children (usually aged <5 years)	Low or moderate	Based on ABA principles; usually home-based or school-based; application of discrete trial training (ie, teaching in simplified and structured steps); 1:1 adult-to-child ratio; intensive teaching for 20–40 h/week for 1–4 years
SCERTS	Children	Not established but potentially useful	Social Skills, Communication, Emotional regulation, Transactional Support.
ESDM	Young children	Moderate or insufficient	ESDM and integration of ABA principles
Floortime	Young children (usually aged <5 years)	ESDM; established floortime	or for not for ESDM and integration of ABA principles and pivotal response training (ie, focus on core areas in a more naturalistic setting and process)
RDI			Floortime: emphasises functional emotional development, individual differences in sensory modulation, processing and motor planning, relationships, and interactions
<u>Teaching Based</u>			
Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH)	Children, adolescents, and adults	Low	Based on the strengths and weaknesses model—uses core strengths like visual skills and supplements weaker areas for eg. Social skills to build on learning towards meaningful communication.
<u>Targeted skill-based intervention</u>			
Picture Exchange Communication System	Non-verbal individuals	Moderate	Teaches spontaneous social-communication skills through use of symbols or pictures
Focus on areas like: Joint attention, imitation, emotion recognition, theory of mind, and functional communication	Children. Can be done in a group too.	Not established, but potentially effective	Social communication and interaction.
Teaching social skills (eg, emotion recognition, turn-taking) with a focus of	Children, adolescents,	Not established, but	Short-term (weeks to months) interventions with DVDs (eg, <i>Mindreading</i> or <i>The Transporters</i> ) or Lego therapy. Use of many

specific areas or skills of interest (eg, in machines and systems)	and adults	potentially effective	apps available on tablets and smartphones.
Social skill training	Children aged $\geq 6$ years,adolescents, and adults. Can be in a group format.	Low or moderate	
Training in living skills and autonomy	Children, adolescents, and adults	Not established	Autonomy and self- management
Vocational intervention	Adolescents and adults	Insufficient	Eg, interview training and on-the-job support
Targeted behavioural intervention for anxiety and aggression	Children to adults		Using ABA and Behaviour therapy
Cognitive behavioural therapy	Children, adolescents, and adults	Not established	Particularly works with comorbidities like intellectual disability, anxiety, depression etc.
Animal Assisted therapy	Young children	Not established	Bonding releases oxytocin

**a) Pharmacological treatments:**

Medication is indicated if the child is unresponsive to non-pharmacological intervention or when behaviour has a negative impact on functioning. In cases when the problem behavior is responsive to medication, it is with the understanding it is a symptomatic treatment, not a cure and not a substitute for appropriate behavior and education programming.

**Medications Commonly used in Autism include:**

- Antipsychotics(Conventional and Atypical)
- Stimulants
- Antidepressants-SSRI
- Alpha 2 agonists
- Anticonvulsants and mood stabilisers
- Anti anxiety and benzodiazepines
- Sleep medication

#### **Recent Update of Pharmacotherapy in Children and Adolescents with ADD:**

Atypical antipsychotics, particularly risperidone and aripiprazole, are effective in reducing irritability, stereotypy and hyperactivity. Methylphenidate is effective in reducing attention-deficit hyperactivity disorder (ADHD) symptoms.

Atomoxetine and alpha-2 agonists appear effective in reducing ADHD symptoms. SSRI's are not effective in improving repetitive behaviors in children with ASD, and in fact, frequently cause activating adverse events. Efficacy of antiepileptic drugs is inconclusive. Newer agents, including glutamatergic agents and oxytocin, appear promising albeit with mixed results.

Serious behavioral disturbance (irritability) involving severe tantrums, aggression, and self-injury is frequent in ASD. A multimodal approach is used in the management of irritability in ASD. Individuals with mild irritability may benefit from treatment with an  $\alpha$ 2 adrenergic agonist. Risperidone and aripiprazole are the only two FDA-approved atypical antipsychotics medications for irritability in children and adolescents with autism. Evidence to date has been mixed regarding the effectiveness of other pharmacologic agents for irritability in ASD. Research into the pharmacotherapy of serious behavioral disturbance is needed to develop more effective and better tolerated treatments.

**Table 8: Selected published double-blind, placebo-controlled trials in ASD**

Drug	Study	Subjects		Design	Results
		N	Age (years)		
<b>Antipsychotics</b>					

<b>Aripiprazole</b>	Marcus et al. 2009	8	21	6-17	8 weeks, parallel groups	Aripiprazole > placebo (29/52 (56%) responders)
<b>Aripiprazole</b>	Owen et al. 2009		98	6-17	8 weeks, parallel groups	Aripiprazole > placebo (24/46 (52%) responders)
<b>Haloperidol</b>	Anderson et al. 1989		45	2-7	12 weeks, crossover	Haloperidol > Placebo
<b>Risperidone</b>	McDougle et al. 1998		31	Adults	12 weeks, parallel groups	Risperidone > placebo (8/14 (57%) responders)
<b>Risperidone</b>	RUPP Autism Network 2002	1	10	5-17	8 weeks, parallel groups	Risperidone > placebo (34/49 (69%) responders)
<b>Risperidone</b>	Shea et al. 2004		79	5-12	8 weeks, parallel groups	Risperidone > placebo (35/40 (87%) responders)

Drug	Study	Subjects		Design	Results
		N	Age (years)		
<b>Serotonin reuptake inhibitors</b>					
<b>Citalopram</b>	King et al. 2009	149	5-17	12 weeks, parallel groups	Citalopram = placebo

<b>Clomipramine</b>	Gordon et al. 1993	24	6-23	10 weeks, crossover	Clomipramine >placebo Clomipramine > desipramine (19/28 (68%) responders)
<b>Clomipramine</b>	Remington et al. 2001	36	10-36	7 weeks, crossover	Clomipramine > Placebo
<b>Fluoxetine</b>	Hollander et al. 2005	39	5-16	20 weeks, crossover	Fluoxetine > placebo
<b>Fluoxetine</b>	Autism speaks 2009	158	5-17	14 weeks, parallel groups	Fluoxetine = placebo
<b>Fluvoxamine</b>	McDougle et al. 2000	34	5-18	12 weeks, parallel groups	Fluvoxamine = placebo

Drug	Study	Subjects		Design	Results
		N	Age (years)		

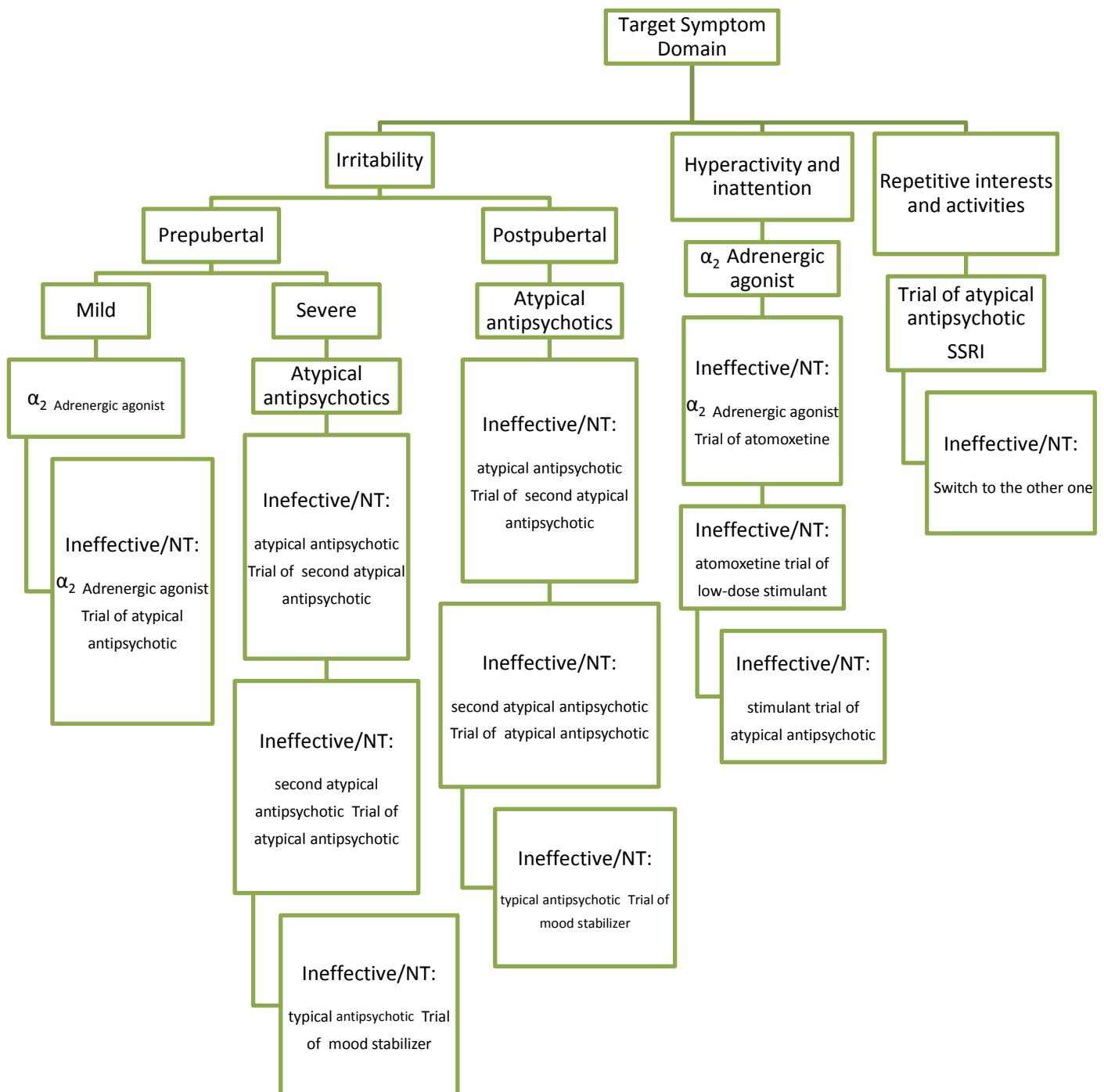
### **Alpha<sub>2</sub> Adrenergic agonists**

<b>Clonidine</b>	Jaselskis et al. 1992	8	5-13	14 weeks, crossover	Clonidine >placebo by teacher and parent, but not by clinician, ratings (6/8 (75%) responders)
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## Psychostimulants

<b>Methylphenidate</b>	Quintana et al. 1995	10	7-11	4 weeks, crossover	Methylphenidate> placebo
<b>Methylphenidate</b>	Handen et al. 1995	13	5-11	3 weeks, crossover	Methylphenidate> Placebo (8/13 (62%) responders)
<b>Methylphenidate</b>	RUPP Autism Network 2005	72	5-14	4 weeks, crossover	Methylphenidate> Placebo (35/72 (49%) responders)

**Figure 2: A target symptom approach to pharmacotherapy of ASD**



SSRI: Selective Serotonin Reuptake Inhibitors, NT: Not tolerated.

### **Expert Opinion:**

- ✓ Psychopharmacological treatment of core and associated symptoms in ASD is challenging
- ✓ Currently, risperidone and aripiprazole are the only medications
- ✓ They have been (relatively) reliably, shown to help treat certain symptom clusters associated with ASD, namely severely disruptive behavior and hyperactivity.
- ✓ Recent studies have begun to look at medications with mechanisms that are novel in the treatment of ASD like the glutamate-modulating agents.
- ✓ Overall, randomized, placebo-controlled studies of medications for the treatment of ASD are scarce.

### **Psychopharmacology adverse effects**

Psychopharmacological agents used in the management of various issues in children with ASD are associated with a number of adverse effects. A summary of the common adverse effects can be seen in the table below:

**Table 9: Common Adverse effects of drugs used for ASD**

<b>Class of Drug</b>	<b>Common Side Effects</b>	<b>Recommendation</b>
<b>SSRI</b>	-Gastrointestinal side effects like nausea, abdominal discomfort -Emergence of suicidal ideation or behavior -Hyponatremia -Hostility and aggression	-Watch for the above symptoms, especially at the beginning of treatment -Dose adjustment may be needed – start with low doses (eg. 2.5 mg of Fluoxetine as a starting dose, with a weekly increase to a maximum of 0.8 mg/kg/day) -Monitoring – especially if there are signs of hyponatremia -Stop medicines, if needed
<b>SDA's</b>	-Weight gain -Increased appetite -Somnolence -Sialorrhoea -EPS -Hyperglycaemia	-Monitoring for the above symptoms -Dose adjustment may be needed – start with low doses -Stop medicines, if needed -Management of diet, nutrition, weight
<b>Methylphenidate&amp; Atomoxetine</b>	-Loss of appetite -Abdominal discomfort - Headaches - Increase in irritability,	-Dose management – start with low doses (eg. 0.125 mg/kg/day of Methylphenidate as a starting dose, small increments) -Stop treatment

	worsening of behavior	
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### **Psycho-education for the family:**

It can be very challenging to break the diagnosis to parents, when their child has Autism Spectrum Disorder. A few points to be kept in mind while informing them are:

- Autism is a neuro-developmental disability.
- It is lifelong.
- It starts in utero.
- It is not produced by vaccines.
- It is not caused by bad parenting.
- All children may not be similar
- Early therapy helps
- Education may not be the only aim
- Talk to others about ASD openly
- Talk to other parents of children with ASD
- The path ahead may be difficult, but reach out for help at every step of the way
- Furnish examples of individuals with autism spectrum disorder

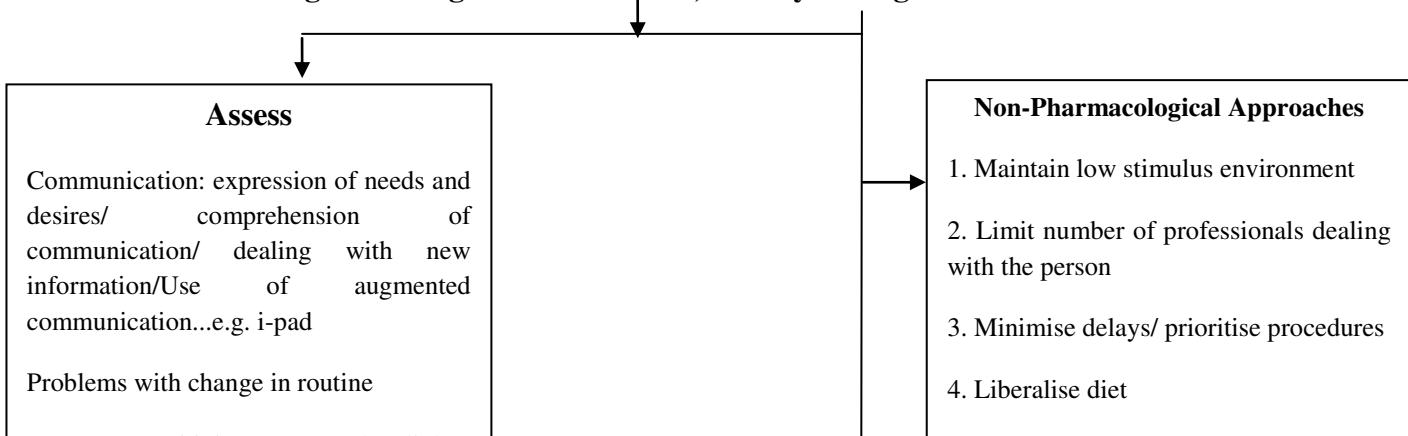
**Table 10: Overview of Recommendations in the management of ASD**

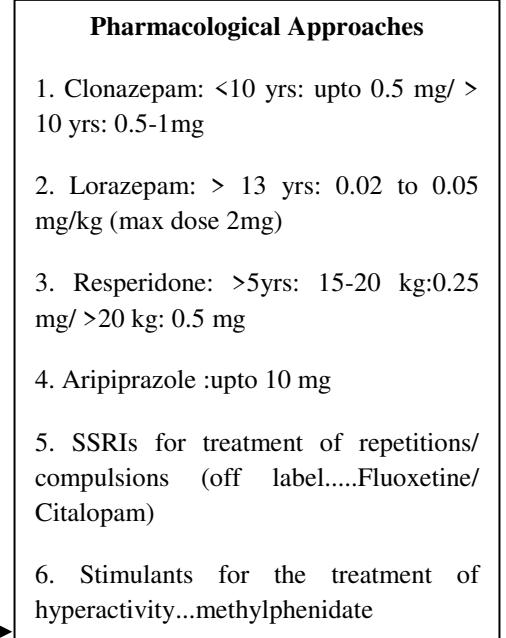
Overview of Recommendations at a glance	Non-Pharmacological	Pharmacological	Other
	ABA	Risperidone, Aripiprazole	Sensory Integration
	PECS	SSRI's for anxiety	Special education
	Social Stories	Co-morbidity to be treated symptomatically	Social Skills training
			Animal Assisted therapy

### **Special Issues**

#### **1. Distress, anxiety and agitation in ASD:**

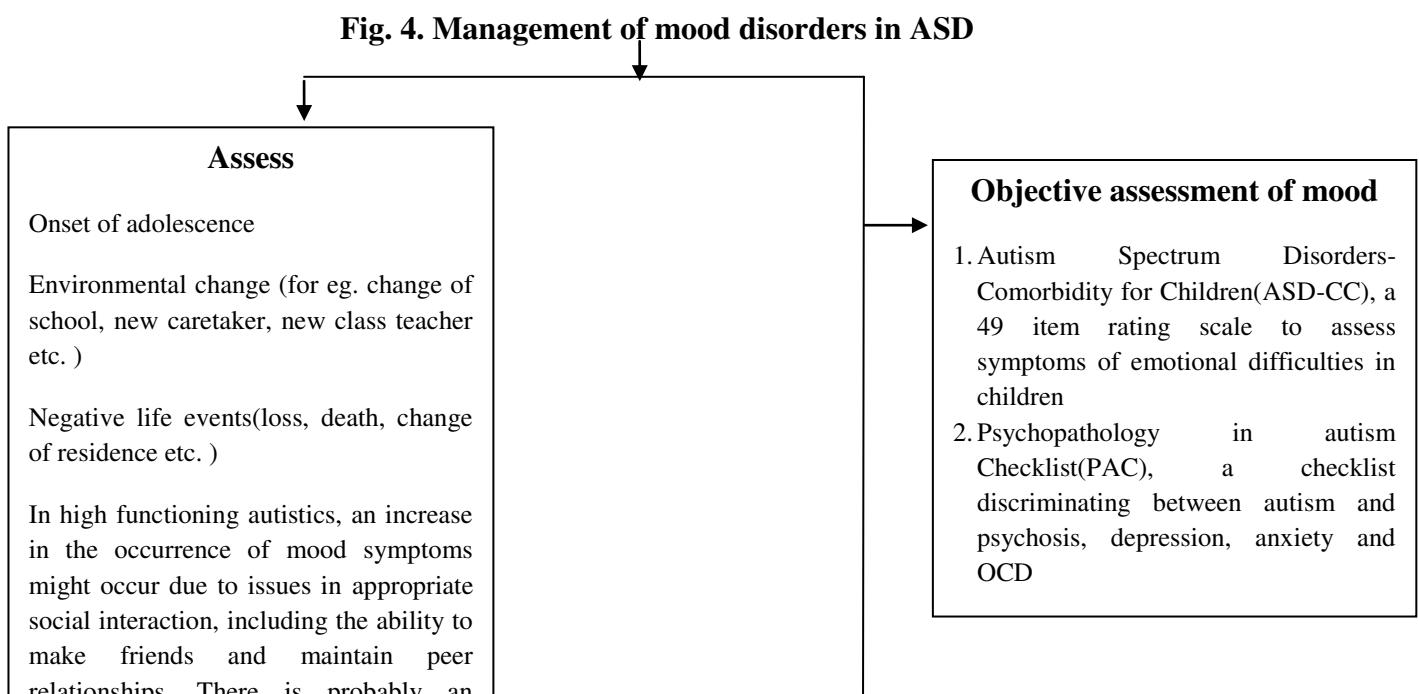
**Fig. 3. Management of distress, anxiety and agitation in ASD**





**Note:** Patients with ASD may require much lower or much larger doses than commonly prescribed..thus individual titration of dose is a must.

## 2. Mood Disorders in ASD



### **Management Approaches**

1. For Depression: SSRIs, TCA's, Stimulants
2. For Bipolar Disorder- Lithium, Divalproate
3. CBT particularly for high functioning individuals with good insight into social impairment and awkwardness.

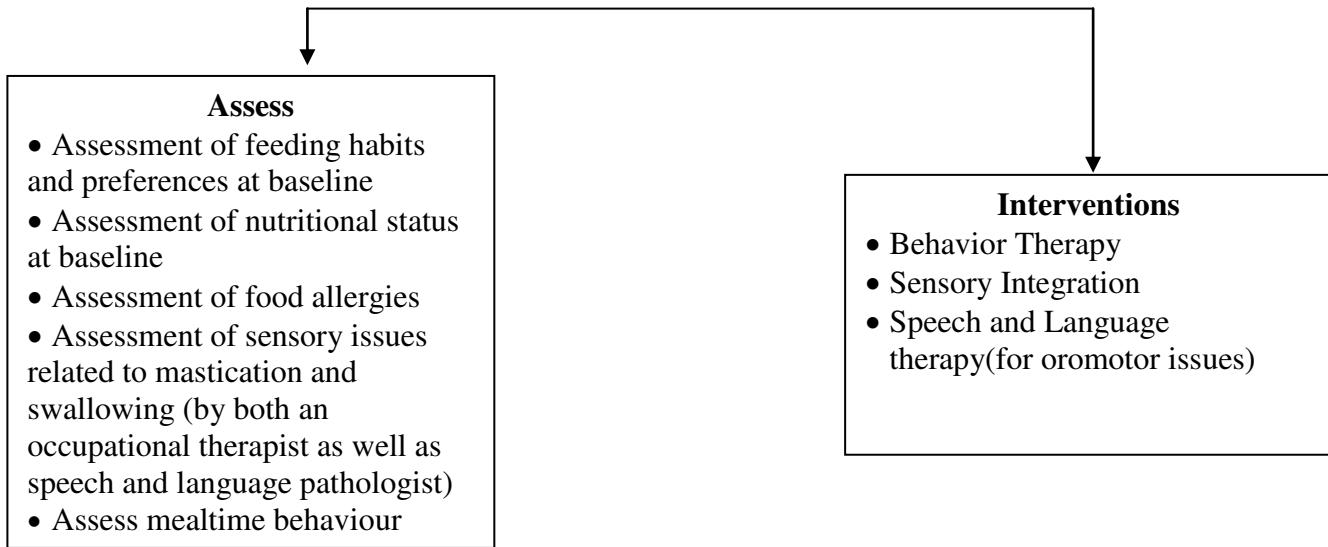
### **3. Feeding Disorders**

Feeding issues are common in children with ASD. These include:

- Poor eating schedules
- Poor eating skills
- Poor nutrition
- Preference for specific foods
- Weight gain

There is an overlap of phenomenology of ASD in girls suffering from Anorexia Nervosa. This is an area of further study that may help in understanding the individual and combined trajectories of these disorders.

**Fig 5. Management of feeding disorders in children with ASD**



#### **4. Sleep Issues**

Sleep issues are common in children with ASD. These include:

- Insomnias (Initial, middle, terminal)
- Sleep-wake cycle abnormalities

Impairment in the circadian rhythms are associated with Melatonin functioning. Melatonin, as treatment for sleep issues in ASD, has been found to be effective in numerous studies.

- **Dose requirements:** 1 – 10 mg hs
- Very few mild and transient side effects may be seen
- Low risk of seizure precipitation

Risperidone, Clonazepam, and Clonidine may also be of benefit in sleep disorders in individuals with ASD.

#### **5. Other issues that may be of importance:**

##### **a. Personality Disorders**

DSM 5 has made it possible to diagnose personality disorders in adolescence. This will facilitate early recognition of and intervention for personality disorders. Personality disorders may be comorbid with ASD. However, the relation between the two is very complex. Personality disorders like Schizotypal PD have a significant overlap with the symptomatology of ASD.

Studies are needed to understand the outcome of a comorbid personality disorder with ASD. A dual morbidity severely impacts executive, social and vocational functioning.

- **Intervention** – Psychotherapies, Medication (as necessary)

#### **b. Schizophrenia**

Both ASD and Schizophrenia have been conceptualized as neurodevelopmental disorders, and share many phenotypical patterns. Recent studies have shown the rates of co-occurrence between ASD and Schizophrenia to be highly variable (0% - 50 to 60%). There is an urgent need to develop specific tools to diagnose these two disorders, and further, develop intervention strategies for them.

#### **c. Gender Dysphoria and ASD**

Multiple studies show that individuals with ASD were significantly more likely to report experiencing gender-dysphoric symptoms than were typically developing individuals.

Why could gender dysphoria be more prevalent in ASD?

1. Hormonal factors Foetal testosterone (fT) strongly contributes to sexually dimorphic cognition and behaviour
2. Elevated levels of prenatal testosterone might predispose the male foetus to homosexuality
3. Relationship between the anti-Mullerian Hormone and ASD, where lower levels of AMH have been associated with ASD symptoms in males. It is believed to play a role in the masculinisation of, or the defeminisation of the male foetus

These have a huge potential for future research and diagnostic potential.

#### **d. Certification and Insurance**

Certification is necessary to quantify disability, avail of the benefits from the various schemes, and qualify for insurance.

- Disability assessment should be done using INCLEN tools & India Scale For Assessment of Autism (ISAA), following a clinical diagnosis of ASD using DSM 5 or ICD 10 or other prevalent criteria.
- Various other schemes available to autistic individuals are Niramaya (Insurance), Aspiration (Early intervention) and GyanPrabha (scholarship)
- According to the Government guidelines have requested state governments to constitute certification medical boards immediately. The appropriate government shall constitute Autism Certification Medical Board comprising of a Pediatrician/Pediatric neurologist, a clinical

Psychologist or Rehabilitation Psychologist, and a Psychiatrist. Further, it is stated that the certificate should be valid for a period of five years for individuals below 18 years of age with temporary disability; and for those who have acquired permanent disability, should receive ‘permanent’ validity on their certificates.

#### e. Travel

- Certification for ASD may be necessary for availing concessions by various travel authorities – buses, trains, air travel. This is important for both local and distance traveling.
- Considering the symptomatology of ASD like inability to tolerate change, thorough planning for picnics and excursions will be needed. It will also be helpful, if the child is repeatedly reminded of the event so that they are prepared. Specifics regarding food and clothing should also be considered.
- Use of pictures or a scrapbook can be very useful to prepare a child beforehand for the trip.
- At times, particularly for long journeys or change in altitude, one may prescribe a small dose of an anxiolytic or an anti-histaminic like promethazine.

#### f. Planning another child

Parents are often in a dilemma about whether or not to have a second child, when the first has been diagnosed on the spectrum. The tussle lies between the energy required for a child with special needs, and the hope of having a child with regular needs. Unfortunately, genetic studies and robust evidence is lacking in the area. Studies done estimate the risk to be between 3-10%, and more recently, upto 20% for a second child; when the first has received a diagnosis of ASD. The broadening of the spectrum, could be an additional contributory factor to these elevated figures. Nevertheless, infant screening and genetic counseling are advisable, for such families.

#### g. Care after parents

Caring for a child with ASD can be an extremely difficult and challenging task for parents. A permanent worry faced them is the fate of their child as she grows up to be an adult, and their future care after their passing away.

Newer concepts that have come up to address such difficult issues are:

- Lifespan-Carers – individuals who are well versed with ASD in its totality, and the manner in which it affects the individual at all levels of functioning. They can provide help at various crucial points to individuals with ASD, throughout their lifespan.
- Positive Behavior Support (PBS) – It is based on the principles of Applied Behavior Analysis, Inclusion Movement, and Personalized Values.
- Multidisciplinary teams consisting of professionals, family members, friends, neighbors, social workers, and volunteers can ensure care and support to an individual at all times.
- Strong support from parents groups like Forum for Autism, Action for Autism etc. These also help deal with caregiver distress and burn out by forming a support network for the parents themselves as well.
- Recently built centres for assisted living for autistic individuals in Gurgaon, Hyderabad and Bengaluru to name a few, have given some hope to worried parents as to what after them.

Continued efforts are needed in a multicultural society like India to provide long term care for individuals suffering from ASD.

### **Non evidence based treatments**

As stated by the FDA, there is no ‘cure’ for autism, and any treatment claiming to be curative can be treated as a lie. Autism is a lifelong disorder which responds to intervention over a period of time, but does not disappear.

It is thus recommended that one should educate parents about the following:

1. Be suspicious of products that claim to treat a wide range of diseases
2. Not accept personal testimonials as a substitute for scientific evidence
3. Few diseases or conditions can be treated quickly, so be suspicious of any therapy claimed as a “quick fix”
4. So called “miracle cures” which claim scientific breakthroughs or contain secret ingredients, are usually a hoax

A list the therapies which have poor evidence, often can be exorbitant, to some extent even prohibitive in cost and thus not recommended are:

- A. Stem cell therapy
- B. Hyperbaric oxygen therapies
- C. Detoxinating Clay baths
- D. Products such as essential oils

- E. Snake oil
- F. Dietary plans : Gluten free/ Casein free diet and the addition/deletion of specific nutrients
- G. Lupron Therapy: Testosterone therapy
- H: Chelating therapies
- I. Secretin Injection
- J. Major Vitamin supplements
- K. Marijuana Therapy
- L. Bleach therapy
- M. TMS
- N. Dolphin assisted therapy
- O. Holding therapy
- P. Prism glasses etc.

Sometimes in the absence of facilities for recommended therapies, parents of autistic children(who by themselves form a vulnerable population), may resort to any/ many of the above. It is important thus for a psychiatrist to be aware of that what is not recommended or has a poor evidence base.

It is important to also mention here, that the Centre for Disease Control, USA has clearly stated that vaccines play no role in causing autism. Parents at times, under the influence of non-scientific hearsay, do not follow the vaccination schedule, as a preventive measure for autism. The converse is actually true and lack of routine vaccination can be more detrimental to the child.

Autism, despite being a challenge for most clinicians, and a lifelong condition, has found tremendous potential for research as well as intervention in the last decade. What is definitely evidenced is that earlier the diagnosis and earlier the intervention, better is the overall outcome and quality of life for not only the autistic individual, but the entire family.

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Below are given 40 statements which are divided under six domains. Please tick () mark the appropriate rating for each item of the scale by observing the child & by interviewing the parents in order to assess Autism

**Indian Scale for Assessment of Autism(ISAA)**

**Appendix**

**Proforma**

Name of the child \_\_\_\_\_

Gender \_\_\_\_\_ Date \_\_\_\_\_

D.O.B. \_\_\_\_\_ Age \_\_\_\_\_ Examiner \_\_\_\_\_

Items	Rarely upto 20% Score 1	Sometimes ≥21-40% Score 2	Frequently ≥41-60% Score 3	Mostly ≥61-80% Score 4	Always ≥81- 100% Score 5
<b>SOCIAL RELATIONSHIP &amp; RECIPROCITY</b>					
1 Has poor eye contact					
2 Lacks social smile					
3 Remains aloof					
4 Does not reach out of others					
5 Unable to relate to people					
6 Unable to respond to social/environmental cues					
7 Engages in solitary & repetitive playing activities					
8 Unable to take turns in games					
9 Does not maintain peer relationships					
<b>EMOTIONAL RESPONSIVENESS</b>					

<b>10</b>	Shows in appropriate emotional responses					
<b>11</b>	Shows exaggerated emotions					
<b>12</b>	Engages in self-stimulating emotions					
<b>13</b>	Lacks fear of danger					
<b>14</b>	Excited or agitated for no apparent reason					

### **SPEECH-LANGUAGE COMMUNICATION**

<b>15</b>	Acquired speech & lost it					
<b>16</b>	Has difficulty in using non-verbal language or gestures to communicate					
<b>17</b>	Engages in stereotyped or repetitive use of languages					
<b>18</b>	Engages in echolalic speech					
<b>19</b>	Produces infantile squeals/ unusual noises					
<b>20</b>	Unable to initiate or sustain conversation with others					
<b>21</b>	Uses Jargon or meaningless					
<b>22</b>	Pronouns Reversal					
<b>23</b>	Unable to grasp the pragmatics of communication					

### **BEHAVIOURAL PATTERNS**

<b>24</b>	Engages in stereotyped or repetitive motor mechanisms					
<b>25</b>	Shows na attachment to inanimate objects					
<b>26</b>	Show hyperactivity/restlessness					
<b>27</b>	Exhibits aggressive behaviour					
<b>28</b>	Throws temper tantrums					
<b>29</b>	Engages in self-injurious acts					

<b>30</b>	Insists on sameness					
<b>SENSORY ASPECTS</b>						
<b>31</b>	Unusually sensitive to stimuli					
<b>32</b>	Stares into space for long time					
<b>33</b>	Has difficulty in tracking objects					
<b>34</b>	Has unusual vision					
<b>35</b>	Insensitive to pain					
<b>36</b>	Responds to objects/people unusually by smiling, touching or tasting					
<b>COGNITIVE COMPONENT</b>						
<b>37</b>	Inconsistent attention & concentration					
<b>38</b>	Shows delay in responding					
<b>39</b>	Has unusual memory					
<b>40</b>	Savant Ability					

## **CERTIFICATE OF DISABILITY OF PEOPLE WITH AUTISM**

**Government of \_\_\_\_\_**

(Name & Address of State/Authorised Autism Certification Medical Board issuing the

Recent attested  
Photograph

Affixed here

certificate)

This is to certify that  
Shri/Smt./Kum. \_\_\_\_\_ Son/Daughter

of \_\_\_\_\_ of Village/Town/City (complete address of the applicant) with particulars given below

- Date of Birth
- Sex
- Signature & Thumb impression

has been examined by the State/Authorised Autism Certification Medical Board & he/she is found to be categorised as person with No Autism/ Mild Autism / Moderate Autism / Severe Autism

His/Her percentage Disability is \_\_\_\_\_.

Signature & Seal

Chairperson of State/Authorised Autism Certification Medical Board

Date

Place