

Access this article online :

Quick Response Code:



Website :

<https://ijdbp.in>

DOI :

doi.org/10.5281/zenodo.10441243

Everything We Need to Know about Autism Spectrum Disorder

Authors: Dr. PunamUke, Dr. Sarika Gaikwad, Dr. Shailesh Wandile, Dr. Varsha Lamture

Correspondence: Dr. PunamUke, E-mail : drukepunam@gmail.com, Mob. no: 8551839785

Department of Pediatrics, AVBRH, Sawangi, Wardha , Pin code 442001.

Abstract:

Autism Spectrum Disorder(ASD) is a complex neurodevelopmental condition characterized by deficits in social interaction, communication difficulties and repetitive behaviors that profoundly impacts the lives of affected individuals and their families .This article provides comprehensive overview of ASD, focusing on screening, diagnosis and intervention strategies.

Early signs of ASD can manifest as early as six months, but parents may not recognize them until their child falls behind in meeting social milestones. This delay in recognition is often due to a lack of awareness, societal stigma and limited knowledge about developmental and behavioral disorders.

Globally, ASD prevalence is on the rise, potentially due to broader diagnostic criteria, increased awareness and improved screening practices. Screening for ASD is crucial for early identification and intervention. Various tools are available such as Modified Checklist for Autism in Toddlers (M-CHAT), Trivandrum Autism Behavioral Checklist (TABC) and the Social Communication Questionnaire (SCQ) .Diagnosing ASD involves using established criteria such as the DSM-5(Diagnostic and Statistical Manual of Mental Disorders, Fifth

Edition) and specific diagnostic tools like the Autism Diagnostic Observation Schedule (ADOS) and the Indian Scale for the Assessment of Autism (ISAA).

Interventions for ASD should be multidisciplinary, involving professionals such as developmental pediatrician, psychologist, special educators, occupational therapist, speech therapist and social workers. Applied Behavior Analysis(ABA), Naturalistic Developmental Behavioral Interventions(NDBIs) and parent mediated treatment are among the evidence based approaches.

Additionally, speech-language therapy, motor therapies and sensory integration therapy play vital roles in addressing the diverse needs of individuals with ASD. Medical interventions should be used alongside behavioral and environmental strategies.

Early screening accurate diagnosis and tailored interventions are essential for improving the lives of individuals with ASD. A multidisciplinary approach and increased awareness are crucial in addressing the growing prevalence of ASD worldwide.

Key words: Autism Spectrum Disorder, Screening, Multidisciplinary, Diagnostic Criteria, Sensory integration therapy

Introduction:

Autism Spectrum Disorder (ASD) is a neurological disorder characterized by limitations in social interaction, social communication, and repetitive, restricted patterns of behavior [1]The two main domains that make up the core characteristics of autism are deficits in social interaction and communication as well as constrictive, repetitive behavioral patterns. It is a neurodevelopmental conditions with major life altering implications and high rates of medical and psychiatric comorbidities.[2,3]“Spectrum” in ASD indicates that each individual is affected in different ways, with mild-to-severe symptoms often with overlapping comorbidities.

The earliest indications of autism can be seen as early as 6 months, but parents may not notice them until their kid falls behind other youngsters his or her age in meeting social needs. When their child cannot verbally communicate in the early years, parents of autistic children grow increasingly concerned. Parents gradually notice social impairments as children become more ambulatory. Parents couldn't notice signs and symptoms of ASD at earlier age mainly because of not being aware of this condition, profound ignorance and social stigma in society regarding developmental and behavioral problems. In 2016 ASD is included in disability certification under Indian Rights of Persons with Disability Act.

Although there is no conclusive evidence to support the precise cause of autism, numerous studies conducted globally suggest that many genetic or chromosomal conditions, such as fragile X syndrome or tuberous sclerosis, complications during delivery and a stay in the neonatal intensive care unit, and children born to older parents have a higher risk of developing

ASD than children without these conditions. The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition clubs all subgroups of autistic disorder, including Asperger syndrome and pervasive developmental disorder (PDD), as single entity ASD.[1]

Disease Burden in India and World:

Once considered as a rare disorder, autism spectrum disorders affects as many as 1 in 65 children in age group of 2-9 years in India. [4] Autism is contributed as serious public health problem in India because as many as 1.8–2 million children said to be affected with autism spectrum disorder. A recent systematic review of the South Asian (Bangladesh, India, Sri Lanka) population has reported prevalence rate of 0.09% to 1.07% among children in 0–17 years with ASD.[5] ASD affects more than 5 million children in America , with an estimated prevalence of 1 in 59 approximately 1.7%. [6] Systematic research is lacking in the field of autism in India as compared to developed countries because of which many cases goes undiagnosed resulting in reduced prevalence rate than actual value. So cases which come to health facility can be just a peak of an iceberg, many cases are still hidden and undiagnosed.

Prevalence of ASD is increasing drastically all over the world causing societal impact of ASD.[7,8,9] Increasing prevalence of ASD can be because of several factors such as broadening of diagnostic criteria with repeated timely revisions of the Diagnostic and Statistical Manual of Mental Disorders (DSM) along with pervasive developmental disorder and other autistic conditions considered as single entity as ASD in recent time. Public awareness about symptomology of condition and increased

practice of universal screening for ASD by health practitioner lead to early and increased detection of children with autism. Easily available facilities of early intervention and active school participation in providing school-based services for children with ASD might add to increased prevalence.^[10]

Symptoms of ASD:

ASD children have characteristic features which are abnormal variation in normal social and ritualistic behavior for children of that age. ASD presented with main two core features i.e. deficit in social communication/interaction and restricted, repetitive patterns of behavior as described in the DSM- 5.^[11] Lack of social communication/interaction can manifest as abnormalities in initiating and maintaining back-and-forth conversations, failing to respond to others by name, making very poor eye contact while speaking with them, using gestures in unusual ways, failing to understand imaginative play, and displaying very little interest in other kids.

Restrictive repetitive patterns of behavior can take the shape of a set routine and interests, repetitive body movements (such spinning and flapping the hands), echolalia, and unusual processing of sensory stimulus from the auditory, visual, and tactile senses. Children with ASD frequently have co-morbid conditions, which have a severe negative impact on how well the kid and family function as well as on management. Developmental or behavioral issues, such as attention-deficit/hyperactivity disorder (ADHD), anxiety, mood disorders, sleep disorders, and seizures are frequently present coexisting comorbidities with autism spectrum disorder (ASD). Food refusal, constipation, self-injury,

aggressiveness, and depression are additional prevalent issues.^[11]

Need of Early Screening in ASD:

Many recent studies and research done all over globe came with outcome of increased in prevalence of ASD worldwide which lead to targeting our focus to identify children with signs of an ASD as early in development as possible and optimal early intervention in the toddler, and preschool children. Reliable age to identify and diagnose ASD could be as low as 2 years as observable symptoms are present in this age.^[12] Autism screening is a very effective way to standardized process to keep a watch so that children are systematically and regularly monitored for early signs of ASD which will ultimately lead to earlier diagnosis which in a long term helps to reduce delays and encourage early intervention to reduce disease burden in society.^[13] Recent systematic studies done all over the world in different cultural settings have proved that early intervention can improve outcomes mainly in core features of ASD, IQ, language outcome, and symptom severity.^[14,15] Universal screening for ASD for all children has been recommended during well-child visits at ages 18 and 24 months along with developmental screening by the American Academy of Pediatrics (AAP).^[16]

Screening Tools for ASD:

Screening tools are small questions based brief assessments for identifying children at risk of a neurodevelopmental disorders such as autism. Autism being a behavioral diagnosis, it's very important to mainly focus on autism specific observable behaviors while developing a screening tool. Screening tools based on parents report are easy to administer and require less of

a professional assistance but close vigilance is needed while interpreting by a professional as some parents specially first time parents, may be unaware of appropriate developmental milestones

and atypical pattern of behavior in their children. Commonly used screening tools are listed below (Table 1).

Table I – Screening Tools for ASD

Sr. No.	Name of Screening Tool	Age group for application
1.	Modified Checklist for Autism in Toddlers (M-CHAT)	16-30 months
2.	Trivandrum Autism Behavior Checklist (TABC)	2-6 years
3.	Social Communication Questionnaire (SCQ)	4 years and above
4.	Autism Behavior Checklist (ABC)	18 to 35 months
5.	Ages and stages questionnaires (ASQ)	6 months to 5 years
6.	Screening Tool for Autism in Toddlers (STAT)	24 to 35 months
7.	Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP)	6 to 24 months
8.	Parents' Evaluation of Developmental Status (PEDS)	birth to 7 years and 11 months
9.	Indian Autism Screening Questionnaire (IASQ)	3-18 years
10.	Chandigarh Autism Screening Instrument (CASI)	1.5–10 years

M-CHAT:

A free screening tool that is available in many different languages is the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT R/F). It is a two-stage parent report that takes around 10 minutes to complete and comprises 20 closed-ended questions with Yes/No responses to screen children between the ages of 16 and 30 months who are at high risk for ASD.^[17] Children who score higher than 8 are at a high risk for ASD or another developmental problem and should be sent for a diagnostic evaluation to confirm the diagnosis. Children who scored between 3 and 7 should go through additional interview questions for the items that were positive. Children who continue to score between 3 and 7 items positively for ASD should be referred for a diagnostic evaluation. Scores

below 3 are considered to be negative for ASD.

TABC:

Autism Behavior Checklist of Trivandrum TABC test is a straightforward instrument created by the Child Development Center at the Medical College in Thiruvanthapuram, India, whose evaluation results were compared to the Childhood Autism Rating Scale (CARS).^[18] The four developmental domains of social interaction, communication, behavioral traits, and sensory integration are evaluated by the TABC. Responses include never (1), occasionally (2), frequently (3), and always (4). It also helps to classify autism according to severity, with scores of 20 to 35 denoting non-autism, 36 to 43 denoting mild to moderate autism, and 44 and higher denoting severe autism.^[19]

Social Communication Questionnaire (SCQ):

Previously it is called as Autism Screening Questionnaire, was derived from the ADI-R. It's available in many Indian languages and is often considered the gold-standard questionnaire used in many autism research studies.^[20] The SCQ have 40 questions with answers in yes or no to be completed by parents. It is available in two forms i.e. less than 6 years and more than 6 years. It takes less than 10 minutes for caregiver/parents to complete the test and less than minutes to score it.

Autism Behavior Checklist (ABC):

Children between the ages of 18 and 35 months can benefit from the autism screening tool known as the Autism Behavior Checklist (ABC). It assesses 57 behaviors in five different domains: social, relational, body and object usage, language, and sensory. The checklist can be completed by parents or instructors since they are fully aware of the many behaviors that children exhibit.

Ages and stages questionnaires (ASQ):

The parent or primary caregiver should fill out this general developmental screening tool. It consists of 19 age-specific questions with a pass/fail response for 19 different developmental categories, including communication, gross motor, fine motor, problem-solving, and personal adaptation skills.

Screening Tool for Autism in Toddlers (STAT):

It is an activity-based screening tool made for kids who are at high risk for neurodevelopmental disorders like autism. The administration of the assessment, which is done in 12 different tasks including play, communication, and imitation abilities, takes about 20 minutes. Children 24 to 35 months old can participate in it as an

interactive session.

Communication and Symbolic Behavior Scales Developmental Profile (CSBS DP):

The Communication and Symbolic Behavior Scales Developmental Profile was developed as a screening tool by Wetherby and Prizant. The Infant/Toddler Checklist, which evaluates communication and symbolic behavior, is the first step in a routine. Children between the ages of 6 and 24 months are screened with this test. If the first step doesn't work; the kid must assess communication with the other two CSBS DP components, namely the follow-up Caregiver Questionnaire and Behavior Sample (BS), based on the response.

Parents' Evaluation of Developmental Status (PEDS):

A 10-item questionnaire that parents must answer as part of the PEDS screening tool focuses mostly on behavioral and developmental issues. It is used for kids from birth to seven years and eleven months old and aids in the early detection of kids who exhibit indications of autism.

Indian Autism Screening Questionnaire (IASQ):

The Indian Scale for Assessment of Autism (ISAA), a frequently used diagnostic test for autism in India, served as the basis for the Indian Autism Screening Questionnaire (IASQ). This 10-item questionnaire has a yes/no response format and requires little training to use, making it crucial in areas with few medical services.

Chandigarh Autism Screening Instrument (CASI)

Chandigarh Autism Screening Instrument (CASI) specifically designed for community screening with the help of health workers. It is a 37-item questionnaire-based tool for children between 1.5–10 years.

Diagnostic Tools for ASD:

Children who are positive or high risk in screening tools should undergo evaluation for diagnostic tools for the confirmation of diagnosis. Different diagnostic tools are available but a DSM-5 criteria is an easy and comprehensive diagnostics tool for initial diagnosis by general pediatrician

and child psychologist. Formal assessment of hearing, vision and cognitive skills along with complete physical examination is of crucial importance before diagnostic assessment of ASD. Commonly used screening tools are listed below (Table 2).

Table II: Diagnostic Tools for ASD

Sr.No.	Name of Screening Tool	Age group for application
1.	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)	Above 1 year
2.	Autism Diagnostic Observation Schedule (ADOS)	Above 1 year
3.	Indian Scale for the Assessment of Autism (ISAA)	3-9 years
4.	INCLEN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD)	2-9 years
5.	Childhood Autism Rating Scale (CARS)	2 years and above
6.	Autism Diagnostic Interview Revised (ADI-R)	2 years and above
7.	Gillian Autism Rating Scale (GARS)	3-22 years

Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5):

The basic symptoms in the DSM-5 were divided into two categories: restricted, repetitive behavioral patterns and social communication and interaction. The DSM-5 requires that two of the four symptoms linked to restrictive and repetitive behaviors, along with all three symptoms of social emotional reciprocity, be present in order for the diagnosis of ASD to be made.^[1] The DSM-5 also helps in grading severity of ASD. It is a very easy to administer tool for pediatricians and child psychologists so that child can be started on early intervention at the earliest.

Autism Diagnostic Observation Schedule(ADOS):

The Autism Diagnostic Observation Schedule was the first instrument for diagnosing ASDs that was standardized and performance-based. It helps in the evaluation of social play and communication through a series of “planned social occasions” that provide the youngsters the chance to respond to varied social circumstances. The ADOS consists of four 30-minute units. Each module is designed to assess the child at the appropriate linguistic and developmental level. Children as early as 12 months old can have ASD diagnosed using the ADOS-2 (Autism Diagnostic Observation Schedule, Toddler Module).^[21]

Indian Scale for the Assessment of Autism (ISAA):

There wasn't previously a scale that was suitable for use in an Indian context because the bulk of scales were developed in western countries.^[22] The National Institute for the Mentally Handicapped developed the Indian Scale for the Assessment of Autism (ISAA), a diagnostic test for autism in India, in 2009 to solve this problem. The ISAA is a locally developed and standardized diagnostic tool for ASD. The ISAA includes screening questions on behavioral patterns, sensory and cognitive abilities, emotional receptivity, speech, language, and communication, as well as social interaction and reciprocity. It takes 45 to 60 minutes to administer and requires training. It is a comprehensive 40-item tool that relies on information from parents and a child's observation. It can be used for follow-up and certification, but not for screening in population research.^[23] The ISAA score ranges from 40 to 200, and as the number rises, so do the severity of the disorders.

INCLIN Diagnostic Tool for Autism Spectrum Disorder (INDT-ASD):

Diagnostic Tool for Autism Spectrum Disorder developed using DSM-5 criteria created by AIIMS (INDT-ASD). It has a sensitivity of 98.4% and specificity of 91.7% to diagnose ASD.^[24] The tool has two sections: Section A1 (1a, 1b, 1c) covers item related to social communication deficit type of symptoms of ASD and A2 (2a, 2b, 2c, 2d) covers restrictive repetitive behavior related symptoms which are 2 core domain of DSM-5. The process of scoring and administering the test takes about 45 to 60 minutes. Regarding peer interaction and play skills, it takes into account the diverse ethnic and religious variety prevalent in this country with its vibrant culture. It is to be

utilized by trained individuals and is based on both direct observation of a child between the ages of 2 and 9 years old as well as history from primary caregivers.

Childhood Autism Rating Scale (CARS):

Because it was created mostly by people with concurrent intellectual functioning, the original CARS was criticized for failing to accurately identify better functioning autistic individuals.^[25] The CARS-2 is an upgraded version of the Childhood Autism Rating Scale (CARS). is the most widely used behavioral rating scale for children older than two. The CARS-2 retained the original CARS form (now known as the CARS2-ST for "Standard Form") for use with children under the age of six or older but with an estimated IQ of 79 or less.

A special rating scale known as the CARS2-HF for "High Functioning" was developed for kids aged 6 and older with an estimated IQ of 80 or higher and fluent communication. To collect data from parents, use the CARS2-QPC (Questionnaire of Parent Concerns), an ungraded form for parents to report observations. The 15th category on the childhood autism rating scale (CARS), which consists of 15 categories, assesses how people perceive autism generally. The first 14 domains look at autism-related characteristics like verbal-nonverbal communication and restraint.

The severity of the impairment is indicated by a number between one and four assigned to each domain. The severity of the impairment is indicated by a number between one and four assigned to each domain. Total scores can range from 15 to 60; numbers under 30 are seen as being within the normal range, 30-36.5% is regarded as being mild to moderate autism, and 37-60% is regarded as being severe autism.

Autism Diagnostic Interview Revised (ADI-R):

A diagnostic approach that emphasizes behavior in three main areas namely reciprocal social contact, communication and language, and limited and repetitive, stereotyped interests and behaviors can be used to identify children and people with autism. The ADI-R can be used by children and adults with mental ages of at least 18 months. This measure includes a standardized, in-depth parent interview lasting 1.5 hours for parents of 3 to 4 year olds and older children, and 3 hours for older children.

Gilliam Autism Rating Scale (GARS)

By using this scale, schools, parents, and medical professionals can detect and diagnose autistic children between the ages of 3 and 22. It also assigns an ASD severity rating. It is a 42-item norm-referenced screening tool that includes a developmental history and collects data on certain traits frequently seen in kids with autism spectrum disorders in three domains (stereotypical behaviors, communication, and social interaction).

Key Points to Remember while Using Screening or Diagnostic Tool:

The AAP does not recommend any specific screening method, but recommendations clearly say that kids who receive a positive or at-risk result at any time should be referred.^[26] Effective screening tools exist but are not regularly utilized because of variety of factors including a lack of training in the use of tools, lack of awareness about the condition or a lack of time and resources. Screening and diagnostic tools should be used considering cultural and language preferences in that country. As prevalence of ASD has increased drastically worldwide effective screening of children at early age will help for early

identification and initiation early intervention which in long term seen as positive outcomes in form of improvement in communication, social interaction and cognitive development.

Different Intervention for ASD:

Because of complexity of Autism, the assessment and management should be with the help of multidisciplinary team which consist of developmental pediatrician, psychiatrist, psychologist, a special educator, an occupational therapist, an audiologist, speech therapist and social worker.

Applied Behavior Analysis (ABA):

To significantly alter socially significant behaviors and demonstrate how interventions result in improved behavior, it is based on learning theory concepts. Treatments utilizing ABA may concentrate on improving already-present skills (like social engagement) or minimizing harmful behaviors (like aggression) that might obstruct a child's development.

Naturalistic developmental behavioral interventions (NDBIs):

The administration of therapies within the context of naturally occurring social activities inside natural surroundings is a feature of naturalistic developmental behavioral interventions (NDBIs), which combine components of ABA and developmental principles. These therapies emphasize essential social learning abilities and learning objectives that are based on developmental stages.

Parent-Mediated Treatment

Numerous studies have shown that concentrated interventions delivered by trained parents or other caregivers can be beneficial to a therapeutic program.^[27] Students with ASD should normally

be educated in the least restrictive environment possible using the Treatment and Education of Autism and Related Communication Handicapped Children (TEACCH) curriculum and an individually tailored program adjusted to meet the goals of the Individualized Education curriculum (IEP).

Speech-language therapy

Speech-language therapy is the intervention that is most usually utilized with children who have ASD. [28] Children who struggle with conversational skills may benefit from using AAC (augmentative and alternative communication). AAC methods include sign language, the Picture Exchange Communication System (PECS), and speech-generating equipment. [29]

Motor Therapies:

Children with ASD may have hypotonia and coordination difficulties. The use of occupational therapy services is recommended to support fine motor and adaptive abilities, such as self-care, using toys, and handwriting. Toe walking is common among children with ASD which respond well to passive stretching, orthotics, and casting.

Sensory Integration Therapy

“Sensory Integration Therapies for Children with Developmental and Behavioral Disorders,” offering clinicians crucial baseline knowledge and suggestions common sensory-based therapies include skin brushing, wearing weighted vests

for proprioceptive stimulation, or engaging in kinesthetic stimulation. Play and sensory activities with child helps to improve sensory responses.

Medical Interventions:

Always utilize medication in conjunction with the proper behavioral and environmental interventions. For the treatment of co-morbid psychiatric or neurodevelopmental problems, as well as behavioral symptoms that impair the child’s ability to work on a daily basis, pharmaceutical therapy may also be necessary. Risperidone, Aripiprazole (maladaptive Behaviors), Methylphenidate, Atomoxetine (ADHD), Fluoxetine (Repetitive Behaviors and Rigidity), Melatonin, and Serotonin (Sleep Disturbances) are some of the medications frequently used in ASD.

Summary:

ASD is neurodevelopmental condition with a varied presentation mainly causing impairment in social communication and restrictive repetitive activities in children with associated comorbid conditions. Because of its diverse behavioral problems child along with the family has to go through adjustment issues while living in the society. Screening of autism at the early age along with appropriate diagnostic method can play a pivotal role for future outcome of these children. Multidisciplinary approach should be built while managing patient with ASD.

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