# Dubai Clinical Practice Guidelines for Autism Spectrum Disorder (ASD) in Children and Adolescents

(from Birth to 18 Years of Age)

**Version 1**

August 2021

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## INTRODUCTION

This document is dedicated to Ibrahim Hussein. Thank you for inspiring our mission.

“My name is Ibrahim” was the title of a two-day think tank that included experts in the field of Autism Spectrum Disorder in Dubai, which was organized to provide the framework for a comprehensive system of care for Autism in Dubai. “Ibrahim” is an Emirati boy with Autism, whose name was included in the title to represent a person-centered approach.

His Highness Sheikh Hamdan Bin Mohammed Al Maktoum, Crown Prince of Dubai, visited the working group on the second day, March 21, 2017. At the end of his speech, his highness expressed his appreciation for the chosen title and the meaning behind it, and concluded by saying: “We are all Ibrahim”.

"We are ALL Ibrahim”: Dubai Declaration on Autism, His Highness Sheikh Hamdan Bin Mohammed Al Maktoum.

**ACKNOWLEDGMENT**

Dubai Government would like to acknowledge Ibrahim and his family, every family supporting a child with Autism in Dubai, members of the Dubai Autism Guidelines Working Group and representatives of "My Name is Ibrahim" initiative for inspiring, efforts and commitment in developing these guidelines. Dubai Government also would like to acknowledge the contribution of Dubai Health Authority and Dubai HealthCare City Authority to this document.

Dubai Autism Guidelines Working Group (DAGWG):

The DAGWG was assigned to oversee the process of developing clinical guidelines for Autism Spectrum Disorder (ASD) through coordinating local efforts with advisory consultants and planning for the consensus process below:

- Dr. Ammar Albanna, Head of the Mental Health Center of Excellence at Al Jalila Children's Specialty Hospital, Chaired the DAGWG and coordinated global and local consultations.
- Dr. Sandra Willis, Co-Chaired the DAGWG and coordinated multiagency involvement, to ensure alignment with the Dubai strategic goals.

The DAGWG performed a comprehensive literature review and developed the first draft of the Guidelines, led by*:

- Dr. Hanan Derby, Consultant Child and Adolescent Psychiatrist at Al Jalila Children's.
- Dr. Meshal Sultan, Consultant Child and Adolescent Psychiatrist at Al Jalila Children's.
- Dr. Fekreya Arjamand, Former Director of Clinical Affairs from Dubai HealthCare City Authority.
- Ms. Nazneen Majid, Former Project Manager from Dubai HealthCare City Authority.

*The professional affiliations reflect the positions the team members held at the time of developing the document.

Further, the draft was comprehensively reviewed by ASD experts from the ASD team at Al Jalila Children's Hospital, including:

- Dr. Zeinab Alloub, Consultant Developmental Pediatrician.
- Mr. Hawk Kair, Affiliate Psychologist.
- Ms. Suha AlShuaibat, Senior Speech and Language Pathologist.
- Ms. Rasha Al Hejailan, Behaviour Analyst.
- Ms. Maya Helou, Affiliate Psychologist.

Additional support was provided by team members from Dubai Healthcare City Authority (DHCA) and Dubai Health Authority (DHA) to publish the document.

- Dr. Abdul Rahman Mahmood, Senior Executive of Professional Licensing Department, DHCA.
- Dr. Nadia Taysir Dabbagh, Consultant Child & Adolescent Psychiatrist, Rashid Hospital, DHA.
- Dr. Hanan Obaid, Director of Health Policies and Standards Department (HPSD), Health Regulation Sector (HRS), DHA.
- Dr. Latifa Alrustamani, Head of Monitoring and Evaluation Section, HPSD, Health Regulation Sector (HRS), DHA.
- Ms. Shatha Ghandi Muhsineh, clinical auditor, HPSD, HRS, DHA.

Consultations:

Local and International consultations were obtained from international experts in the field of Autism Spectrum Disorder. The two international experts selected to review the document were invited speakers at the "Systems of Care for Autism Spectrum Disorder: A Global Perspective" conference held by Al Jalila Children's from March 30 to April 1 2017.

- Professor Bennett Leventhal, a renowned expert in the field of ASD, is a Professor of Psychiatry at the University of California San Francisco, the Deputy Director of Child and Adolescent Psychiatry, Director of Psychiatry Training, and establisher of the STAR Center for Autism in San Francisco. Board member of the American Association of Child and Adolescent Psychiatrists and Allied Professionals and Chair of the Child Psychiatry Division under the World Psychiatry Association.
- Professor Valsamma Eapen is the Chair of Infant, Child and Adolescent Psychiatry Department at the University of South Wales, Sydney, Australia. She is a prominent researcher in neurodevelopmental disorders, including Autism Spectrum Disorder, and has conducted studies in the UAE. Her main area of focus includes epidemiology, genetic underpinnings, neurocognitive processes and clinical presentation of neurodevelopmental disorders. She is a Fellow of the Royal Australian and New Zealand College of Psychiatrists and the Royal College of Psychiatrists, UK.

**Dubai Government**

## ABBREVIATIONS

**AAC** : Augmentative Alternative Communication

**AAP** : American Academy of Pediatrics Childhood Genetics

**ABA** : Applied Behaviour Analysis

**ABC** : Autism Behavioural checklist

**ADD** : Attention Deficit Disorder

**ADI** : Autism Diagnostic Interview

**ADI-R** : Autism Diagnostic Interview Revised

**ADHD** : Attention-Deficit/Hyperactivity Disorder

**ADHD-RS** : Attention-Deficit/Hyperactivity Disorder Rating Scale

**ADOS-2** : Autism Diagnostic Observation Schedules Second Edition

**ADOS-G** : Autism Diagnostic Observation Schedules Generic

**ASD** : Autism Spectrum Disorder

**ASDI** : Asperger Syndrome Diagnostic Interview Review

**ASDS** : Asperger Syndrome Diagnostic Scale

**BCBA** : Board Certified Behaviour Analyst

**BCaBA** : Board Certified Assistant Behaviour Analyst

**CARS** : Childhood Autism Rating Scale

**CBC** : Complete blood Count

**CDC** : Centers for Disease Control and Prevention

**CSBS- DP- IT checklist**: Communication and Symbolic Behaviour Scales Development Profile Infant- Toddler checklist

**DAGWG** : Dubai Autism Guidelines Working Group

| | | |
|---|---|---|
| **DHA** | : | Dubai Health Authority |
| **DHCC** | : | Dubai HealthCare City |
| **DIR** | : | Developmental Individual -Difference Relationships- based Model |
| **DISCO** | : | Diagnostic Interview for Social and Communication Disorders |
| **DSM-5** | : | Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition |
| **EIBI** | : | Early Intensive Behavioural Intervention |
| **EDSM** | : | Early Start Denver Model |
| **FutureXchanges** | : | Future Exchanges |
| **GADS** | : | Gilliam Asperger's Disorder Scale |
| **GDD** | : | Global Developmental Delay |
| **ICD-11** | : | International Classification of Diseases, version 11 |
| **MASC** | : | Multidimensional Anxiety Scale for Children, second edition |
| **M-CHAT** | : | Modified Checklist for Autism in Toddlers |
| **MDT** | : | Multidisciplinary Team |
| **MMR** | : | Measles, Mumps, Rubella and Varicella combination vaccine |
| **OCD** | : | Obsessive Compulsive Disorder |
| **OT** | : | Occupational Therapist |
| **PECS** | : | Picture Exchange Communication System |
| **PCP** | : | Primary Care Provider |
| **RBT** | : | Registered Behaviour Technician |
| **RCT** | : | Randomized Controlled Trial |
| **SCQ** | : | Social Communication Questionnaire |
| **SDQ** | : | Strengths and Difficulties Questionnaire |

| | | |
|---|---|---|
| **SERT** | : | Serotonin Transporter |
| **SLP** | : | Speech and Language Pathologist |
| **SMD** | : | Stereotypical Movement Disorder |
| **SNAP** | : | Special Needs Assessment Profile |
| **SNP Microarray:** | | Single Nucleotide Polymorphism Microarray |
| **SRS** | : | Social Responsiveness Scale |
| **SSRI** | : | Selective Serotonin Reuptake inhibitors |
| **TEACCH** | : | Treatment and Education of Autism and relation Communication Handicapped children program |
| **WHO** | : | World Health Organization |

## 1. BACKGROUND

This document introduces the first edition of the Dubai Clinical Practice Guidelines for Autism Spectrum Disorder (ASD) in Children and Adolescents. These Guidelines substantiate Dubai Government's commitment to ensure all healthcare service providers and healthcare professionals in the Emirate of Dubai are in line with the government objective which declares that "... *all individuals with Autism receive adequate and equal opportunities to enjoy health, educational and employment opportunities and achieve their optimal development potential and quality of life, be self-determined and participate in, and contribute towards, society...".*

A focus group, dedicated to improving systems of care for Autism Spectrum Disorder (ASD) in Dubai, took place during the FutureXchanges in 2017, under the umbrella of the Dubai Executive Council. A multiagency plan followed, with the goal of improving current practices for the care of children and adolescents suspected of having ASD. The report following the FutureXchanges emphasized the importance of developing clinical practice guidelines for ASD in order to align recognition, assessment, and management processes into a unified model of best practice in Dubai. The model is designed to improve standards of care and promote much needed multi-agency work amongst professionals and service providers. Al Jalila Children's Specialty Hospital, the first dedicated pediatric hospital in the UAE, was assigned to lead and coordinate efforts towards completing the development of these guidelines.

DAGWG was tasked to develop these guidelines, which aim to identify and articulate a clear, robust, comprehensive framework of evidence-based models of care aimed to improve services for children and adolescents with ASD. This collaborative effort included input from various government agencies as well as medical, educational, community and service providers

along with parents of children and adolescents with ASD. The results reflect significant input and accomplishments from all its contributors.

**About Autism spectrum disorder (ASD):**

## 1.1 Background:

Autism Spectrum Disorder (ASD) represents a pattern of behaviours characterized by impairments in social interaction and communication, along with restricted interests and repetitive behaviours. The term "spectrum" refers to the heterogeneity of ASD, including its clinical presentation, severity of symptoms, and the level of the intellectual ability. ASD is a lifelong condition that can have a profound impact on the child or adolescent, his/her family/care-providers, and the community in which they live. ASD can affect individual functioning in areas such as learning, relationships, and daily life functioning. Co-occurrence of ASD with other conditions is common, including epilepsy, attention-deficit/ hyperactivity disorder (ADHD), intellectual disability and other psychiatric disorders. Manifestations of ASD may range from subtle problems of understanding and impaired social functioning to severe disabilities. Although services in the UAE for children and adolescents with ASD are improving, there is an urgent need to improve the quality and quantity of services within a comprehensive system of care. These Guidelines represent a key first step in achieving the Dubai Systems of Care initiative.

## 1.2 Etiology:

The etiology of ASD is understood to be multifactorial. Genetic influences appear to play a significant role in its etiology. Twin and family studies have shown that ASD often runs in families. Evidence from expanded family studies suggests that sibling recurrence rate is approximately 10%-27%. Additionally, prenatal, perinatal and postnatal environmental

factors are associated with ASD. However, the role that each of these factors plays in the etiology of ASD is not fully understood and continues to be the subject of research.

Disproven Etiologies: Despite strong evidence to the contrary, childhood immunizations have been highly publicized as a possible cause of ASD. There has been parental concerns around the immunization of MMR to children and Healthcare professionals are often confronted with questions about vaccine safety and asked to delay or defer vaccinations. Various theories have been offered for how vaccinations might contribute to the development of ASD, including the thimerosal hypothesis; the role of measles, mumps, and rubella (MMR) vaccine; and exposure to multiple vaccine antigenic components.

However, there is no credible evidence for the role of vaccines in the etiology of ASD. Further, this has been extensively studied in high quality research that included more than 1.2 million children from around the world consistently reporting that there is no association between childhood immunizations and ASD.

Studies conducted in the US through the Institute of Medicine of the National Academy of Sciences), reviewed all the evidence and concluded that there is no causal relationship between both thimerosal or MMR vaccine and autism.

Another recent study from Japan, where MMR vaccine was withdrawn for reasons unrelated to the autism controversy, demonstrated that the incidence of ASD continued to rise in a cohort of children, none of whom received MMR.

Another controversial area has been the role of gastrointestinal atypicality and specific diets in the development of ASD. Inadequate metabolism of gluten—a wheat protein— and casein—a milk protein—have been hypothesized to result in peptides that cross the blood-brain barrier, bind to endogenous opioid receptors, and negatively affect behaviour, cognition,

and interaction. However, there is no evidence to support this etiology, and special diets for ASD have been studied with no impact on outcomes.

### 1.3 Prevalence and Burden of Autism Spectrum Disorder

Since there are no comprehensive prevalence studies of ASD in the UAE, and estimates are, therefore, guided by global prevalence data. In the USA, the Center for Disease Control and Prevention (CDC) estimated the prevalence of ASD among children at 1 in 59. Other data from the CDC reports average prevalence of ASD as approximately 1% from data obtained from numerous studies conducted in Asia, Europe and North America. ASD is also reported to be more common among boys than girls. A survey in South Korea, which screened children in schools reported a prevalence of 2.6% (3.7% among boys and 1.5% among girls). Recent numbers for the US and Scandinavia suggest that the prevalence is well above 2 % in most countries.

The prevalence of ASD in children and adolescent in the Dubai population remains unknown. There is no reason to believe it is any less than that is in Korea and the US; for a variety of reasons, in fact, it could be higher. Administrative data indicate that pervasive developmental disorders in general, and ASD in particular, constitute approximately 40-55% of the caseloads in selected private and public sector providers.

In the absence of reliable local data, international data have been used to estimate 1 in 68 children at the age of 8 years will be identified with ASD. Recent studies suggest however, that the prevalence may even be higher.

## 1.4 Identification

Autism spectrum disorder (ASD) can be identified at any age, despite being a lifelong disorder that starts in early childhood. Although identification of ASD is usually made during childhood, some individuals will not present to a healthcare professional until later in life, if at all.

Importance of Early Identification and intervention: Benefits of early identification and intervention for children and adolescents with ASD have been widely reported. These include but are not limited to: reduced stress and reduced occurrence of challenging behaviour in the child/ adolescent with ASD, and better outcomes for their families and caregivers. Early intervention has been associated with gains in verbal and nonverbal communication, higher intelligence test scores, and improved peer interactions. In addition, family specific intervention techniques are reported to improve the family's ability to interact with their child and to have a greater understanding of ASD

The management of children and adolescents diagnosed with ASD who present with behavioural, emotional and mental health difficulties can often be challenging. Treatments are likely to be more successful if they are tailored to target the individual's specific skill development.

Parents are keen to access appropriate interventions and services following the completion of the assessment and diagnostic process. With this high need, and the notion that ASD has no cures, current best practice treatment comprises interventions tailored to help the individual with an ASD to adapt as effectively as possible to their environment.

There are various forms of ASD interventions available but the effectiveness of some of them is not supported by the available evidence based practice. Some interventions and approaches make compelling claims to cure ASD, a great deal of the information that is readily accessible

is biased, and claims that certain interventions 'cure' ASD or lead to 'recovery' have been described as misleading and irresponsible.

It is important for parents and carers to be informed about the potential risks and benefits from any intervention for their child so that they can make an informed decision.

Healthcare professionals are required to be familiar with evidence based interventions and the availability of community and educational resources.

A range of treatment approaches for ASD exist which include behavioural, medical, educational, speech/language, occupational therapy and complementary and alternative medicine approaches.

Good treatment of ASD encourages normal development and skills for independent living, improved quality of life, while minimizing the stress of the person with ASD and their family.

### 1.5 Guidelines Significance:

Despite the limited availability of reliable epidemiological data, the Government of Dubai is determined to respond to the need for services because there is a steady increase in the number of children and adolescents seeking a diagnosis and treatment for ASD. The guidelines is intended to address the gaps in the fragmented services, encourage evidence based practices and stop the non-evidence based and potentially harmful practices.

The completion of the Guidelines represents one of the key first steps in achieving the Dubai Systems of Care initiative. This Clinical Practice Guidelines document acts as a tool to guide health care providers, professionals, families, carers, and policymakers to arrive at informed decisions based on evidence-based recommendations. These recommendations will inform all aspects in the ASD pathway including screening, diagnosis, assessment, and treatment for children and adolescents suspected of ASD.

### 1.6 Limitations of the Guidelines

The Guidelines have been developed based on the best available resources and evidence in clinical practice and they cover a wide range of critical aspects in the management of children and adolescents with ASD. However, it does not cover all aspects related to ASD. It is anticipated that the missing elements of the guidelines will be addressed in future editions of the guidelines. There might be some situations where clinical guideline recommendations are not readily applicable. This guideline does not, therefore, override the individual responsibility of healthcare professionals to make appropriate decisions in the circumstances of the individual, in consultation with the child or young person with autism or their carer

## 2. SCOPE

2.1. Management of children and adolescents with ASD by DHA and DHCC licensed healthcare professionals.

## 3. PURPOSE

3.1. To provide DHA/DHCC licensed healthcare professionals with consistent and comprehensive evidence-based recommendations regarding the management of autism spectrum disorder in children and adolescents.

3.2. To assure the highest levels of safety and quality in the management of autism spectrum disorder in children and adolescents.

3.3. To provide a framework for educating and training healthcare professionals managing individuals with autism spectrum disorder.

3.4. To assure the adoption of the principles of the Dubai Declaration on Autism.

3.5. To inform-policy decision making.

## 4. APPLICABILITY

Healthcare professionals and other multi-agency professionals who work with children and adolescents at risk for or diagnosed with ASD, This includes:

4.1. DHA/DHCC licensed healthcare professionals involved in the management and care of children and adolescents with autism spectrum disorders within their scope of education, experience, and responsibilities including but not limited to: Primary Care Providers (PCP), Paediatricians, Child and Adolescent Psychiatrists, Psychologists, Occupational Therapists, Speech and Language Pathologists, Behaviour Analysts, Nurses, Pharmacists and Program Managers.

4.2. Families and the care-providers of children and adolescents at risk for or diagnosed with ASD.

4.3. These guidelines were prepared in order to inform Regulators and Policy Makers.

## 5. HOW TO READ THE GUIDELINES

The recommendations presented in the Guidelines are graded based on standard assessments of the strength of evidence in the judgment of the Dubai Autism Guidelines Working Group (DAGWG), following the criteria in Table (1). A table will be provided after each section summarizing the statements whenever applicable specifying the level of evidence. Each table will include three sections:

1. Recommended, which are subcategorized into:
    - Level 1: strongly supported by rigorous empirical evidence;
    - Level 2: supported by empirical evidence, and
    - Level 3: for recommendations backed by insufficient evidence but are recommended by most international guidelines.

2. Not Recommended: which are statements that are supported by expert opinion with emerging evidence that requires further investigation.
3. Contraindicated: which are statements where there is evidence of inefficacy and/or harm associated.

**Table 1:** Criteria for Levels of Recommendation

| **Levels of Recommendation** |
|---|
| **Recommended** |
| **Level 1**<br>The recommendation is supported by rigorous empirical evidence (e.g., meta-analyses, systematic reviews, and/or randomized controlled trials). |
| **Level 2**<br>The recommendation is supported by empirical evidence (e.g., nonrandomized controlled trials, cohort studies, and/or case-control studies). |
| **Level 3**<br>Insufficient evidence **and** endorsed by international guidelines. |
| **Not Recommended** |
| Supported by expert opinion, but not endorsed by international guidelines. Emerging evidence that requires further investigation (e.g. uncontrolled trials/studies). |
| **Contraindicated** |
| Evidence of inefficacy. |
| Insufficient Evidence and evidence of associated harm. |

## 6. **RECOMMENDATION ONE:** IDENTIFICATION OF CHILDREN AND ADOLESCENTS WITH ASD

6.1. Early identification, assessment, and diagnosis is recommended to enhance the effectiveness of educational and behavioural interventions.

6.2. The initial identification of ASD can be summarized as a three-step process: developmental surveillance; screening, which usually begins with the child or adolescent's primary care provider (PCP); and a referral for a comprehensive multidisciplinary team (MDT) evaluation.

6.3. Child health surveillance can contribute to the early identification and diagnosis of ASD; it should take a broad approach involving collaboration between parents, children and professionals.

6.4. All professional encounters with children should be viewed as an opportunity to gather developmental history. For example, at visits with PCPs, day-care providers, school personnel, teachers, etc.

6.5. Developmental surveillance refers to the routine monitoring and tracking of specific developmental milestones and processes. This includes gathering information using reliable standardized instruments, combined with parent and professional observations, and tracking developmental progress.

6.5.1. General child health surveillance contributes to the early recognition and diagnosis of ASD as long as it includes a broad approach involving collaboration between parents, children and professionals.

6.5.2. Healthcare professionals conducting developmental surveillance are recommended to gather information using reliable standardized

instruments, combined with parent and professional observations, and tracking developmental progress.

6.5.3. Any concerns raised during developmental and child health surveillance should lead to prompt screening and/or referral for diagnostic evaluation.

6.5.4. Surveillance for ASD should be included in general developmental surveillance and be a part of the responsibility of all professionals working with children and adolescents.

6.5.5. It is recommended that general developmental screening tests be administered during standard well child visits at 9-, 18-, and 30-months; in the U.S., this has led to a national effort to improve developmental screening in primary care setting which includes specific screening for ASD at 18 and 24 months.

6.5.6. It is recommended to use surveillance and screening algorithms for early identification of children with ASD.

6.6. Healthcare professionals should elicit and value parental concerns during the visit.

6.7. Screening refers to the identification of signs, symptoms and risk factors for a disorder. When concerns about developmental disorders and ASD are raised either as a result of parental reporting or developmental surveillance, screening for ASD should be undertaken.

6.7.1. Screening instruments used in suspected ASD are not intended to provide diagnoses, but rather to suggest a need for definitive diagnostic evaluation and intervention planning assessment, when appropriate.

6.7.2. Healthcare professionals should be aware of the clinical signs, or "red flags" that can help identify children at-risk for developmental delay and/or ASD.

6.7.3. These clinical signs should be tracked as an integral part of routine health and developmental surveillance procedures.

6.7.4. Most common clinical signs or "red flags" include delay in communication.

a. Any child not using single words by 16 months of age or some two-word phrases by 2 years of age should be further evaluated.

b. Children who do not use gesture (i.e., pointing, waving, etc.) or who cannot follow nonverbal communication by 12 months should also be referred for evaluation.

6.7.5. Loss of skills at any age is a serious warning sign that warrants immediate referral to an appropriate diagnostic team.

6.7.6. A list of the Red Flags for ASD in children aged 12-18 months can be found in **Table 2**.

6.8. Healthcare professionals need to provide adequate time and communicate effectively with parents regarding concern about their child's development. This may mean scheduling another appointment if time was not adequate at the initial visit.

6.9. Healthcare professionals need to communicate information about developmental concerns with parents in a sensitive and understanding manner, emphasizing the child's strengths and challenges.

6.10. Healthcare professionals should seek additional information from other agencies, such as school, nursery or other centers. This should be a part of the assessment process.

6.11. All professionals involved in the care of children should adopt referral pathways to follow when concerns are raised.

6.12. A collaborative multidisciplinary, multiagency process is essential for screening/early identification, diagnostic evaluation, and developmental assessment of individuals at risk for ASD.

**Table 2:** Red Flags for ASD in 12-18 month old children*

| **Social communication** | **Language** |
|---|---|
| • Reduced or atypical:<br>• Eye gaze and shared or joint attention.<br>• Sharing of emotion (less positive and more negative affect).<br>• Social or reciprocal smiling.<br>• Social interest and shared enjoyment.<br>• Orienting when his or her name is called.<br>• Coordination of different modes of communication (e.g., eye gaze, facial expression, gesture, vocalization)<br>• Regression or loss of social-emotional connectedness. | • Delayed or atypical:<br>• Babbling, particularly back-and-forth social babbling.<br>• Language comprehension and production (e.g., delayed or odd first words or unusually repetitive).<br>• Unusual tone of voice (including crying).<br>• Development of gestures (e.g., pointing, waving).<br>• Regression or loss of communication skills (including words). |
| **Play** | **Visual or other sensory and motor skills** |
| • Reduced or atypical: | • Atypical visual tracking, visual fixation (e.g., on lights, extreme lateral gaze). |

| | |
|---|---|
| • Imitation of actions.<br>• Functional and imaginative play.<br>• Excessive or unusual manipulation or visual exploration of toys and other Objects<br>• Repetitive actions with toys and other objects; often not in the manner in which the toys or objects are intended | • Under- or over-reaction to sounds or other forms of sensory stimulation.<br>• Delayed fine and gross motor skills, atypical motor control (e.g., reduced muscle tone, reduced postural control for age).<br>• Repetitive motor behaviours, atypical posturing of limbs or digits. |

*Adapted from Anagnostou, Evdokia, et al. (2014).

6.13. ASD specific screening Instruments should be available for Primary Healthcare professionals. They should be used to gather information about ASD risk as the basis of referral for ASD assessment (**Table 3**).

6.13.1. A variety of screening tools specific to ASD have been developed. Such tools have limitations and their use should be considered as a supplement to clinical assessment and referral for specialist diagnostic assessment. Both general developmental tools, as well as screening tools specific for ASD may be used in the initial assessment process.

6.13.2. Providers and professionals may use different tools, depending on their training, expertise and Scope of practice (i.e. primary care, child development center).

**Table (3):** Summary of screening tools recommended for ASD

| Tool | Age Range | Method of Administration |
|---|---|---|
| Autism Behaviour Checklist (ABC) | Children (2 to 14 yrs) | Parent rated |
| Asperger Syndrome Diagnostic Interview (ASDI) | Children/ Adults | Interview and Clinician rated |
| Asperger Syndrome Diagnostic Scale (ASDS) | Children/ Adolescent (5 to 18 years) | Parent or Teacher rated |
| Autism Screening Questionnaire (ASQ) | Children/ Adults | Parent rated |
| Autism Quotient (AQ) | Children/ Adults | Self or Parent rated |

| | | |
|---|---|---|
| Childhood Autism Rating Scale (CARS)* | Children (2 yrs and above) | Clinician rated |
| Childhood Autism Screening Test (CAST) | Children (4 to 11 years) | Parent rated |
| Communication and Symbolic Behaviour Scales Developmental Profile Infant-Toddler Checklist (CSBS-DP-IT-Checklist)* | Toddlers (6 to 24 months) | Parent rated |
| Gilliam Asperger's Disorder Scale (GADS) | Children/ Youth (3 to 22 years) | Parent or Teacher rated |
| Checklist for Autism in Toddlers (M-CHAT R/F)* | Toddlers (16 to 30 months) | Parent rated |
| Social Responsiveness Scale (SRS) | Children/ Adolescents (4 to 18 years) | Parent or Teacher rated |

*Tool available in Arabic

## 7. **RECOMMENDATION TWO:** REFERRAL OF CHILDREN AND ADOLESCENTS WITH ASD

7.1. Primary care practices/ health facilities should establish resource directories with:

7.1.1. Geographic location served;

7.1.2. Contact individual within the team;

7.1.3. An explanation of the referral process;

7.1.4. Accepted insurance plans; and

7.1.5. Services rendered.

7.2. Healthcare professionals and other professionals in education, social and early years care are essential team members for initiating referrals to specialist ASD services.

7.3. ASD services should be provided by an integrated, specialized, multidisciplinary team (MDT) of healthcare professionals experienced in undertaking ASD diagnostic assessment and service recommendations.

7.3.1. The individual contributions of all members of a multidisciplinary team should inform the construction of the overall formulation for the child or adolescent.

7.3.2. It is strongly advised to involve a multidisciplinary team and multiagency collaborations in the screening/early identification, diagnostic evaluation, treatment planning, and follow-up assessments of individuals with ASD. It is critical that service providers promote collaboration across all disciplines, agencies and programs.

7.3.3. Collaborative efforts should be made to maximize efficient use of resources in the pursuit of optimal outcomes for the individual with ASD and their family.

7.3.4. The MDT core members should include at least 2 specialists.

a. Physician specializing in assessing children with Autism; and

b. Licensed Clinical professional with experience in early childhood development and trained in standardized assessment tools. For example (psychologist, SLP, behavioural analyst or OT)

7.3.5. The MDT should have regular access to the following specialist professionals:

a. Paediatric Neurologist;

b. Child and Adolescent Psychiatrist;

c. Paediatric Geneticist;

d. Occupational Therapist; and

e. Clinical Social Worker.

7.3.6. The MDT should aim to provide the autism diagnostic assessment within 2-4 weeks of receiving referral for children under 6 years old and within 3 months of receiving the referral for older children and adolescents.

7.3.7. The MDT should agree on the timeframe required to conduct the assessments, complete the report, and provide feedback to the family.

7.4. ASD Clinical Care Coordinator/Case Manager should manage the following tasks:

7.4.1. Serve as the single point of contact for parents or carers and, if appropriate, the child or adolescent being assessed.

7.4.2. Ensure appropriate prerequisite tests, screening questionnaires and applicable reports are completed prior to arrival for the autism diagnostic assessment.

7.4.3. Obtain missing information relevant to the autism diagnostic assessment.

7.4.4. Oversee the waiting lists and keep families informed.

7.4.5. Coordinate the work among MDT team.

7.4.6. Arrange the provision of all relevant information concerning support and services for parents or carers as directed by the MDT.

7.4.7. Provide psychological support to families through counseling and family guidance.

7.5. Standardized online reporting system could assist with avoiding duplication of effort and max efficient use of time, by collating info gathered by team.

7.6. Healthcare professionals and other professionals in the community should be well informed about the referral process and Specialist ASD services in Dubai.

7.7. Healthcare professionals may consider referral to a paediatrician, paediatric neurologist or child psychiatrist for children older than 3 years with regression in language or at any age with regression in motor skills.

7.8. Referrals should be accompanied by sufficient information for the multidisciplinary team to understand the concerns the child present with, while also providing background information about the child and their family.

7.9. The DAGWG recommends the following be completed prior to referral to the MDT Diagnostic assessment:

7.9.1. Audiology assessment.

7.9.2. Age-appropriate screening questionnaires by parents including M-CHAT or SCQ, SDQ, MASC, SNAP, ASD-intake sheet.

7.9.3. Physical examination, including a general systematic assessment, neurological and dysmorphology examination.

7.9.4. Social, medical and developmental history.

7.9.5. Report from pre-school or school with consent from parents or carers (and/or the child or adolescent if appropriate).

7.9.6. Any additional health or social care information, including results from hearing and/or vision assessments.

7.10. Primary care practitioners should be aware of parent support networks, family support services and other appropriate community resources. These should be suggested to families as appropriate resources.

7.11. It is recommended that families receive a follow-up phone call after initial referral to ensure that it is progressing and that services have been initiated.

7.12. Healthcare professionals and other professionals in the community should obtain parental consent for the referral to the ASD Diagnostic service.

7.13. Referring sources must be highly sensitive to the fact that parents often do not understand the difference between screening and definitive diagnostic processes. Clinicians must repeatedly stress that referral for a comprehensive developmental and ASD evaluation does not mean that the child has ASD.

## 8. **RECOMMENDATION THREE:** DIAGNOSIS OF CHILDREN AND ADOLESCENTS WITH ASD

8.1. Professional qualifications for diagnosing ASD should align with the following:

8.1.1. Autism spectrum disorder is a clinical diagnosis that can only be made by appropriately trained healthcare professionals.

8.1.2. All healthcare professionals require licensure in a medical or mental health field to provide a diagnosis of autism in children and adolescents.

8.1.3. Specific training in the diagnosis and management of ASD is essential for those making a diagnosis.

8.2. Professional codes of conduct and ethical standards require that such professionals should not render diagnostic conclusions in clinical populations with whom they have had limited or no experience.

8.3. Healthcare professionals should utilize standardized instruments to make a diagnosis based on internationally accepted criteria:

8.4. There are two major diagnostic classification systems currently in use, the International Classification of Diseases, version 11 (ICD-11) and the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, 2013 (DSM-5). Autism Spectrum Disorder, as referred to by this guideline is based on the most current, DSM-5:

8.4.1. **DSM-5:** is a standard tool to inform clinical judgment in the diagnosis and classification of ASD. The use of the DSM requires specialized training that provides a body of knowledge and clinical skills to inform diagnosis. Differential diagnosis between ASD and other psychiatric or developmental disorders should employ the DSM-5 criteria to reach diagnostic impressions.

a. The DSM-IV, DSM-5's predecessor, previously considered Autistic Disorder to be a subdivision under *Pervasive Developmental Disorders,* along with other subtypes including, Rett's Disorder, Asperger's Disorder; Childhood Disintegrative Disorder; and Pervasive Developmental Disorders - Not Otherwise Specified. However, in the latest edition, the DSM-5, subdivisions are replaced by a single diagnosis of Autism Spectrum Disorder (ASD). Further, there are now two core domains that characterize ASD, rather than three domains in the previous edition. These two domains are:

- Social communication and interaction
- Restricted, repetitive patterns of behaviour, interests, or activities.

b. There are now a total of 7 items that fall under the two domains, as opposed to 12 items in the previous edition. Currently, to meet the criteria for a diagnosis of ASD, deficits must be manifested by all 3 items under the "social-communication and interactions" domain, and by at least 2 out of 4 items under the "restricted, repetitive pattern of behaviour and interests" domain. In addition, symptoms must be present from early childhood, and some symptoms do not have to necessarily be manifested at the present. Sensory sensitivities, described as, "hypo- and hyper-reactivity to sensory input or unusual interest in sensory aspects of the environment" are now included under the restricted, repetitive patterns of behaviours domain in the DSM-5.

8.4.2. **ICD-11**: The World Health Organization's International Statistical Classification of Diseases and Related Health Problems, version 11 (ICD-11), which was released in June 2018, classifies autism as a spectrum to be more in line with the DSM-5.

8.4.3. All professionals involved in the diagnosis of ASD in children and adolescents should use DSM-5 and ICD-11 criteria.

8.4.4. The classification system used for diagnosis should be recorded in the patient's clinical notes (**Table 4** can provide guidance).

**Table 4:** ASD and ASD related codes

| DSM-5 | ICD Code | Disorder | Specifiers | Severity |
|---|---|---|---|---|
| 315.39 | F80.9 | Language Disorder | | |
| 315.39 | F80.89 | Social (Pragmatics) Communication Disorder | | |
| 299.00 | F84.0 | Autism Spectrum Disorder | Associated with a Known Medical or Genetic Condition or Environmental Factor<br>Associated with another neurodevelopmental, mental or behavioural disorder<br>With or without intellectual impairment<br>With or without language impairment<br>With Catatonia (293.89 , F06.1 ) | Level 1<br>Requiring support<br>Level 2<br>Requiring substantial support<br>Level 3<br>Requiring very substantial support |
| 319 | F70<br>F71<br>F72<br>F73 | Intellectual Disability (Intellectual Developmental Disorder) | | F70: Mild<br>F71: Moderate<br>F72: Severe<br>F73: Profound |
| 315.8 | F88 | Global Developmental Delay | | |
| 314.00<br>314.01 | F90.0<br>F90.1<br>F90.2 | Attention-Deficit/Hyperactivity Disorder (ADHD) | 314.01 (F90.2)<br>Combined presentation<br>314.00 (F90.0)<br>Inattentive presentation<br>314.01 (F90.1)<br>Hyperactive Impulsive Presentation | |

8.5. Diagnostic Criteria must be interpreted within a Developmental Framework.

8.5.1. Diagnostic criteria for children and adolescents with neurodevelopmental disorders indicate that impairments and deficits should be interpreted relative to the child's developmental level. Thus, children with ASD present with significant differences in their nonverbal cognitive ability and

social/communicative functioning. This disparity can be difficult to detect in toddlers and older preschool-age children with developmental ages below 12–18 months.

8.5.2. Healthcare professionals are encouraged to look for discrepancies in nonverbal skills development in young children below the age of one year.

8.5.3. Re-evaluation of diagnostic conclusions for young children is essential for monitoring progress and intervention objectives.

8.5.4. Children with ASD should receive regular follow up evaluations and monitoring by a member of the MDT (care coordinator/treating therapist/team member) to review progress and comprehensive re-evaluation if clinically indicated or when there is significant change in presentation.

8.5.5. Experienced healthcare professionals should provide follow-up on a regular basis for children with ASD.

8.5.6. A diagnostic label, on its own, is insufficient to guide recommendations for interventions, as children or adolescents with ASD can present with varying levels of skills and impairments, both across the spectrum and within the specific diagnostic category.

8.5.7. The multidisciplinary team is a critical component of the larger system of services and supports for children and families and can help in establishing a comprehensive developmental and psychosocial profile of the child and family to guide intervention planning.

8.6. Providing timely diagnostic assessment is critical in children and adolescents with ASD.

8.6.1. While many procedures are needed to complete an accurate diagnostic assessment, obvious and necessary interventions (e.g., behaviour therapy, speech therapy) should not be delayed until other testing is completed.

8.7. Children are often referred to several specialists (audiologist, neurologist, etc.) before referral to the clinician who will provide the diagnostic evaluation. While evaluations from other specialists are important for a comprehensive diagnostic picture, they may not have direct impact on intervention planning. For example, while hearing results would have an obvious impact on treatment options, a later finding (at least as of today) of Fragile X Syndrome will not significantly alter intervention plans.

8.8. Evaluation methods may include both standard and informal assessment to assess developmental challenges faced by children and adolescents.

8.8.1. Standardized assessments are necessary to ascertain the specific symptoms and level of functioning of an individual, in relation to age-related peers.

8.8.2. Formal cognitive/intelligence testing should be conducted, measuring both verbal and nonverbal functions.

8.8.3. Informal measures should include modifications to usual procedures as well as careful observation of behaviour in low demand situations. The use of both procedures allows for an estimation of child or adolescent

functioning relative to peers, pre-learning skills, communicative abilities and needs and typical skills presented in daily life situations.

8.9. The setting or environment in which diagnostic evaluation occurs can significantly impact the skills and behaviours observed when the child or adolescent is being evaluated. When clinically indicated, observations in a variety of settings, and at different times, increase the validity of the information obtained.

8.10. Diagnostic Evaluation in children and adolescents is a concurrent, multilinear process.

8.10.1. The diagnostic evaluation of ASD requires thorough examination of the following core components, in addition to the medical history, physical examination and assessment:

a. Social behaviour;

b. Communication;

c. Activities and interests; and

d. Adaptive behaviour.

8.10.2. Healthcare professionals should follow a consistent approach in collecting background information.

a. Obtaining a detailed history and reviewing background information helps guide the diagnostic assessment.

b. The diagnostic evaluation should consider the influence of diversity such as sense of self, ethnicity, culture, gender, sexuality, religion, socioeconomic status, and geographic factors.

c. The healthcare professional leading the MDT may seek the support of the Clinical Coordinator to obtain records from all sources of relevant information.

8.10.3. Results from prior screening questionnaires, evaluations and treatments may help guide the diagnostic evaluation. Relevant patient records suggested for review may include:

a. Developmental and/or ASD screening.

b. Medical records or reports.

c. Previous assessments.

d. Progress reports from previous and/or current Intervention plans.

e. School reports.

f. Parent records of early development (i.e. development book/recorded videos or notes).

8.10.4. Healthcare professionals should conduct interviews with parents and caregivers where the child has not yet started school.

a. Healthcare Professionals' undertaking the parental interview must be experienced and equipped in collating relevant and sufficient information on the child's developmental and behavioural history as well as current levels of functioning, with particular attention to diagnostic criteria for ASD.

b. At a minimum, the parent and caregiver interview should include:

(i) Detailed history of pregnancy, birth and neonatal period, in addition to results from newborn hearing test and metabolic screening.

(ii) Comprehensive developmental history detailing early and current developmental milestones, developmental delays, history of any developmental regression. This history should be ASD-specific focusing on developmental and behavioural features consistent with ASD DSM-5 criteria.

(iii) Comprehensive Family history, including: consanguinity; three generation pedigree for evidence of ASD; speech and language difficulties; developmental disorders; genetic conditions; psychiatric disorders; learning/intellectual disabilities; epilepsy; and neurological disorders.

(iv) Social history including family structure and function.

(v) Review of systems: comprehensive systematic review of:

- Constitutional: dietary habits, weight gain/loss.
- Head, ears, eyes, nose, throat, and hearing.
- Skin: Neurocutaneous markers, bruises.
- Cardiovascular: general.
- Respiratory: general.
- Gastrointestinal: diet and bowel movement.
- Genitourinary: general.
- Neurological: general, history of seizures.

- Musculoskeletal: general, gait problems.
- Hematologic/Lymphatic: general.
- Endocrinology: general.
- Sleep History.
- Any known allergies.
- Immunization history.

8.10.5. Medical evaluation of children and adolescents at risk of ASD is conducted to determine the status of the child's general health and to identify conditions that may contribute to the characteristics associated with ASD. The components of the medical evaluation should include:

a. Hearing examination: Hearing evaluation should be done prior to the specialist assessment. Case coordinator to ensure referral to audiology services has been made simultaneously at the time of referral to ASD specialist services.

b. Visual examination.

c. Physical examination: A comprehensive physical examination performed by a qualified healthcare professional experienced in ASD is essential to evaluate the general health, monitor physical growth as well as metabolic syndrome screening, signs or symptoms of genetic disorders; congenital anomalies and dysmorphic features, including macrocephaly or microcephaly; neurocutaneous stigmata; neurofibromatosis or tuberous sclerosis

using Wood's light. Physical assessment and examination should include the following:

(i) Constitutional (e.g., vital signs, general appearance): Weight, height, head circumference, dysmorphic features, including but not limited to, inspection of eyes; head shape and size; ears; hands and limbs.

(ii) Eyes: To determine squint or nystagmus; eye movement; general visual acuity.

(iii) Ears, nose, mouth and throat: To determine Dental and palate anomalies; ear shape and position.

(iv) Cardiovascular: General examination.

(v) Respiratory: General examination.

(vi) Gastrointestinal: General examination.

(vii) Genitourinary: General examination.

(viii) Musculoskeletal: Gait, Spine.

(ix) Skin: To determine Neurocutaneous stigmata, for example, café au lait spots, hypopigmented macules, axillary and inguinal freckling, bruises.

(x) Neurological: Muscle power; tone and deep tendon reflexes; cranial nerves; cerebellar symptoms; tremor, screening for emergence of seizure or epilepsy.

(xi) Hematologic/lymphatic/immunological: Bruises, petechiae, pallor, lymphadenopathy.

(xii) Dental screening and treatment.

d. Trained and Certified Specialist in structured assessments should include direct observation of the child or Adolescent's social and communication skills and behaviour.

e. Healthcare professionals should also be conscious of signs of injury, for example, as a result of self-Injurious behaviour or child mistreatment.

f. Dietary and exercise assessment to prevent secondary health issues.

g. Providing sleep management.

8.10.6. Differential diagnosis must be covered during the diagnostic evaluation and should include all commonly associated conditions and/or those known to present as comorbid with ASD.

a. Healthcare professionals must have a good understanding of the different forms of expression of ASD symptomatology across developmental stages and the symptomatology of common coexisting and alternative conditions (**Table 5**).

**Table 5:** Differential Diagnosis of ASD*

| Condition | Description |
|---|---|
| **Rett syndrome** | Disruption of social interaction may be observed during the regressive phase of this condition (typically between 1-4 years of age). However, after this period, most individual with Rett syndrome improve their social communication skills, and autistic features are no longer a major area of concern. |
| **Selective mutism** | In this condition early development is not typically disturbed. Appropriate communication skills are exhibited in certain settings, and even when the child is mute, social reciprocity is not impaired. |
| **Language disorders and social (pragmatic) communication disorder** | There may be problems with communication and secondary social difficulties, however, nonverbal communication is usually reserved in specific language disorder. Restricted, repetitive patterns of behaviour, or interests are generally not present in these conditions. |
| **Intellectual disability without autism spectrum disorder** | Differentiating between these two conditions may be difficult in young children. However, a diagnosis of ASD in an individual with ID is appropriate when social communication is significantly impaired relative to the developmental level of the child's nonverbal skills. The diagnosis of ID is appropriate when there is no apparent discrepancy between the level of social-communicative skills and other intellectual skills. |
| **Stereotypic movement disorder** | An additional diagnosis of SMD is not given when the motor stereotypies are better explained by the presence of ASD. However, when stereotypies cause self-injury and becomes a focus of treatment, both diagnoses may be appropriate. |
| **Attention-deficit/hyperactivity disorder** | A diagnosis of ADHD should be considered when attentional difficulties or hyperactivity exceeds that typically seen in individuals with comparable mental age. |
| **Childhood onset schizophrenia** | This condition usually develops after a period of normal, or near normal, development. The social impairment and atypical interests during the prodromal phase can be confused with symptoms of ASD. However, hallucinations and delusions, which are defining features of schizophrenia, are not features of ASD. |

*Adopted from DSM-5, American Psychiatric Association, American Psychiatric Pub., 2013

8.10.7. Assessment refers to the systematic evaluation and measurement of psychological, biological, and social factors in a person through collecting information and drawing conclusions through the use of observation, tests, interviews, collecting information, and learning about a person's skills, abilities, personality characteristics, cognitive and emotional functioning, social context. Important to the assessment process are three critical concepts: reliability, validity, and standardization.

8.10.8. Healthcare professionals should adopt comprehensive assessment of individual profile which evaluates the following:

a. Cognitive and academic functioning including:
    (i) Child's current developmental level or level of cognitive functioning.
    (ii) Review of any prior cognitive testing that may indicate changes over time.
    (iii) Academic and/or pre-academic skills, as indicated.
    (iv) Neuropsychological functioning, as indicated.
b. Adaptive functioning such as level of day-to-day functioning in domains relevant to the individual's developmental level.
c. Communication assessment of relevant domains of speech and language functioning as well as social and pragmatic language.
d. Sensory and motor functioning including:
    (i) As indicated, assessment of fine and gross motor skills, feeding and oral motor skills, and sensory profile.

(ii) Assessment of sensory functioning with specific attention to both hypo- and hyper- sensitivity to stimuli.

e. Aberrant Behaviour: assessment of functional behaviour is recommended when concerns are raised by the family or school.

f. Co-existing psychiatric conditions

(i) An assessment should be made of co-morbid psychiatric disorders. Strong family history of psychiatric disorder may be considered in the differential diagnosis the possibility of those disorders.

(ii) It should be noted that there is also a moderate increased risk of co-occurrence of mood disorders and anxiety disorders in family members of persons with ASDs.

g. Family Functioning including:

(i) Level of parenting stress.

(ii) Impact on siblings and family functioning.

(iii) Extent of family's support network.

(iv) Resources accessed and of interest.

(v) Financial impact of ASD diagnosis.

(vi) Legal considerations.

h. Community resources such as:

(i) Appreciation of school, healthcare and other local resources.

(ii) Assessment of community support for the family of child with disability.

(iii) Access to transport and other resources to get to services.

8.10.9. The use of ASD-specific history-taking diagnostic tools or instruments is important during the evaluation process. Healthcare professionals should also be mindful of the need for a global perspective when examining the circumstances of an individual, taking into consideration the possibility of coexisting conditions and possible differential diagnoses.

8.10.10. Evidence suggests that ASD specific Diagnostic Assessment Tools may be used as supplements but do not replace informed clinical judgement.

a. Healthcare professionals should consider using ASD-specific observational Tool for improving the reliability of ASD diagnosis.

b. ASD Gold standard assessment tool include ADI plus ADOS(**Table6**).

8.10.11. The clinician should observe behaviours relevant to ASD diagnostic criteria and differential diagnosis, such as:

a. Reciprocal social communication and interaction.

b. Initiation and response to social overtures.

c. Shared enjoyment.

d. Initiation and response to joint attention.

e. Response to name.

f. Verbal and Non-verbal communication.

g. Restricted, Repetitive, Stereotypical interests and behaviours.

h. Sensory sensitivities.

i. Hand, finger, or complex mannerisms.

j. Imaginative and creative play

**Table 6:** ASD Assessment Tools

| Scale | Age Range | Method of Administration | Validity (Specificity/Sensitivity/ Positive Predictive Value) |
|---|---|---|---|
| **3DI** | Early childhood/<br>Adulthood | Computerized procedure and interview | Specificity: 0.97<br>Sensitivity: 1.0<br>PPV:<br>Only 3di and the combination of ADI/ADI-R and ADOS met the pre-defined levels of diagnostic accuracy for all studies.<br>3DI (Dimensional) is reliable and valid |
| **ADI** | Children/ Adults<br>(2 years and older) | Standardized semi structured interview and clinician rated<br>Individual - 1.5 hrs - 2.5 hrs including scoring | Specificity: 0.92 and 0.89<br>Sensitivity: 0.55<br>PPV:<br>For pre-school (5 years or under) only the combination of ADI/ADIR and ADOS meet the pre-defined levels of accuracy<br>ADI-R (Categorical) is reliable but should be used with caution in children below 3. |
| **DISCO** | Children/ Adults<br>DISCO doesn't have age or ability restrictions | Semi-structured interview and clinician rated<br>Individual 2 - 4 hrs including scoring | PPV:<br>DISCO (Dimensional) is reliable for ICD 10 categories. |
| **Autism Diagnostic Observation Schedule–** | Children/ Adults | Semi-structured interactive session administered to individual by clinician and takes 30-60minutes | Specificity: higher than 0.7<br>Sensitivity: PPV: the PPV of the revised algorithm was considerably lower than that of the original |

| | | | |
|---|---|---|---|
| **Generic (ADOS-G)** | | | algorithm although it remained above the 0.70 threshold. |
| **Autism Diagnostic Observation Schedule–Second Edition (ADOS-2)** | Children/ Adults | Semi-structured interactive session administered to individual by clinician and takes 30-60minutes | Specificity: 0.94 and 0.89<br>Sensitivity: 0.76 to 0.98 |

*All of the tools are available in English. Only the ADI has been translated and validated in Arabic.

8.10.12. Medical and Genetic Investigation: ASD can be associated with a wide range of underlying conditions, including genetic abnormalities. Medical investigations should be performed routinely, and must be modified to reflect the individual circumstances, based on physical examination, clinical judgment and the child or young person's profile.

a. The autism spectrum is highly variable and the choice of medical, laboratory and genetic tests will depend on each case.

b. Genetic and metabolic studies are not routinely done in children with ASD.

c. No tests should be undertaken unless clinically indicated. Genetic tests are done usually when there is a suspicion of syndromes e.g., when there is dysmorphism or macrocrania.

(i) Chromosomal microarray: oligonucleotide array-comparative genomic hybridisation or single-nucleotide polymorphism array

DNA testing for fragile X to be performed routinely for male patients only.

(ii) MECP2 sequencing to be performed for all females with ASD and suggestive clinical symptoms, e.g. history of regression, microcephaly, midline hand mannerisms.

(iii) MECP2 duplication testing in males, if phenotype is suggestive.

(iv) PTEN testing only if the head circumference is >2.5 SD above the mean.

d. EEG is indicated when there is seizures, or suspicion of subclinical seizures, and a history of regression (clinically significant loss of social and communicative function).

e. Brain magnetic resonance imaging only recommended in the presence of specific indicators (e.g. microcephaly, regression, seizures, history of stupor/coma or abnormalities on physical examination e.g. neurocutaneous markers, focality).

f. There is no significant association between ASD and food allergies, therefore testing is not recommended unless medically indicated.

g. There is no evidence to support conducting mineral analysis tests.

h. Healthcare professionals are recommended to refer to the medical diagnosis etiology associated with ASD when conducting a genetic investigation (**Table 6**).

**Table 6:** Medical diagnosis etiology associated with ASD

| | |
|---|---|
| **Genetic /Chromosomal disorders (20-30%)** | |
| Single gene disorder (5%) | Fragile X |
| | Neurocutaneous disorder |
| | PTEN |
| Cytogenetically visible chromosome disorders (~5%) | Prader-Willi Syndrome |
| | Turner Syndrome |
| | Trisomy 21 |
| Copy number variants (CNV) (10–20%) | |
| **Metabolic Disorders (1-3%)** | |
| Phenylketonuria | |
| Creatine transporter and biosynthesis disorders | |
| Mitochondrial disorders | |
| Smith-Lemli-Opitz Syndrome | |
| **Other Disorders** | |
| Fetal toxins | |
| Structural brain malformation | |
| Moebius Syndrome | |
| Epileptic encephalopathy (Infantile spasms, Landau-Kleffner Syndrome) | |

8.10.13. Children who fail developmental screening may need further medical evaluation as follows:

a. Evaluation for iron deficiency anemia.

b. Evaluation for lead poisoning (if risk factors for lead poisoning present).

c. Formal hearing testing (BAER).

d. Vision testing (full ophthalmologic exam).

e. Thyroid function testing (if no NBS, or signs of thyroid disease).

f. Metabolic , genetic screening .

g. Neuroimaging (as indicated).

h. Assessing co-morbid mental and physical health issues.

8.10.14. Diagnostic uncertainty may be the result of several factors such as:

a. Examining very young children.

b. Variability in ASD presentation.

c. High levels of medical and psychiatric comorbidity.

**Table 7:** Summary of Medical and Genetic Investigations for ASD

| Specialty | Indication for Testing | Test | Recommendation level |
|---|---|---|---|
| **Genetics** | All | Genome-wide microarray, fragile X syndrome (FMR1 gene) | Level 1 |
| | Head circumference > +3 SD | PTEN gene | Level 1 |
| | Concerns about other condition History or physical examination suggestive of specific genetic or metabolic disorder | Specific genetic , metabolic testing e.g.: Tuberous sclerosis | Level 1 |
| | Consider for females with intellectual disability | MECP2 gene | Level 1 |
| **Neuroimaging** | Complex ASD (clinical focal findings, major dysmorphology, micro- or extreme (≥ 4 SD) macrocephaly, skin lesions, seizures, focal EEG abnormalities, motor regression) | Brain magnetic resonance imaging | Level 1 |
| **Metabolic** | If clinically indicated (e.g., severe intellectual disability and seizures, developmental regression) | Levels of venous blood gas; serum ammonia; lactate, pyruvate, uric acid; plasma amino acid; total, free and acylcarnitine; urine organic acids, mucopolysaccharides | Level 1 |
| **General Medicine** | Should be considered, especially for developmental delay | T4, TSH, complete blood count, ferritin level | Level 1 |
| | If neuroleptic therapy is considered | Fasting lipid profile, glucose, HbA1c, Electrocardiogram | Level 1 |

| | | | |
|---|---|---|---|
| **Gastroenterology** | Pain after meals, night awakening despite good sleep hygiene | Rule out gastroesophageal reflux disorder | Level 1 |
| | High eosinophil count | Rule out eosinophilic esophagitis | Level 1 |
| | Bloating (2 or 3 times per wk for more than 2 wk) | Tissue transglutaminase levels (to rule out celiac disorder) | Level 1 |
| | Failure to thrive, weight loss | Serum albumin, total protein, calcium, vitamin D levels | Level 1 |
| **Neurology** | Suspected seizures, documented regression | EEG (ideally sleep record) | Level 1 |
| **Psychology /psychiatry** | Mental health concerns (e.g., anxiety, mood) | Comorbidity assessment | Level 1 |
| **Psychology** | Need to establish mental age | Cognitive and adaptive behaviour assessment‡ | Level 1 |
| | Learning concerns | Cognitive, academic assessment | Level 1 |
| **Speech-language** | Speech or language concerns | Preschool Language Scales, Fifth Edition, CELF Preschool-2, The CELF, PLS-5E | Level 1 |
| **OT/PT** | Motor or sensory concerns | Motor and/or sensory assessment | Level 1 |
| **Behaviour therapy** | Behavioural concerns | Behavioural assessment | Level 1 |

Note: EEG = electroencephalogram, HbA1c = glycated hemoglobin, SD = standard deviation of the mean,T4 = tetraiodothyronine,TSH = thyroid stimulating hormone.*This list does not imply uniform practice.†Consider adding magnetic resonance spectroscopy if there is regression or other clinical indicators of metabolic disease. ‡May not be needed at the time of diagnosis,but may be required later to ensure appropriate academic support

8.11. Feedback: Following completion of the diagnostic assessments, the MDT should ensure that the outcome of assessments are thoroughly and promptly discussed with the parents or carers and when appropriate, the individual.

8.11.1. MDT must explain the diagnostic conclusions along with the procedures used to arrive at the conclusions.

8.11.2. Treatment options and prognosis should be clear and possible referrals for therapeutic interventions should be offered within the parameters of empirical research.

8.11.3. MDT should discuss with parents or carers the risk of autism occurring in siblings and future children.

8.11.4. Care must be taken to inform the family of the differences between the medical diagnosis, educational and community-based program eligibility processes.

a. This includes addressing issues that affect parents and carers directly, providing recommendations related to available support and resources, further assessment, and intervention, as soon after the evaluation is completed as possible.

8.11.5. MDT should highlight the significant role of parent involvement and advocacy in determining prognosis.

8.11.6. The MDT should ~~also~~ ensure that the diagnostic assessment findings are communicated to all relevant professionals and services that will be involved in the care of the child and family.

8.12. Report Writing: Written documentation serves as an essential means of communication between the clinician and the family, and other professionals involved in intervention planning and services for future follow-up evaluation.

8.12.1. The MDT should produce a comprehensive written report to be provided to the individual's family and the initial source of referral. The recommended core components of the written report include:

a. Description of the diagnostic process, any diagnostic instruments used, diagnostic conclusions, the data obtained via record review,

parent interview, and direct behavioural observation and interaction that support making or ruling out the diagnosis.

b. Description of individual strengths or areas of typical development noted in the diagnostic evaluation process.

c. Specific descriptors related to ASD areas of impairments as specified in the DSM5 diagnostic criteria for ASD.

d. Specific description of the child's developmental level, adaptive functioning, and presentation of any maladaptive behaviours.

e. Diagnostic conclusions that are supported with sufficient detail in order to be understood by another professional.

f. Quantitative and qualitative evaluation data that allow an experienced reviewer to readily verify the diagnosis or the reasons it was ruled out.

g. Appropriate referrals for services and additional assessment needed for intervention planning.

h. Provide basic resources for ASD for family reference and further follow up plan.

8.12.2. The overall evaluation report must be comprehendible for parents as well as other professionals and programs in order to facilitate enrollment in educational and/or other services.

8.13. Community Collaboration: A clear explanation that diagnostic evaluation provides medical diagnoses and that eligibility for social or educational services may have different or additional criteria that require further evaluation.

## 9. RECOMMENDATION FOUR: NON-PHARMACOLOGICAL INTERVENTIONS

9.1. General Recommendations: Individuals and families should have access to educational resources and information on various types of interventions provided in multiple settings.

9.1.1. Early intervention can have a significant impact on a child's ability to learn new skills, overcome challenges and can increase success in school and life.

9.1.2. The active involvement of the family is important in ensuring that skills acquired during intervention are generalized to different settings.

9.1.3. Intervention plans should always include parent training in order to support and educate the family on how to facilitate their child's communication and social interaction.

9.1.4. Parent-mediated interventions can involve delivering structured training programs, in a group setting or one-to-one, in parallel with their child's individualized intervention plan. Such programs allow parents to utilize individualized strategies and techniques to facilitate skill acquisition, and manage any challenging behaviours.

9.1.5. Intervention plans should incorporate the use of natural environment and the daily routine of the child/ adolescent.

9.2. Applied Behaviour Analysis interventions are recommended for managing ASD following a comprehensive behavior assessment.

9.2.1. Early intensive behavioural intervention(EIBI)is a treatment based on the principles of applied behavior analysis.Instructions are provided at home or in classrooms and is one of the more well-established treatments for ASD.

9.2.2. Early intensive behavioural intervention (EIBI) of more than 20 hours a week, should be considered as a treatment of value for young children with ASD to improve outcomes such as cognitive ability, language skills, and adaptive behaviour.

9.2.3. The application of EIBI, a comprehensive approach based on the principals of ABA, focuses on acquisition of adaptive behaviour (e.g., language, play, social interaction, imitation, motor skills etc.) and reduce problematic behaviours that may interfere with learning (e.g., tantrum, inattention, noncompliance, aggression etc.)

9.2.4. Applied Behaviour Analysis (ABA)is a science that focuses on treating the core deficits associated with ASD and the development of abilities. This is done through analyzing and modifying the social and learning environment to produce socially valid and significant changes in behaviour to maximize adaptive functioning in individuals with ASD. It is a well-developed discipline that is based on a wealth of scientific knowledge with standards for evidence-based practice, with distinct methods of service delivery, and recognized experience and educational requirements for practice.

9.2.5. Providing Applied Behaviour Analysis (ABA) services should align with the following:

a. Be provided and supervised by Licensed Behaviour Analysts, who are:

I. Board Certified Behaviour Analysts (BCBA) or Board Certified Assistant Behaviour Analysts (BCaBA) or equivalent

internationally recognized board certification as Behaviour Analyst.

II. With expertise and formal training in ABA for the specific treatment of ASD.

b. Delivered by Licensed Behaviour Technicians, that are:

I. Registered Behaviour Technicians(RBT or equivalent internationally recognized certification as a Behaviour Technician.

II. Under the direct supervision of a Behaviour Analyst.

c. Include the core characteristics of:

I. The assessment and analysis of the child's condition based on evidence from data collected while observing how the environment affect's the child's behaviour.

II. Understanding the context of the target behaviour and its social significance to the individual, their family and the community.

III. Utilizing principles of ABA to improve quality of life.

IV. Ongoing assessment and analysis to inform clinical decisions.

V. Involving the parents in setting of goals and implementation of ABA program.

9.2.6. Comprehensive skill assessment is recommended to be conducted to identify strengths and weaknesses across developmental domains, ibarriers to progress and to inform an individualized ABA treatment plan.

9.2.7. Comprehensive Behavioural Interventions and strategies based on applied behaviour analysis (ABA) principles, developmental and combined approaches should be considered for all children with ASD.

a. A comprehensive ABA assessment should include indirect and direct methods.

(i) Indirect methods include:

- Record review.
- Interviews and rating scales.

(ii) Direct methods include:

- Observations.
- Data collection and Analysis.
- Functional Analysis (when indicated).

9.2.8. Treatment may vary in terms of intensity and duration, the complexity and range of treatment goals, and the extent of direct treatment provided, based on the number and intensity of behavioural targets.

a. Treatment may vary in terms of how 'structured' or 'naturalistic' they are, and may include family or peers, based on the child's age, rate of progress, available resources etc.

b. It is important that ABA treatment is delivered in multiple settings (e.g. home, school, community etc.) and multiple people (e.g. parents, siblings, peers etc.) to promote generalization and maintenance.

c. ABA treatment models can be generally categorized as Focused or Comprehensive.

(i) Focused ABA is provided directly to the client when there is a limited number of behavioural targets and may involve either increasing socially appropriate behaviour and key functional skills, or reducing acute problem behaviour.

- Focused ABA can be delivered individually or in small groups when targeting functional skills, while for problem behaviour it will depend on the developed treatment plan.
- Focused ABA will typically involve 10-25 hours per week of direct therapy.
- Focused interventions to target specific behaviour or developmental outcome should be available for all children.

(ii) Comprehensive ABA is provided when there are multiple affected developmental domains (e.g. cognitive, communicative, social, emotional, and adaptive functioning) and maladaptive behaviours (e.g. noncompliance, tantrums, and stereotypy).

- One example is early intensive behavioural intervention (EIBI) which are ABA programs that range from 20-40 hours of direct therapy per week, in addition to direct and indirect supervision and caregiver training.

- This model should involve 1:1 staffing; and are provided in structured therapy sessions, which are integrated with more naturalistic methods as appropriate.
- As the child progresses, treatment in different settings and in the larger community should be provided.
- Training the family and other caregivers on how to manage problem behaviour and how to interact with the child is an essential component of this treatment model.
- Components of comprehensive ABA programs may include:
    - Adaptive and self-care skills.
    - Attending and social referencing.
    - Cognitive functioning.
    - Community participation.
    - Coping and tolerance skills.
    - Emotional development.
    - Family relationships.
    - Language and communication.
    - Play and leisure skills.
    - Pre-academic skills.
    - Reduction of interfering or inappropriate behaviours.
    - Safety skills.

- Self-advocacy and independence.
- Self-management.
- Social relationships.
- Vocational skills.

9.2.9. Supervision is an important component of an ABA program that facilitates the ongoing monitoring fidelity of implementation, re-evaluation of goals. Supervision hours for each child will vary depending on their needs.

a. It is generally recommended to provide 2 hours of supervision for every 10 hours of direct therapy, and should include in vivo supervision.

9.2.10. The appropriate caseload for a Behaviour Analyst may vary depending on the service delivery model and other variables. However, the caseload of Behaviour analysts should allow them to facilitate effective treatment delivery, and will typically be based on the complexity of the case, the availability of assistant behaviour analysts, the modality of treatment and the expertise of the behaviour analyst.

9.3. Speech and language interventions are recommended to be used to treat social and communication deficits associated with ASD.

9.3.1. Speech and language intervention services should be provided and supervised by

a. Licensed Speech and Language Pathologist/ Speech and Language Therapist.

b. With expertise and formal training in SLP for the specific treatment of ASD.

9.3.2. Individuals diagnosed with ASD are referred to an SLP, and other professionals as needed, for a comprehensive assessment.

a. Assessment of social communication skills should be culturally sensitive, functional, and sensitive to the wide range of acceptable social norms that exist within and across communities; and involve the collaborative efforts of families, caregivers, classroom teachers, SLPs, special educators, and psychologists as needed.

b. Depending on the individual's age and abilities, the SLP typically assesses:

(i) Receptive language.

(ii) Expressive language, including:

- Sound and word production.
- Frequency and function of verbal (vocalizations/verbalizations), and nonverbal (e.g., gestures) communication.

(iii) Social communication including:

- Use of gaze.
- Joint attention.
- Initiation of communication.
- Social reciprocity and the range of communicative functions.

- Sharing affect.
- Play behaviours.
- Use of gestures.

(iv) Conversational skills, including:

- Topic management (initiating, maintaining, and terminating relevant, shared topics).
- Turn-taking.
- Providing appropriate amounts of information in conversational contexts.

(v) Speech prosody.

9.3.3. Children with ASD should receive varieties of speech, language and communication interventions tailored for their need.

9.3.4. Speech and language interventions for disorders that are considered in differential diagnosis such as Apraxia and Dysarthria will depend on the SLP evaluation of the child and review of their record of verbal skills.

9.3.5. Speech and language treatment modes and modalities are technologies or other support systems that can be used in conjunction with or in the implementation of various treatment options. For example, video-based instruction can be used in peer-mediated interventions to address social skills and other target behaviours.

a. The use of Speech generating device and Technology based interventions is useful for children with limited or no speech.

b. Comprehensive SLP is provided when communicative, social, and language skills are affected.

   (i) One example is early intensive speech and language therapy intervention which are communication, speech and language programs that range from 2-5 hours of direct therapy per week, in addition to direct and indirect caregiver training; involve 1:1 staffing; and are provided in structured therapy sessions, which are integrated with more naturalistic methods as appropriate. As the child progresses, treatment in different settings and in the larger community should be provided.

c. Augmentative and Alternative Communication (AAC) involves supplementing or replacing natural speech and/or writing with aided (e.g., Picture Exchange Communication System [PECS], line drawings, Blissymbols, speech generating devices, and tangible objects) and/or unaided (e.g., manual signs, gestures, and finger spelling) symbols. Whereas aided symbols require some type of transmission device, production of unaided symbols only requires body movements.

d. Activity Schedules/Visual Supports include objects, photographs, drawings, or written words that act as cues or prompts to help individuals complete a sequence of tasks/activities, attend to tasks, transition from one task to another, or behave appropriately in various settings. Written and/or visual prompts that initiate or sustain interaction are called scripts. Scripts are often used to

promote social interaction, but can also be used in a classroom setting to facilitate academic interactions and promote academic engagement.

e. Social Communication Interventions and frameworks are designed to increase social skills, using social group settings and other platforms to teach peer interaction skills and promote socially appropriate behaviours and communication.

(i) Social Skills Groups—groups in which appropriate ways of interacting with typically developing peers are taught through direct instruction, role-playing, and feedback. Groups typically consist of two to eight individuals with social communication disorders and a teacher or adult facilitator.

(ii) Social Stories—a highly structured intervention that uses stories to explain social situations to children and to help them learn socially appropriate behaviours and responses.

9.4. Occupational Therapy (OT)

9.4.1. Occupational therapists study human growth and development and a person's interaction with the environment through daily activities. They are experts in the social, emotional, and physiological effects of illness and injury. This knowledge helps them promote skills for independent and adaptive living in people with autism and other developmental disorders.

9.4.2. OTs work as part of a team that includes parents, teachers, and other professionals. They help set specific goals for the person with autism. OTs

can help by means of evaluation and therapy looking at the child's ability to do tasks they are expected to do at their ages such as motor skills such as posture, balance, or manipulation of small objects like stringing beads or doing puzzles. They also help a child develop coordination, body awareness, and play skills.

9.4.3. Other area that OTs can support children with autism with is developmental activities, domestic skills, personal skills such as toilet training, bathing, dressing, feeding, brushing teeth, combing hair and other grooming skills.

9.4.4. Additionally, OTs provide training In fine motor skills required for holding objects while handwriting or cutting with scissors.

9.4.5. It is not recommended to depend solely on sensory oriented interventions, such as auditory integration training, sensory integration therapy, and touch therapy/massage in the management of ASD in children and adolescents due to lack of strong evidence.

9.4.6. At present, there is not enough scientific evidence to support sensory integration therapy as an intervention for improving academic performance, behaviour, or social communication skills.

9.5. Structured Educational Interventions for children and adolescents with ASD with explicit teaching and the development of an appropriate individualized educational plan is central in providing effective service to the individual and families.

9.5.1. Effective educational programs have the following key components:

a. Programs shown to be effective typically involve planned, intensive, individualized intervention with an experienced, interdisciplinary team of providers, and family involvement to ensure generalization of skills.

b. The educational plan should reflect an accurate assessment of the child's strengths and vulnerabilities, with an explicit description of services to be provided, goals and objectives, and procedures for monitoring effectiveness.

9.5.2. Goals of educational programs should be enhancing verbal and nonverbal communication, academic skills, and social, motor, and behavioural capabilities. In some instances, particularly for younger children, a parent-education and home component may be important.

9.5.3. Examples of structured educational models supported by evidence include:

a. Early Start Denver Model (ESDM).

b. Treatment and Education of Autism and related Communication Handicapped Children program (TEACCH).

9.5.4. The development of the educational plan and should reflect an accurate assessment of the child's strengths and vulnerabilities, with an explicit description of services to be provided, goals and objectives, and procedures for monitoring effectiveness.

9.6. Other Forms of Psychosocial Interventions: There is a lack of evidence for most other forms of psychosocial intervention, although cognitive behavioural therapy has shown efficacy for anxiety and anger management in high functioning youth with ASD.

9.6.1. Cognitive behavioural therapy approach should be adapted for people with ASD and may be considered to treat co morbid conditions such anxiety in cognitively able children.

9.7. Developmental, Social-Pragmatic Models of Intervention: It is not recommended to depend on developmental, social-pragmatic models of intervention, such as Developmental-Individual Difference- Relationship Based/Floortime, Relationship Development Intervention, Social Communication Emotional Regulation and Transactional Support, and Play and Language for Autistic Youths massage in the management of ASD in children and adolescents due to lack of strong evidence.

**10. RECOMMENDATION FIVE:** PHARMACOLOGICAL INTERVENTIONS

10.1. There are no controlled long term studies demonstrating that pharmacological treatment affect core difficulties or outcomes in children and adolescents with ASD

10.2. Pharmacological interventions should be considered as part of a multi-component intervention and should not be used solely.

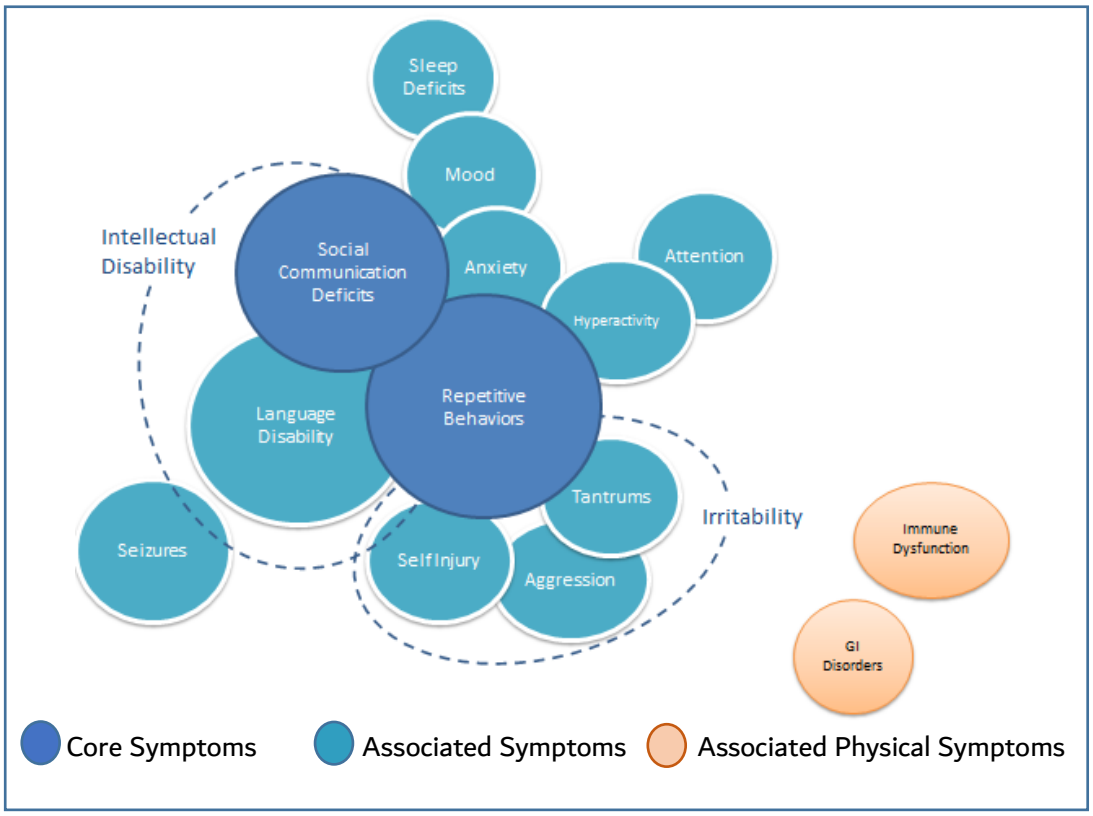
10.3. Pharmacological interventions should be used appropriately to target specific signs and symptoms of comorbid psychiatric or neurodevelopmental conditions.

10.4. Clinicians should seek the balance of potential risks and benefits of each pharmacological treatment and this should be discussed appropriately with the family.

10.5. Dieticians advice may be considered when children's weight changes due to their eating habit

10.6. Pharmacological treatment prescribing for children with ASD should be conducted by experienced physician with adequate knowledge and skills in ASD in a setting that has available resources for necessary monitoring.

10.7. Medications Commonly Used and Mode of Action: At the present, there is no medication approved for core symptoms of Autism. Therefore, prescribing any medications to target core ASD symptoms is at least not recommended and may be contraindicated. (see graph (1) regarding core symptoms). There are approved medications for comorbid conditions in children with ASD , based on empirical evidence.



Medication used for comorbid conditions:

10.7.1. Risperidone:

a. Mode of action: Receptor antagonist of dopamine (D2), serotonin (5-HT2), and norepinephrine (NE alpha-2).

b. Recommended use:

(i) It can be used as first line for managing aggression/irritability unless contraindicated.

(ii) When prescribing risperidone clearly document its indication.

(iii) Start with a low dose and increase slowly if required.

(iv) It can be useful as a short term treatment of significant aggression and irritability, tantrums, self injurious behaviour.

(v) It might be beneficial in reducing repetitive restricted behaviours.

(vi) It does not have any effects on social behaviour.

(vii) It is associated with potentially high risk of side effects such as sedation, weight gain with increasing appetite, and high prolactin.

(viii) The long term impact of the side effects such as high prolactin is unknown.

(ix) Monitoring of children and adolescents on risperidone or other types of antipsychotic medications is mandatory. This includes monitoring for metabolic syndrome, and regular checking of growth parameters and vital signs.

(x) Growth parameters need to be reviewed once every 6 months.

(xi) Metabolic syndrome needs to be reviewed annually or more frequently if clinically indicated. This included blood tests such as (CBC, fasting blood glucose, LFT, lipid profile, and prolactin).

10.7.2. Aripiprazole

a. Mode of action: Receptor partial agonist of dopamine (D2), and serotonin (5-HT1A); receptor antagonist of serotonin (5-HT2A).

b. Recommended use:

(i) It can be used as a second line medication for managing aggression/irritability or first line if risperidone was tried and has shown poor efficacy or major side effects.

(ii) When prescribing aripiprazole clearly document its indication.

(iii) Start with a low dose and increase slowly if required.

(iv) It can be useful as a short term treatment of significant aggression and irritability, tantrums, hyperactivity and stereotype behaviour.

(v) It does not have any effect on social behaviour.

(vi) It is associated with potentially high risk of side effects in children such as extrapyramidal symptoms, drowsiness and weight gain.

(vii) Monitoring of children and adolescents on aripiprazole or other types of antipsychotic medications is mandatory. This includes

monitoring for metabolic syndrome, and regular checking of growth parameters and vital signs.

(viii) Growth parameters need to be reviewed once every 6 months.

(ix) Metabolic syndrome needs to be reviewed annually or more frequently if clinically indicated. This included blood tests such as (CBC, fasting blood glucose, LFT, lipid profile, and prolactin).

10.7.3. Methylphenidate

a. Mode of action: Reuptake inhibitor of dopamine transporter (DAT) and norepinephrine transporter (NET); releaser of dopamine (DA) and norepinephrine (NE).

b. Recommended use:

(i) Methylphenidate may be considered for treatment of attention deficit/ hyperactivity disorder (ADHD) in children with ASD.

(ii) It is evident that the response rates to methylphenidate in children diagnosed with ASD are lower than in children with typical ADHD as such it is acceptable to consider a test dose with short acting medication prior to a longer trial.

(iii) Research is lacking on the benefits and tolerability of sustained release preparations of methylphenidate and other psychostimulant medications.

(iv) Methylphenidate was shown to be ineffective for the treatment of restricted, repetitive behaviours or irritability (StART).

(v) Start with a low dose and increase slowly if required, taking into consideration the weight of the child, maximum therapeutic dose, efficacy, and potential side effects.

(vi) Monitor compliance and adverse effects such as appetite and weight loss, decreased sleep, irritability and mood changes by conducting regular visits. Additionally, monitor growth parameters and vital signs.

(vii) If methylphenidate is not tolerated, using other ADHD medications could be considered based on ADHD evidence based international guidelines.

10.7.4. Atomoxetine

a. Mode of action: Reuptake inhibitor of norepinephrine transporter (NET).

b. Recommended use:

(i) Atomextine may be considered in the treatment of ADHD among children with ASD, if trial of stimulant medication was not effective or associated with significant side effects.

(ii) As per a systematic review and meta-analysis including 241 children a reduction in hyperactivity and inattention was reported by parents, however, the magnitude of effects is uncertain.

(iii) Atomextine can be associated with non-serious side effects including nausea, vomiting, decreased sleep, and decreased

appetite. Less common side effects include, irritability, blood pressure and pulse changes, depression, and anxiety.

(iv) Monitor growth, vital signs, attention, hyperactivity, anxiety, aggression, and suicidal ideation.

10.7.5. Clonidine

a. Mode of action: Receptor agonist of norepinephrine alpha-2.

b. Recommended use:

(i) The evidence of using clonidine for behavioural problems in children with ASD remains to be limited.

(ii) Clonidine can be used to help with sleep initiation and reduces nighttime awakening.

(iii) Regarding side effects, it is generally well tolerated, with sedation being a common side effect. Consistency in use is recommended to avoid fluctuations in blood pressure.

10.7.6. Guanfacine

a. Mode of action: Receptor agonist of norepinephrine alpha-2.

b. Recommended use:

(i) An RCT by Scahill et al. 2015 reported that extended-release guanfacine is effective in reducing hyperactivity, impulsiveness, and distractibility in children with ASD. Blood pressure declined in the first 4 weeks, with return nearly to baseline by week 8. Pulse rate showed a similar pattern but remained lower than baseline at week 8.

(ii) Possible benefit for treating insomnia and tics.

(iii) More studies are needed.

10.7.7. Selective Serotonin Reuptake Inhibitors (SSRI)

a. Mode of action: Selective serotonin reuptake inhibitor (inhibits serotonin transporter SERT).

b. Recommended use:

(i) SSRIs may be effective for some children with ASD and high anxiety, depression and/or obsessive symptoms. However, in the absence of good evidence, these drugs should be used with caution and careful monitoring

(ii) There is insufficient evidence to make any recommendation in relation to the use of other types of antidepressants in children with ASD.

(iii) There is some evidence of benefit for the use of SSRIs but more studies are needed.

10.7.8. Fluoxetine

a. Mode of action: Selective serotonin reuptake inhibitor (inhibits serotonin transporter SERT).

b. Recommended use:

(i) Evidence from a single RCT research suggested a small clinical benefit from fluoxetine use in ASD children with repetitive behaviour but with significant statistical benefit. A study found high dose of fluoxetine given to ASD children may

result in increased agitation, therefore dose adjustments need to be done cautiously.

(ii) Case series of children with ASD found parents reporting positive response but correlated with features suggestive of affective disorder.

10.7.9. Citalopram/ Escitalopram

a. Mode of action: Selective serotonin reuptake inhibitor (inhibits serotonin transporter SERT).

b. Recommended use:

(i) Some research suggests reduction in irritability.

(ii) It is not associated with change in repetitive behaviours.

(iii) Studies are statistically significant but not clinically significant.

(iv) Adverse effects may include activation symptoms, diarrhea, and dry or itchy skin.

10.7.10. Sertraline

a. Mode of action: Selective serotonin reuptake inhibitor (inhibits serotonin transporter SERT).

b. Recommended use:

(i) Sertraline is licensed for treatment of OCD in children and adolescents. It can be considered for children with ASD and comorbid OCD.

(ii) One small study (202 pub in signs) showed benefit of treatment with low dose rather than high dose.

10.7.11. Clomipramine

a. Mode of action: Tricyclic antidepressant (inhibits reuptake of serotonin and norepinephrine).

b. Recommended use:

(i) One study showed decrease in repetitive behaviour on CPRS. Another study showed no difference.

10.7.12. Sleep medications:

a. Mode of action: Modes of action vary, as per below.

b. Recommended use:

(i) Obtain appropriate sleep assessment history prior to prescription.

(ii) Obtain sleep diary baseline prior to prescription.

(iii) First line of intervention is sleep hygiene strategies.

(iv) Consider Melatonin in those children with ASD as a treatment for sleep problems when all psychosocial interventions are ineffective.

(v) Benefits and adverse effects of longer term treatment of melatonin requires further investigation.

10.7.13. Melatonin

a. Mode of action: Receptor agonist (Mel1 and Mel2).

b. Recommended use:

(i) There is evidence that Melatonin is tolerated in a study conducted on developmentally disabled children.

(ii) In a small RCT study melatonin has shown improvement in sleep in children with ASD. Melatonin mainly helps in sleep initiation in children with prolonged sleep latency.

10.8. Complementary Alternative Treatments: Healthcare professionals should specifically inquire about the use of alternative/complementary treatments and be prepared to discuss their risk and potential benefits.

10.8.1. Alternative or complementary approaches are often pursued by families, despite a lack of empirical support. Indirect potential harm includes, diverting financial or psychosocial resources.

10.9. The use of treatments that have no scientific evidence to support them should be avoided by healthcare professionals managing ASD (**Table 8, 9, 10**).

**Table 8:** Summary of Evidence on Pharmacological Interventions

| **Outcome Domain** | **Medications** | **Level of Recommendation** |
|---|---|---|
| Core ASD symptoms | Medications are not indicated for core symptoms | Not Indicated / Contraindicated |
| Irritability | Aripiprazole | Level 1 |
| | Risperidone | |
| Sleep | Melatonin | Level 1 |
| | Clonidine | Level 1 |
| ADHD | Stimulants | Level 1 |
| | Atomoxetine | Level 1 |
| | Guanfacine | Level 1 |
| | Clonidine | Level 2 |
| Anxiety / Depression | SSRI | Level 1 |
| | Clomipramine | Not recommended |

**Table 9:** Ineffective Complementary/ Alternative Treatments of ASD

| Treatments that have been shown to be ineffective | Level of Recommendation |
|---|---|
| Memantine | Not Recommended |
| Secretin | Not Recommended |
| Fenfluramine | Not Recommended |
| Oral magnesium | Not Recommended |
| Gluten-free, casein-free diet | Not Recommended |
| Oral human immunoglobulin | Not Recommended |
| Omega-3 fatty acids | Not Recommended |
| B complex vitamins | Not Recommended |
| Divalproex Sodium | Not Recommended |
| Naltrexone | Not Recommended |
| Amantadine | Not Recommended |
| Intravenous Immunoglobulin | Not Recommended |
| Chelation | Contraindicated |
| Hyperbaric oxygen | Contraindicated |

**Table 10:** Ineffective Complementary therapies

| Intervention Name | Level of Recommendations |
|---|---|
| Animal-assisted Therapy | Not Recommended |
| Concept Mapping | Not Recommended |
| DIR/ Floor Time | Not Recommended |
| Facilitated Communication | Not Recommended |
| Movement-based Intervention | Not Recommended |
| SENSE Theatre Intervention | Not Recommended |
| Sensory Intervention Package | Not Recommended |
| Shock Therapy | Not Recommended |
| Social Behavioural Learning Strategy | Not Recommended |
| Social Cognitive Intervention | Not Recommended |
| Social Thinking Intervention | Not Recommended |

*Source: Report of the Ontario Scientific Expert Taskforce for the Treatment of Autism spectrum disorder,April2017

## 11. **RECOMMENDATION SIX:** SUPPORT FOR INDIVIDUALS, FAMILIES, AND CARERS

11.1. Families with children with autism often experience high stress levels as a consequence of their care giving responsibilities, the child's cognitive impairment and the need for long term support.

11.2. Providing immediate access for families during crisis management is highly recommended.

11.3. Proactive crisis support planning should be routinely undertaken and reviewed on a regular basis.

11.4. Resources of information and service support: Emotional support, advice and education are required by parents to enable them to work effectively with their children.

11.4.1. Parents also need access to up-to-date information about treatment options and support services. Research evidence acknowledged that information, support and education should be provided for the entire family unit.

11.4.2. Parents identified good support aspects in two studies which included[1]:

a. Involving the school and the family in the child's assessment.

b. Providing social skills training.

c. Joint work between school and home to facilitate child placement and support.

11.4.3. Parent identified poor support in two studies[2] as:

a. Service did not provide parents with any support.

b. Lack of provision of emergency or immediate support in crisis times.

c. Uneasy access to professionals.

d. Poor communications among various agencies.

11.5. Social Services: Families of children with ASD should be referred to social services for additional social support. Research shows that there is an economic and social impact on families caring of children with ASD.

11.6. Evidence suggests that the provision of respite care and a care coordinator model of care is likely to lead to the most positive outcomes for parents. Children and adolescents need to access social support packages in the form of special needs benefits and other available benefits.

11.7. Physical and Mental Healthcare: Children with ASD require clinical monitoring for physical growth, health and development, as well as co-morbidities.

11.7.1. The main goal is for children with ASD to enjoy a stable physical health which will improve quality of life. However, there is a lack of reliable and valid measures to evaluate progress and change of a child's behaviour and functioning over time after the diagnosis of ASD.

11.7.2. Mental health conditions have substantial personal and economic costs for children with autism spectrum disorder (ASD), they are prevalent in children with ASD from a young age and characterize > 85% by adolescence.

11.7.3. The most common mental health conditions are behaviour/conduct problem, anxiety problem, attention deficit disorder (ADD)/attention-

deficit/hyperactivity disorder (ADHD) and depression. There is an outsized need for effective mental health assessment and treatment of these youth.

11.8. Transition from Adolescents to Adult Services: A transition plan for children with ASD should be set up by the all professional involved in child care at an early stage.

11.8.1. ASD children have varying intellectual and functional abilities, hence the transition into adulthood has to be planned early according to their individual abilities.

11.8.2. Availability of vocational training, post-secondary education, day care activities and supported employment are options for these.

11.8.3. Care for children and adolescents with ASD should be continued in adult health services.

## 12. **RECOMMENDATION SEVEN:** EDUCATIONAL SUPPORT FOR INDIVIDUALS AND FAMILIES

12.1. Regardless of the intervention, implementation across home, early childhood education, school and community settings is important to the outcomes.

12.2. Children with ASD regardless of their abilities need to access an appropriate academic framework with a therapeutic environment in which the requisite supports are provided.

12.3. Educational staff should have knowledge and some training about the presenting features of ASD.

12.4. Educational staff should have smooth access to information, resources on ASD and how to manage it within school environment.

12.5. Educational staff should ensure that all staff are aware of a child or young person's needs and the strategies and interventions to be used with them.

12.6. Educational Interventions should start early. The child or young person's programme should be individualized and designed to engage the child or young person and provide a highly supportive environment.

12.7. Educational Interventions should be monitored and evaluated on an ongoing basis. Where there is no evidence of progress within a few months, changes should be made to the curriculum or intervention goals or increasing consultation and support for staff.

12.8. Educational interventions should incorporate principles of positive behaviour support, particularly a focus on understanding the function of the child's or young person's behaviour.

12.9. All transitions for students with ASD should be carefully planned and the child or young person and the new environment carefully prepared.

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## APPENDICIES

### APPENDIX 1: SUMMARY OF RECOMMENDATIONS

Assessment and management of children and adolescents diagnosed with ASD who present with behavioural, emotional and mental health difficulties can often be challenging.

This guidelines reviews current evidence for autism spectrum disorder (ASD) assessment and management based on research and best practice, provides a standardized process to ensure that children are systematically monitored for early signs of ASD to promote earlier diagnosis. We identify ASD-specific and broadband assessment and management tools that have been approved and tested in research.

**Summary of Recommendations and Level of Evidence**

| Key recommendation | Recommendation Level |
|---|---|
| An ABA based parents- mediated interventions play an important role in improving outcomes | Level 1 |
| Comprehensive Behavioural Interventions and strategies based on applied behaviour analysis (ABA) principles, developmental and combined approaches should be considered for all children with ASD | Level 1 |
| Early intensive behavioural intervention (EIBI) of more than 20 hours a week, should be considered as a treatment of value for young children with ASD to improve outcomes such as cognitive ability, language skills, and adaptive behaviour | Level 1 |
| ABA interventions can be provided in a variety of settings. | Level 1 |
| Focused interventions to target specific behaviour or developmental outcome should be available for all children | Level 1 |
| Cognitive behavioural therapy approach should be adapted for people with ASD and may be considered to treat co morbid conditions such anxiety in cognitively able children | Level 2 |
| Children with ASD should receive varieties of speech, language and communication interventions tailored for their need | Level 1 |
| The use of Speech generating device and Technology based interventions is useful for children with limited or no speech | Level 1 |

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| Educational interventions should include the availability of structured educational models such as TEACCH or EDSM | Level 1 |
| The development of the educational plan and should reflect an accurate assessment of the child's strengths and vulnerabilities, with an explicit description of services to be provided, goals and objectives, and procedures for monitoring effectiveness | Level1 |
| Families and children with ASD should have access to social support packages in the community | Level 2 |
| The values, knowledge, preferences and cultural perspectives of the family/carers should be respected and evident in services and resources | Level 2 |
| Provide easy access for families to information and support relating to their needs in an easy written material with different languages through a national ASD resource centre | Level 2 |
| Empowering the role of the ASD care coordinator to manage the needed care and provide support for the child and family | Level 2 |
| Involve families and individuals affected by ASD in decision making and care planning | Level 2 |
| Parent-led support networks should be recognized and encouraged to increase awareness and exchange of information and support among parents | Level 3 |
| ASD-related counselling and/or advocacy services and education should be available to all family members and carers including siblings and extended family. | Level 2 |
| Employer supports are crucial to support parents of children with disabilities to enable them to work and care for their children | Level 2 |
| Providing immediate access for families during crisis management | Level 1 |
| Proactive crisis support planning should be routinely undertaken and reviewed on a regular basis. | Level 1 |
| Availability of respite care is helpful in providing extra social support for the family | Level 3 |
| People with ASD should have equal access to physical and their physical care package should be comprehensive | Level 1 |
| ASD children physical healthcare assessment profile should include:<br>1. Screening for emergence of epilepsy<br>2. Screening for hearing loss, eyesight changes.<br>3. Monitoring of physical growth | Level 1 |

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| 4. Metabolic syndrome screening<br>5. Dental screening and treatment<br>6. Dietary and exercise guidelines to prevent secondary health issues, especially for those on medication<br>7. Screening for motor, sensory and perceptual difficulties.<br>8. Proper support and procedure to facilitate blood investigation<br>9. Providing sleep management | |
| There are no controlled long term studies demonstrating that pharmacological treatment affect the core difficulties or outcomes in children and adolescents with ASD, therefore, Antipsychotic medications should not be used for that purpose | Level 1 |
| Antipsychotics may be considered to reduce irritability and hyperactivity in children and young people with autistic spectrum disorders in the short term (eight weeks). | Level 3 |
| Methylphenidate may be considered in the treatment of attentions Deficit Hyperactivity Disorder | Level 3 |
| Physical health monitoring is indicated on antipsychotic prescription to prevent complications | Level 3 |
| Pharmacological interventions should be considered as part of a multi-component intervention and should not be used solely. | Level 3 |
| Pharmacological interventions should be used appropriately to target specific signs and symptoms of comorbid psychiatric or neurodevelopmental conditions. | Level 3 |
| Clinicians should seek the balance of potential risks and benefits of each pharmacological treatment and this should be discussed appropriately with the family. | Level 3 |
| Pharmacological treatment prescribing for children with ASD should be conducted by experienced physician with adequate knowledge and skills in ASD in a setting that has available resources for necessary monitoring. | Level 3 |
| Children with ASD who suffers sleep problems needs to access appropriate therapy through behavioural strategies and appropriate medications | Level 3 |
| Healthcare professional should have skills and experience in managing ASD challenging behaviour and understand its functions. | Level 3 |

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| Dieticians advice may be considered when children's weight changes due to their eating habit | Level 3 |
| Clinicians should specifically inquire about the use of alternative/complementary treatments and be prepared to discuss their risk and potential benefits | Level 2 |
| Complementary therapies that are not evidence based:<br>1. Animal-assisted Therapy<br>2. Concept Mapping<br>3. DIR/ Floor Time<br>4. Facilitated Communication<br>5. Gluten-free/Casein-free Diet<br>6. Movement-based Intervention<br>7. SENSE Theatre Intervention<br>8. Sensory Intervention Package<br>9. Shock Therapy<br>10. Social Behavioural Learning Strategy<br>11. Social Cognitive Intervention<br>12. Social Thinking Intervention | Not Recommended<br>Not Recommended |
| Alternative Treatment with conflicting evidence:<br>1. Omega-3 fatty acids<br>2. B complex vitamins | Not Recommended |
| Complementary/alternative treatments that are ineffective:<br>1. Memantine<br>2. Secretin<br>3. Fenfluramine<br>4. Oral magnesium<br>5. Gluten-free, casein-free diet<br>6. Oral human immunoglobulin | Not Recommended |
| Complementary/Alternative treatment with insufficient evidence:<br>1. Divalproex Sodium<br>2. Naltrexone<br>3. Amantadine<br>4. Intravenous Immunoglobulin | Not Recommended |
| Treatments that are potentially harmful, i.e. associated with mortality and morbidity:<br>1. Chelation<br>2. Hyperbaric oxygen | Contraindicated |