DEVELOPMENT OF SEVERITY RATING SCALE FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

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ABSTRACT

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Aim and Objectives: The objectives of the present study were to formulate the severity rating scale (SRS) and to investigate the feasibility of administering the developed severity rating scale for assessing the severity levels of Indian children with autism spectrum disorders.

Method: The severity rating scale consisted of a total of 100 statements addressing the core features of ASD divided across five domains such as Speech and Language skills, Cognitive skills, Social Communication skills, Medical and Sensory issues, and self-help skills respectively. Sixty participants with a diagnosis of autism between 2-8 years of age were considered for the study. The scale was rated based on a five point rating scale namely: "5- always", "4- frequently", "3- intermittently", "2- rarely", and "1- never. Based on the cut-off scores, the severity levels of autism were categorized as: 1- No autism, 2- Mild Autism, 3- Moderate autism, and 4- Severe autism.

Results: Descriptive statistics was compiled to estimate the mean scores and cut-off scores for severity levels of autism. Inter-rater reliability of the scores were calculated using Cronbach's alpha coefficient and the sensitivity of the developed severity rating scale was analyzed by comparing it with Childhood autism rating scale (CARS) using Spearman's correlation. The results indicated that the mean scores decreased with increase in age. The cut-off levels of severity of autism was estimated as 161 for the diagnosis of autism. Inter-rater reliability indicated a positive reliability between the two raters in all the domains. The agreement between the two scales also indicated a high positive correlation between SRS and CARS.

Conclusions: In view of the results, the developed SRS is found as sensitive as CARS and can be used to determine severity levels of autism and to differentially diagnose between autism and other developmental disorders. The severity rating scale can also serve as a prognostic indicator to monitor the progress of intervention in children with autism.

Key words: Autism spectrum disorders (ASD), severity rating scale (SRS), childhood autism rating scale (CARS), domains.

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CHAPTER 1

INTRODUCTION

"Autism can't define me. I define autism"- Kerry Magro, 2010

Autism Spectrum disorders (ASDs) are neurodevelopmental conditions characterized by qualitative impairment in communication and social interaction in addition to a range of restricted stereotyped, repetitive behaviours and interests as described in the Diagnostic and Statistical Manual of Mental Disorders, 4th Revision (DSM-IV) (American psychiatric association, 2000). In addition to these core deficits, individuals with ASD also experience a number of comorbid deficits such as cognitive delays/intellectual disabilities, motor delays, adaptive skill deficits, anxiety and aggressive/destructive behaviour (Volkmar, Klin, Siegel, Szatmari, 2004). The Center for Disease Control (CDC, 2016) reports an overall prevalence rate for ASDs of one in 68, with boys affected at greater rates than girls (4.5:1). The disorder was initially considered to be non-treatable and its impact had been emotionally disturbing for families.

Short and Schopler (1988) considered the reports from the parents and caregivers who had described symptoms of autism within the first two years of life. Howlin and Moore (1997) suggested that parents displayed concerns of autism to their Paediatricians by the time their children were nearing 2 years of age. National Research Council (Lord & McGee, 2001) suggested that ASD can be reliably diagnosed at age 2 and/or younger and the average age for diagnosis of children with an autism is 3 to 4 years of age (Woods & Wetherby, 2003). By considering the early behavioural profiles of children with ASD, Johnson and Myers, 2007 recommended routine ASD screening as young as 18 and 24 months of age.

As reported in the literature, among children who are diagnosed with Autism, majority of them were observed to be mildly disabled whereas some of them were severely disabled. Children with Autism whose severity was reported to be mild may develop speech and language skills, social interaction skills and life skills at an early age and they will be able to function with minimal assistance, whereas those whose severity was reported to be severe may develop speech and language skills, social interaction skills and life skills slowly and require constant support in performing the functional activities in real life situations.

Children categorized as autistic disorder usually are the ones to meet the complete diagnostic criteria of ASD. Children are diagnosed with PDD-NOS when the symptoms are not adequate to be diagnosed with autistic disorder. Children with high-functioning autism may be referred to as Asperger's disorder which the least severe subtype of ASD. Although, children with Asperger's disorder display impairments in social interactions, however, have intact cognitive abilities and have normal to near normal early language development.

According to the Diagnostic and statistical manual of Mental Disorders (DSM-IV), the subtypes to classify ASDs include Autistic disorder, Rett's disorder, Childhood disintegrative disorder, Asperger's disorder, and Pervasive developmental disorder – not otherwise specified (PDD-NOS). The subtypes of ASDs are categorized into a single diagnostic category according to the Diagnostic and statistical manual of Mental Disorders fifth edition (DSM-5). However, a heterogeneity exists in the symptoms of children with ASD with respect to age, type of onset, severity, range of delay in language development and intellectual deficits.

A complete understanding of the child's abilities such as developmental, language, communication, cognitive, social, adaptive, sensory behaviours, and unusual behaviours for the diagnosis of ASD subtypes. The major condition that is used to profile the presence or absence of autistic disorder is the delay or absence of development of spoken language. Previous researches have postulated that this domain is important in differentiating between autism and other related developmental disorders and issues in language are vital to our understanding of autism since they are often the initial presenting symptom. Luyster, Kadlec, Carter, Tager-Flusberg (2008), suggested receptive and expressive language impairments are common in children with ASD and the extent of language impairment are dependent on age and developmental factors. The developmental processes in children with ASD are compromised by underlying delayed or impaired language at a very young age.

Children with normal language development use language for social purpose to initiate conversational interactions. Conversely, children with ASD specifically use the words restricted to basic communication needs (e.g., to demand, protest). Kjelgaard, Tager-Flusberg (2001) also suggested that individuals with ASD especially have very limited language, with progress depending on intelligence quotient/ developmental quotient, comprehension and attention skills. Although, verbal children of ASD do not have difficulty with speech sound articulation, but the speech can be perseverative (echolalia, idiosyncratic use of language), and inappropriate prosody in speech (monotonic, atypical stress). The researchers postulate a strong link between language and social skills since children with ASD show limited use of language in social context (rarely comment or request information), and pointing (to indicate social interest).

Lord (1985) indicated that children with ASD have a disengagement from the social world since they have a tendency to display inconsistent response to name-calls and ignore social cues around their environment but instead respond to other non-vocal stimuli. These children also frequently display issues in attention and gives inconsistent responses to language tasks involving auditory attention. Children at pre-verbal phase display evident qualitative differences in communication between ASD and typically developing children.

Rutter, Mawhood, Howlin (1992) indicated that specifically, children with ASD display lack of use of symbolic gestures such as showing or pointing out objects of interest, rather use physical cues such as pushing or directing another's hand as a tool for communication. The attentional difficulties in young children with ASD attributes to two factors: a) ability to involve attention mutually with others (joint attention/joint engagement), and b) the ability to initiate and maintain quality interaction skills with peer groups.

Children with autism are identified by their apparent lack of awareness of others, demonstrated by marked difficulties in coordination of attention between self and others (joint attention). For example, they may be so focused on playing with a toy that it is difficult for another person to initiate the attention with the child. Tager-Flusberg and (1993) discovered that primarily, children with autism fail to represent the mental states of self and others which was described as a deficit referred to as 'theory of mind'. Authors accounted this theory to reason the inability children with autism to have difficulty with joint attention, pretend play and false beliefs.

Need for the study

A qualitative assessment of ASD is required to monitor the prognosis since the behaviours of children with autism vary across different age. Hence, screening is the first step in the assessment designed to identify children who are in need of more comprehensive evaluation of autism. There are numerous standardized screening tools on the western forefront, to assess the severity of ASD including the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1994) and Autism Treatment Evaluation Checklist (ATEC; Rimland & Edelson, 1999). Both the measures were reported to be a well-established, professional rated measures and aimed to quantitatively measure the severity level of children with Autism Spectrum Disorders.

Conversely, DSM IV (APA, 2000) criteria for autism spectrum disorders, assesses only the presence of triad characteristics of autism. In Indian context, the differential diagnosis checklist for autism spectrum disorders documents the overall severity of autism based on subjective perception of the health professionals but however, it does not assess the severity of functioning of specified skills in different areas.

There is a dearth of studies that focus on the severity aspects of autism in Indian context. Therefore, an attempt to develop a severity rating scale to assess the severity level of each functional skills was made for children with autism. The severity rating scale would serve as a prognostic indicator and assist the speech language pathologists in assessing the functional, level of independence in carrying out routine activities, and monitoring the quality of life of children with ASD during the progress of intervention.

Aim of the study:

To develop and implement a severity rating scale in Indian context for children with Autism spectrum disorders (ASD)

Objectives of the study:

- To formulate the severity rating scale for assessing the severity level of Indian children with autism

- To investigate the feasibility of administering the developed severity rating scale by assessing their severity level in several domains such as Speech and Language skills, Cognitive skills, Social Communication skills, Medical and Sensory issues, and self-help skills on a group of autistic children.

CHAPTER 2

REVIEW OF LITERATURE

"Autism: Where the randomness of life collides and clashes with an individual's need for the sameness"- Eileen Miller, 2008

Autism Spectrum disorders (ASDs) are neurodevelopmental disorders which refers to a range of disorders characterized by deficits in social reciprocity, communication, and unusual, repetitive, and stereotyped behaviours (American Psychiatric Association, 2000). The severity of children with ASD vary from mild to moderate and severe and the autistic behaviours are mainly influenced by different aspects of learning, family and environmental influences. Children with milder severity of autism may develop speech and language skills, social interaction skills and life skills at an early age and they will be able to function with minimal assistance, whereas those with severe autism may have accompanying learning challenges and require constant support in performing the functional activities in real life situations. The spectrum of ASD include the following: Autistic disorder, Rett's disorder, Childhood disintegrative disorder, Asperger's disorder, and Pervasive developmental disorders-Not otherwise specified.

Globally, according to the Centre for Disease Control and Prevention (2014), the overall prevalence of ASD was 14.7 per thousand children. The studies also revealed that the prevalence varied with gender and race/ethnicity. Prevalence rate were found to be higher in males (18.4/1000) than females (14.7/1000). In India, the prevalence rate of autism was found to be 0.9 per 1000 children and highest prevalence was found in rural areas.

Studies revealed that socioeconomic status (SES) were principle indicators of ASD and individuals with autism belonged to the "lower middle class" on socioeconomic status. Lower SES, mental illness and conditions such as childbirth at home and respiratory distress during birth contributed to higher prevalence rates of autism. (Raina, Kashyap, Bhardwaj, Kumar, and Chander, 2015)

Speech and language skills deficits

Receptive language: Non- verbal cues: Eye-gaze, mime; gestures: pointing (considering both imperative and declarative pointing skills), Functional vocabulary, Auditory comprehension including listening skills while spoken to and following instructions and directions, identification of names, objects, and pictures, and concepts.

Expressive language addressed in ASD are mutism, mean length of utterance (predominantly telegraphic speech), idiosyncratic use of language, semantic errors such as word finding difficulties, grammatical errors, echolalia (immediate, mitigated, and delayed), deficits in verbal and non-verbal imitation skills, deficits in narrative and conversational discourse skills, and prosodic skills including inappropriate stress or emphasis in sentences/phrases, intonation- Monotone, and loudness such as increased loudness during conversations.

Cognitive skills addressed in the following include mutual gaze, gaze shifts, and joint attention; Memory such as rote memory and working memory, reasoning, and problem solving.

Medical issues includes the following:

1. Seizures and epilepsy
2. Sleep disturbances
3. Gastrointestinal problems

4. Feeding difficulties

5. Anxiety

6. Depression

Physical and atypical behaviours such as:

1. Toe walking

2. Postural abnormalities

3. Repetitive motor behaviours (hand flapping, twisting, spinning)

4. Motor delays (gross and fine motor skills)

Hypersensitivity and Hyposensitivity issues in the following:

1. Sight

2. Touch

3. Taste

4. Smell

5. Sound

6. Sense of balance

7. Sense of movement

8. Temperature

9. Pain

Adaptive skills addressed as deficits in toileting skills, feeding skills, physical hygiene, oral hygiene, and grooming.

Social skills deficits are addressed as following:

1. Inadequate social interactions including difficulties with developing social relationships such as remaining aloof and indifferent to other counterparts.

2. Social communication - difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice

3. Social imagination - difficulty in the development of interpersonal play and imagination

4. Peer relationships (aloofness/withdrawal)

5. Play such as reduced symbolic play, imaginative play, and group activities.

Lack of emotional skills/Empathy explained in terms of:

1. Recognition of facial expressions and the emotions

2. Copy or use emotional expressions

3. Understand and control own emotions

4. Understand and interpret emotions

5. Imitating self and others' emotions

6. Managing of emotions

Behavioural skills characterized by the following:

- Preoccupation

- Repetitive behaviours

- Restricted interests

- Self-stimulatory behaviours

- Self-injurious behaviours

- Hyperactivity, and aggressiom

Academic skills characterized by deficits in the following:

- Reading- reading comprehension,

- Writing- spelling, grammar, organization or usage of written language

- Auditory processing: understanding spoken language, following directions, repetition in learning new concepts.

Classification of Autism Spectrum Disorders

Leo Kanner (1943) in his description of cases of children with autism, first defined the concept of infantile autism. The author reported autism on 11 children between 2-8 years of age who exhibited a preference of aloneness, restricted attention to social environment, insistence of sameness or resistance to change, evident problems in communication with either total absence of spoken language or perseverative language such as echolalia, atypical language such as pronoun reversal, idiosyncratic language, socially inappropriate language and atypical behaviours including repetitive motor movements such as hand flapping and body rocking. Kanner in his study, outlined the parents' perspectives of autistic behaviours and also the socioeconomic and educational background of the family of children with autism.

Autistic Disorder

The onset of autism is usually in the first three years of life and parents often first become concerned of autism in the first year of life (Volkmar, Klin , Siegel, Szatmari, Lord, Campbell, Freeman, Cicchetti, Rutter, and Kline; 1994). American psychiatric association (2000) determined diagnostic criteria of autistic disorder according to Diagnostic and statistical manual of mental disorders- fourth edition (DSM-IV). The characteristics of autism were manifested by the following symptoms:

1. Qualitative impairment in social interaction : Use of non-verbal behaviours such as mutual eye gaze, facial expression, body postures ,gestures, difficulty to develop peer relationships appropriate to developmental level, lack of empathy, difficulty to establish friendships, and limited showing or pointing out to objects or people to share interests or to request action.

2. Qualitative impairments in communication: delay or limited development of spoken language, failure to sustain conversation, idiosyncratic or repetitive use of language such as echolalia, lack of social initiative or imaginary play.

3. Restricted, repetitive or stereotyped behaviours: preoccupation with objects, interests and routine, repetitive motor movements (flapping of hands, body rocking behaviours) and preoccupation with parts of objects.

Hermelin (2001) indicated that approximately 10 percent of children with autism display some amount of proportions of unusual skills or savant abilities. Savant skills include prodigious capacities in music, drawing, extraordinary rote memory, outstanding abilities to decode letters and numbers, and calendrical calculation. Hence, these skills exceed overall intellectual abilities than typical range of skills.

Paul and Wilson (2005) suggested that atypical development of early communication skills are directly correlated to risk of autism. This includes the following: Deficits in attention to people, social smile, sharing of emotion of affect, and usage of pre-verbal behaviours used in social communication such as gaze and gestures during joint attention. Communication impairments include limited responsiveness to speech, delayed development of language, use of language in a social context, echolalia, and disordered pragmatic language. Stereotyped behaviours, repetitive interests and unusual responses to the environment interfere in learning.

Asperger's disorder

Asperger's disorder was first discovered by an Austrian paediatrician Hans Asperger in 1944 who described children having lack of non -verbal communication, lack of empathy and physically clumsy. With reference to ICD-10 (1992) and DSM-IV (2000), children with Asperger's disorder had qualitative impairments in social interaction, social communication, and encompassed stereotyped and repetitive interests and behaviours. The charecteristics are described in the following headings:

Repetitive and stereotyped interests:

DSM-IV (2000) suggested that individuals with Asperger's disorder display behaviours and activities that are restricted and repetitive and in some cases abnormally intense or focused. Individuals may give major preference to inflexible routines, preoccupy themselves with parts of objects such as spinning or display compulsive behaviors such as lining objects up to form patterns, and display repetitive motor behaviours

McPartland and Klin (2006) indicated that the quest of specific and narrow areas of interest is the major striking features of Asperger's disorder. These individuals may give detailed preference of information on a relatively narrow topic without essentially having a general understanding of the broader topic and these behaviours are more apparent between 5-6 years of age.

Speech and Language

There is no clinically significant general delay in language in AD, however, language acquisition and use are atypical (Klin, 2006). Abnormalities include using more words than necessary, miscomprehension of shade of emotions, auditory perception deficits, unusually stilted speech, formal or idiosyncratic speech, and monotonous speech and rhythm, echolalia, incoherence in speech, difficulty in understanding figurative language, humour and literal interpretations of language.

Pervasive Developmental Disorder-Not Otherwise Specified/atypical autism

Pervasive developmental disorders (PDD) are included in the sub-threshold category which manifest slight differences of the symptomatology of autistic disorder as suggested by ICD-10 and DSM-IV classification of ASD. PDD-NOS is not a milder disability, instead individuals who receive this diagnosis do not meet the diagnostic criteria of other pervasive developmental disorders. Individuals with PDD-NOS have significant social communication deficits as seen in autistic disorders, but these individuals display fewer intellectual impairments unlike autistic disorder and the intellectual impairments become more apparent at later age.

Childhood disintegrative disorder

The condition is referred to as Heller's syndrome (Theodore Heller, 1908) or disintegrative psychosis, characterized by a prolonged period of normal development (typically 3 or 4 years) followed by a dramatic developmental deterioration in multiple areas and has a developmental similarity of childhood autism. Recovery is usually limited. Although this was at first thought to be a childhood dementia, development stabilizes at a lower level but no further deterioration occurs.

Volkmar and Rutter (1995), in a study and using DSM-IV criteria, identified 26 individuals of CDD. In their study, comparisons of CDD were made to children with autism. Results revealed that CDD confirmed to be a distinct disorder from another ASD. The authors gave a description of individuals with CDD who were characterized by normal or near normal development during the first two years of life followed by regression in receptive and expressive language skills, social communication skills, cognitive deterioration, self-help skills, bowel and bladder control, play skills, gross and fine motor skills. Following this loss of skills, most behavioural triad symptoms of autism are usually met.

Rett's disorder

Rett's disorder was first described by Rett in 1966, characterized by a condition mostly prevalent in females. Wein (1966) described that Rett's disorder is a rage genetic postnatal disorder in which early development is normal, but the acquired skills deteriorates with a marked clinical pattern including some amounts of social unresponsiviness (in the preschool years), motor and respiratory problems, seizures, and profound developmental delay including small hands and feet and deceleration of head growth. The signs of this disorder are most easily confused with those of cerebral palsy.

Hagberg, Aicardi, Dias, and Ramos (1983) studied a detailed report of thirty five patients (preferable females) from three Countries of Europe and the participants had history of progressive encephalopathy. The authors described a normal psychomotor development till 7-18 months of age followed by rapid deterioration of higher brain functions. The authors categorized the features of Rett's disorder in two categories as follows:

Category 1: Signs of Rett's syndrome similar to autism: Seizures, Temper tantrums, Breathing and swallowing difficulties, Avoidance of eye contact, Lack of social/emotional reciprocity, Strikingly impaired use of nonverbal behaviours to regulate social interaction, Loss of speech, Sensory issues, and Sleep disturbances. Category 2: Neurologial signs of Rett's syndrome, Short stature, difficulty in walking ,difficulty in swallowing, Weak muscle tone, Gait/movement abnormalities, Ataxia, Microcephaly , Minimal forms of spasticity, Spasmodic/choreatic movements of hand or facial muscles, and Bruxism (grinding of teeth).

Assessment of Autism

A detailed comprehensive evaluation of autism involves a systematic procedure that is required to be conducted by a clinician specifically trained in ASD. Differential diagnosis of autism from other disorders of similar presentation including intellectual disability, hearing impairments, speech and language disorders are exceptionally difficult to detect at very young age. (Rogers, 2001). An interdisciplinary assessment is essential for the assessment of ASD which includes assessment of language, communication and social behaviour, adaptive skills, motor skills, sensory issues, atypical behaviors, and cognitive functioning (National Research Council, 2001).

Wilkinson (2010) suggested the evidence based assessment of core autism domains as follows:

1. Collection of demographic data

2. Developmental and medical history

3. Medical screening and/or evaluation

4. Parent/caregiver interview

5. Parent/teacher ratings of social behaviour

6. Direct child observation

7. Cognitive assessment

8. Academic assessment

9. Adaptive behavioural assessment, and

10. Communication and language assessment.

Screening is defined as the fundamental step in the assessment to identify children who are required for comprehensive evaluation of autism (Meisels, 1985). Screening measures indicate risk levels of autism instead of providing a diagnosis and essentially require less time. Screening measures are often used in paediatric practices to identify children at risk of autism, identify broader range of developmental problems such as cognitive, motor, and/or language delay, and also for differential diagnosis with other co-morbid disorders. The accuracy of screening measures have been evaluated in terms of the proportion of the population identified as at risk (sensitivity) and not at risk (specificity) for ASD.The screening tools developed specifically for ASD are reviewed as follows:

1. A standardized parental interviews: Autism Diagnostic interview (ADI)

2. A standardized observation schedule: Autism diagnostic observation schedule (ADOS)

3. Checklists: Modified checklist for autism in toddlers (M-CHAT), and Autism treatment evaluation checklist (ATEC)

4. Rating scales: Childhood autism rating scale (CARS), Gilliam autism rating scale (GARS), and Indian scale for assessment of autism (ISAA)

1. Autism Diagnostic Interview – Revised (ADI-R)

The Autism Diagnostic Interview- Revised (Rutter, Le Couteur, & Lord, 2003) is an interview conducted to the parents/caregivers to obtain information about the behavioural and developmental history of children with autism above 2 years of age. It is an extended structured interview, which includes questions addressing the triad symptoms of ASDs as follows: Language/Communication such as instrumental gesture/pointing, expressive and

inactive gesture, attention to instructions, range of facial expression, nonverbal intentionality, Intonation/rhythm/rate, vocal expression, stereotypic speech, pronoun reversals, neologisms, idiosyncratic speech, initiation of activity/play, conversation, amount of social language; Reciprocal social interactions such as social responsiveness, social reciprocity, greeting, response to comfort, affection, separation anxiety, friendship, cooperative play, turn taking, imitation skills, share pleasure, inappropriate facial expression, and quality of social overtures; and Restricted, repetitive, and stereotyped behaviours and interests such as resistance to change, compulsions and rituals, verbal rituals, unusual sensory behaviour, Hand and finger mannerisms, curiosity/play, Share others' activities, sensitivity to noise, self-injury ,unusual preoccupations, and unusual attachments.

ADI-R consists of 93 yes/no questions followed by probe questions, which are scored on a scale of 0 to 2 and the administration duration of the tool is approximately 90-180 minutes. The measure uses a new algorithm to categorize ASDs with other disorders by converting the scores into diagnostic criteria based on the International Classification of Diseases –10th Revision (ICD-10; World Health Organization, 1993) and DSM-IV criteria for ASDs. The measure focuses on behaviours that are typical in autism, and results are profiled in a categorical manner rather than providing scales or norms.

2. Autism Diagnostic Observation Schedule (ADOS)

The Autism Diagnostic Observation Schedule (Lord, Rutter, DiLavore, & Risi, 1989) is a semi-structured autism observation measure that is designed to measure presentation of behavioural response and communicative attempt as compared to the triad features of autism. The ADOS is the standardized diagnostic measures that involves scoring direct observations of the child's interactions and that accounts for the developmental level and age of the child. This measuring tool has become the gold standard for assessing autistic

behaviour and diagnosing ASDs across the age span, developmental levels and language skills. The measure takes 30 to 60 minutes to administer and has four modules depending on the child's level of communicative functioning which covers: (1) Preverbal/single words; (2) phrase speech; (3) Fluent speech child; and (4) Fluent speech adolescent/adult. Activities vary based on the language level and chronological age of the child. For example, Module 1 (for children who do not use phrase speech) and Module 2 (children who use phrase speech but are not verbally fluent), which are designed for use with children with a language level of less than 48 months, and Modules 3 and 4, which are designed for older children, adolescents, and adults who have the ability to use complex sentences.

The activities addressed in each of the domains are listed as following:

1. Preverbal or single words: Social smile, social initiation, play (free or parallel play), snack, response to name, joint attention, birthday party, bubble play, routine activity with objects.

2. Flexible phrase speech: Construction task, make-believe play, joint interactive play, free play, snack, response to name, response to joint attention, birthday party, bubble play, anticipation of a routine with objects, demonstration task, conversation, description of picture, and looking at a book.

3. Fluent speech child/ adolescent: Construction task, make-believe play, joint interactive play, break, cartoons, socio-emotional questions- emotions, friends; creating a story, demonstration task- conversation/reporting a non-routine event; description of picture, telling a story from a book.

4. Fluent speech adolescent/adult: construction task, current work/school/daily living, socio emotional questions- plans and dreams, social difficulties/annoyance; break, cartoons, creating a story, demonstration task, conversation/reporting a non-routine event, description of picture, telling a story from a book.

For each task, a hierarchy of social structures is provided. During the first administration of a task a child is able to take as much initiative as possible; if this does not occur, the examiner gradually makes the tasks more specific and increasingly structures the situation to observe the child's response (Lord & Risi, 2000). Following the administration of the ADOS, behaviours are coded using a 0- to 3-point coding system, with a 0 indicating that the behaviour is not abnormal in the way specified in the coding description and a 3 indicating that a behaviour is abnormal and interferes in some way with the child's functioning. The examiner or clinician records the range of core triad features of autism along with presentations of poor imagination or symbolic play skills. The ADOS also uses algorithm to classify features of ASDs and is used alongside with ADI- R.

3. Modified Checklist for autism in toddlers (M-CHAT)

M-CHAT (Robins, Fein, & Barton, 2001) is parental report measure consisting of a total of 23 yes/no questions administered on children between 16 to 30 months of age to assess risk of ASD. M-CHAT was the extension of Checklist for autism in toddlers (CHAT) developed by (Baron-Cohen, Allen, & Gillberg, 1992) and also consists of additional items representing autism symptoms not assessed by CHAT. The primary goal of M-CHAT is to maximise sensitivity (to identify maximum number of children with ASD) and to minimize the false positive responses (not all the children who fail in M-CHAT will meet the criteria of diagnosis of ASD). The cut-off score for M-CHAT is the failure of 2 or more critical items or failure of any three items.

Robins et al. (2001) evaluated M-CHAT on 1,293 children between 18-30 months of age at the time of early intervention. Totally, 58 children received further developmental evaluations, 74 were recommended for telephone follow-up but no evaluation, and remaining 1,161 were not recommended for follow-up. Out of the children receiving developmental evaluations, 39 children received ASD diagnoses. Results of Discriminant functional analysis (DFA) on the population administered had maximum discriminant coefficients on seven critical items (protodeclarative pointing, following a point, showing objects, imitation, interest in other children, and response to name) and two cut-off scores were examined: failure on any three items on the entire checklist or failure of two of the six critical items.

Eaves, Wingert, and Ho (2006) evaluated M-CHAT on a group of 84 children between 24–48 months on the basis of referral of autism to a speciality clinic. 64% of children received a diagnosis of ASD and remaining children had more than one diagnosis such as language disorder and intellectual delay. Sensitivity was 77 % for 2/6 critical item score and 92 % for the 3/23 item score. Authors suggested that the differences in the sampling procedure between Robins et al. (2001) and Eaves et al. (2006) were responsible for the differences such as: (a) Telephone follow-up was used by Robins et al., and (b) the age range of Robins et al's study sample was 16–30 months whereas it was 24–48 months of age in Eaves et al's study sample.

4. **Autism Treatment Evaluation Checklist (ATEC)**

The Autism treatment evaluation checklist was developed by Rimland and Edelson (1999) specifically for individuals with ASD. The ATEC is a short, one page checklist which is designed to be completed by parents, and teachers of children with ASD. This

checklist is free, easy to administer, can be accessed and scored online, and is intended to measure the effects of treatment. The scale consists of 77 items and few examples of phrases addressed across each domain are mentioned in the following:

- Speech/ Language/Communication

a) Knows own name, can follow some commands, can use one word/two words/ three words at a time, can use sentences.

- Sociability

b) Seems to be in a shell, ignores other people, uncooperative and resistant, no eye contact, fails to greet parents.

- Sensory and cognitive awareness

c) Responds to own name, responds to praise, plays with toys appropriately, appropriate facial expression, aware of environment, aware of danger.

- Health and physical behaviour

d) Bed wetting, wets pants, sleep problems, hyperactive, lethargic, hits or injures self, hits or injures others.

The examiner is instructed to circle the letter to indicate how true the phrase is as following:

Domain 1- [N] – "Not true", [S] – "Somewhat true", and [V] – "Very true".

Domain 2 and 3- [N] – "Not descriptive", [S] – "Somewhat descriptive", and [V] – "Very descriptive".

Domain 4- [N] – "Not a problem", [MO] – "Moderate problem", [MI] – "Minor problem", [S] – "Serious problem".

5. Childhood Autism Rating Scale (CARS)

The Childhood Autism Rating Scale (Schopler, Reichler, DeVellis, & Daly, 1980) is based on direct behavioural observation of the child. CARS consists of 14 domains assessing core behaviours associated with autism, and the 15th domain rates general impressions of autism. CARS is used to subjectively rate fifteen items that include: relationship to people, imitation, emotional response, body, object use, adaptation to change, visual response, listening response, taste-smell-touch response and use, fear and nervousness, verbal communication, non-verbal communication, activity level, level and consistency of intellectual response, and general impressions.

This scale is rated based on subjective observations of the child's behaviour by a clinician or teacher and/or parent. Each of the fifteen criteria listed above is rated on a four point rating scale with a score of: 1- normal; 2- mildly abnormal; 3- moderately abnormal; 4- severely abnormal; and midpoint scores of 1.5, 2.5, and 3.5 are also used. Total CARS scores range from a minimum score of fifteen to maximum score of 60, with the scores ranging from 15 to 29.5 as non- autistic, 30 to 36.5 as mild to moderately autistic, and 37 to 60 as severely autistic.

Schopler et al., (1980) administered CARS on 537 children with autism enrolled in the 10 year period of the Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) program. A cut-off score of 30 (for the diagnosis of autism) was obtained in fifty-one percent of the children and the authors developed a criteria to differentiate between those with mild to moderate autism and those with severe autism due to the presence of bimodal distribution of the scores. Children those score exceeded 36

and who received a rating of three or greater on at least five subscales were categorized as severe autism.

Schopler, Reichler, and Renner (1988) made an update of the Childhood Autism Rating Scale (CARS), an older and widely-used rating scale for autism. It was developed to meet the administrative and research objectives for the treatment and education of autistic and related communication handicapped children (TEACCH) program in 1966, for children with autism in North Carolina. The original CARS was developed primarily with individuals with comorbid intellectual functioning and was criticized for not accurately identify higher functioning individuals with ASD. The CARS2 has the forms designed for the clinicians in the form of questionnaire for parents and caregivers (CARS2-QPC). The revised version of CARS has two forms such as: a) CARS2-Standardized clinical tool (CARS2-ST) for assessing children below 6 years of age, children with communication difficulties, and below average intelligence quotients, and b) CARS2-High functioning (CARS2-HF) for assessing children above 6 years of age who are verbally fluent and have intelligent quotients of above 80. The revised edition expands the tests from the original CARS to cover high-functioning autism or Asperger's disorder, making it more responsive to those with more subtle social impairments and behavioural problems.

EVIDENCE-BASED COMPARISONS OF CARS WITH DIFFERENT DIAGNOSTIC TOOLS

Tammy, Nurit, Cory, and Ronit (1998) compared ADI-R and CARS in eighty-three participants (62 males and 21 females) between the ages of 20 months to 34 years of age who were suspected with autism. Among 83 participants, 76 were assessed with the ADI-R, 77 were assessed with the CARS, and 70 were assessed with both the ADI-R and the CARS, and mental abilities were also assessed using a Wechsler's intelligence scale. Results show

that there was 85.7% (60 participants received the diagnosis of autism with ADI-R and CARS) degree of agreement of autism between the two diagnostic procedures.

Authors observed that there were disagreements of diagnosis of autism in remaining 10 participants and attributed to the difference between the two diagnostic tools with respect to the sources of information collected from parents and the clinician.

A retrospective study was done by Katherine Mick (2002) and comparisons of CARS and ADOS (both the modules) were administered for 220 children with autism below 6 years of age at Developmental disability centre at University of Kansas. Parental interview were takinn prior to the administration of the CARS and ADOS. The tools were administered to the parents of children with autism and scores were also noted on the basis of clinical observations of the child's behaviour. Results indicated through clinical observations suggested that there was stronger agreement between CARS and ADOS module 1 as compared to ADOS module 2. Authors concluded that although, both CARS and ADOS were similar in their ability to contribute in the diagnosis of autism, they may be measuring slightly different dimensions of autism. The authors also suggested that the diagnosis of autism seemed to be influenced more by communication factor in both the rating scales rather than taking considerations of other dimensions. The researchers also noted that direct comparisons could not be made between the two rating scales since the items used in both the rating scales were not similar.

Another study of comparisons of ADI-R and CARS were investigated by Evald, Pall, Jakob, and Solveig (2003) on 54 children between 22–114 months of age referred for autism. The researchers observed 66.7% of agreement between the two systems. The cut-off scores of three domains of CARS were in agreement with the ADI-R criteria. Authors observed that CARS identified more cases of autism than the ADI-R.

Another observation was that children classified as autistic disorder according to both the instruments had significantly lower Intelligence Quotient/Developmental Quotient and also found more severe autistic disorder cases than those classified with the CARS only.

Rellini, Tortolani, Trillo, Carbone, and Montecchi1 (2004) studied the correspondence between DSM-IV ,CARS, and Autism behavioural Checklist (ABC) in children with ASD. The sample consisted of 65 children (58 males and 7 females) aged 18 months to 11 years of age respectively.

Results suggested that:

1) According to the DSM-IV criteria, of the 65 children that completed the diagnostic process, 54 had Autistic Disorder, 5 had Asperger's Disorder and 4 with PDD-NOS, 1 had ADHD and 1 had Receptive-Expressive Language Disorder.

2) The 54 children with Autistic Disorder, as defined by DSM-IV criteria, had a CARS cut-off score above 30 (cut-off for the diagnosis of autism), and there was 100% sensitivity of CARS in all the cases tested. The CARS test also had sub-group of autistic categories as follows: (a) 24 children (44%) with mild-moderate autism and (b) 30 (56%) with severe autism. The five cases of Asperger's Disorder, the four cases of PDD-NOS, the case of ADHD and the case with Language Delay had CARS scores below 30 (Non Autistic). Hence, the scale did not identify Asperger's Disorder, PDD-NOS as belonging to the autistic spectrum disorders as they had scores below the cut-off category.

3) Of all 54 children with Autistic Disorder, 29 had a total ABC score that was greater than or equal to 57 (cut off for diagnosis of autism); 2 (4%) had a severe emotional disorder; 19 (35%) had severe mental retardation; and 4 (7%) were deaf/blind The five cases of Asperger's Disorder had a mean total score in the deaf/blind category. The four cases identified as PDD-NOS using criteria DSM-IV, the ABC categorized two cases as

normal and two cases as deaf/blind. The sensitivity of ABC was 54% and less as compared to CARS in distinguishing ASDs.

Another study was done by Perry, Condillac, Freeman, Geier, and Belair (2005) which included 274 preschool children between 2-6 years of age (204 boys (75%) and 70 girls (25%). The participants were referred from three sites for initial diagnostic assessment as follows: 56 from the first site (a comprehensive specialized autism service), 35 from the second site (a center for developmental disabilities, including autism), and 183 from the third site (a bilingual children's hospital with a diagnostic clinic for developmental disabilities and also included children from French speaking families). Similar results were obtained in consensus with the study of Rellini et.al which indicated that CARS categorical diagnosis presented cut-off scores greater than 30 indicating autism and also showed strong agreement with 88% sensitivity with clinical diagnosis of autistic disorder according to DSM-IV.

In Indian context, Russell, Daniel, Russell, Mammen, Abel, Raj, Shankar, Thomas (2010) conducted a study at the Autism Clinic in Southern India. The charts of children and adolescents referred to the clinic with a suspected diagnosis of autism (Pervasive Developmental Disorder of ICD-10) were identified from the unit's database for a six year period (2001-2007). The diagnostic criteria for autism was done using ICD-10; CARS as a severity rating scale, and Binet- Kamat Scale of Intelligence test (BKT) was administered as a cognitive scale in Indian context. BKT assessed the skills of children in areas of memory, language, conceptual thinking, reasoning, numerical reasoning, visuo-motor coordination and social intelligence. Reliability, sensitivity, and specificity of the cut-off scores of CARS were compared to ICD-10 and BKT. Totally 86 children with autism were identified according to the results from the data base. Results revealed that higher mean cut-off score

for autism in CARS provided good diagnostic accuracy with the features of autism profiled in ICD- 10 and helped in the better diagnosis of Indian children with autism.

Secondly, a moderate correlation were observed in CARS cut-off score and BKT scores suggesting that the concept of childhood autism with impairment in socialization and communication measured by the CARS and BKT were theoretically related to each other and helped in the diagnosis of autism.

A recent study done by Chlebowski, Green, Barton, and Fein (2010) assessed the sensitivity and specificity of CARS in relationship to DSM-IV in 606 children (482 males and 124 females) with samples of 2 (376 children – 296 males, and 80 females) and 4 (230 children- 186 males and 44 females) year olds. The children received the first evaluation at 2 years of age with follow up evaluation at 4 years of age. For the purpose of analyses, the participants were divided into four groups as follows: Autistic disorder group, PDD-NOS group, non-ASD diagnosis (non-ASD) group consisted of children with diagnoses of intellectual disability, global developmental delay, developmental language disorder, and no-diagnosis group which consisted of typically developing children. The tools that were administered for the purpose of assessment were as follows: M-CHAT, ADI- R, ADOS, DSM-IV criteria, cognitive assessment tool, and CARS. Results indicated the following points of interest:

1. Of the 376 children who were evaluated at age two, 142 were in the autistic disorder group, 101 in the PDD-NOS group, 95 in the non-ASD group, and 38 were in the no diagnosis group. Of the 230 children who were evaluated at age four, 104 were in the autistic disorder group, 44 in the PDD-NOS group, 34 in the non-ASD group, and 48 in the no diagnosis group.

2. There was 76% agreement between ASD diagnoses made by the CARS using the cut-off score of 30 and with those made with ADOS (88% agreement in 2 year old sample and 86 % agreement in 4 year old sample).

3. Greater than 70% agreement occurred between ASD diagnoses made by the CARS using an autism cut-off score of 30 and those based on DSM-IV criteria.

4. The results regarding the ASD cut-off in both the 2-year-old and 4-year-old sample were consistent with the cut-off of 25.5 suggesting that this cut-off score works effectively in preschool aged children with autism.

Santos, Barbosa, Pimentel, Lacerda, Balestro, Amato, Fernandes (2012) conducted a study on 28 individuals aged between 4 to 17 years of age. The participants underwent ASD diagnosis specialized service and were attending language therapy for 6 months. CARS and ABC was administered to the participants within few weeks of therapy and results were indicated as follows: a) Diagnosis of "non-autistic" in CARS were observed in 50% of the participants. ABC obtained "high" (33%) or "moderate" (67%) probability of autism for the participants classified as "non-autistic" in CARS. b) In CARS, 57% were diagnosed with High Functioning Autism (HFA), Asperger Syndrome (AS) or Semantic-Pragmatic Syndrome (SPS) respectively. Thirdly, in the cases where CARS indicated "slight-moderate autism",

ABC indicated low probability for autism with an agreement of only 30%. Hence, the authors concluded that CARS was sensible to identify autism by its cut-off score, lesser sensitive to identify Asperger's disorder and PDD-NOS and sensible to subjects with more characteristic behaviours.

The authors also indicated that verbal abilities may mask the severity of autism in CARS because of the fact that verbal individuals, regardless of their functional performance, usually had higher scores in the language domain of the ABC. The authors suggested that

although, the results of participants with "severe autism" were similar in CARS and ABC, however there was lesser agreement in the diagnosis of all severities of cases of ASD in both the protocols.

Nouf (2016) conducted a cross-sectional study was conducted at Saudi Arabia which included 40 children between 3-12 years of age and the participants were already diagnosed with autism using the ADOS scale. The subjects were independently assessed using both ATEC and CARS during the immediate clinical visit and the scores of both the tools were tabulated. Results indicated that CARS presented high sensitivity and specificity in distinguishing children with autism from other developmental disorders and learning disabilities and 70% of the participants experienced a regressive episode in their course of development after birth. According to the CARS scale, 21 participants (52.5%) had mild to moderate ASD and 19 participants (47.5%) had moderate to severe ASD. Although, authors indicated that there was no significant correlation between CARS and ATEC, however, ATEC scale gave a better understanding of health and systemic issues in ASD such as sleep problems, seizures, eating, gastrointestinal issues, hyperactivity, and self-injuries.

6. **Gilliam autism rating scale-2 (GARS-2)**

Gilliam autism rating scale-2 was developed by Gilliam and James (1995), designed for use by parents, teachers and professionals. GARS-2 is a norm referenced screening instrument designed for individuals between 3-22 years of age having behavioural problems symptomatic to autism. The GARS-2 gathers information about specific characteristics typically noted in children with autism spectrum disorders in three areas namely,

Stereotyped behaviours (items 1-14)

- Avoidance of eye-contact

- Stares at hands, objects, or items in the environment for at least 5 seconds

- Rapidly flicks fingers or hands in front of eyes for periods of 5 seconds or more

Communication (items 15-28)

- Repeats (echoes) words verbally or with signs

- Repetition of words out of context

- Repetition of words or phrases

- Speaks or signs with monotone or with dysrhythmic patterns

Social Interaction (items 29-42)

- Avoidance of eye-contact

- Vacant staring or reduced emotional response when praised, humoured, or entertained

- Resists to be touched by others

- Does not imitate other people when imitation is required or desirable, such as in games or learning activities

Criteria of autism is "Unlikely", "Possibly", and "Very Likely". On this tool, if the subject's Autism Index is 85 or above, the person is very likely autistic, and if the Autism Index is 70-84, the person is possibly autistic. Autism Indexes of 69 or less indicate that the person is unlikely to be autistic. The tool also contains a parental interview. Parents or caregivers describe child's behaviour and the questions are scored "yes" or "no". The first 10 questions are addressed with respect to delays and the next 15 questions are addressed with respect to abnormal functioning.

Luc Lecavalier (2005) conducted GARS on 284 (295 males and 47 females) subjects with ASD from 29 different school districts with mean age of 9.3 years. The GARS form were distributed among two hundred and forty-one parents and ninety five teachers. Comparisons of GARS and DSM-IV criteria for ASD were made during the process of the study.

Results revealed the following points of interest:

1. Researchers found more emphasis of items measuring stereotyped and repetitive use of language and motor behaviours and less emphasis in items measuring social communication.

2. Positive agreement were noticed between GARS and DSM-IV criteria of autism since GARS emphasised more on repetitive and stereotyped behaviours and criteria of social deficits were in consensus with the DSM-IV diagnosis.

3. Reliability analysis of GARS yielded fair inter-rater reliability.

4. Although GARS had several negative factors, authors postulated that the administration time and scoring of this instrument are relatively quick and simple.

5. Authors also suggested that GARS can be used as an indicator of severity of autism and can also be used to measure specific behaviours related to stereotyped and repetitive behaviours.

7. Indian scale for assessment of autism (ISAA)

ISAA is an Indian tool developed by National institute of mentally handicapped (NIMH, 2008) for children with autism in Indian context. The scale consists of 40 statements divided across 6 domains as follows:

- Social relationship and reciprocity: eye contact, social smile, aloofness, reaching to others, relation to people, solitary and repetitive play activities, taking turns in social play activities, and maintaining peer relationships.

- Emotional responsiveness: inappropriate emotional response, exaggerated emotions, self-stimulating emotions, response to fear of danger, and Excited or agitated for no apparent reason.

- Speech-language and communication: regression of speech, using non-verbal language, stereotyped and repetitive use of language, echolalic speech, infantile squeals or unusual noises, initiating or sustain conversation with others, jargon or meaningless words, pronoun reversals, and pragmatics of communication (real meaning)\

- Behaviour patterns: stereotyped and repetitive motor mannerisms, attachment to inanimate objects, hyperactivity, aggressive behaviour, temper tantrums, self-injurious behaviour, and insistence on sameness

- Sensory aspects: sensitivity to sensory stimuli, vacant staring, visual tracking, unusual vision, pain sensitivity, sensitivity of smell, and sensitivity to touch and taste.

- Cognitive component: attention and concentration, delay in response, unusual memory, and savant abilities.

The rating scale was administered on the informants of children with autism and responses obtained from the rating scale are scores on a 5 point rating scale namely: 1-never, 2-sometimes, 3- frequently, 4- mostly, and 5-always. The rating scale was administered on a three groups namely: Group1: Autism (400 children), Group 2: MR and others (322 children), and Group 3: Normal (400 children). Results from clinical validity indicated that mean scores of autism group were found to be significantly higher than other groups and hence, ISAA clearly differentiated autism from non-autism groups.

Comparisons total scores of ISAA were made with CARS and results revealed that there was a significant high correlation between the two tests. Sensitivity and specificity were also investigated between the two diagnostic tools and on the basis of CARS cut-off score of 30, ISAA cut-off score was estimated at 70 and cut-off scores of severity levels were computed as follows: 70-106: Mild autism, 107-153: Moderate autism and scores greater than 153 indicated severe autism.

Suravi and Prithi (2011) conducted ISAA on 35 patients diagnosed with autism between 2-29 years of age (mean age was 8.4 years) in the Child Guidance Clinic at Chandigarh, in children of autism. ISAA were rated on cases diagnosed with autism by a psychiatrist in using ICD 10 criteria from July 2005 to June 2009. Complete physical and neurological examination was done and exclusion criteria included: cases with hearing difficulty, visual defects, or neurological disorders were excluded.

A detailed history of prenatal and perinatal events and developmental milestones were taken and antenatal complications were present in 10 cases, of which three mothers had hypertension, one had diabetes mellitus, and foetal distress was present in six cases. Post-natal history revealed that after birth, complications were present in nine cases. Seizures were present in one case, low birth weight in two cases, delayed cry in four, and jaundice in two cases. Delayed milestones were present in 19 cases. Mental retardation was noted in 18 cases, whereas epilepsy was present in only three cases.

Authors postulated that ISAA was quick and easy to administer. There was difficulty in scoring the items grouped under emotional responsiveness category. The overall sample scored within the range of mild-to-moderate autism, with 12 cases in mild category and 23 in moderate category. Majority (46%) of the patients had ISAA scores between 106-123 followed by another 31% had scores between 89-105.

A symptom severity score of 70 in ISAA corresponds to 40% disability; 71-88 (50%), 89-105 (60%), 106-123 (70%), 124-140 (80%), 141-158 (90%), whereas >158 (100%) disability. The subgroup of mild autism (70-106) had two different disability scores and the group with moderate autism (107-153) has different disability scores.

A score of 153 meant severe autism, but 100% disability benefits can be expected only if disability score is >158. Hence, the authors concluded that the scale is useful and feasible for use in routine clinical settings. The researchers also suggested that the use of the scale would lead the way for addressing the long-standing concerns about identification and quantification of autism and to rate the associated disability in Indian population

Satabdi, Pramod, Tripish, Vishwajit, Nimgaonkar and Smita (2015) conducted another study of ISAA at RML Hospital, New Delhi. Children visiting the outpatient departments were evaluated in detail and assigned clinical diagnoses of developmental disabilities based on ICD 10. Probable participants were referred to the investigators by their therapists after the consent with the parents. The following groups were included in the study namely: Autistic Disorder (AD); Intellectual Disability (ID); Attention Deficit Hyperactivity Disorder (ADHD); Other Psychiatric disorders (PD) and children without psychiatric disorders (controls). The AD group included children with varied levels of IQ scores. The 'other psychiatric disorders' (PD) group included Conduct disorder, Schizophrenia, Bipolar disorder, Depression, Oppositional Defiant Disorder (ODD) and Selective Mutism. Children with multiple psychiatric diagnoses were excluded.

Children were recruited from three sites, namely Postgraduate Institute of Medical Education and Research and RML hospital Delhi (all the groups), the National Institute for Mentally Handicapped (NIMH) (ID group), and GB Pant Hospital, New Delhi (other diagnostic groups). Approximately 40% of the participants included in the earlier pilot study were included in the final study.

Results indicated several points of interest:

1. There was a significant correlation between the CARS and ISAA total scores (r = 0.73), but the cut-off points for the CARS differed for Indian children compared to those on the western forefront. The cut-off points of CARS was 45 for the in their study which was higher as compared to the suggested cut-off score of 30 for the diagnosis of autism. authors also postulated that total scores obtained in ISAA differentiated between the other diagnostic groups.

2. Originally, the CARS was considered as a total score and items regarding special skills or savant abilities were not included in the CARS, unlike the ISAA. However, the CARS score was significantly correlated with all the individual domains of the ISAA with the exception of the cognitive component.

3. The mean ISAA score in the ADHD group were higher than the ID group and children in the ADHD group received relatively high scores for hyperactivity, aggressive behaviour, temper-tantrums, self-injurious behaviour, insensitive to pain and poor peer relations.

4. Scores on other domains such as social relationships and reciprocity or emotional responsiveness in ADHD group were much lower than the ratings among the children with AD.

5. Generally, males were over-represented in sample of the study suggesting higher prevalence of male children with AD, ADHD and other psychiatric disorders.

6. Therefore, authors postulated that ISAA is sensitive to diagnose autism with other developmental disorders.

A recent hospital-based study by Sharmila, Manoj, Satinder, Satabdi, and Smitha; 2015 was conducted Medical Colleges from different parts of Northern India. The participants recruited for the study were children considered at high risk of autism between 2-9 years of age. The parental concerns of children with autism were addressed as follows:

- Delay in the developmental milestones,

- Delay or inappropriate cognition,

- Speech delay

- Inadequate social communication

- Abnormal behaviour or play

A total of 90 children (63 males) with mean age of 4.5 years and the participants from the middle/lower socio-economic backgrounds were considered from which the conditions such as hearing impairment, neurological impairment, previously diagnosed PDD or attention deficit hyperactivity disorder were excluded from the study. An informed consent were collected from all the parents/caregivers of the participants.

The following assessments were done:

- Comprehensive language assessment (standardized) was administered on the initial phases of the study which included parental interview and clinical observation of the child's behaviour.

- Cognitive tools were administered to estimate the developmental quotient (DQ) and derived intelligence quotient (IQ) of the participants.

- Vineland Adaptive Behavior Scale (VABS II) was administered to assess adaptive and maladaptive behaviours of the subjects.

- DSM IV diagnostic criteria for the diagnosis of ASD were administered.

- CARS for assessing severity levels of autism were administered.

- ISAA tool were administered during the next visit (within 3 months) of the study period.

The study yielded the following results:

- 77 participants were diagnosed with PDD, and others included participants with isolated Global Developmental Delay, isolated Intellectual delay, syndromic, ADHD, and behavioural problems.

- CARS scores indicated "No autism" in 12, "Mild to moderate autism" in 16 and "Severe autism" in 62 participants respectively.

- Co-morbid GDD/ID were observed in 87% of the children with PDD; moderate cognitive impairment in children with Mild to moderate autism, and severe cognitive impairment in severe autism.

- ISAA cut-off score of 70 (diagnostic of autism) was observed in 76 children, with rating severity rating of mild in 53%, and moderate in 46 % of children with autism.

- Level of agreement of ISAA and CARS were low according to Kappa's coefficient (0.14)

Hence, the authors concluded that the study had several negative factors such as: younger participant age (study objective), smaller sample size, lower socio-economic and literacy levels (hospital patient profile), undisclosed diagnosis, all the rating scales were administered by a paediatrician, and use of comprehensive assessment as the reference standard instead of only CARS.

To summarize the review of existing literature, it suggests that a systematic assessment of severity of autism varies with children at different settings. There are lack of studies investigating the severity levels and differentially diagnosing children with ASD at different age groups in Indian context. Hence, the present developed severity rating scale can be designed to focus on the severity levels and can be used to monitor the progress of the functional levels of independence of Indian children with autism.

CHAPTER-3

METHOD

"Change the environment and behaviours will change" - Lana David, 2017

The present study aims to develop and implement the severity rating scale in Indian context for pre-school children with Autism Spectrum Disorders.

The study was carried out in four phases as follows:

Phase 1: Development of Severity Rating scale

Phase 2: Framing the scoring scale

Phase 3: Administering the developed severity rating scale to measure inter-rater reliability

Phase 4: Administering the developed severity rating scale on a population of ASD to measure the sensitivity of the developed scale

Phase 1- Development of the severity rating scale

The severity rating scale consists of a total of 100 items belonging to those domains will be adapted from ASD assessment tools such as Childhood Autism Rating Scale (Schopler, Reichler & Renner, 1988), Autism Diagnostic Observation Schedule (Lord, Rutter, Dilavore & Risi, 2001), Autism Diagnostic Interview - Revised (Rutter, Le Counter & Lord, 2003) and Autism Treatment Evaluation Checklist (Rimland & Edelson, 1999). The items which are sensitive enough to assess the severity level of children with Autism will be adapted from the above mentioned ASD assessment tools. The domains of the Severity rating scale are as follows:

1. Speech and language skills

2. Cognitive functions

3. Social communication skills

4. Medical and sensory issues

5. Self-help skills

The items of the rating scale were categorized as mentioned in table 3.1.

Table 3.1. *Domains and items categorized*

Sl no	Domains	Items categorized
A.	**Speech and language skills**	Eye contact Pointing/Gestures Body language Comprehension of Commands, concepts, "wh" questions, time, and conversations Naming Vocabulary Mean length of utterance Answering to open ended and to closed ended questions Questioning Topic initiation Topic maintenance Echolalia
2.	**Cognitive functions**	Object permanence, Use of gestures (Conventional and unconventional) Joint attention Imitation Cause and effect Matching Working memory Association Categorization Reasoning Sequencing
3.	**Social communicative skills**	Social interaction Peer interaction Social smile Acknowledgement/Sharing Emotional expression Empathy Preoccupied interests General behaviour Self-stimulatory behaviour Self-injurious behaviour Solitary play Pretend play/ Symbolic play Interaction during play Flexibility during play Turn taking Structured play Group interaction

D.	Medical and sensory issues	Seizures
	A. Medical issues	Gross motor abnormalities
		Fine motor abnormalities
		Genetic conditions
		Family history
		Sleep
		Abdominal issues
	B. Sensory issues	Hyposensitivity and hypersensitivity with respect to the following:
		Auditory
		Visual
		Tactile
		Taste
		Smell
		Vestibular
E.	Self-Help skills	Self-help skills pertaining to the following:
		Feeding
		Toileting
		Oral hygiene
		Personal hygiene

The items categorized as shown in table 3.1 were formulated into 100 statements across the five domains. The severity rating scale was developed to be administered to the target population of autism spectrum disorders.

For example: Domain C- social communication skills

Item: Social interaction

Statement: The child is generally withdrawn/aloof

Item: Peer interaction

Statement: Less interested to interact with peers at development level

The developed severity rating scale was then given to five experienced Speech Language pathologists for the process of validation.

Process of validation of the severity rating scale

Initially, 150 statements were framed across 5 domains and the experienced Speech Language Pathologists were asked to judge these adapted items with respect to its sensitivity and rate by marking each item as: "Slightly appropriate (25%)" "Moderately appropriate (50%), "Mostly appropriate (75%)", and "Appropriate (100%)".The items with 60 % of agreement across three out of five judges were included in the tool whereas the items rated as "moderately appropriate" and "slightly appropriate" by three out of five judges were excluded from the tool. The final version of the rating scale were re-structured and consisted of 100 statements divided across 5 domains.

Pilot study

Initially, a pilot study of the severity rating scale were administered on twelve parents/caregivers of children with ASD in the age range of 2-8 years of age. The participants included different types of ASD such as autism, PDD-NOS, Rett's syndrome, and high functioning autism. The parents were clearly instructed about the nature of the statements addressed in the rating scale and provide appropriate information. The parents/caregivers were also asked to provide to provide information regarding additional autistic behaviours and were included in the final questionnaire. The participants selected for the pilot study were included in the final study, however, the participants with Rett's syndrome and high functioning autism were excluded for the final study due to the incongruent nature of the scores.

Final field study: The final study consisted of sixty participants of ASD and the details participants are as follows:

Participants

Sixty children diagnosed with Autism at special clinic unit for Autism Spectrum Disorders at All India Institute of Speech and Hearing (AIISH, Mysore) participated in the study. The participants mainly included children with autism. The age-range of the participants were between 2-8 years of age.

Inclusion criteria

The following criteria was followed for the inclusion of participants for the present study.

1. Participants underwent basic language evaluation by using routine screening tests and diagnostic tests to profile the language and communication skills by qualified Speech-Language pathologists. Basic clinical observations of the behaviours with respect to autism were made mandatory prior to the process of assessment of ASD.

2. The diagnosis of autism was made using the standardized test named Differential diagnosis checklist for Autism Spectrum Disorders (DDC-ASD) (Chengappa et al. 2007).

3. The participants attending therapy at special clinics unit for ASD and speech –language therapy unit at AIISH, Mysore were considered for the study.

Language specificity: There was no language specificity. The participants included speakers of Kannada, Tamil, Malayalam, Telugu, Hindi, and English.

Cultural, Socioeconomic, and Family background: Participants included for the study comprised of people from different regions of Karnataka, Tamil Nadu, Kerala, Andhra Pradesh, and parts of North India from various cultural backgrounds. The participants belonging to both urban and rural communities were considered for the study. Majority of the family pattern consisted of nuclear families and few of them belonged to joint families.

Language assessment: Basic language profiling and assessment tools such as Receptive Expressive Emergent Language Scale (REELS) (Bzoch & League, 1971) and 3-Dimensional Language acquisition test (3D-LAT) (Geetha Herlekar, 1986) were used as language and communication measures and majority of the participants were found to have delayed speech and language skills, inadequate speech and language, and few of the participants exhibited intellectual deficits.

Language Intervention: During the time of administering the rating scale, all the participants were receiving speech and language therapy since 2 months. Language intervention included setting up goals based on assessment data and core deficits of ASD and focusing on initiating spontaneous functional communication, engaging in reciprocal communication interactions, using a multimodal communication system (e.g., spoken language, gestures, sign language, picture communication, written language), and improving parent-child interactions. The children are either mainstreamed, schooled or unschooled.

Procedure

The severity rating scale is a parent/caregiver self-report measure and the statements listed in the rating scale across each domain were administered based on parental interview of children with ASD. An informed consent was taken from the parents/caregivers of children with ASD prior to the administration of the rating scale. Ethical concerns were taken into consideration for the selection of the participants for the study.

- The data collection of the participants was done in a quiet room without any distractions. Preferably a play area/therapy room was preferred to also monitor and observe the child's play behaviour and parent-child interaction.

- Initially rapport was built with the child and informal parental interview were administered to the parents prior to the actual administration of the rating scale. The parents were asked the introductory questions about the child's communication and general behaviour

- The parents were given a brief description on the rating scale and the nature of the statements asked and were given clear instructions to provide appropriate descriptions about the same. The parents/caregivers were asked to give a score of "always", "frequently", "intermittently", "rarely", and "never" based on the statements asked.

- The responses were noted clearly on the basis of parental interview and observing the child's behaviour whenever necessary

- To the statements which were unclear to understand to the parents/caregivers, examples were provided for the same that were appropriate to the target statement.

- The duration of the administration of the tool was approximately forty-five minutes to one hour ten minutes including the necessary procedures to be taken for the parental consent, informal interview, and rapport building with the child.

Phase 2 – Framing a scoring scale for the five domains

The scale was administered to 60 children with Autism. All the items from each domain were rated on this above mentioned four point rating scale as follows:

- 1 - No autism

- 2 – Mild autism

- 3 – Moderate autism

- 4 – Severe autism

With respect to the average domain scores, cut off scores were given to discriminate severity levels. The scores obtained from 60 participants with ASD were divided to three age groups as follows:

Group I (Lower): 2 - 4 Years

Group II (Middle): 4 - 6 Years

Group III (Higher): 6 - 8 Years

Group I consisted of 30 participants, Group II consisted of 18 participants and Group III consisted of 12 participants. This grouping was done for the purpose of convenience to compare and discuss the results.

Phase 3 -Administering the developed severity rating scale for measuring inter-rater reliability

The developed severity rating scale were administered by two master's degree holders in Speech Language Pathology on one half of the sample within two weeks (1 week for each) and the Inter-rater reliability will be assessed. Both the raters will be informed about the guidelines to administer the developed severity rating scale for children with Autism (including the scoring guidelines).

Phase 4 – Administering the developed severity rating scale on a population of ASD to measure the sensitivity of the developed scale

The developed severity rating scale were administered to a group of 30 children with ASD within the total participants considered. The scores of the severity levels of the domains of speech and language skills, cognitive functions, social communication skills, medical and sensory issues, and self -help skills were noted. Then, the sensitivity of the developed severity rating scale were measured by comparing and correlating it with Childhood Autism Rating Scale (Schopler et al. 1994).

Statistical analysis

The scores obtained from three age-groups of sixty participants were statistically analyzed using SPSS version 21 software. The scores of 100 statements across five domains and the total scores obtained for all the domains were analyzed.

1. Descriptive statistics was used to obtain mean, median and standard deviation of scores obtained on the severity rating scale. Cut-off scores of the severity levels of autism as "normal", "mild", "moderate", and "severe" will be obtained using the mean scores and standard deviation.

2. Cronbach's alpha was used to determine the inter-rater reliability.

3. Spearman's correlation was done to analyze the sensitivity of the developed severity rating scale with Childhood Autism rating scale.

4. As the normality was not observed consistently for all the five domains across the three age-groups, non-parametric tests were performed and the results obtained will be discussed in the next chapter.

CHAPTER-4

RESULTS

"Children with Autism are visual thinkers and not language-based thinkers"-Temple

Grandlin, 2010

The current study aimed at developing and implementing the severity rating scale for children with Autism Spectrum Disorders aged between 2-8 years of age. The severity rating scale consisted of a total of 100 statements with 20 statements across the 5 domains. The domains were divided as follows: Speech and Language skills, Cognitive functions, Social communication skills, Medical and sensory issues and Self-help skills. The participants were divided into three age groups namely: Group I- 2-4 years, Group II- 4-6 years, and Group III- 6-8 years of age respectively. The severity rating scale were administered on 60 participants by interviewing the parents and monitoring the behaviours of children with ASD and the responses were noted on the basis of a "5" point rating scale namely: "5"- Always, "4"- Frequently, "3"- Intermittently, "2"- Rarely, and "1"- Never respectively. Statistical analysis of the scores obtained from three age-groups of sixty participants were done using SPSS version 21 software. The scores of 100 statements across five domains and the total scores obtained for all the domains were analyzed. The statistical analysis was done in the following steps:

1. 1.1 Descriptive statistics to obtain mean, median and standard deviation of scores obtained on the severity rating scale.

   1.2 Cut-off scores of the severity levels of autism as "normal", "mild", "moderate", and "severe"

2. Inter-rater reliability of the developed severity rating scale across the domains.

3. Analysis of the sensitivity of the developed severity rating scale with Childhood Autism rating scale (CARS).

1. 1.1. Comparison of overall mean, median, and standard deviation across the domains:

Descriptive statistics was compiled for all the 60 participants across the five domains of the severity rating scale. As represented in table 4.1, it was observed that the overall mean scores and standard deviation (SD) of all the five domains was 270.85 and 53.6 respectively. The mean scores of the five domains speech and language skills, cognitive functions, social communication skills, medical and sensory issues, and self-help skills were 69.78, 69.36, 65, 31.41, and 34.28 respectively.

For better understanding, figures 4.1 represents the mean scores obtained across the five domains. X- axis denotes the five domains namely: Speech and language skills, cognitive functions, social communication skills, medical and sensory issues, and self-help skills, and Y-axis represents the mean scores of all the five domains. It can be noticed that the mean scores were higher in the domains speech and language skills, cognitive functions, and social communication skills in all the participants as compared to medical and sensory issues and self-help skills. The mean scores of domains across the age groups were in the trend as follows:

Speech and language skills > Cognitive functions > Social communication skills > Self-help skills > Medical and sensory issues.

Table 4.1: *Mean, median, and standard deviation (SD) of all the domains*

Domains	Mean	Median	SD
Speech and Language skills	69.78	74.5	14.17
Cognitive functions	69.36	72.5	14.65
Social communication skills	65	65.5	12.48
Medical and Sensory issues	31.41	30	8.7
Self-help skills	34.28	33	11.25
Total	270.85	277.5	53.6
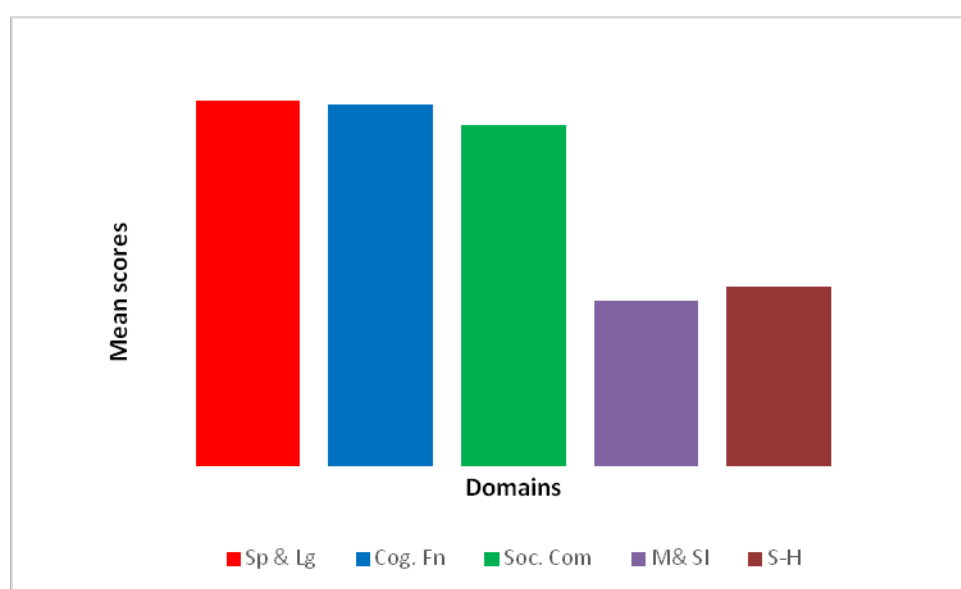
Figure 4.1: Mean scores of all the five domains

1. 1.2. Comparison of mean, median, and standard deviation (SD) across the age groups:

Descriptive statistics was used to obtain mean, median and standard deviation of scores was obtained across the age groups. The total mean, median, and SD scores across the three age groups are compiled in table 4.2 for all the domains of the severity rating scale. The mean scores obtained by the participants for all the 100 statements in the Group I, II, and III are 284.7, 276.6, and 227 respectively. On observation, the mean scores were maximum in Group I (2-4 years) and minimum in Group III (6-8 years) respectively.

Figure 4.2 gives a better clarity of a graphical representation of the mean scores across the age groups. X- axis represents the three age groups namely: Group 1: 2-4 years, Group 2: 4-6 years, and Group 3: 6-8 years; and Y- axis represents mean scores of all the five domains. It can be observed that the overall mean scores are decreasing with increase in age.

Table 4.2: *Mean, Median & SD scores for all the three age groups*

	N	Mean	Median	SD
Group I (2-4 years)	30	284.9	291.5	43
Group II (4-6 years)	18	276.6	283.5	54.4
Group III (6-8 years)	12	227.08	205	56.7
Total	60	263.2	258.4	50.4
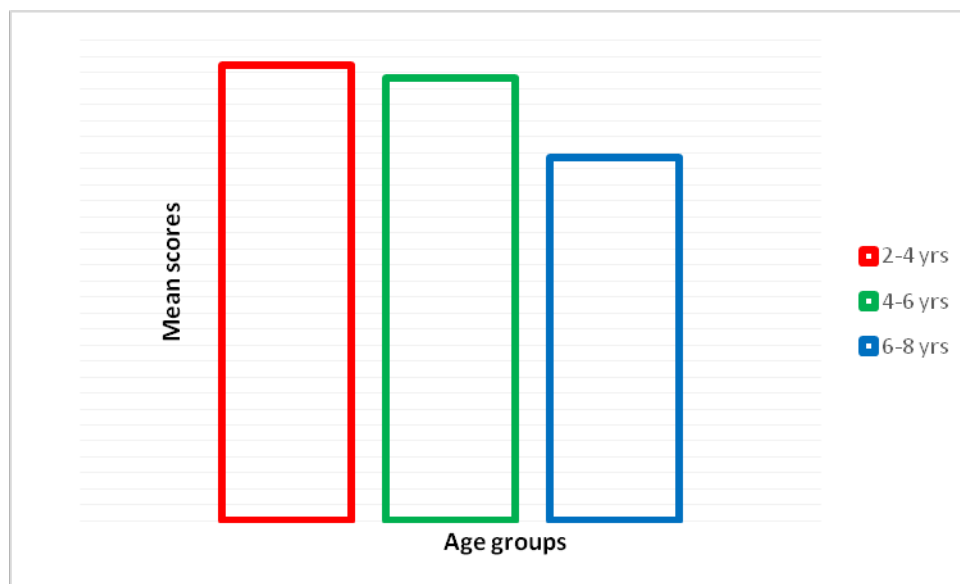
Figure 4.2: Mean scores across age group

b. Cut-off scores for severity levels of autism:

The cut-off levels of autism as "mild", "moderate", and "severe" was tabulated with respect to the levels obtained based on the total scores across all the five domains such as Speech and language skills, Cognitive functions, Social communication skills, Medical and

sensory issues and Self-help skills respectively. The cut-off scores of all the five domains were calculated based on minimum, maximum, mean, and standard deviation of the total scores. As observed from table 4.3, the cut-off score was estimated as 161 and scores ranging from cut-off score to mean (161-270.85) was estimated as "Mild Autism", scores ranging from mean to mean +1SD (270.85- 324.45) was estimated as "Moderate Autism", and scores greater than 324.45 was above mean +SD (> 324.45) was estimated as "Severe Autism."

Table 4.3: *Cut-off scores and severity levels of autism*

SRS scores	Degree of Autism
< 161	No Autism
161 to 270.85	Mild Autism
270.85 -324.45	Moderate Autism
> 324.45	Severe Autism

Frequency of the responses were tabulated (table 3.4) across all the 60 participants and the levels of autism was also estimated based on the frequency of occurrence of the responses obtained in the rating scale as 5-"always", 4-"frequently", 3-"intermittently", 2-"rarely", and 1-"never". As observed in table 4.4, the frequency of responses were strongly correlated to the total scores of the severity rating scale across all the participants as follows:

1. **For mild levels of autism:** The responses obtained in 28 participants (participants 1, 5, 10, 15, 19, 20, 22, 23, 25, 26, 28, 37, 38, 42, 44, 45, 46, 47, 48, 50, 52, 53, 55, 56, 57, 58, 59, and 60) were in agreement with the total scores (257, 271, 263, 228, 254, 195, 213, 229, 257, 222, 230, 264, 219, 165, 262, 195, 228, 267, 222, 190, 205, 253, 205, 244, 192, 187, 162, and 172) of cut-off levels of mild autism.

2. **For moderate levels of autism:** The responses obtained in 22 participants (participants 3,4, 6, 7, 8, 9, 11, 16, 17, 18, 24, 27, 29, 30, 31, 32, 33, 35, 39, 40, 49, and 51) were in agreement with the total scores (291, 308, 302, 311, 291, 274, 313, 319, 292, 283, 297, 314, 293, 312, 281, 286, 318, 290, 310, 293, 274, and 289) of cut-off levels moderate autism.

3. **For severe levels of autism:** The responses obtained in 10 participants (2, 12, 13, 14, 21, 34, 36, 41, 43, and 54) were in agreement with the total scores (345, 365, 327, 345, 345, 353, 344, 338, 344, and 353) of cut-off levels of severe autism.

Table 4.4: *Percentage of occurrence of scores and levels based on total scores*

Subjects	Frequency of responses (in %)					Total scores (Mean $\pm$ SD)	Severity levels
	1	2	3	4	5		
1	37	7	31	9	15	257	Mild
2	21	7	11	29	32	345	Severe
3	28	10	21	25	16	291	Moderate
4	29	6	10	38	17	308	Moderate
5	33	9	27	15	16	271	Mild
6	28	4	27	20	21	302	Moderate
7	28	8	10	24	30	311	Moderate
8	32	4	21	27	16	291	Moderate
9	27	11	38	9	15	274	Moderate
10	24	11	43	22	0	263	Mild
11	21	8	24	31	16	313	Moderate
12	16	8	14	19	43	365	Severe
13	25	8	7	35	25	327	Severe
14	20	9	6	30	35	345	Severe
15	42	11	30	11	6	228	Mild
16	38	4	8	28	22	319	Moderate
17	26	6	17	25	26	292	Moderate
18	32	10	23	13	22	283	Moderate
19	26	14	41	18	1	254	Mild
20	36	39	19	6	0	195	Mild
21	20	9	6	30	35	345	Severe
22	32	28	34	6	0	213	Mild
23	37	15	35	7	6	229	Mild
24	23	12	24	25	16	297	Moderate
25	30	14	34	13	9	257	Mild
26	26	9	22	32	11	222	Mild
27	24	5	21	33	17	314	Moderate
28	27	9	8	37	19	230	Mild
29	30	24	36	8	2	293	Moderate

30	42	11	33	11	3	312	Moderate
31	35	7	22	14	22	281	Moderate
32	34	6	16	28	16	286	Moderate
33	23	6	21	30	20	318	Moderate
34	16	3	30	14	37	353	Severe
35	34	5	14	31	16	290	Moderate
36	21	8	11	26	34	344	Severe
37	38	6	20	26	10	264	Mild
38	37	10	49	4	0	219	Mild
39	38	3	8	13	38	310	Moderate
40	24	17	14	32	13	293	Moderate
41	23	6	18	10	43	338	Severe
42	57	17	23	3	0	165	Mild
43	1	31	19	27	22	344	Severe
44	37	7	22	25	9	262	Mild
45	50	8	39	3	0	195	Mild
46	34	15	42	9	0	228	Mild
47	36	9	23	16	16	267	Mild
48	42	13	26	19	0	222	Mild
49	36	7	21	19	17	274	Moderate
50	50	10	40	0	0	190	Mild
51	20	10	33	35	2	289	Moderate
52	41	16	40	3	0	205	Mild
53	37	6	33	17	7	253	Mild
54	19	2	18	29	32	353	Severe
55	44	8	38	9	1	205	Mild
56	41	2	31	24	2	244	Mild
57	50	14	31	4	1	192	Mild
58	53	15	24	8	0	187	Mild
59	67	10	20	1	2	162	Mild
60	56	17	26	1	0	172	Mild

2. Inter-rater reliability of the developed severity rating scale:

Inter-rater reliability was calculated on all the domains using Cronbach's alpha reliability coefficient (table 4.5) between the two different raters who independently administered the severity rating scale on one-fifth (20%) of the sample (12 participants). High degree of inter-rater reliability between the two raters was observed in all the domains namely: Speech and language skills (α = .991), Cognitive functions (α = .995), Social communication functions (α = .995), Medical and sensory issues (α = .981), Self-help skills (α = .990), and global score of .996 were obtained respectively. Therefore, the results suggested that the agreement between the two raters were good.

Table 4.5: *Inter-rater reliability coefficient on severity rating scale (SRS)*

Domains	Cronbach's alpha
Speech and Language skills	**.991**
Cognitive functions	**.995**
Social communication skills	**.995**
Medical and Sensory issues	**.981**
Self-Help skills	**.990**
Total	**.996**

3. Sensitivity of the developed severity rating scale with Childhood Autism rating scale (CARS).

Sensitivity of the developed severity rating scale was analyzed by comparing it with a standardized rating scale named CARS. CARS was administered along with SRS to 30 participants with ASD (one-half of the sample) between 2-8 years of age. Table 4.6 represents the total scores (Mean$\pm SD$) of SRS and CARS and correlation was done using Spearman's product moment correlation. The results indicated a high positive correlation of $r_s =.832$ at $p<0.001$ level of significance. Percentage of scores of SRS and CARS were also computed (in table 4.6) and reliability between the two rating scales was checked using Cronbach's alpha coefficient. The results indicated a good reliability of $\alpha =.765$ between the two rating scales. From the above results, it suggests that SRS is sensitive as CARS and can be used to diagnose children with ASD.

Table 4.6: *Total scores and percentage of scores of SRS and CARS*

Subjects	Total scores (Mean $\pm$ SD)		Percentage of scores (%)	
	SRS	**CARS**	**SRS**	**CARS**
1	257	33	51.40	55.00
2	291	36	58.20	60.00
3	311	36	62.20	60.00
4	291	36	58.20	60.00
5	319	36.5	63.80	60.83
6	283	31	56.60	51.67
7	254	33	50.80	55.00
8	213	30	42.60	50.00
9	297	36	59.40	60.00
10	257	35	51.40	58.33
11	293	36	58.60	60.00
12	230	30	46.00	50.00
13	318	36.5	63.60	60.83
14	290	34	58.00	56.67
15	219	30	43.80	50.00
16	310	35	62.00	58.33
17	262	32	52.40	53.33
18	228	30	45.60	50.00
19	267	34	53.40	56.67
20	222	36	44.40	60.00
21	274	32	54.80	53.33
22	190	30	38.00	50.00
23	289	34	57.80	56.67
24	205	31	41.00	51.67
25	258	32	51.60	53.33
26	205	31	41.00	51.67
27	244	32	48.80	53.33
28	192	31	38.40	51.67
29	187	30	37.40	50.00
30	172	30	34.40	50.00

CHAPTER-5
DISCUSSION
"Behaviour is communication."-Lana David, 2017

The present study was aimed at developing a severity rating scale (SRS) for children with Autism spectrum disorders (ASD). The rating scale consisted of a total of 100 statements divided across five domains namely: speech and language skills, cognitive functions, social communication skills, medical and sensory issues, and self-help skills. The scale was administered to 60 subjects with ASD between 2-8 years of age who were divided into three age groups such as: Group 1: 2-4 years, Group 2: 4-6 years, and Group 3: 6-8 years respectively. The administration of the rating scale was mainly based on parental interview and clinical observation of the behaviours and the responses were scored based on the degree and extent of behaviours namely: "5- always", "4- frequently", "3- intermittently", "2- rarely", and "never." The mean scores were calculated across all the domains and age-groups and cut-off scores were established. The cut-off scores were categorized into a four point rating scale of severity of autism such as: 1- No autism, 2- Mild Autism, 3- Moderate autism, and 4- Severe autism. The sensitivity of the developed SRS was studied by comparing it with childhood autism rating scale (CARS). The results of the present study stipulated several points of interest.

First, it was observed that the absolute mean scores were higher in speech and language skills, and social communication skills in all the participants. According to DSM-IV (American Psychiatric Association, 2000) children with ASD have significant deficits reciprocal social interaction, and social communication. The similar findings can be supported to the observations of Smitha (2008) who stated that the results of Indian scale for assessment of autism (ISAA) suggested maximum mean scores in the domains of social relationship and reciprocity, emotional responsiveness, and speech-language communication

as compared to other domains. New findings in the current study also indicated higher mean scores in the cognitive linguistic skills in all the participants with ASD. The factors which contributed to higher mean scores in the cognitive domain were inconsistency or delay in the listening response, more use of unconventional gestures in which majority of children did not point or depended on parents to request for action, impaired joint attention, deficits in working memory, and reduced reasoning skills.

Secondly, the absolute mean scores decreased with increase in age. Maximum mean scores were observed in group 1 and followed by decrease in the mean scores in group 2 and group 3. Hence, the decrease in the scores contribute to the improvement of symptoms of autism with increase in age. The factors which resulted in the maximum overall scores in group 1 (2-4 years) was because of the fact that during the administration of rating scale, these children demonstrated major signs of deficits in use of non-verbal behaviours (eye contact, gestures, and body language), difficulty to understand basic commands and recognizing common names and objects, speech was characterized by absolute mutism or meaningless jargon utterances, inconsistency in listening response, no pointing, aloofness and withdrawal responses in reciprocal social interaction, restlessness, sensory issues and severe deficits in basic toilet skills and feeding skills. Furthermore, group 2 (4-6 years) also indicated had similar signs of autism as group 1, however, some of these children were using single word or fewer utterances, had parallel play behaviours, and also had basic self -feeding skills and toilet skills.

The findings are supported to the study of Colby et. al., (2010) who administered Childhood autism rating scale (CARS) in 376 children with ASD of 2 years of age and 230 children with ASD of 4 years of age. Results indicated that 2-year old children demonstrated higher mean scores of CARS (35.1) as compared to 4 year old children (34.2) with ASD.

Conversely, Group 3 (6-8) had minimum absolute mean scores as compared to group 1. Although, majority of these participants had basic language skills and cognitive skills (use of descriptives in phrases, intact working memory) which contributed to the improvement in the overall mean scores. On the other hand, these children demonstrated major signs of deficits in socio-pragmatic skills (turn taking, initiating conversation), impulsivity, preoccupied interests, emotional instability (aggressive behaviour and lack of empathy), attention deficits, learning difficulties (reading, writing) and hesitation in group interactions that postulated some points of interest in the present study.

Thirdly, the cut-off levels of severity of autism were computed based on the total mean scores obtained in all five domains. The cut-off score was determined as 161 and scores ranging from cut-off score to mean (161-270.85) was estimated as "Mild Autism", scores ranging from mean to mean +1SD (270.85- 324.45) was estimated as "Moderate Autism", and scores greater than 324.45 was above mean +1SD (> 324.45) was estimated as "Severe Autism." The present study is in consensus to Smitha (2008) study, comparisons of cut-off scores ISAA and CARS were made on 400 children with autism. Cut-off score of ISAA was determined at 70 and the scores ranging from cut-off score to mean score (70-106) was determined as "mild autism"; scores ranging from mean score +2SD (107-153) were determined as "moderate autism"; and the scores ranging above mean score +2 SD were determined as "severe autism."

There are no studies that determine the comparisons of the frequency of responses obtained with the total scores obtained across the domains in the severity rating scales. Hence, in the present study following observations were made:

1. Participants having maximum scores in the "never" responses were observed in 70% (19/28) of the subjects and minimum scores in the "always" responses were observed in 75% (21/28) of the subjects, and the maximum scores of combination of "never" and "rarely" responses were observed in 90% (26/28) of the subjects were attributed to the levels of mild autism.

2. The maximum scores of combination of "intermittently" and "frequently" responses were observed in 80% (18/22) of the subjects were attributed to the levels of moderate autism.

3. The maximum scores of "severe" response category were observed in 80% (8/10) of the subjects were attributed to levels of severe autism. Hence, the frequency of the responses can be considered as good predictors to correlate with the mean scores and helps in determining the better diagnosis for severity levels of ASD

Finally, inter-rater reliability indicated a good agreement between the two raters with a reliability quotient of .996. Similarly, on testing the feasibility of using the SRS when comparing it with CARS, results indicated a good reliability of .765 and highly positive correlation of .823 at $p<0.001$ level of significance between the two rating scales. Hence, it can be concluded that the developed SRS is sensitive as CARS and can be used to determine severity levels of autism.

Satabdi et al., (2015) suggested the cut-off points for the CARS differed for Indian children compared to those children in the western forefront. The present study also yielded similar results in support to Satabdi et al., 2015, which revealed that CARS cut-off score was 30 which differed from developed SRS which yielded a cut-off score of 161 for the diagnosis of autism. Despite the fact of different cut off points, the total scores of both the tools yielded significant high correlation across all the domains considered.

Furthermore, the present rating scale has an additional domain named self-help skills to assess the abilities of children with ASD in five areas namely: feeding skills, toileting skills, oral hygiene, personal hygiene, and grooming respectively. Results from the present study indicated that 34.28% of the participants had significant issues in adaptive functioning across all the age groups. The feeding behaviours displayed by children with autism were predominantly associated with difficulties in eating/drinking, food refusal, food selectivity, preferences to spicy foods and/or bland foods, clumsiness during the process of feeding, fine motor deficits, dietary issues, and gastrointestinal issues such as constipation. The observations made from the present study supports the evidence provided by Ledford (2006) who indicated that children with autism display higher incidence of feeding problems such as greater food refusal, preference of specific utensils for feeding, preference of a specific food presentation, acceptance of specific food textures, and selectivity of narrower variety of food. Wakefield (2002) suggested that children with autism may have an increased prevalence of gastrointestinal symptoms, including constipation, chronic loose stools, abdominal pain, and gaseousness/bloating. Some investigators have reported a significant association between autism and chronic inflammatory intestinal disease. In the present study, 10% of the participants between 6-8 years of age had a history of constipation and were recommended for gluten free dietary modifications.

Lorraine (2014) discussed toileting issues in children with autism such as difficulties in learning to use the toilet, communicating the need to use the toilet, learning to use different toilets, and sensory and environmental challenges. 20% of the children with autism between 2-4 years of age displayed difficulties in learning to use toilet, and communication for the need to use the toilet and 5% of the participants displayed sensory sensitivities such as fear and anxiety to use the toilet. Wheeler (2007) attributed the factors leading to difficulties with learning to use the toilet to confusions in language and communication used in the child's environment, and social motivational factors.

Hence, the rating scale developed in the present study consisted of the statements that were designed in specific to the core features of children with autism in Indian context. Hence, it can be suggested that the statements in specific to core features can be considered preferable for determining severity levels. The current rating scale is in consensus with ISAA (NIMH, 2008) in Indian context which consisted of 40 statements designed specifically to address the core features of autism under 7 domains. Results from ISAA suggested better diagnostic categorization (as mild, moderate, and severe autism) as compared to other rating scales. The statements addressed in the present developed severity rating scale (SRS) gives a more elaborate and comprehensive description with appropriate examples of the core behaviours of autism as compared to ISAA. Hence, the developed SRS can be considered as a more advanced version than ISAA and can practically supplement the standard diagnostic comprehensive autism assessment procedures.

Daley (2004) suggested that awareness about disability certification for autism is relatively low in Urban and Rural India and also lack of availability of tools to assess the severity of autism. Similar to ISAA, the present developed severity rating scale is based on functionally relevant domains and facilitates broader analysis on specific skills than other rating scales. CARS, GARS provide more fine-grained analysis on the western forefront,

while the present developed SRS is designed to monitor and facilitate functional skills particularly for Indian children with autism. Secondly, the frequency of the scores were also taken into consideration along with the overall mean scores above. The current study yielded significant and highly positive correlations between the frequency of responses and the overall mean scores.

Hence, the presently developed severity rating scale (SRS) can help to assess and differentiate the severity levels of autism in children with ASD between 2-8 years of age. The scale can also be used to assess the severity of specific domains of autism such as speech and language skills, cognitive functions, social communication skills, medical and sensory issues, and self-help skills among the Indian children with ASD. The developed SRS is in diagnostic agreement with CARS and hence it simplifies the diagnostic process and increases the accuracy of diagnosis of autism in children. The tool can also be used as a prognostic indicator to monitor the child's level of independence in different areas and social situations.

CHAPTER-6
SUMMARY AND CONCLUSIONS
"It is never too late to expand the mind of a person on the autism spectrum"- Temple Grandlin, 2010

The current study aimed at developing a severity rating scale (SRS) for children with Autism spectrum disorders (ASD). The scale was administered to 60 subjects with ASD between 2-8 years of age and tool consisted of a total of 100 statements divided across five developmental domains namely: speech and language skills, cognitive functions, social communication skills, medical and sensory issues, and self-help skills. The administration of the rating scale was mainly based on a five point rating scale namely: "5- always", "4- frequently", "3- intermittently", "2- rarely", and "never. Based on the cut-off scores the severity levels of autism were categorized as: 1- No autism, 2- Mild Autism, 3- Moderate autism, and 4- Severe autism.

For the process of content validation, the rating scale initially consisted of 150 statements and were given to the experienced Speech Language Pathologists to judge these adapted items with respect to its sensitivity and rate by marking each item as: "Slightly appropriate (25%)" "Moderately appropriate (50%), "Mostly appropriate (75%)", and "Appropriate (100%)".The items with 60 % of agreement across three out of five judges were included in the tool whereas the items rated as "moderately appropriate" and "slightly appropriate" by three out of five judges were excluded from the tool. The final version of the rating scale were re-structured and consisted of 100 statements divided across 5 domains.

The participants were divided into three age groups namely: Group 1 (2-4 years), Group 2 (4-6) years, and Group 3 (6-8 years) and the results indicated that the mean scores decreased with increase in age and the scores were higher in speech and language skills, and social communication skills in all the participants. Inter-rater reliability of the developed SRS was measured using Cronbach's alpha coefficient which indicated a good agreement between the two raters. Similarly, on testing the feasibility of using the SRS and comparing it with CARS, results indicated a higher positive correlation between the two rating scales. Hence, it can be concluded that the developed SRS is as sensitive as CARS and can be used to determine severity levels of autism.

Implications of the study

The developed severity rating scale provides the clinicians the qualitative outlook of the parent's perspectives on children with ASD and helps to determine the severity levels. Rating scale serves as a screening tool to differentially diagnose autism with other developmental disorders and comparisons across age groups can be made according to the severity levels. Comparisons of the developmental severity rating scale also can be made with normal children and normative scores can be obtained and the clinical findings can be strengthened during a comprehensive language evaluations of children with ASD. The total scores obtained from the presently developed SRS can be studied and compared between autism and other diagnostic groups on Indian population.

The statements from the rating scale provides a better clarity of autism symptoms across different areas and can be utilized in formulating goals during therapy. During the process of intervention, the scores from the severity rating scale can be monitored for progress by comparing the scores achieved by children with ASD on the basis of pre-therapy and post-therapy sessions.

Future directions

- The developed severity rating scale can be administered to a larger population of ASD by including different types of ASD such as PDD-NOS, CDD, Rett's disorder and High functioning autism.

- The developed severity rating scale can be standardized to extended age-group beyond 8 years of age and severity levels of autism can be compared

- The present severity rating scale can be adapted and standardized in various Indian languages

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Sl no.	Items	Always (Score of 5)	Frequently (Score of 4)	Intermittently (Score of 3)	Rarely (Score of 2)	Never (Score of 1)
A)	**Speech and Language skills**					
a.	**Receptive language skills**					
1.	Lack/limited facial expressions, eye-contact and use of body language when spoken to					
2.	Difficult to comprehend simple one step instructions					
3.	Demonstrates difficulty in identifying objects of daily use					
4.	Demonstrates difficulty in distinguishing objects by function					
5.	Demonstrates lack or limited understanding of simple concepts (prepositions- in/on/under; pronouns, adjectives, and attributes)					
6.	Demonstrates lack or limited understanding of spatial concepts (front/behind/far/near)					
7.	Difficulty to understand two-three instructions in series					
8.	Displays confusions in the awareness of time in relation to past/present/future					
9.	Demonstrates difficulty in understanding simple "wh" questions					
10.	Does not pay attention to the conversations					
b.	**Expressive language skills**					

11.	Speech utterances are generally meaningless or jargon-type					
12.	Limited usage of single words in context					
13.	Limited spontaneous naming of the common objects					
14.	Limited usage of pronouns in the utterances					
15.	Restricted or limited vocabulary					
16.	Uses telegraphic speech for basic communication needs					
17.	Demonstrates confusions in answering close ended questions (YES/NO)					
18.	Uses incomplete sentences and limited use of descriptives (Ex: "in", "on", "big", "small" etc)					
19.	Difficulties in initiating conversation					
20.	Uses repetitive speech/echolalia					

Sl. no.	Items	Always (Score of	Frequently (Score of	Intermittently (Score of	Rarely (Score of	Never (Score of
B)	**Cognitive functions**					
21.	Inconsistent response to name-call					

22.	Does not look for objects removed from the line of vision					
23.	More use of unconventional gestures (Takes the parent/caregiver's hand to lead to the desired object)					
24.	No pointing to request for desired object					
25.	Inadequate shared attention in a joint attention activity					
26.	Inadequate imitation to actions/sounds					
27.	Limited exploration with the cause and effect during play					
28.	Displays confusions in the object picture matching (or vice versa)					
29.	Leaves the task/activity incomplete					
30.	Takes longer time to learn new skills					
31.	Limited generalization of learned skills to new settings					
32.	Limited labeling of known pictures/objects					
33.	Less attentiveness in solving simple puzzles					

34.	Impaired working memory (Counting, recall of information)					
35.	Remains engaged only in the areas of restricted interests					
36.	Demonstrates confusions in ordering pictures into a category					
37.	Demonstrates lack of interest in reading					
38.	Cannot create/understand make believe stories					

Sl no.	Items					
39.	Lack/limited reasoning skills					
40.	Demonstrates confusions in sequencing of events in a daily routine					

Sl no.	Items	Always (Score of 5)	Frequently (Score of 4)	Intermittently (Score of 3)	Rarely (Score of 2)	Never (Score of 1)
C) Social Communication functions						
41.	The child is generally withdrawn/aloof					
42.	Displays inappropriate emotional responses (crying, laughing, temper tantrums)					
43.	Less interested to interact with peers at developmental level					
44.	Limited social smile					
45.	Does not show/bring the objects to share experience					
46.	Cannot predict emotions or thoughts of other people (lacks empathy)					

a.	**Behaviour**					
47.	Displays preoccupied interests (playing the same game repeatedly)					
48.	Gets distressed with change of routine (different room for play area, furniture or child's toys are moved)					
49.	Demonstrate idiosyncratic patterns during routine activities (drinking water from the same cup, insists food to be arranged in a certain pattern of interest)					
50.	Engages in repetitive interests (Hand flapping, clapping of hands, toe walking, body rocking, unusual head movements)					
51.	Displays aggressive behaviour and temper tantrums					
52.	Displays self - injurious behaviours (Biting, head banging, excessive self - rubbing, excessive self - scratching)					
b.	**Play**					
53.	The child generally engage in Solitary/solo play (prefers to play self)					
54.	The play of the child generally destructive (throwing, pulling objects)					
55.	The child's play lacks imagination					
56.	The child generally acts as an observer or a spectator and does not participate in the activity with the peers					
57.	Lack of flexibility within the play theme (following the same set of play sequence)					
58.	Shows little/no involvement in structured play activities					
59.	Lack of flexibility within the play theme					

Sl no.	Items	Always (Score of 5)	Frequently (Score of 4)	Intermittently (Score of 3)	Rarely (Score of 2)	Never (Score of 1)
	(following the same set of play sequence)					
60.	Shows little/no involvement in structured play activities					

Sl no.	Items	Always (Score of 5)	Frequently (Score of 4)	Intermittently (Score of 3)	Rarely (Score of 2)	Never (Score of 1)
D) Medical and Sensory issues						
61.	Episodes of recurrent attacks of seizures/convulsions					
62.	Displays difficulty in walking and other gross motor activities (Specify)					
63.	Displays fine motor abnormalities (Specify)					
64.	Associated genetic conditions such as Mental retardation, syndromes or any other conditions (Specify)					
65.	Abnormal sleeping patterns					
66.	Complaints of constipation/diarrhoea					
a.	**Hyposensitivity**					
67.	Displays unusual finger movements near the face					

68.	Vacant staring at the lights/objects					
69.	High pitched shrieking/ repeating vocal sequences at inappropriate times					
70.	Persistent mouthing of fingers or objects					
71.	Generally clingy or has a tendency of hugging onto others/ Lethargic					
72.	Has a tendency of smelling or licking objects					
73.	Over-active/restless					

b.	**Hypersensitivity**					
74.	Sensitive to bright lights/colours					
75.	Sensitive to sounds/loud noises (covers the ears or exhibit temper tantrums)					
76.	Becomes frustrated in large groups					
77.	Resists to be touched or hugged					
78.	Dislikes common tastes and smells					
79.	Has food preferences					
80.	Fears or anxious on falling					

Sl no.	Items	Always (Score of 5)	Frequently (Score of 4)	Intermittently (Score of 3)	Rarely (Score of 2)	Never (Score of 1)
E) Self-Help skills						
a.	**Feeding**					
81.	Requires assistance for self – feeding					
82.	Leaves the meal incomplete					
83.	Displays difficulty in swallowing and chewing certain textures of food					
84.	Displays aversions to certain food textures					
85.	Clumsy or messy during feeding (spills food)					
86.	Inappropriate meal times					
b.	**Toileting**					
87.	The child does not indicate the need to go to the toilet					
88.	Displays irregular bowel/bladder control					
89.	Soils dress/pants (unaware if they are wet or have soiled themselves)					
90.	Displays fear/ anxiety on using the toilet					
c.	**Oral hygiene**					
91.	Occurrence of tooth decay/ cavities in the mouth					
92.	The child engages oneself in grinding of teeth (bruxism) or other self- injurious behaviours					
93.	Displays fear/irritability to brush teeth (sensitive to the texture of the bristles of tooth					

	brush and types of tooth paste)						
d.	**Personal hygiene**						
94.	Resists to wash hands (Insists the hands to be dry)						
95.	Resists to take bath (resists to be cleaned)						
96.	The child feels painful or uncomfortable on the water being splashed on the body						
97.	Feels discomfort to have a shower on the head						
e.	**Grooming**						
98.	Displays fear/irritability while getting the nails cut						
99.	Displays fear/irritability on combing hair						
100.	Displays irritability on clothing self						

APPENDIX-B
SCORE SHEET

Case Name: **Case Number:**
Age/Gender: **Language:**
Examiner: **DOA:**
Provisional Diagnosis:

A		B		C		D		E	
1.		21.		41.		61.		81.	
2.		22.		42.		62.		82.	
3.		23.		43.		63.		83.	
4.		24.		44.		64.		84.	
5.		25.		45.		65.		85.	
6.		26.		46.		66.		86.	
7.		27.		47.		67.		87.	
8.		28.		48.		68.		88.	
9.		29.		49.		69.		89.	
10.		30.		50.		70.		90.	
11.		31.		51.		71.		91.	
12.		32.		52.		72.		92.	
13.		33.		53.		73.		93.	
14.		34.		54.		74.		94.	
15.		35.		55.		75.		95.	
16.		36.		56.		76.		96.	
17.		37.		57.		77.		97.	
18.		38.		58.		78.		98.	
19.		39.		59.		79.		99.	
20.		40.		60.		80.		100.	

A- Speech and Language skills, B- Cognitive functions, C- Social communicative functions, D- Medical and Sensory issues, E- Self-help skills

Domains		Client's scores	Total scores
A.	Speech and Language skills		100
B.	Cognitive functions		100
C.	Social communicative functions		100
D.	Medical and sensory issues		100
E.	Self-help skills		100

Classification of Severity of Autism	No autism	Mild autism	Moderate autism	Severe autism
Total score for Severity				