



IDENTIFICATION, EVALUATION, AND MANAGEMENT OF CHILDREN WITH AUTISM SPECTRUM DISORDER

A GUIDELINE FOR THE CLINICIANS AT CHILD
DEVELOPMENT INTERVENTION CENTERS



World Health
Organization



Identification, Evaluation, and Management of Children with Autism Spectrum Disorder

A Guideline for the Clinicians at Child Development Intervention Centers

Child care, Development and Special Needs Unit

Family Health Bureau

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Identification, Evaluation and Management of Children with Autism Spectrum Disorders: A guideline for the Clinicians at Child Development Intervention Centers

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Guideline Development Committee

- Dr. Swarna Wijethunga, Consultant Child and Adolescent Psychiatrist, Lady Ridgeway Hospital for Children
- Prof. Samanmalee Sumanasena, Professor in Pediatric Disabilities, Ayati, Faculty of Medicine, University of Kelaniya
- Dr. Darshani Hettiarachchi, Consultant Child and Adolescent Psychiatrist, Teaching Hospital, Karapitiya
- Dr. Wajantha Kotalawala, Consultant Child and Adolescent Psychiatrist, National Institute for Mental Health
- Dr. Yashoda Rohanachandra, Consultant Child and Adolescent psychiatrist, Senior Lecturer, University of Sri Jayawardenapura
- Dr. Dulangi Dahanayake, Consultant Child and Adolescent Psychiatrist, Senior Lecturer, Faculty of Medicine, University of Colombo
- Dr. Dilini Vipulaguna, Acting Consultant Community Pediatrician, RDHS Gampaha
- Dr. M.U.G.Sampath, Associate Specialist in Community Pediatrics, Lecturer, Faculty of Medicine, Sabaragamuwa University of Sri Lanka
- Dr. S.R.Vithana, Associate Specialist in Pediatrics, Lecturer, Faculty of Medicine, Sabaragamuwa University of Sri Lanka
- Dr. Nimisha Muttiah, Speech & Language Therapist, Senior lecturer, Ayati, Faculty of Medicine, University of Kelaniya
- Dr. Asiri Hewamalage, Consultant Community Physician, Family Health Bureau
- Dr. Tamara Handi, Educational Psychologist, Ayati, Faculty of Medicine, University of Kelaniya
- Dr. Manjula Danansuriya, National Professional Officer, WHO Sri Lanka
- Ms. Thilini Madushika, Physiotherapist, Ayati, Faculty of Medicine, University of Kelaniya
- Ms. Yvonne Weerasinghe, Speech & Language Therapist, Lady Ridgeway Hospital for Children
- Dr. Rasika Aluthwalage, Medical Officer, Family Health Bureau
- Ms. Amandi Caldera, Psychologist, Ayati, Faculty of Medicine, University of Kelaniya
- Ms. Sakuni Hingurangala, Speech & Language Therapist, Child Development Intervention Center, Maligawatta DH
- Dr. Anjela Arulpragassam, Consultant Pediatrician, Senior lecturer, Faculty of Health Care Sciences, Eastern University of Sri Lanka
- Ms. Sujatha Gunawardena, Occupational Therapist, Ayati, Faculty of Medicine, University of Kelaniya
- Ms. Ashoka Elvitigala, Occupational Therapist

Coordinator:

Dr. Asiri Hewamalage

Consultant Community Physician, National Program Manager Child Care, Development and Special Needs Unit
Family Health Bureau

Synopsis of IncluDe Logo

The IncluDe logo depicts the concept of ‘embracing diversity’. All children are valuable for our motherland. Children are diverse and their diversity brings different strengths to the development of the country. Hence, as a country we include all the children in any health program. The different shape and coloured letters of the logo symbolizes the diversity. Some may be with disability but they too stand bold. The Inclusive Early Childhood Development program is about all children in Sri Lanka! All are INCLUDED!



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Message from the Director General of Health Services

Autism Spectrum Disorder is related to brain development which commence in early childhood. As it is characterized by problems in social interactivity, communication and confined, monotonous behavior patterns, these children and their families face many difficulties in their day-to-day life. Due to the diversity of this condition, often the presentation is delayed leading to a delay in initiation of timely interventions.

Autism Spectrum Disorder is a widely prevalent condition around the world among children in early life. This situation is more or less similar in Sri Lanka. These children have a right for a beautiful future similar to all the other children. As health care workers there is a huge responsibility in management of such individuals. In order to address the prevailing situation, Ministry of Health along with the World Health Organization has taken steps to bring out this publication. This booklet is a blueprint to guide the healthcare workers through screening, assessment, setting long-term and short-term goals, interventions and follow-ups in relation to Autism Spectrum Disorders. I believe this will be an asset to provide timely interventions for the children with ASD.

The development of this handbook would not have been possible without the valuable contribution of all the clinicians, Family Health Bureau of Ministry of Health and the World Health Organization. I would like to take this as an opportunity to extend my heartfelt gratitude to all those contributors.

Dr. Asela Gunawardena,
Director General of Health Services,
Ministry of Health, Sri Lanka

Message from the Director, Maternal and Child Health

As the national focal point for child care, Family Health Bureau of Ministry of Health along with World Health Organization developed the Inclusive early childhood development program (IncluDe) which addresses both normal as well as children with special needs. Until the development of such a program no population-based screening programs were available for screening of Autism Spectrum Disorders. This program includes primary care at field level, secondary care at MOH level and tertiary care at child development intervention center (CDIC) in pre-determined apex hospital of each district.

Timely and standardized interventions for autism are found to be very productive. Public health care staff at field and MOH levels as well as multi-disciplinary team at tertiary level requires an universally accepted guidance for the early identification and management of autistic children. Following countless struggles this booklet was evolved. It is our responsibility to utilize this precious piece of work to the maximum to lift up the lives of affected children and their families.

Furthermore, I would like to acknowledge the utmost support provided by the child care, development and special needs unit of Family Health Bureau and World Health Organization to make this a success.

Dr. Chithramalee de Silva

Director Maternal and Child Health
Family Health Bureau

Message from the WHO Country Representative to Sri Lanka

Global research highlights that one child in 160 suffers from Autism Spectrum Disorder (ASD). In 2014, the 67th World Health Assembly adopted a resolution to promote comprehensive and coordinated efforts for the management of autism spectrum disorders (ASD). The resolution requested Member States to give appropriate recognition to the specific needs of individuals affected by ASD in policies and programmes; to increase the capacity of health and social care systems to provide services for individuals and families; and to mainstream into primary health care services the promotion and monitoring of child development for timely detection and management of ASD.

Sri Lanka has attempted to introduce services to identify and manage children with disabilities including ASD via Social Service sector since early 2000. However, sustainability of such efforts was a challenge due to lack of trained human resources in delivering multidisciplinary care for the needy children.

Government of Sri Lanka is attempting to re-introduce these needy services via health and other sectors accommodating slowly expanding trained human resource pool in the country. Ministry of Health has already introduced, a child development intervention package and a special need care package. Capacity building of health staff on these intervention packages is progressing. The present guideline is a new addition to existing intervention package and will be an important resource to health staff.

WHO will continue to partner with the Ministry of Health and other stakeholders in further strengthening the health system to deliver quality child health services; and promote inclusive and empowering environments for children with ASD.

Dr. Alaka Singh

WHO Country Representative for Sri Lanka

List of Abbreviations

AAC	- Augmentative and Alternative Communication
ABA	- Applied Behaviour Analysis
ABC form	- Antecedent Behaviour Consequence model form
ABR	- Auditory Brainstem Responses
ADDM	- Autism and Developmental Disease Monitoring Network
ADHD	- Attention Deficit Hyperactivity Disorder
ADL	- Activities of Daily Living
ADOS-2	- Autism Diagnostic Observation Schedule Second Edition
AIM	- Autism Impact Measure
AIMS	- Alberta Infantile Motor Scale
ASD	- Autism Spectrum Disorders
BMI	- Body Mass Index
CARS-2	- Childhood Autism Rating Scale Second Edition
CBCL	- Child Behaviour Checklist
CDC	- Centre for Disease Control
CDIC	- Child Development Intervention Centre
CHDR	- Child Health and Development Record
COPM	- Canadian Occupational Performance Measure
CTM	- Comprehensive Treatment Model
DASS-2	- Depression, Anxiety and Stress Scale- 2
DAYC	- Development Assessment of Young Children
DO	- Development Officer
DSM 5	- Diagnostic and Statistical Manual of Mental Disorders - 5
ECI	- Early Childhood Interventions
EEG	- ElectroEncephalogram
EI	- Educational Interventions
EIBI	- Early Intensive Behavioural Interventions
ENT	- Ear, Nose, Throat
ESES	- Epileptical status epilepticus in sleep
ET	- Educational Therapist
GI	- Gastro Intestinal
GORD	- Gastro Oesophageal Reflux Disease
HIC	- High Income Countries
HINE	- Hammersmith Infantile Neurological Evaluation
ICD	- International Classification of Disease
ICF	- International Classification of Functioning
IEP	- Individualized Education Plan
IIP	- Individualized Intervention Plans
IncluDe	- Inclusive Early Childhood Development programme
IQ	- Intelligent Quotient

JASPER	- Joint Attention Symbolic Play Engagement and Regulation programme
MACS	- Manual Ability Classification System
M-CHAT	- Modified Checklist for Autism
MO	- Medical Officer
MOH	- Medical Officer of Health
MOH CDC	- Medical Officer of Health Child Development Clinic
NDBI	- Naturalistic developmental behavioural interventions
ND issues	- Neuro Developmental issues
NLP	- Natural Language Paradigm
NO	- Nursing Officer
OCD	- Obsessive Compulsive Disorders
OT	- Occupational Therapist
PACT	- Preschool Autism Communication Therapy
PASS Plus	- The parent-mediated intervention for Autism Spectrum Disorders in South Asia Plus
PECS	- Picture Exchange Communication System
PHM	- Public Health Midwife
PRT	- Pivotal Response Treatment
PSW	- Psychiatric Social Worker
PT	- Physiotherapist
QCIIT	- Quality of Caregiver–Child Interactions for Infants and Toddlers
RCT	- Randomised Controlled Trial
REEL-3	- Receptive – Expressive Emergent Language Test 3 rd edition
SCATA	- Social Communication Assessment for Toddlers with Autism
SHUEE	- Shrine Hospital Upper Extremity Evaluation
SLT	- Speech and Language Therapist
SKS	- Saukya Karya Sahayaka
SMART	- Specific, Measurable, Achievable, Realistic, Time sensitive
SOG	- Schedule Of Growing skills
SOS approach	- Sequential Oral Sensory Approach to Feeding
SSP	- Short Sensory Profile
STEP Assessment	- Screening Tool for Feeding Problems Assessment
TEACCH	- Treatment and Education of Autistic and Related Communication-Handicapped Children
TPP	- Test of Pretend Play
USA	- United State of America
VABS	- Vineland Adaptive Behaviour Scales
WHO	- World Health Organization
WHO- QOL-BREF	- Abbreviated World Health Organization- Quality of Life

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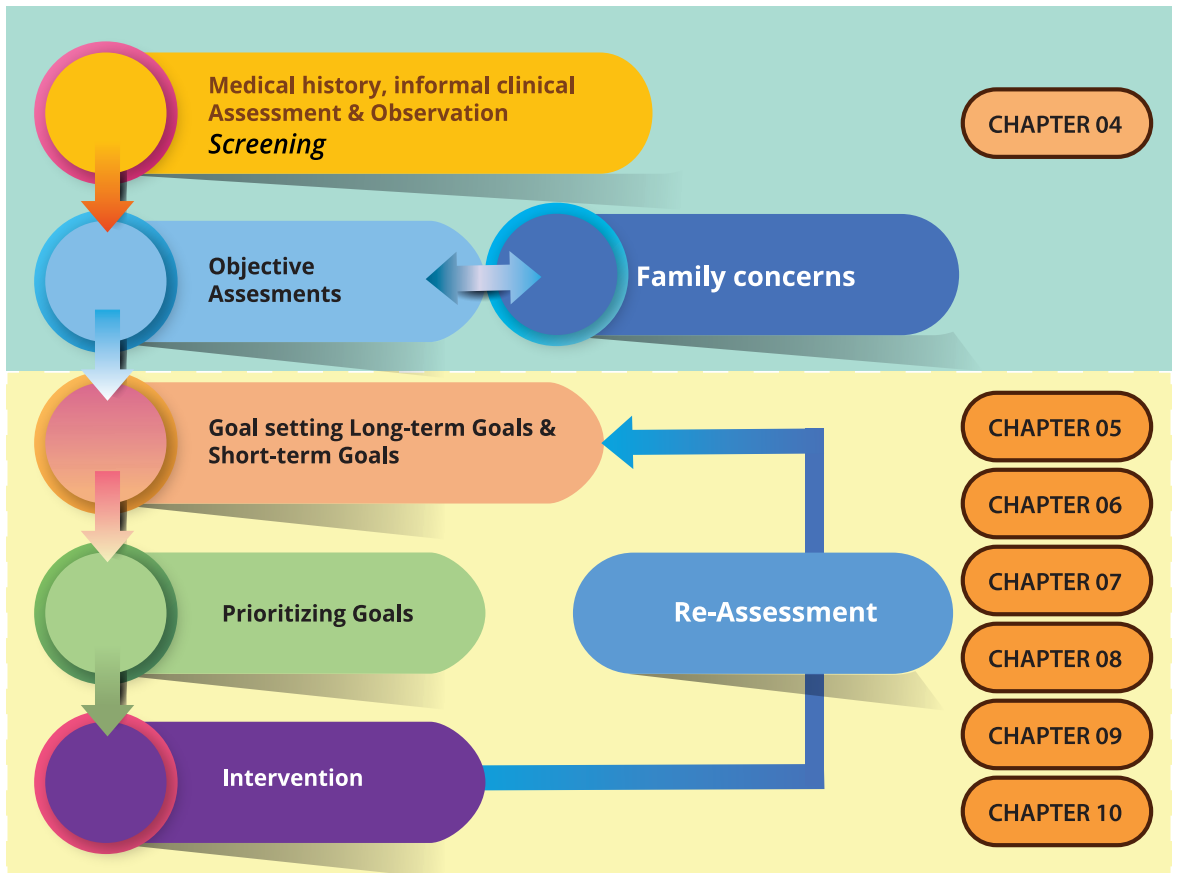
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How to utilize the book

The details provided in this book are only a guideline. It is mandatory to cater the assessments and interventions based on the individual need of the child through a proper clinical assessment. The Inclusive Early Childhood Development Program in Sri Lanka (IncluDe) attempts to utilize multi-disciplinary teams for early identification, evaluation and management of children with autism spectrum disorders in an intra-disciplinary manner. Following is the overview of the above service delivery model used by the multidisciplinary teams, and the relevant chapters discussing these approaches are indicated.

figure 1: Overview of how to utilize the book



Chapter 1 is an introduction to the ASD and program IncluDe

Chapter 2 is an overview of the epidemiology of ASD.

Chapter 3 gives a road map of the whole process of identification, evaluation and management of ASD as a snapshot view.

Chapter 11 briefly discusses how to empower the parents.

Chapter 12 is a description of management of the co-occurring conditions/issues of ASD.

Chapter 13 discusses an important issue; the educational aspects of children with ASD and how to intervene.

Chapter 14 is about the long-term follow-up

Chapter 15 briefly discusses safeguarding of the children with ASD.

Additional reading and theoretical facts which are good to read are in the Appendix.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social communication & reciprocal social interactions and presence of restricted repetitive interests or behaviors. This is identified as a developmental disability of a child which poses significant impact on the child, parents, family and the community. In recent years, global epidemiological studies have shown an increase in the prevalence of ASD. Though there is a lack of prevalence studies in Sri Lanka, most clinicians report increased prevalence in their clinical practice. Due to the complexity and the heterogeneity of the clinical features of this condition, identification by caregivers and confirmation by the healthcare providers may lead to delays resulting in missed opportunities for timely and optimal interventions for these children.

There is adequate evidence to show that early identification of the features and red flag signs of ASD and early intervention significantly enhances the outcomes of the affected children. This is reinforced by the recent scientific evidence on brain plasticity and brain development. Therefore, the Ministry of Health has commenced the Inclusive Early Childhood Development Program (IncluDe) in Sri Lanka, which targets to systematically screen all children to identify the development delays and disabilities as early as possible and to provide early childhood intervention via a multidisciplinary team.

Under the inclusive early childhood development program there will be a child development intervention center (CDIC) for every District in the Country. The CDIC will function with the multi-disciplinary team (MDT). The MDT comprises of Consultant Community Pediatrician, Medical officer- Child Development, Nursing Officer, Speech and Language Therapists (SLT), Physiotherapist (PT), Occupational Therapist (OT), Educational Therapist (ET), Psychologist, Audiologists, Orthotist and prosthetist, Orthoptist, Development Officer (DO) and Saukya Karya Sahayaka (SKS). They will be responsible to evaluate each child, develop individualized intervention plans (IIP), link with social services, educational services, counseling and other necessary services and to refer back the child to the MOH CDC for home-based follow-up.

This management guideline for the ASD is intended for the clinicians working in the multidisciplinary teams in regional child development intervention centers (CDIC). The objective of this guideline is to assist the MDT at the CDIC to comprehensively manage the child presented with a symptom or sign of autism spectrum disorder. This includes how to arrive at a diagnosis, what are the assessments to be conducted and to assist the team in initiating the early childhood interventions (ECI). Hence, the target audience of this guideline is the clinical multidisciplinary team at the CDIC. In addition, any primary health care worker can utilize this book as a source of information and a reference guide.

At the same time this management guideline targets very early presentations of ASD especially children below the age of five years. However, in certain sections some assessments and interventions extend beyond the scope of five years of age.

The prevalence of ASD has shown a rapid rise in the past decade. The World Health Organization states a global prevalence of one in 160 children having ASD in 2021, based on a study published in 2012. Further, the WHO mentions that the above is an average figure with significant variation across the different regions.

This rapid increase in prevalence as well as significant variations across the regions may underpin the inherent complexity of ASD, accounting for simultaneous changes in diagnostic practice, coding tendency, and community awareness. In addition, the different diagnostic criteria and different age populations under study in the published research may have contributed to the variation of prevalence estimates.

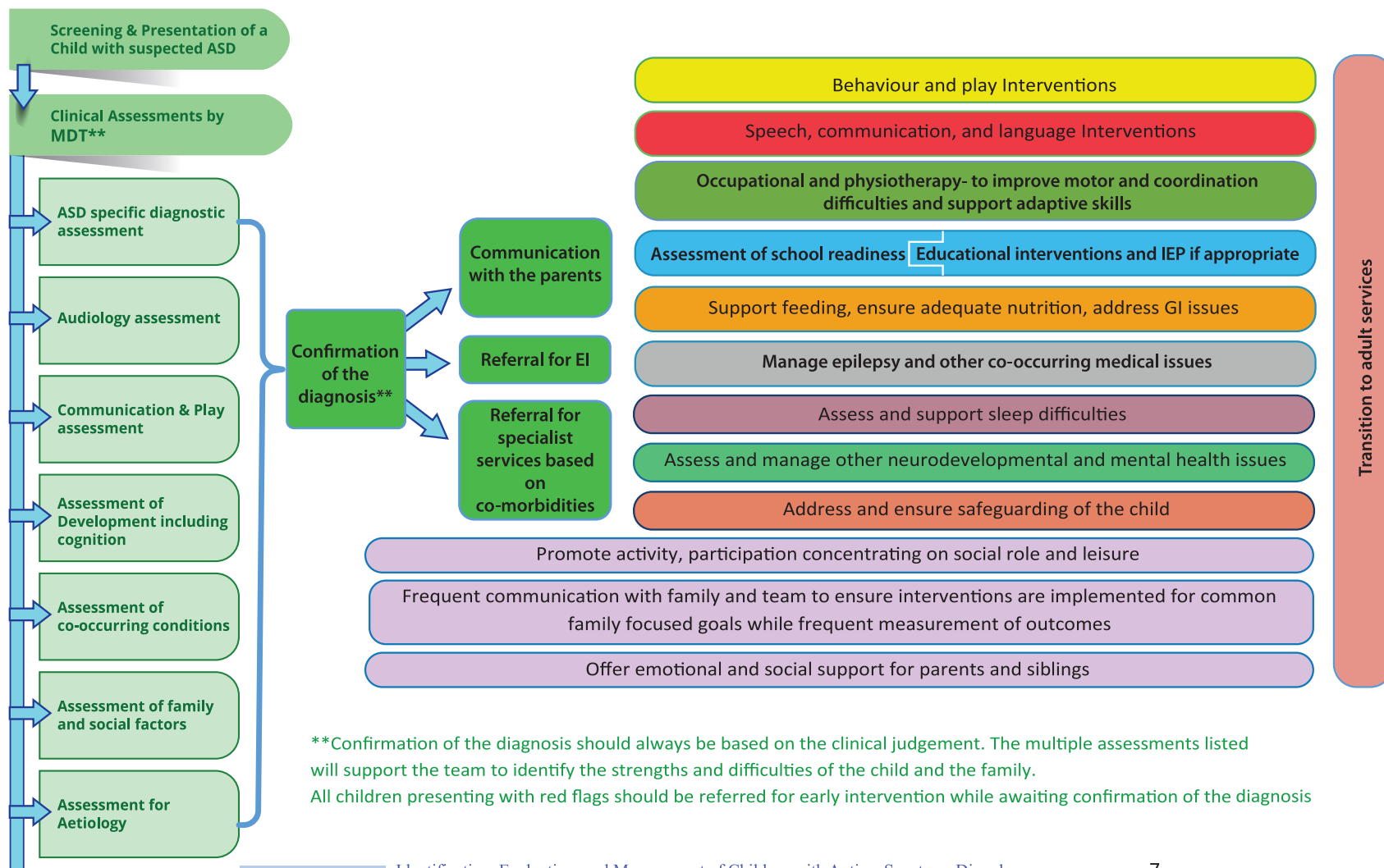
According to estimates of the Centre for Disease Control and Prevention (CDC)'s Autism and Developmental Disease Monitoring (ADDM) Network, in the USA it is estimated that 1 in 54 children are identified with ASD. This is seen across ethnic, racial and socio economic groups. The prevalence of ASD is four times higher among boys than girls.

In the European region the prevalence data varies from 0.19 to 7.2 per 1000 with an age range of birth to adulthood. In South Asian countries the prevalence data ranged from 0.9 to 10.7 per 1000 children in a recent systematic review.

In Sri Lanka there is only one study on the prevalence of ASD conducted in the year 2009 in a limited geographical region which states a prevalence of 1.07% or 1 per 93 in the 18–24-month age group of children. The situation in Sri Lanka is similar to many low to middle income countries where valid comparable prevalence data is not available.

The following graphical illustration presents an overview of identification, evaluation and management of children with autism spectrum disorder.

Figure 2 : Overview of identification, evaluation and management of children with ASD



4.1 Screening for Autism Spectrum Disorder

Table 1: Screening for ASD

Screening tool name	Age category	Description	To be used by whom
Child Health Development Record (CHDR)	2 months to 60 months of age	A generic development screening tool used by the National child health program in Sri Lanka	PHM, MOH, Primary care clinicians, General practitioners or any other clinician
Modified Checklist for Autism in Toddlers (M-CHAT R/F)	16 months to 30 months of age	Specifically assess the risk for ASD. Score ≤ 8 : high risk 3-7: moderate risk: needs follow up. The primary goal of the M-CHAT is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk for ASD will be diagnosed with ASD. The estimated sensitivity of the M-CHAT-R with Follow-Up is 85% and specificity is 99%.	Can be used by a specialists or other professionals

Annexure 1: Development screening tool of the CHDR

Annexure 2: Modified Checklist for Autism (MCHAT R/F)

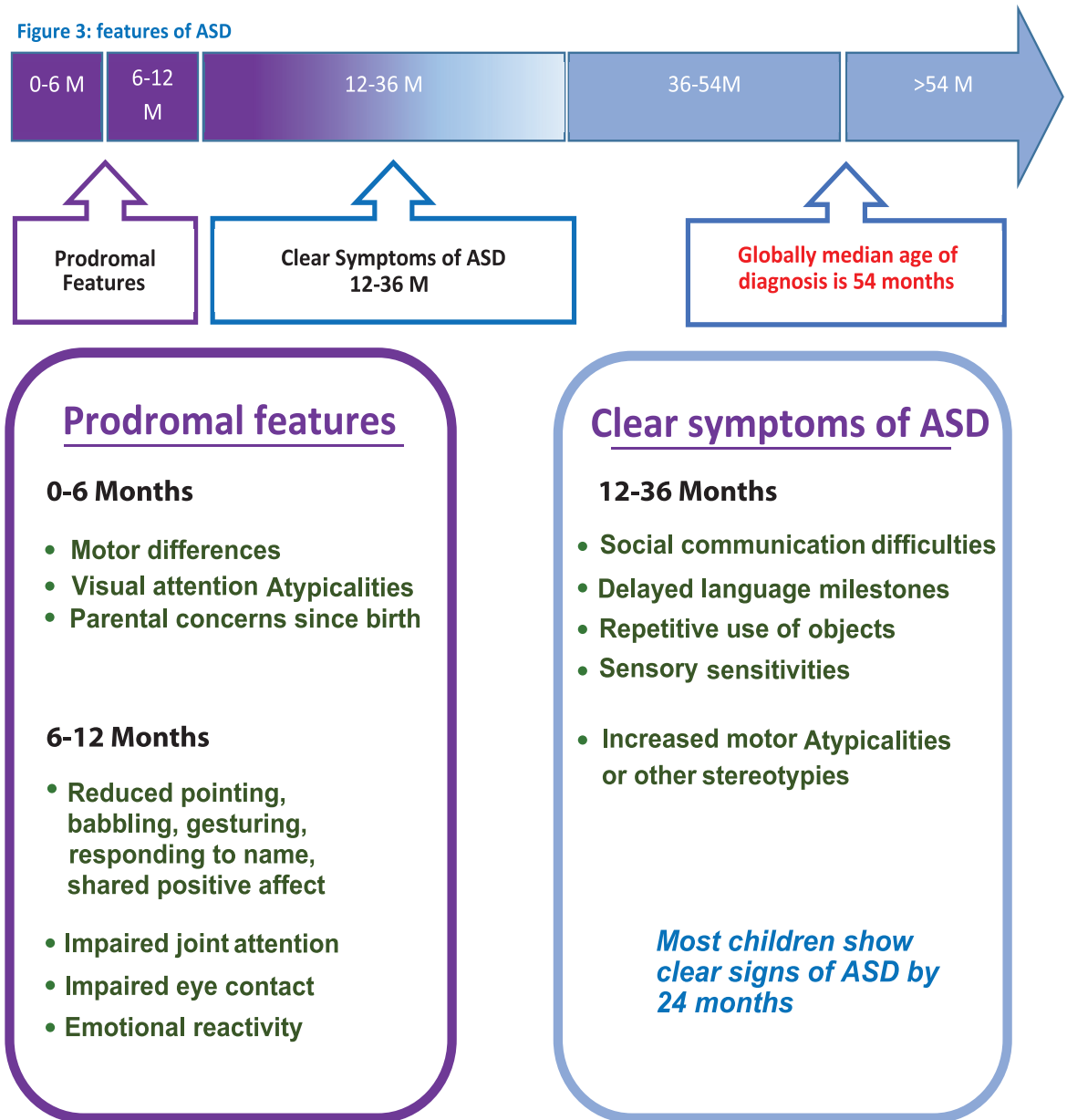
4.2 Red flag signs for screening

Autism Spectrum Disorder has an early onset. However, to arrive at a diagnosis based on the ‘core’ criteria of DSM-5, the symptoms are required to be present in the first 3 years of life. Nevertheless, it is very important to identify the early appearance of some symptoms and signs which are now identified as ‘prodromal’ features. These are signs or indicators that will be present very early in life, certainly in infancy. Identification of the prodromal features is very important as we can attempt to ameliorate early presentation and even 'prevent' emergence of the full syndrome.

Further the “IncluDe” National program targets early identification and early intervention. Therefore, knowledge about prodromal features is essential.

In the global data, the prevalence of ASD among lower age groups is less compared to the higher prevalence rates of children over 4 years of age with ASD and intellectual disabilities. This may be due to lack of early identification and later diagnosis of children with ASD and average range cognitive abilities.

Figure 3: features of ASD



4.3 Red flag signs by age

Because there is currently no biological marker for ASDs, screening and diagnosis must be based on behavioural features. There is a growing body of research on early red flags of ASDs in the first and second years of life from retrospective parent report and home video analyses and from prospective research on siblings of children with ASDs and on general population samples.

Table 2: Red flag signs of ASD by age

Age	Social Communication and interaction	Restricted repetitive behaviors
By six months	Few or no big smiles or other warm, joyful and engaging expressions	Very difficult to console, requires rocking and unusual movements in excessive amounts to console
	Limited or no eye contact	
By 9 months	Does not respond to name	Unusual repetitive movements of limbs and body.
	Does not show facial expressions like happy, sad, angry, and surprised	Prefers to stare at rotating objects such as fans for prolonged periods
	Little or no back and forth sharing of sounds, smiles or other expressions	
By 12 months	Little or no babbling	Obsessed with parts of toys or clings on to same toys
	Little or no back-and-forth gestures such as pointing, showing, reaching or waving	Spins toys or objects frequently
	Does not play simple interactive games like 'athuru-mithuru' – or hand games involving clapping with each other by 12 months of age	
By 15 months	Does not share interests with others (e.g., shows you an object that he or she likes)	
	Very few or no words	
By 18 months	Does not point or look at what you point to	Lining up or stacking toys
	Unusual squealing	Repetitive humming or repetitive use of same words/phrases
By 24 months	Does not engage in pretend play	Gets upset for minor changes often
	Very few or no meaningful two-word phrases	Flapping, Rocking and unusual tensing of the body
At any age	Loss of babbling, speech or social skills acquired at any age before 3 years	

4.4 Arriving at a diagnosis and other assessments

Autism Spectrum Disorder is diagnosed clinically by observing a child during play for a behaviorally defined set of clinical features complemented with the information gathered to fulfill the diagnostic criteria. There is no single specific assessment, investigation or test to diagnose autism spectrum disorder. Some specific assessments in language and communication, play and child behavior by themselves or in combined assessments will support this diagnosis (refer table3)

DSM- 5 is the gold standard in defining the core symptoms in ASD and the criteria to arrive at a diagnosis. These symptoms were divided into 2 domains (social communication and social interactions and restrictive, repetitive patterns of behaviors). To fulfill diagnostic criteria for ASD by using the DSM-5, all 3 symptoms of social affective difference need to be present in addition to 2 of 4 symptoms related to restrictive and repetitive behaviors. DSM- 5 also includes a severity rating ranging from 1-3 to define the levels of support these individuals may need in terms of ASD symptoms and the services required. This is not a quantifiable system but a qualitative assessment.

“International Classification of Diseases,” is a diagnostic manual produced by the World Health Organization (WHO). The latest draft of the manual, dubbed ICD-11, identifies ‘Autism Spectrum Disorder 6A02’ and is more or less similar to the DSM-5 criteria. Further, the ICD-11 provides detailed guidelines for distinguishing between autism with and without intellectual disability. Unlike the DSM-5, the ICD-11 does not specify the number or combination of features to meet the threshold for autism. Instead, it lists various defining features and lets a clinician decide whether a child could be given the diagnosis.

It is mandatory to conduct a complete ENT assessment and audiological evaluation of all children suspected of ASD prior to confirming the diagnosis.

Table 3: Comparison of DSM-5 and ICD 11 diagnostic criteria

	DSM-5 (American Psychiatric Association, 2013)	ICD-11 beta draft (World Health Organization, 2017)
1	Persistent deficits in social communication and social interaction across multiple contexts (currently or by history): social-emotional reciprocity non-verbal communicative behaviours developing, maintaining and understanding relationships	Persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication
2	Restricted, repetitive patterns of behaviour, interests or activities in at least two of the following(currently or by history): • stereotyped or repetitive motor movements, use of objects,	Restricted, repetitive and inflexible patterns of behaviour and interests

DSM-5 (American Psychiatric Association, 2013)	ICD-11 beta draft (World Health Organization, 2017)
or speech (eg: simple motor stereotypes, lining up of toys or flipping objects, echolalia, idiosyncratic phrases). • Instances on sameness, inflexible adherence to routines, or ritualized patterns of verbal or non-verbal behavior (eg: extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). • Highly restricted, fixated interests that are abnormal in intensity or focus (eg: strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). • Hyper- or hypo reactivity to sensory inputs or unusual interest in sensory aspects of the environment (eg: apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).	
3 Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)	Onset during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities
4 Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning	Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational or other context
5 Not better explained by another diagnosis	

Annexure 3: Severity Scoring in DSM 5 Criteria

Annexure 4: Specifics in DSM 5

Table 4: Summary of Assessments for ASD

Assessment	Assessment Category	Description	To be used by whom
ASD Specific Diagnostic Evaluation	Comprehensive History and Clinical Examination of the child	Detailed perinatal and family history. A detailed developmental history with a specific focus on core symptoms, play, communication and behavior will be elicited. This will help to confirm the progression of the condition and to elicit the clinical features to support the DSM-5 criteria to arrive at a diagnosis.	Suitably qualified medical specialist
	Clinical Assessment based on DSM-5 criteria or ICD 11 criteria	The gold standard ASD specific diagnostic evaluation. Based on a developmental history and observation of the child. Commonly used criterion is the DSM-5. No specific laboratory investigations or imaging studies are necessary to confirm the diagnosis.	Suitably qualified medical specialist
	Autism Diagnostic Observation Schedule Second Edition (ADOS-2)	A validated observation tool to support the diagnosis of ASD based on DSM-V criteria. Internationally used. Still not validated to Sri Lanka	Specifically, trained clinicians in ADOS
	Childhood Autism Rating Scale Second Edition (CARS-2)	A tool used in establishing the diagnosis and assessing the severity of ASD	Specifically, trained clinicians in CARS-2
Audiology assessment	Comprehensive ENT and audiology assessment	Mandatory to complete an audiology assessment including ABR prior to the confirmation of the diagnosis. Central auditory processing disorder is a key co-existing condition with ASD. Therefore, may be helpful in some children based on clinical findings	Assessment by an ENT surgeon and clinical audiologist
Communication & Play assessment	This includes specific language and communication assessments and observation of play hierarchy	These will identify the qualifiers of ASD. Eg: language skills and will also define the functional levels of children helping the clinicians to plan interventions appropriately.	SLT, OT, Psychologist

Assessment	Assessment Category	Description	To be used by whom
Assessment of the development including cognition	Bayley Scales of Infant and Toddler Development or any appropriate standard development tool (Schedule of Growing Skills)	This will help the team to gauge the developmental skills of the child including formal assessments in cognitive, language, motor, social-emotional and adaptive skills. That will indicate the functional abilities of a child less than 42 months	Suitably trained clinician.
	For children older than 36 months		
	Good Enough Harris Draw a person test or any other appropriate cognitive test available	A psychological cognitive test used to evaluate children and adolescents for measuring of non-verbal intelligence, screening emotion and behavior disorders.	Suitably trained clinician.
	School readiness assessments are also cognitive assessments including pre-literacy, pre-number and adaptive skills	Helpful to prepare the child for schooling	Psychologists, educationists
Assessment of co-occurring conditions	Comprehensive History and Clinical Examination of the child	A comprehensive developmental history is necessary to identify co-occurring conditions. Laboratory investigations, neuroimaging, electroencephalography and hearing/visual assessments are some of the investigations that may be used to assess for co-occurring conditions and to exclude differential diagnoses. <i>Do not forget to assess for epilepsy.</i>	Suitably qualified medical specialist
Assessment of family & social factors	Comprehensive History of the child with family and social history Assessment of the preschool/school environment if relevant	Family history, income, educational level, and social support are important factors to be assessed. Clinical features or any element in the clinical history that suggest maltreatment or exposure to violence. Any recent or ongoing severe stressors in the family. Presence of any priority MNS condition among the carers that could impact their ability to care for the child. Whether the child getting adequate opportunities for play and social interaction/ communication at home	Suitably qualified medical specialist /MO/NO

Assessment	Assessment Category	Description	To be used by whom
Assessment of aetiology	Comprehensive History and Clinical Examination of the child	Majority of children will have no pointer towards an aetiology Always look for café au lait spots, hypo pigmented skin patches and any features of tuberous sclerosis. Clinical features of Fragile X syndrome or family history. A referral to a Clinical Geneticist can be offered in instances where there is a suspicion of a genetic condition due to dysmorphic features (e.g. fragile X syndrome, Tuberous sclerosis) or there is a strong family history	Suitably qualified medical specialist

4.5 Aetiological factors of ASD

Table 5: Aetiological factors of ASD

Genetics	Heritability >80% Due to multiple genes with small effect
Obstetric complications	Extreme prematurity Hypoxia Antepartum haemorrhage Gestational diabetes Breech presentation Use of sodium valproate during pregnancy
Environmental factors	Increased parental age Exposure to pesticides during pregnancy

4.6 Common Co-occurring conditions with ASD

Table 6: Common co-occurring conditions with ASD

Mental and behavioural disorders	• Anxiety disorders • Mood disorders • Obsessive compulsive disorders • Oppositional defiant disorder • Tics/Tourette syndrome • Self-injurious behaviour/aggression • Sleep disorders • Feeding problems
Neuro developmental disorders	• Global developmental delay/intellectual disability • Attention Deficit Hyperactivity disorder • Speech and language disorder • Learning disorders • Developmental coordination disorder
Medical/genetic disorders	• Epilepsy • Gastrointestinal problems - gastritis, GORD, altered bowel habits, constipation • Genetic disorders - Fragile X syndrome, tuberous sclerosis, neurofibromatosis, Trisomy 21, Muscular dystrophies- particularly Duschenne

Early intervention is an umbrella term that describes all the services and supports available for children with disabilities and their families. This may include a blend of different services which are individualized for the needs of the child and the family.

Early interventions have proven to enhance the functional outcomes of the children with ASD. The evidence base has increased recently supporting the early behavioral, developmental and various other interventions for autism spectrum disorder.

It is important to identify the goals of management of children with ASD in deciding on the early interventions to be provided for a particular child and the family.

The goals of management of children with ASD are to;

- Minimize core features (social communication and interaction and restricted or repetitive behaviors and interests) and co-occurring associated developmental, behavioural and learning impairments/ comorbidities;
- Maximize functional independence by facilitating learning and acquisition of adaptive skills
- Eliminate, minimize, or prevent problem behaviors that may interfere with functional skills.
- Improving quality of life of the child and family
- Promotion of social inclusion
- Protection of human rights and dignity



Following facts should guide the management of a child with ASD

1. Effective early interventions should be started as early as possible, ensuring active engagement with intensive involvement of the family and multi-disciplinary team
2. Management should be based on a child's developmental level.
3. It should be individualized depending on the clinical profile, strengths and difficulties of the child and the family, WHO International Classification of Functioning (ICF) conceptual framework should be the guiding decision making

Annexure 5: WHO ICF Conceptual framework.

4. Interventions are targeted to achieve a set of SMART (Specific, Measurable, Achievable, Realistic, Time sensitive) goals
5. All interventions should be based on sound theoretical constructs, rigorous methodologies, and objective scientific evidence of effectiveness.
6. Interventions could be provided through educational practices, developmental therapies and behavioral interventions.
7. Caregiver skills training is an evidence-based intervention modality particularly in delivering early interventions. It is used to describe a wide range of interventions including care coordination, psycho education, and treatment for language or social development.
8. Interventions may differ in theoretical approach and scope (eg, focused and targeted or comprehensive), settings and/or modality of delivery (eg, individual versus group or classroom, delivered by a professional versus a trained parent, and school versus home setting), and targets of intervention.
9. Shared decision-making involving family, educational and other stakeholders is the key to success in delivering interventions.
10. ASD is most often a lifelong diagnosis, with long-term implications for the individual and their family, so a lifespan perspective should be acknowledged at clinical decision making.

ASD is a highly heterogeneous condition. In many individuals, autism results in significant social and functional impairments. Nevertheless, for some children and families, autism is part of the normal diversity of human nature, so they do not wish to be considered as having a disability, but instead stress the positive aspects and strengths of the individuals. Even so, many children and their families will need the support from a multitude of professionals throughout the lifespan. Early support, especially caregiver skills training is crucial to improve parental confidence and competence, and may also facilitate following evidence-based interventions through better rapport with the health care provider.

- Consider conclusions from standardized assessments while considering the individual's profile of strengths, difficulties, and needs, and the family and social context, across the lifespan.

Special interests can be utilized to improve academic and adaptive skills and to facilitate behavioral and developmental interventions.

- Identify environmental factors (social, sensory, cognitive, physical, etc.) that may be limiting progress and/or quality of life. Addressing environmental modifications to be more “autism friendly” could result in significant changes.
- Treatment should not be based on a prescribed number of hours or sessions per day or week of therapy. Instead, the aim of therapy should be to ensure that all possible opportunities during the day are used to facilitate progress and minimize difficulties.
- The clinician or therapist should serve as a coach for the key people directly involved in the child's life—i.e., parents, teachers, extended family, etc and caregiver skills training should be offered to families, if available.
- Recognize the value and effort of parents, facilitating access to all relevant support services and providing them with information about local autism support groups if available.
- Whenever possible, a child should have a care coordinating professional from any professional background, whose responsibility is to integrate recommendations for intervention, monitor progress, and support planning for the future. This should allow us to establish a referral mechanism and to coordinate key agencies.
- Support should be provided within all contexts, including the family home, educational, community leisure facilities and health services, to optimize inclusion and full participation.

6.1 For toddlers/ infants:

1. Provide practical advice to parents, educational staff, and all other people playing an important role in a child's life, by means of written, verbal and other media modes, that are available in language appropriate for their level of understanding and linguistic and cultural backgrounds.
2. Implement general strategies, based on typical developmental trajectories, to enhance learning and skill acquisition.
3. Address the specific social, communication, and behavioural challenges. Individually structured sessions and naturally occurring opportunities throughout the day can be used to enhance joint attention, engagement, and reciprocal communication.

6.2 Pre/ School aged children:

There is no evidence for the superiority of any single model of schooling. Inclusive education is promoted, and the focus should be on building bridges between community and specialist provision. In this way, expert knowledge and experience can be shared across different environments and many more students offered the opportunity to access and profit from inclusive schooling.

Table 7 Summary of ASD interventions from late infancy to toddler age group

Late infancy-toddler		
Family support and communication	Explain the condition clearly to the family: use simple clear, non-medical terms. Provide written, verbal and other media modes to complement the information, in suitable languages. Be empathetic and provide support. Explain need for long term commitment and discuss the positive outcomes of early intervention. Invite for parent coaching programs, explain the need to generalize intervention in the home setting and the need for consistency. Frequent communication with family and team to ensure interventions are implemented for common family focused goals while frequent measurement of outcomes Promote activity, participation concentrating on social role and leisure	Continuous Consider MDT meeting with family at least twice in the first year of diagnosis
Behavioural Interventions	Comprehensive Behavioral Treatment/ / Parent-implemented Intervention in natural environment (home) Differential Reinforcement of Alternative, Incompatible, or Other Behaviors and positive reinforcement of desired behaviors Pivotal Response Training, Prompting, Schedules/Visual Supports Self-management	Follow up at least 4-6 weekly in first year. Then it's individualized.
Speech, communication, and language Interventions	"Parent-implemented Intervention in natural environment (home)" and "parent mediated communication training by using play and day to day activities to build up joint engagement, meaningful social communication" Adapting the communicative, social and physical environments to promote social communication	1-2 weekly within first 2 months after diagnosis. Then 4-6 weekly in first year. Then it's individualized.

physiotherapy	and routines in daily life. Sensory profiling and interventions for sensory processing difficulties through play based and ADL integrated interventions Specific interventions if associated hypermobility, developmental coordination disorder present.	
Educational interventions	Assess cognitive level and monitor development with appropriate interventions	Continuous
Feeding and GI	Address feeding difficulties and provide support and interventions Monitor growth and ensure adequate nutrition, if needed refer to dietetics' team/ nutritionist Manage any associated GORD, constipation	As appropriate, growth monitoring as usual
Medical management	Manage epilepsy and other co-morbid medical issues	As appropriate
Sleep	Assess and support sleep difficulties- behavioural, bed time routine, avoid screens	Continuous
Other ND issues	Assess and manage if present	As appropriate
Safeguarding	Address and ensure safeguarding of the child	As appropriate

Table 8: Summary of ASD interventions from preschool age group

Pre - school		
Family support and communication	Practical advice to family, by means of written, verbal and other media modes, that are available in language appropriate for their level of understanding and linguistic and cultural backgrounds. Offer emotional and social support for parents and siblings Frequent communication with family and team to ensure interventions are implemented for common family focused goals while frequent measurement of outcomes Promote activity, participation concentrating on social role and leisure	Continuous

Behavioural Interventions	Comprehensive Behavioral Treatment/ Naturalistic Intervention/ Parent-implemented Intervention/ Technology-aided Intervention Differential Reinforcement of Alternative, Incompatible, or Other Behaviors, Discrete Trial Teaching Pivotal Response Training, Prompting, Reinforcement Response Interruption/Redirection Schedules/Visual Supports Self-management Social Skills Training, Story-based Interventions/Social Narratives Task Analysis, Time Delay, Video Modeling	Follow up at least 1-2 weekly within first 2 months after diagnosis. Then 4-6 weekly in first year. Then it's individualized.
Speech, communication, and language Interventions	Picture Exchange Communication System (PECS), AAC, Functional Communication Training, Language Training (Production), Modeling, Scripting Adapting the communicative, social and physical environments to promote social communication	1-2 weekly within first 2 months after diagnosis. Then 4-6 weekly in first year. Then it's individualized.
Occupational and physiotherapy	Advice and support in adapting environments, activities and routines in daily life. Specific interventions if associated hypermobility, developmental coordination disorder present.	As appropriate
Educational interventions	Assess school readiness, monitor development with appropriate interventions	Continuous
Feeding and GI	Address feeding difficulties and provide support and interventions Monitor growth and ensure adequate nutrition, if needed refer to dietetics team/ nutritionist Manage any associated GORD, constipation	As appropriate, growth monitoring as usual

Medical Mx	Manage epilepsy and other co-morbid medical issues	As appropriate
Sleep	Assess and support sleep difficulties- behavioural, bed time routine, avoid screens	Continuous
Other ND issues	Assess and manage if present	As appropriate
Safeguarding	Address and ensure safeguarding of the child	As appropriate

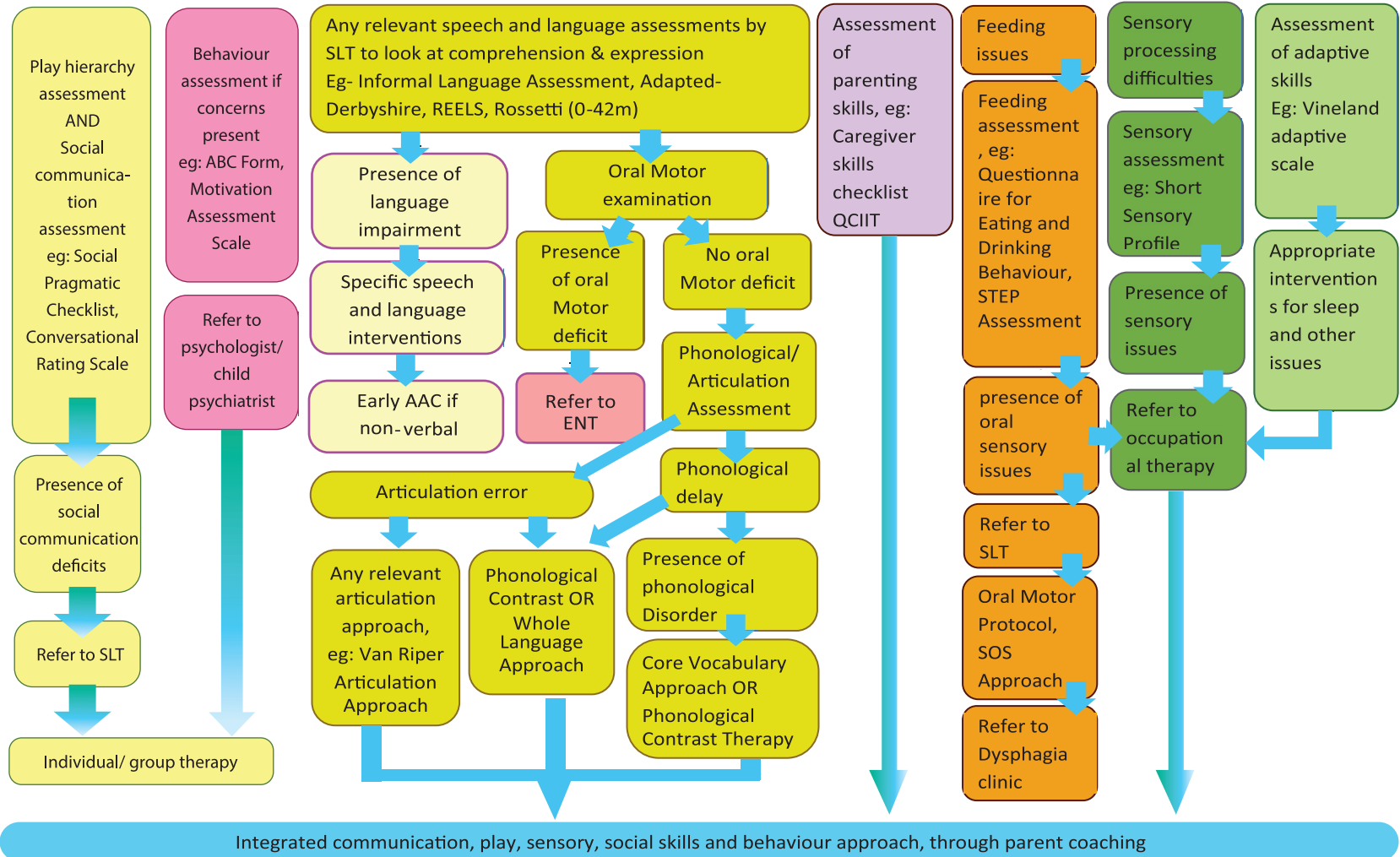
Table 9: Summary of ASD interventions from school age group

School Aged		
Family support and communication	Practical advice to family, by means of written, verbal and other media modes, that are available in language appropriate for their level of understanding and linguistic and cultural backgrounds. Offer emotional and social support for parents and siblings Frequent communication with family and team to ensure interventions are implemented for common family focused goals while frequent measurement of outcomes Promote activity, participation concentrating on social role and leisure	Continuous
Behavioural Interventions	Comprehensive Behavioral Treatment/ Naturalistic Intervention/ Parent-implemented Intervention/ Technology-aided Intervention Differential Reinforcement of Alternative, Incompatible, or Other Behaviors, Discrete Trial Teaching Pivotal Response Training, Prompting, Reinforcement Response Interruption/Redirection Schedules/Visual Supports Self-management Social Skills Training, Story-based Interventions Cognitive behavioural therapy Task Analysis, Time Delay, Video Modeling	As appropriate

Speech, communication, and language Interventions	Picture Exchange Communication System (PECS), AAC, Functional Communication Training, Language Training (Production), Modeling, Scripting Adapting the communicative, social and physical environments to promote social communication	As appropriate
Occupational and physiotherapy	Advice and support in adapting environments, activities and routines in daily life. Specific interventions if associated hypermobility, developmental coordination disorder present.	As appropriate
Educational interventions	Educational interventions, promote inclusive education, consider developing IEP	Continuous
Feeding and GI	Address feeding difficulties and provide support and interventions Monitor growth and ensure adequate nutrition, if needed refer to dietetics team/ nutritionist Manage any associated GORD, constipation	As appropriate, growth monitoring as usual
Medical management	Manage epilepsy and other co-morbid medical issues	As appropriate
Sleep	Assess and support sleep difficulties- behavioural, bed time routine, avoid screens Consider prescribing melatonin if poor sleep initiation	Continuous
Other ND issues	Assess and manage particularly ADHD, mental health issues	As appropriate
Safeguarding	Address and ensure safeguarding of the child	As appropriate

The following diagram provides a guide for a clinician to follow in managing a child with ASD at the CDIC.

Figure 4: Clinical evaluation, referral and management pathway



The prognosis of ASD varies with the severity of the disorder, presence of comorbidities and the type, timing and intensity of interventions. Symptoms are often most marked in early childhood and early school years, with developmental gains typical in later childhood in at least some areas (e.g., increased interest in social interaction). A small proportion of individuals deteriorate behaviourally during adolescence, whereas most others improve.

Parent styling is associated with outcome. Intrusive parenting results in poor outcomes.

There is wide variation in outcome, with between <5% and 25% having a very good outcome from childhood to adult. Around 10–20% of children with childhood autism begin to improve between 4 and 6 years, and are eventually able to attend an ordinary school and obtain work. A further 10–20% can live at home, but cannot work and need to attend a special school or training center, and remain very dependent on their families and/ or support services. However, at least 60% improve little and are unable to lead an independent life and many needs long- term residential care.

A recent meta-analysis has demonstrated individuals with ASD to have a mortality risk 2.8 times higher than the same aged and sex individuals without ASD. This higher risk of mortality can be attributed to the comorbid medical conditions.



The Major Predictors Of Better Outcomes Are Higher IQ And Presence Of Useful Speech At Age 5 Years.

In addition, early intensive behavioural interventions (EIBI) have been demonstrated to improve the intelligence and adaptive functioning in children with ASD

1. The Child should be follow-up frequently within the first six to eight weeks after the diagnosis. This follow-up is to train and educate parents continuously on interventions
2. Therefore, frequency should be decided according to the parent's ability to catch up on the early intervention programme and the severity of the condition.
3. During the follow-up the practical issues have to be identified and the interventions need to be adjusted accordingly.
4. If needed it is possible to use technologies such as Tele-Health for the follow-up
5. After the initiation and establishment of interventions, the patient should be followed up by the Speech and Language Therapist. The best practice is to follow-up at least with an interval of 4-6 weeks in the first year of diagnosis.
6. After the first year from the diagnosis, the frequency of follow-up can be determined according to the patient response (this should be decided individual basis) and parental factors
7. Specialized doctors should see the child at least three months intervals during the first year and then decide according to an individual basis.
8. Whenever it is possible arrange a multi-disciplinary approach to the patient in every visit and it is important to conduct an MDT review meeting at least once in three months

Family empowerment is a combination of **Knowledge**, **Attitudes**, and **Behaviors** that allows a caregiver to meet their families' needs in day-to-day situations, with professionals and service agencies, or when advocating for greater community change



Empowerment –
increasing the capacity
of individuals or groups
to make choices (about
what they want) and to
transform those choices
into desired actions and
outcomes

World Bank 2002



**The need for parent empowerment
in ASD management**

In ASD parents are the key to
successful intervention.

Studies have shown that
Empowered parents leads to
better outcomes. And also,
child's problem behavior was
related to less parent
empowerment.



Empowerment should focus on 5 main domains

- Education needs of the family
- Health related needs of the family and the child
- Social services/financial support for parents
- Legal entitlements and rights of the parents and the children
- Psychological needs of the parents

Suggestions to empower the families

Figure5: suggestions to empower families

Education needs of the family

1. Provision of Reliable sources of information about the ASD at the time of the initial diagnosis. Inform about the Availability of the services that provide evidence-based practice and information about the harmful practices. (native language) Proper referral pathway from the hospitals and care centers.
Free online courses to support on the knowledge
2. For the child -
Help to access the education and continue the education.

Support system to overcome barriers.
3. For the siblings –
help to continue education without any interruption (lack of attention from the family needs to be considered)

Health related needs of the family and the child

1. Parents of children with ASD reported higher levels of fatigue and greater physical health impairment than parents of both typically developing children and children with Intellectual disability.³
2. Parental psychopathology, and substance use or abuse have all been identified as risk factors for having a child with an ASD and are also correlated with an increase in physical health concerns.
3. Awareness of the support for health care –
No insurance system, being aware of it and information on other available support from the government and the other available systems.

Social Services / Financial support for parents

Family should be informed from the beginning about the potential costs.

Awareness of the support systems.
Provide accessibility for the social services and support systems by proper referral pathways.

Encourage them to follow the pathway to take support after applying even if takes time.

Awareness of the support for health care – No insurance system, being aware of it and information on other available support from the government and the other available systems.

Legal entitlements and rights of the parents and the children

Awareness of the legal entitlements provided by the law.

Awareness about the rights

Empower to protect the children and take Legal Actions against bullying and abuse.

Psychosocial needs of the parents

Parent support groups (social media, face to face) – encourage to reach out and share.

Psychological support

Emotional regulation and coping strategies for parents and family.

Social life – Support system to go out and enjoy while child is being taken care of by centers/ groups.

Family life –educate them about importance of Having time for making love, affection, and communication with the life partner.
Ways of Caring of the other siblings without neglecting them.

Clinicians caring children with ASD should understand and be familiar with problems related to diagnosis; other associated medical and behavioural problems to provide the best care for the patients and their families.

Referrals may need at the diagnosis of the disease

1. Referral for Cognitive and Language assessment
2. Genetic Referral to exclude genetic causes of ASD
3. Referral for Experts in Metabolic diseases for possible metabolic causes
History of atypical regressions (later than 2 years of age, motor regression, or multiple regressions), family history of early childhood death or diagnosed metabolic disorders, and physical features, (hypotonia or weakness, visual and hearing impairment, and dysmorphic features) would suggest consultation with a specialist to guide evaluation for metabolic or mitochondrial disorders.

Referrals may need to assess other associated medical and behavioural problems

12.1 GI symptoms-GORD/Constipation

Because of language delays and atypical sensory perception / report of pain, children with ASD may be less likely to report specific GI discomfort and may present with agitation, sleep disruption, or other behavioral symptoms rather than GI discomfort. Therefore, it is important to dig in to history and ask about these GI problems in children who present with behavioural problems and refer to the relevant specialists in the field.

12.2 Neurology-Epilepsy, ESES

There is both an increased risk for ASD among children with epilepsy and an increased risk for seizures in those with ASD. Risk factors for the increased likelihood of seizures in people with ASD include intellectual disability, female sex, and lower gestational age. Specific genetic disorders associated with ASD, such as tuberous sclerosis, also may contribute to seizure risk in early childhood. It is best to refer to a paediatric neurologist if they have suggestive history of epilepsy/ atypical regression.

Routine EEGs are not recommended, but if there is late or atypical loss of language is observed which may be a presentation of an electrical status epilepticus of sleep and should be evaluated with an overnight EEG.

12.3 Behavioural problem

Behavioural problems associated with ASD are hyperactivity, inattention, aggression, self-injurious behaviour. Psychiatric conditions such as ADHD, anxiety, OCD, mood disorders, conduct disorders, or others) are also commonly seen in children with ASD. Some children who are later diagnosed with ASD may have been diagnosed as having ADHD initially. Therefore, children with ASD should be regularly screened for behavioural/ emotional/ psychiatric conditions as they significant effect on health and quality of life and should make timely referrals.

12.4 Sleep

Sleep disturbances are common. Problems with initiating and maintaining sleep are commonly reported. Adolescents have shorter sleep duration and, daytime sleepiness. As with other children, the evaluation of the child with ASD with delayed sleep onset, night waking, and/or early-morning waking should include a history of comorbid medical conditions that might disrupt sleep, such as gastro-esophageal reflux, seizures, asthma, allergies, eczema, or enuresis. Snoring might suggest obstructive sleep apnea may need referral for additional assessment.

Sleep onset may be aided by treatment with melatonin at doses from 1 to 6 mg and may be maintained with long-acting melatonin.

12.5 Dietician/Nutritionist

Children with ASD have greater risk of overweight and obesity. They may have repetitive eating patterns and less opportunities/interest to engage in leisure/physical activities. Therefore, their age specific BMI percentile should be monitored, and address modifiable risk factors promote healthy dietary and life style modifications in a modified way to attract them.

Children may have dietary issues such under nutrition, food selectivity with regards to texture/ taste/colour etc. too.

12.6 Dental Health

Dental hygienic needs of the children with ASD are mostly unmet. Due to behavioural issues it may be difficult for the parents to maintain it. Therefore, it is important actively look in to it and attend accordingly.

12.7 Transition to Adolescent and Adult Care

Planning for children with ASD to understand and participate in their own health care should begin early in adolescence, with adaptation for developmental abilities. Paediatric health care provider should advise the family about teaching their adolescent with ASD about sexuality.

Planning for medical transition should be initiated around 12-14-year ages and it should be a gradual process with a series of discussion with the sending and receiving ends. Assess transition readiness of patient and the family before complete the transition.

13.1 Pre-School and Schools

1. Encourage parents to send their children into inclusive neighborhood schools and preschools.
2. It is best if the class sizes are smaller so that the child will get ample opportunities to interact with teachers and peers
3. Work with the Special Education ISA or officer in the Education Zone, who might be able to find a suitable placement.

13.2 Language and Literacy

1. Work on play-based tasks that increase receptiveness to language.
2. Encourage children to use language despite their difficulties, be cautious not to over correct language when children are trying to communicate an ideas, feelings and needs.
3. Encourage pretend play activities that allow children to take on multiple roles and perspectives.
4. Create opportunities for children both individually and in groups to share experiences and recount events

13.3 Pre-Reading

1. Read to children, ensure the book is open up so they can see the book clearly. Encourage them to turn the page and point at pictures.
2. Use figure to track while reading so that children learn to scan books from left to right
3. Allow children to handle books on their own, where they can look at the pages, or use it as a part of their play.
4. Encourage pretend reading. When a child is pretending to read, it is important that adults pay attention to the reading activity, as a way of encouraging children to engage and attend to books.
5. With older children, ask questions about the stories they read. Let them re-tell the story before asking questions, as a means of improving their comprehension and working memory
6. Continue to read to children up until late elementary school.

7. Model reading habits. When children see that the adults around them read, children are likely to pick up a book as well.

13.4 Pre-Writing

1. Allow children to use multiple media such as paints, chalk, pens, and crayons of different types of surfaces to build writing fluidity.
2. Discuss free writing/ drawing activities with the child, pointing to colors, lines and attributing approximate visuals. For example, if the child has drawn circular scribbles the adult notes that it looks like noodles or yarn.
3. Avoid over correcting letters and numbers. Ensure that children are not made to overcorrect by erasing and doing repetitive tasks. Instead, model and coach.

13.5 Pre-Mathematics Skills

Numbers and Counting

By understanding that numbers represent objects, your child will begin to understand one-to-one correspondence (each object counted gets its own number and only that number) as well as the counting principle that when counting the number of objects, the last number counted equals the amount present.

Addition and Subtraction

Describing how numbers are the same or different will lead into learning how to combine two numbers to make a new number. Use manipulative to teach these concepts before exposing them to numerical symbols

Geometry and Spatial Reasoning

Shapes are everywhere in our world, which will be one of your greatest assets when it comes to teaching your child about shapes and spatial reasoning. They'll start out by learning about the basic 2-D shapes that are used in math: squares, triangles, circles, rectangles, rhombuses, and ovals. Learning how to draw these basic shape illustrations can be helpful for their learning process.

Sorting and Patterns

Sorting and patterns are related to categorical reasoning. The child will learn how to sort things based on their characteristics and how they are the same or different from other objects. They'll sort objects by weight, shape, quantity, texture, color, and other traits, often without even realizing it

13.6 Attending to task and Completing tasks

1. Assign workspaces inside and outside your home for children to engage in tasks such as making puzzles and coloring. While the place needs to remain the same, it is alright for students to sit at a desk and chair or mat.
2. Break tasks into smaller tasks. Start with tasks the child can do easily, and then move on to tasks that require your support. As the child becomes competent in the task, let them work independently.
3. Cultivate persistence by encouraging your child to follow through on a task. Give them the time and space needed to work independently through problems—even tasks as simple as stacking building blocks.
4. Playing with other children can develop your child's ability to work collaboratively and help your child become more creative by giving them toys that encourage exploration.

13.7 Cognition and General Knowledge

To help your child develop their cognitive skills at home, focus on creating an environment where your child feels comfortable asking questions about the world and the processes that govern it.

Asking open-ended questions also encourages a sense of exploration.

Developing your child's curiosity can inspire them to dive into the subjects that interest them and cultivate background knowledge that will improve their reading comprehension and other essential academic skills.



14.1 Reassessment at 5 years

Main objectives of 5-year assessment

1. Determine the severity of clinical features
2. Identify co-morbidities
3. Assess the level of cognitive abilities
4. Identify challenging behaviour
5. Plan school education
6. Support parents with psychosocial issues during the transition to school

Assessment to be done by a multidisciplinary team consists of a Paediatrician, a Child and Adolescent Psychiatrist, a Psychologist, an Occupational therapist and a speech and language therapist.

The Childhood Autism Rating Scale (CARS) can be used to rate observe and subjectively rate fifteen following items.

1. Relationship to people
2. Imitation
3. Emotional response
4. Body
5. Object use
6. Adaptation to change
7. Visual response
8. Listening response
9. Taste-smell-touch response and use
10. Fear and nervousness
11. Verbal communication
12. Non-verbal communication
13. Activity level
14. Level and consistency of intellectual response
15. General impression

Based on the reassessment at 5 years, management plan and recommendations in following areas can be decided.

1. Education setting and methods (eg. School, inclusive education)
2. Individual learning plan
3. Individual behaviour plan
4. Additional support in classroom (eg. Shadow teacher etc)
5. Support / social benefits for parents

Psychiatric social worker (PSW) can liaise with the Ministry of Education/ school/ Social services department/ other agencies to arrange support to parents and teachers in implementing above management plan. Recommendations should be communicated with Ministry of Education and school when needed.

Above management plan can be revised with the participation of school authority and teachers with the multidisciplinary team in 6 months after commencement of school.

14.2 Reassessment at 8 years

Main objectives of the reassessment at 8 years are as follows

1. Determine academic function and identify specific learning difficulties
2. Determine functional level
3. Identify any co-morbidities
4. Identify behavioural challenges at home and classroom
5. Decide on long term follow up plan.

Assessment to be done by a multidisciplinary team consists of a paediatrician, a child and adolescent psychiatrist, a psychologist, an occupational therapist and a speech and language therapist. liaise with school teachers for assessment and deciding on management plan. recommendations should be communicated with ministry of education, school, social services department and other agencies when needed.

14.3 Parent education to identify the challenging issues and to come back

Parents need to be educated on the possibility of developing co-morbid physical, psychological, behavioural and social issues and to seek medical help.

1. Seizures - risk of seizures that increases throughout childhood, and around at adolescence
2. Sleep disturbances
3. Change in eating pattern
4. Loss of previously acquired skills
5. Aggressive behaviour
6. Recent onset of anger/ anxiety and other emotional issues
7. Self-harm behaviour
8. Sexualized behaviour
9. Any acute behaviour change that concerns parents

Paediatrician can do the initial assessment and refer to a paediatric neurologist and/ a Child and adolescent psychiatrist and other multidisciplinary team members when needed.

14.4 Transition

Transition from childhood to adolescence and adolescence to young adulthood are filled with new challenges, responsibilities, and opportunities.

However, research suggests fewer young people with Autism Spectrum Disorder (ASD) have the same opportunities as their peers without ASD.

- 1 . Low participation in education
2. High rates of unemployment or under-employment
3. Majority continue to live with family members or relatives
- 4 . Limited opportunity for community or social activities—nearly 40% spend little or no time with friends

In addition, individuals with Autism Spectrum Disorder may experience changes in their ASD symptoms, behaviors, and co-occurring health conditions during adolescence and young adulthood. These changes can affect their ability to function and participate in the community.

In addition, individuals with Autism Spectrum Disorder may experience changes in their ASD symptoms, behaviors, and co-occurring health conditions during adolescence and young adulthood. These changes can affect their ability to function and participate in the community.

Functional assessment by an Occupational Therapist at the age of 16 would be helpful to decide on further education, vocational training and occupational therapy for independent living.

Transition of care from paediatric team to adult medical care team and from Child and Adolescent Psychiatry Services to Adult psychiatry services to be decided by the respective teams and need to be clearly communicated among the teams and with care-givers.

14.5 Occupational transitions and advocacy

Services are important to help young people with Autism Spectrum Disorder complete their education or job training, find employment, secure housing and transportation, take care of their health, improve daily functioning, and participate as fully as possible in their communities.

It is important to educate parents / caretaker on importance of above and provide them with information on services available.

When needed refer to Psychiatric Social Worker (PSW) to liaise with relevant agencies to arrange support to the young person and family during occupational transitions.

Behavioural challenges and emotional problems can be expected during transitions when needed to do a psychiatric referral for further management.

Liaising and educating the employers or job trainers from the beginning would be helpful.

ASD children are prone to bullying, physical or sexual abuse when compared to neurotypical peers. It is high as three times. Such maltreatment can cause severe stress and trauma, yet it often goes unrecognized or unreported. Neglect is the most common type of maltreatment in Autism.

Factors affecting for child maltreatment in Autism;

- Presence of challenging behaviour
- Complex cognitive and language impairments
- Increase caregiver stress
- Lower level of family social support
- Higher rate of caregiver isolation and dependence

How do you identify child maltreatment in Autism?

More apparent signs may include unexplained bruises, pain, or weight loss. Additionally, behavior changes, including avoidance of certain people or places, may indicate victimization.

Some behavioral changes to keep an eye out for are social withdrawal, avoidance of particular places or people, behavioral outbursts when presented with particular places or people, or developmental regression

What are some things that families can do to keep their loved ones safe?

Families can educate themselves on how to identify warning signs and how to report if abuse or neglect is suspected. Families should talk to their loved ones openly and honestly about personal safety, boundaries, saying no, and healthy and unhealthy touch. Families should give their loved ones opportunities to role-play potentially dangerous situations and practice how they might respond to these. Teach individuals and families very concrete and specific skills on HOW and WHO to alert for help and WHAT to do if they suspect they are being abused.

Individuals with autism need to be empowered to be leaders and advocate for themselves in a socially appropriate way.

The more individuals with autism know about abuse and “red flags” the better.

Individuals should be able to identify at least two trusted adults they can report abuse to or go to for help

For further details please follow National Guideline for The Management of Child Abuse and Neglect

https://medicine.kln.ac.lk/depts/forensic/images/LearningMaterials/Guidelines/National_Guideline_on_Child_Abuse_and_Neglect.pdf

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Approaches to early intervention – Theoretical facts with evidence

Interventions for children with or at risk for ASD should be initiated as early as possible. There are multiple approaches to interventions based on different theoretical bases. Most of these evidence-based intervention modalities are used in combination, depending on child's developmental stage, clinician's experience and family and social circumstances.

Behavioural/ developmental interventions

Behavioural interventions are mostly based on the science of applied behaviour analysis (ABA) Current evidence supports the integration of ABA-based models with approaches that are informed by developmental theory, particularly with very young children.

Main models adopted in current early interventions for ASD are;

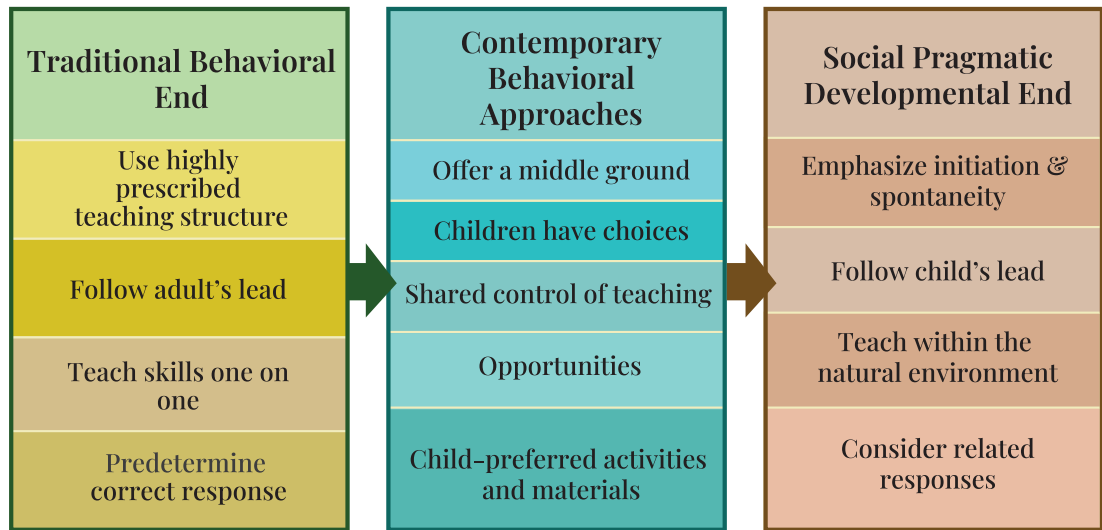
- Parent-Mediated Treatment or Parent Management Training
- Developmental Relationship–Focused Interventions
- Applied Behavioural Analysis
- Naturalistic Developmental Behavioral Intervention
- Combined Approaches

Two categories of evidence-based interventions are utilized in ASD.

Comprehensive treatment model (CTM)	Focused interventions
Address multiple domains or global outcomes	Address a single or limited range of skills, such as increasing social communication or learning a specific task
Replicable, intense	
Delivered over a prolonged period of time	Shorter time period until the individual goal is achieved
Applied behavior analysis (ABA), developmental approaches, and/or naturalistic approaches used	Provided in a structured setting by an adult, in naturalistic environments with peers, or as a component of a more comprehensive approach
E.g.: Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH), Early Start Denver Model (ESDM)	

Two common theoretical approaches to intervention for symptoms of ASD are ABA and developmental models. There are number of practical approaches with overlap between these.

Parent-Mediated Treatment or Parent Management Training



Parent management training is divided into 2 categories: parent support and parent-mediated interventions. Parent support interventions, which are knowledge focused and provide indirect benefit to the child, include care coordination and psychoeducation. Parent mediated interventions, which are technique-focused and provide direct benefit to the child, may target core symptoms of ASD or other behaviors or skills and may be built on ABA approaches in natural settings. Training sessions for caregivers may be delivered in the home, clinic, school, or other community settings or remotely by telehealth.

The main focus is on adult–child synchrony, with parents building certain skills and learning to respond to their child’s communicative cues in ways that encourage spontaneous communication, and create opportunities for shared attention, child initiations, and spontaneous play.

E.g.:

1. The Joint Attention Symbolic Play Engagement and Regulation programme (JASPER) has demonstrated enhanced joint engagement and joint attention with the lower-intensity approaches in preschool children compared to a control group both when delivered by parents in the home and by teaching assistants in school.

2. Preschool Autism Communication Trial (PACT) a lower intensity long term program, which consists of fortnightly parent-therapist sessions for 6 months, then monthly sessions for another 6 months, demonstrated improvements in parent and child dyadic behaviours such as parental synchrony and child initiations when interacting with each other but not symptom reduction at immediate follow-up.
3. The parent-mediated intervention for Autism Spectrum Disorders in South Asia Plus (PASS Plus) is an example of a systematic adaptation and expansion of an evidence-based intervention developed in a high income country (HIC) / (Pre-school Autism Communication Therapy- PACT). The initial randomized controlled trial (RCT) of this PASS intervention against usual care (n = 65), conducted in India and Pakistan demonstrated encouraging results. A second RCT in rural India (n = 40) demonstrated the feasibility, manual fidelity, and initial effectiveness of the PASS Plus intervention delivered in homes of families of children with autism.

Developmental relationship–Focused interventions

Developmental theory, suggest utilizing the relationship between the caregiver's level of responsiveness and the child's development of social communication. The principles are to coach in improving responsiveness and reciprocity by imitating or joining into child led activities. This approach may address joint attention, imitation, and affective social engagement by focusing to teach and train adults to foster interactions, communications and provide opportunities through play.

Applied behavioural analysis

The process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement in behavior. The rationale is to alter behaviors by programmatically reinforcing skills targeting to develop new skills or minimize behaviors. These interventions could be in either end of the approaches varying from structured adult led behavioural to child led play/adaptive skill interventions. The ABA interventions are more useful for older children. Many current interventions based on applied behavioural approaches have now shifted from repetitive “discrete trial” training to more natural, child-initiated, developmentally appropriate strategies and tasks

Naturalistic developmental behavioral intervention

Naturalistic developmental behavioral interventions (NDBIs) incorporate elements of both ABA and developmental principles. Interventions are delivered in context of naturally-occurring social activities within natural environments. They are more child-directed than traditional ABA approaches, and involve intrinsic rewards for learning and participating. This allow a wide range of antecedent stimuli and acceptable responses and use strategies to promote spontaneity, initiative, and generalization, including incorporation of family members in the interventions. They focus on social learning skills like joint attention and facilitate acquisition of language and other higher-level skills through imitation.

Combined approaches

Combined developmental and behavioral approaches include use of standardized intervention/s using principles of ABA to reinforce skill building, child-initiated teaching, imitation, and modeling. The adult prompting fades over time to promote independence. A higher intensity, more comprehensive approach is the Early Start Denver Model (ESDM), which combines behavioural and developmental or dyadic approaches. The ESDM is delivered by therapists for ~15 hours per week, and parents are trained to improve social communication and interaction with their child. Clinical trials have demonstrated conflicting evidence.

Early intervention approaches for ASD- Practical aspects

Parent training intervention

Parent training (PT) is well understood as an evidence –based treatment for typically developing children with disruptive behavior. Parent training has been used to describe a wide range of interventions including care coordination, psychoeducation, and treatment for language or social development.

Children’s targets behaviors/ skills.

1. Eye contact
2. Joint attention
 - Responsive joint attention
 - Initiating joint attention

3. Attention
4. Non verbal communication.
5. Object function play
6. Imitation
7. Turn taking
8. Vocalizing /words

JASPER (Joint attention symbolic play engagement regulation)

A treatment approach that combination developmental and behavioral principals. This approach targets the foundation of social communication (joint attention, imitation, play) and uses naturalistic strategies to increase the rate and complexity of social communication. The approach incorporates parents and teachers into implementation of intervention to promote generalization across setting and activities and ensure maintenance over time (Kasrai, Paparella, Freeman, & Jahromi,2008).

Denver model

The Denver model is a child-led, play- based treatment approach that focuses on the development of Social communication skills through intensive one-on one therapy, peer interaction in the school setting, and home- based teaching (Rogers &Dawson, 2009). The Early start Denver model for toddlers is an extension of the Denver Model; it combines development approaches with behavioral teaching strategies and can be delivered in variety of setting (e.g, by the therapist or parent in group of individual session in the clinic or at home)

AAC (Augmentative and Alternative Communication)

AAC involves supplementing or replacing natural speech and/or writing aided (e.g., Picture Exchange communication System(PECS), line drawings, speech generating devices, and tangible objects) and/or unaided (e.g., manual signs, gestures and finger spelling)

PECS

PECS is an augmentative communication system where children are taught exchange a picture card for something they like and want.

More Than Words

A Hanen Program that offers a parent directed approach focusing on a day to day life, taking advantage of everyday activities to help the child improve communication and social skills. (Sussman,1999). This program is typically used for early language intervention with young children with ASD.

TEACCH

Treatment and education of Autistic and related commination Handicapped children is a whole life program. Its look at the skills and strengths children already have, and it aims to build on these to promote development. The TEACCH program is used to promote learning and development – in particular, communication and social skills, independence, coping skills and skills for daily life. This program might focus on early intervention for a young child

PRT (Pivotal Response Treatment)

A play base, child –initiated behavior treatment. Formerly referred to as Natural Language Paradigm (NLP), PRT has as its goals to teach language, decrease disruptive behaviors, and increase social, communication, and academic skills. Rather than target specific behaviors, PRT targets pivotal areas of development (response to multiple cues, motivation, self-regulation, and initiate of social intervention) that are central to and result in improvements across – a wide range of skills (Koegel & Koegel,2006).

Milieu Therapy

A range of methods (including incidental teaching) that are integrated into a child's natural environment. It includes training in every environment and during activities that take place throughout the day, rather than only at “therapy time” (Kaiser, yoder,7keetz, 1992).

Objective assessments to measure outcomes

Introduction

Objectives assessments help to determine the child's current level of functioning. In addition they can also help to identify specific improvements children have made. These assessments can be administered pre and post to measure changes in various domains.

Subdomains	Tools
Autism symptom severity	Autism Behavior Checklist
	Autism Diagnostic Observation Schedule (ADOS)
	Modified Checklist for Autism in Toddlers (M-CHAT)
	Autism Impact Measure (AIM)
Language	Bayley Scales of Infant and Toddler Development
	MacArthur- Bates Communicative Developmental Inventories
	Mullen Scales of Early Learning
	The Rossetti Infant-Toddler Language Scale (REEL-3) Receptive-Expressive Emergent Language Test, Third Edition
Cognitive ability	Bayley Scales of Infant and Toddler Development
	Other development assessments like SOG, Griffith, DAYC
Attention	Child Behaviour Checklist
Sensory processing	Short Sensory Profile (SSP)
Emotional regulation	Emotional Regulation Checklist
	Infant toddler social emotional Assessment
Physical Skills	Bayley Scales of Infant and Toddler Development
	Peabody Developmental Motor Scales
Social communication	Early Social Communication Scales
	Social Communication Assessment for Toddlers with Autism
Play	Test of Pretend Play (TPP)
	Developmental Play Assessment
Behaviour problems	Child Behaviour Checklist
Feeding problems	The Screening Tool of Feeding Problem (STFP)
Learning	Mullen Scales of Early Learning
Daily Living Skills	Vineland Adaptive Behavior Scales
	Bayley Scales of Infant and Toddler Development
Parental Stress	Depression, Anxiety and Stress Scale- 21 (DASS-2)
Family Quality of Life	WHO- QOL- BREF

Short description of selected outcome measurement tools

Autism Diagnostic Observation Schedule (ADOS)

The ADOS-2 assessment is a semi-structured, standardized assessment instrument that includes a number of play-based activities designed to obtain information in the areas of communication, reciprocal social interactions, and restricted and repetitive behaviors associated with a diagnosis of ASD. Can be completed from 12 months to adults.

Bayley Scales of Infant and Toddler Development

Children are assessed in the five key developmental domains of cognition, language, social-emotional, motor and adaptive behaviour. Can be administered from 1 month-42 months. Takes between 30-90 minutes to administer.

Autism Impact Measure (AIM):

It measures ASD symptoms in children 2-17 years old. The AIM is a 41- item caregiver questionnaire rated on a 5-point Likert scale. The AIM items were developed based on expert review of items from several well-validated measures of ASD symptoms, including the Autism Diagnostic Interview Revised, the Gilliam Autism Rating Scale, the Social Communication Questionnaire, and the Social Responsiveness Scale. Caregivers of children with ASD were also consulted during the item development phase.

Social Communication Assessment for Toddlers with Autism (Freely available)

The SCATA was designed to be a sensitive measure of the (primarily non-verbal) social communication behaviour of preschool children with autism in a semi-structured interaction with an unfamiliar adult. The examiner scoring will need some amount of skill and understanding of ASD.

Test of Pretend Play (ToPP)

The Test of Pretend Play (ToPP) is an assessment of symbolic play ability in young children (aged between 18 months and 6 years).

Child Behaviour Checklist

The CBCL is completed by parents. It assesses based on the following areas: anxiety, depression, somatic complaints, social problems, thought problems, attention issues, rule-breaking behaviour, and aggression. It consists of 113 questions. Can be administered for children between 6-18 years.

Vineland Adaptive Behavior Scales

VABS is a semi-structured interview. It provides valuable information for developing educational and treatment plans. It assesses based on 3 broad areas considered essential for adaptive functioning: communication, daily living skills, and socialization. Can be conducted from birth to adults.

The Screening Tool of Feeding Problems (STFP) – Free

23-item Screening Tool for Feeding Problems (STFP; Matson & Kuhn, 2001). The items on the checklist pertain to chewing problems, rapid eating, food refusal, food selectivity, vomiting, stealing food and other problems. It can be completed with a caregiver who needs to rate each item between 0 and 2 based on how frequently it occurs.

In addition, to the above-mentioned objective assessments it is also essential for clinicians to complete informal assessments on the child as well.

Communication with caregivers

One salient aspect that determines the success of the management of a child with ASD is the communication with the caregivers.

Although a clinician delivering a diagnosis to a family is often a daily occurrence, it is an extremely intricate and challenging task (Alshami et al., 2020). Many studies point out that the training of health care workers in delivering a diagnosis is insufficient (Ferreira da Silveira et al., 2017; Alshami et al., 2020). Delivering a diagnosis to caregivers using evidence-based techniques can positively impact caregiver satisfaction in the health system, positive patient outcomes, trust and caregiver commitment to intervention. Studies show that caregivers remember the experience of receiving a diagnosis vividly and this experience has an impact on the caregiver commitment to the child's intervention plan (Al Ali et al., 2016; Braiden et al., 2010; Chipidza et al., 2015; Keenan et al., 2010).

There are a number of protocols that have been developed to guide clinicians on how to deliver a diagnosis. For instance the SPIKES (Buckman, 2005), ABCDE (VandeKieft, 2001), BREAKS (Narayanan et al., 2010) protocols are widely used by clinicians when delivering a diagnosis. The information given below are based on the above mentioned protocols and guidelines put forward by the Center for Disease Control (CDC, 2018).

Set up a meeting with caregivers

- Select a space with minimal distractions
- Ask caregivers if they feel comfortable to have the discussion in the presence of their child
- Sit down with caregivers
- Remember to make eye contact. This helps to establish trust with caregivers.

Explore caregiver perception about child

- Initiate a discussion on child
- Ask caregivers reason for bringing child (what were their concerns as caregivers)
- Inquire if they have read anything on the internet or discussed their child's condition with friends or family

Inform caregivers

- Tell caregivers that the child is showing developmental concerns (you can give examples based on your assessments)
- Give caregivers the diagnosis. Since ASD is not a well understood area by most persons, explain the condition to the caregivers.
- Give caregivers the opportunity to clear doubts regarding diagnosis

Be prepared to be honest

- Explain to the caregivers where on the spectrum the child lies
- Avoid prognosticating: it is not possible to predict the outcome as children on the spectrum often have a wide variety of outcomes
- Give caregivers information on evidence based intervention strategies
- Emphasize the child will make progress with appropriate evidence based interventions
- Acknowledge the difficulty of having a uncertain prognosis

Empathize with caregivers

- Understand that some caregivers will have an emotional response to the given information
- Some caregivers may show emotions such as silence, disbelief, sadness, denial or anger. Remember their reaction is not a reflection of you, but it is are reflection of what they are going through. Don't take it personally.

- Empathize with caregivers – observe the emotional reaction of caregivers and identify their emotions for yourself. Ask caregivers what they are feeling. Take time to validate the emotional reaction of caregivers (E.g.: I understand why you are feeling sad...). It is extremely important that you are warm and patient with caregivers at this time.
- Identify coping strategies for caregivers. Emphasize the importance of caregiver wellbeing for the development of their child.

Clear message and plan ahead

- Ask caregivers how they will explain what you have told them to close family members and friends. This gives you the opportunity to understand how well they are received the message you have given them.
- Make an intervention plan for the next month and provide the family with a follow up appointment (ideally within 2 weeks).
- Provide resources for caregivers to read and gain knowledge (E.g.: leaflets, books websites). This will reduce the chance of caregivers straying toward non evidence based interventions.
- Take time to write information on client file. Since caregivers are likely to be emotionally preoccupied during the session, it is best to give the caregiver information on the disorder and intervention plan in a written format.

Intervention goals for speech and language therapy based on core challenges of ASD

	Pre- linguistics stages (1-12 months)	Emerging language stages (12-24 months)	Advanced language stages (24 months onwards)
Joint Attention	• Orienting toward people in the social environment • Responding to a caregiver's voice • Shifting gaze between people and objects • Pairing communication gestures with gaze and/or physical contact when requesting and protesting as culturally appropriate • Directing another's attention for the purposes of sharing an interesting item or event • Attending to emotional displays of distress or discomfort • Sharing positive affect • Initiating social routines	• Expanding communication functions to seek specific emotional responses from others (e.g., seeking comfort, greeting others, showing off) • Commenting to share enjoyment and interests • Recognizing and describing emotional states of self and others	• Understanding what others are indicating with gaze and gestures • Determining causal factors for emotional states of self and others • Using emotions of others to guide behavior in social interactions (e.g., selecting topics based on another's preferences, praising others, sharing empathy) • Considering another's intentions and knowledge (e.g., requesting information from others, sharing information about past and future events)

Social Reciprocity	• Responding to the bids of others • Initiating bids for interaction • Increasing frequency of spontaneous bids for communication • Developing persistence in communication attempts	Increasing frequency of communication across social contexts and interactive partners • Maintaining interactions by taking turns • Providing contingent responses to bids for interaction initiated by others • Recognizing and attempting to repair breakdowns in communication	Engaging in topic maintenance (e.g., providing expansion comments) • Maintaining conversational exchanges with a balance between comments and requests for information • Providing essential background information • Initiating and maintaining conversations that are sensitive to the social context and the interests of others
Language & Related Cognitive Skills	Using a range of gestures to share intentions (e.g., giving, showing, waving, pointing) • Using effective strategies for protesting, exerting social control, and emotional regulation in order to replace potential problem behaviors used for these functions • Pairing vocalizations with gestures to share intentions • Observing and imitating the functional use of objects • Turning pages and pointing to pictures in books	• Expanding word knowledge and use to include not only object labels, but also action words, modifiers, and relational words • Understanding and using more creative combinations of words • Understanding and using more sophisticated grammar • Engaging in representational play • Understanding sequences of events in stories, attending to beginning and rhyming sounds, and naming alphabet letters • Producing a variety of speech sounds	• Enacting social sequences in a representational manner by incorporating themes or modifications introduced by others (e.g., role-playing and visualizing an event before it takes place) • Understanding and using nonverbal gestures, facial expressions, and gaze to express and follow subtle intentions (e.g., sarcasm and other nonliteral meanings) • Understanding and using intonation cues to express and follow emotional states • Understanding and using more sophisticated syntax to provide background

			information for one's listener • Understanding and using more sophisticated syntax to show relationships between sentences in conversational discourse • Demonstrating story grammar knowledge, decoding, and letter-sound correspondence and expanding literacy skills (e.g., reading comprehension and written expression) • Problem solving and self-monitoring future, goal-directed, behavior (i.e., executive functioning)
Behaviour & Emotional Regulation	• Attending to salient aspects of the social environment • Expanding the use of conventional behaviors to regulate one's emotional state (e.g., covering one's ears to block out noise, carrying a preferred toy into an unfamiliar setting to assist in the transition, removing oneself from a situation when overwhelmed) • Protesting undesired activities	• Requesting a soothing activity when distressed • Requesting a break from a given activity • Requesting assistance from others • Using language to maintain engagement within an activity (e.g., "first ... then") • Using language to talk through transitions across activities • Expressing one's emotional state and the emotional state of others	• Preparing and planning for upcoming activities • Perceiving one's actions within social events and predicting social behavior in others in order to self-monitor • Negotiating and collaborating within interactions with peers

Intervention Goals for Occupational Therapy

Programme implementation designed to maintain or enhance the Child's development in natural environment as a member of a family/team

- Occupational Therapist practices as a part of a team and contributes occupational therapy findings and suggestions to the individual family
- Child and Family centered treatment plan
- Concerning functional use of skills in child's natural environment
- Addressing family concerns and priorities

ASSESSMENT

informal - formal (Screening process) Informal

- Care giver interviews
- Observing infant's behavior
- Early toy handling in infant
- Competent age-appropriate gross and fine motor skills till early schooling

FORMAL (SCREENING PROCESS)

- Observing general movements before 5/12 of corrected age
- Visual understanding in infant
- Auditory response
- Check for feeding difficulties
- Delays in child's developmental skills
- Areas of dysfunction
- Risk factors either biological or environmental

INTERVENTION GOALS

- To promote changing of the child's functional performance of developmental areas that are delayed
- To reframe Child's behavior (build up parent/child interaction and relationship)
- To assist Child and family by compensating and adapting situations
- To support family members (listening & respecting family concerns, managing stressful situation)

INTERVENTION TOOLS USED IN OCCUPATIONAL THERAPY

- Observing general movements
- Developmental measures – Alberta Infantile Motor Scale (AIMS)
Hammersmith Infantile Neurological Evaluation(HINE)
- Manual Ability Classification System (MACS)
- Fine Motor observation check list
- Early learning disabilities check list
- Barthel Index Scale to measure performance in ADL
- Cognitive, Fine motor and social skill assessment
- Canadian Occupational Performance Measure (COPM)
- Shrines Hospital Upper Extremity Evaluation (SHUEE)
- Sensory profile measures

Annexure 1: Development screening tool of the CHDR

Indicator	Yes	No
2 months completed		
1. Doesn't respond to loud sounds		
2. Doesn't watch things as they move		
3. Doesn't smile at people		
4. Doesn't bring hands to mouth		
5. Can't hold head up when pushing up when on tummy		
4 months completed		
1. Doesn't watch things as they move		
2. Doesn't smile at people		
3. Can't hold head steady		
4. Doesn't coo or make sounds		
5. Doesn't bring things to mouth		
6. Doesn't push down with legs when feet are placed on a hard surface		
7. Has trouble moving one or both eyes in all directions		
6 months completed		
1. Doesn't try to get things that are in reach		
2. Shows no affection for caregivers		
3. Doesn't respond to sounds around him		
4. Has difficulty getting things to mouth		
5. Doesn't make vowel sounds ("ah", "eh", "oh")		
6. Doesn't roll over in either direction		
7. Doesn't laugh or make squealing sounds		
8. Seems very stiff, with tight muscles		
9. Seems very floppy, like a rag doll		
9 months completed		
1. Doesn't bear weight on legs with support		
2. Doesn't sit with help		
3. Doesn't babble ("mama", "baba", "dada")		
4. Doesn't play any games involving back-and-forth play		
5. Doesn't respond to own name		
6. Doesn't seem to recognize familiar people		
7. Doesn't look where you point		
8. Doesn't transfer toys from one hand to the other		
12 months completed		
1. Doesn't crawl		
2. Can't stand when supported		
3. Doesn't search for things that she sees you hide		
4. Doesn't say single words like "amma" or "thaththa"		
5. Doesn't learn gestures like waving or shaking head		
6. Doesn't point to things		
7. Loses skills he once had		

18 months completed

1. Doesn't point to show things to others		
2. Can't walk		
3. Doesn't know what familiar things are for		
4. Doesn't copy others		
5. Doesn't gain new words		
6. Doesn't have at least 6 words		
7. Doesn't notice or mind when a caregiver leaves or returns		
8. Loses skills he once had		

24 months completed

1. Doesn't walk steadily		
2. Doesn't use 2-word phrases (for example, "drink milk")		
3. Doesn't know what to do with common things, like a brush, phone, fork, spoon		
4. Doesn't copy actions and words		
5. Doesn't follow simple instructions		
6. Loses skills she once had		

36 months completed

1. Falls down a lot or has trouble with stairs		
2. Drools or has very unclear speech		
3. Can't work simple toys (such as peg boards, simple puzzles, turning handle)		
4. Doesn't speak in sentences		
5. Doesn't understand simple instructions		
6. Doesn't play pretend or make-believe		
7. Doesn't make eye contact		
8. Loses skills he once had		

48 months completed

1. Can't jump in place		
2. Has trouble scribbling		
3. Shows no interest in interactive games or make-believe		
4. Ignores other children or doesn't respond to people outside the family		
5. Resists dressing, sleeping, and using the toilet		
6. Doesn't communicate toilet needs even during day time		
7. Can't retell a favourite story		
8. Doesn't follow 3-part commands		
9. Doesn't understand "same" and "different"		
10. Doesn't use "me" and "you" correctly		
11. Speaks unclearly		
12. Loses skills he once had		

60 months completed

1. Doesn't show a wide range of emotions		
2. Shows extreme behaviour (unusually fearful, aggressive, shy or sad)		
3. Unusually withdrawn and not active		
4. Is easily distracted, has trouble focusing on one activity for more than 5 minutes		
5. Doesn't respond to people, or responds only superficially		
6. Can't tell what's real and what's make-believe		
7. Can't give first and last name		
8. Doesn't use plurals or past tense properly		
9. Doesn't talk about daily activities or experiences		
10. Doesn't draw pictures		
11. Loses skills he once had		

Annexure 2:

Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)TM

Acknowledgement: We thank Joaquin Fuentes, M.D. for his work in developing the flow chart format used in this document.

For more information, please see www.mchatscreen.com
or contact Diana Robins at DianaLRobins@gmail.com

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The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The M-CHAT-R/F is available for free download for clinical, research, and educational purposes. Download of the M-CHAT-R/F and related material is authorized from www.mchatscreen.com.

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The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from <http://www.mchatscreen.com>. Associated documents will be available for download as well.

Scoring Algorithm

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

- LOW-RISK:** **Total Score is 0-2;** if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.
- MEDIUM-RISK:** **Total Score is 3-7;** Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.
- HIGH-RISK:** **Total Score is 8-20;** It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

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

M-CHAT-R Follow-Up (M-CHAT-R/F)TM

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The Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is designed to accompany the M-CHAT-R. The M-CHAT-R/F may be downloaded from www.mchatscreen.com.

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Instructions for Use

The M-CHAT-R/F is designed to be used with the M-CHAT-R; the M-CHAT-R is valid for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorder (ASD). Users should be aware that even with the Follow-Up, a significant number of the children who fail the M-CHAT-R will not be diagnosed with ASD; however, these children are at risk for other developmental disorders or delays, and therefore, follow-up is warranted for any child who screens positive.

Once a parent has completed the M-CHAT-R, score the instrument according to the instructions. If the child screens positive, select the Follow-Up items based on which items the child failed on the M-CHAT-R; only those items that were originally failed need to be administered for a complete interview.

Each page of the interview corresponds to one item from the M-CHAT-R. Follow the flowchart format, asking questions until a PASS or FAIL is scored. Please note that parents may report “maybe” in response to questions during the interview. When a parent reports “maybe,” ask whether most often the answer is “yes” or “no” and continue the interview according to that response. In places where there is room to report an “other” response, the interviewer must use his/her judgment to determine whether it is a passing response or not.

Score the responses to each item on the M-CHAT-R/F Scoring Sheet (which contains the same items as the M-CHAT-R, but Yes/No has been replaced by Pass/Fail). The interview is considered to be a screen positive if the child fails any two items on the Follow-Up. If a child screens positive on the M-CHAT-R/F, it is strongly recommended that the child is referred for early intervention and diagnostic testing as soon as possible. Please note that if the healthcare provider or parent has concerns about ASDs, children should be referred for evaluation regardless of the score on the M-CHAT-R or M-CHAT-R/F.

M-CHAT-R Follow-Up™ Scoring Sheet

Please note: Yes/No has been replaced with Pass/Fail

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE , if you point at a toy or an animal, does your child look at the toy or animal?)	Pass	Fail
2. Have you ever wondered if your child might be deaf?	Pass	Fail
3. Does your child play pretend or make-believe? (FOR EXAMPLE , pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal)	Pass	Fail
4. Does your child like climbing on things? (FOR EXAMPLE , furniture, playground equipment, or stairs)	Pass	Fail
5. Does your child make <u>unusual</u> finger movements near his or her eyes? (FOR EXAMPLE , does your child wiggle his or her fingers close to his or her eyes?)	Pass	Fail
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE , pointing to a snack or toy that is out of reach)	Pass	Fail
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE , pointing to an airplane in the sky or a big truck in the road)	Pass	Fail
8. Is your child interested in other children? (FOR EXAMPLE , does your child watch other children, smile at them, or go to them?)	Pass	Fail
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE , showing you a flower, a stuffed animal, or a toy truck)	Pass	Fail
10. Does your child respond when you call his or her name? (FOR EXAMPLE , does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Pass	Fail
11. When you smile at your child, does he or she smile back at you?	Pass	Fail
12. Does your child get upset by everyday noises? (FOR EXAMPLE , a vacuum cleaner or loud music)	Pass	Fail
13. Does your child walk?	Pass	Fail
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Pass	Fail
15. Does your child try to copy what you do? (FOR EXAMPLE , wave bye-bye, clap, or make a funny noise when you do)	Pass	Fail
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Pass	Fail
17. Does your child try to get you to watch him or her? (FOR EXAMPLE , does your child look at you for praise, or say “look” or “watch me”)	Pass	Fail
18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE , if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”)	Pass	Fail
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE , if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Pass	Fail
20. Does your child like movement activities? (FOR EXAMPLE , being swung or bounced on your knee)	Pass	Fail

Total Score: _____

Annexure 3

TABLE 2 Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.

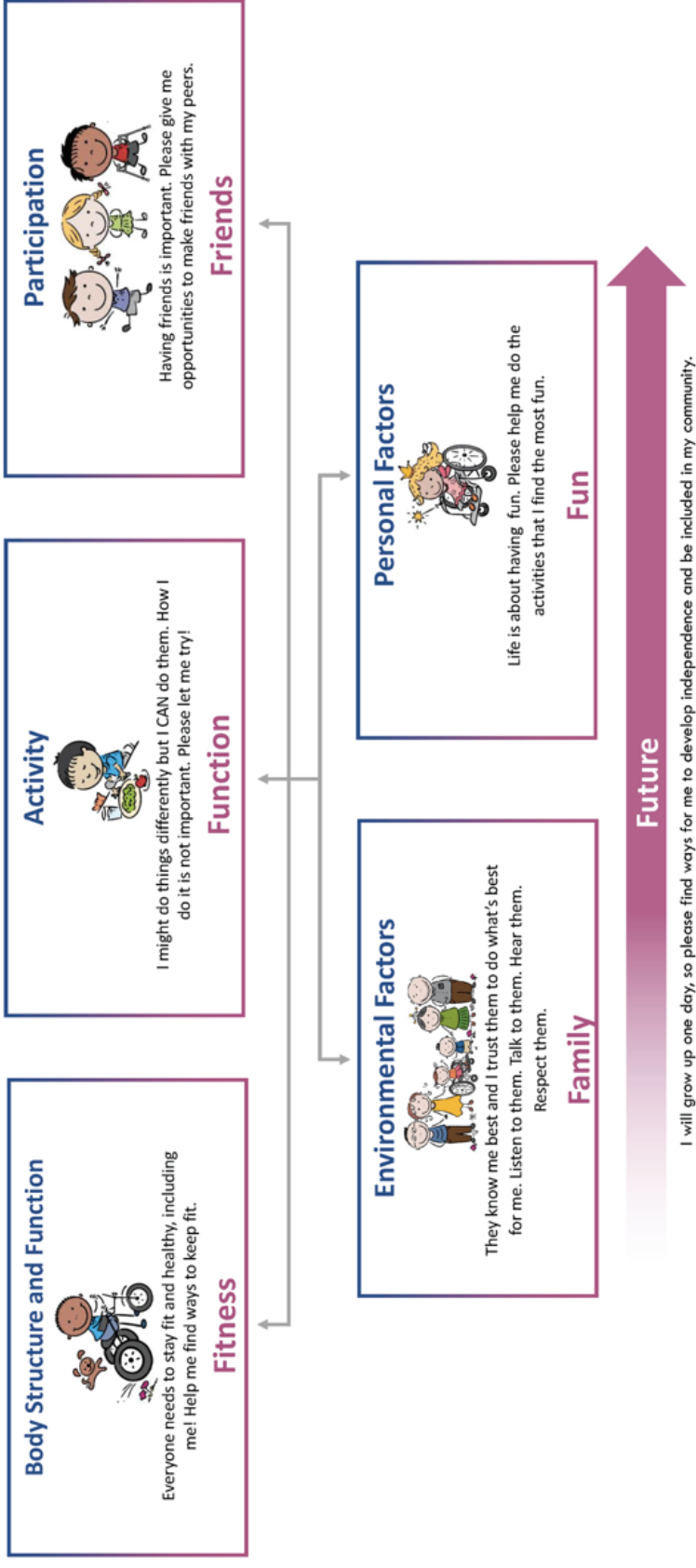
Annexure 4:

ASD Specifiers

Specify if;

- With or without accompanying intellectual impairment
- With or without accompanying language impairment
- Associated with a known medical or genetic condition or environmental factor
- Associated with another neurodevelopmental, mental, or behavioural disorder
- With catatonia

The ICF Framework and the F-Words



For more information visit the F-words Knowledge Hubs:
www.canchild.ca/f-words



- 1) World Health Organization. (2001). *International Classification of Functioning, Disability and Health (ICF)*
- 2) Rosenbaum P & Gorter JW. (2012). The F-words in childhood disability: I swear this is how we should think! *Child Care Health Dev.* 38.



**World Health
Organization**

Child Care, Development and Special Needs Unit
Family Health Bureau
Sri Lanka.

Tel : +94 112696508 / +94 112696697
cdsunit.fhb@gmail.com

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