Dr. Thomas Kishore

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<u>Research & clinical interests</u>

1. Child and Adolescent Mental Health, Neurodevelopmental disorders
2. Early detection and intervention of child mental health problems
3. Infant Mental Health and school mental health
4. Psychodiagnostics in children
5. Family functioning, stress and coping related to childhood disorders

Awards and Achievements

- IASSIDD Membership Number: 1236
- Member, Rehabilitation Council of India (A 04689)

- International Affiliate of APA (ID # 00969180)
- Fellow of Indian Association of Clinical Psychologists (IACP) (F239/01//11)
- Fellow of the Indian Association of Child and Adolescent Mental Health since 2015 (LF/K-026)
- Life Associate Member of Indian Psychiatric Society (LAM/T02/18)
- Section Editor, Indian Journal of Psychological Medicine (2018- till date)
- Editor, Special Issue of the Journal of Intellectual Disabilities on Service Delivery Models for People with Intellectual Disabilities in Developing Countries, September 2017.
- Reeta Peshawaria Fellowship 2014 for carrying out research in the area of autism
- Conferred IACP Child and Adolescent Mental Health Award for the year 2014 by the Indian Association of Clinical Psychologists [during the 40th National Annual Conference of the Indian Association of Clinical Psychologists held at SRM University, Chennai, 28 February to 2 March 2014].
- SC Gupta Award for best paper presented in the Annual Conference of the Indian Association of Clinical Psychologists, 2003

Research projects

1. Developmental progression of executive functioning, adaptive behaviour and pre-academic skills in preschool children with ADHD. Funded by NIMHANS [As Principal Investigator]
2. Reeta Peshawaria Fellowship for conducting research on autism, 204-15. [As Principal Investigator]
3. UPE-2 Interface Studies Project on ‗Prevalence of depression in patients reporting cardiac, gastro-intestinal, pulmonary and skin problems: Implications for Health Policy'. [As Co-Investigator: Order No. UH/UGC/UPE Phase-2/Interface studies/ Research projects/R-67 dated 19/04/2012]
4. Trends in Intelligence Testing of Persons with Mental Retardation and its Implication for Certification of Disability and Service Provisions (2011)

Scientific Report on the development of a scale for identifying autism spectrum disorder during early childhood

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Dedication

To the loving memory of an inspiring teacher, astute clinician, action researcher, and a well-balanced person

Late Dr Reeta Peshawaria
Faculty, Department of Clinical Psychology
National Institute for the Empowerment of Persons with Intellectual Disabilities
(Formerly, National Institute for the Mentally Handicapped)
Secunderabad, India
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Scientific Report on the Development of a Scale for Identifying Autism Spectrum Disorder during Early Childhood

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Preface

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterised by social communication deficits and limited interests and repetitive behaviours. Though it is thought to be present since birth, it could be reliably identified only by the age of 3 years. Scientific data indicates that early detection and intervention before the age of three years with an extensive focus on social skills and communication skills will be really helpful. But, somewhat paradoxically early identification is missed for various reasons and it further causes a delay in the intervention. In high-income countries the gap between early identification of developmental issues and ASD diagnosis/intervention is two years as opposed to upward three years in the low and middle-income countries. One of the reasons for this situation is the lack of reliable, simple tools for frontline professionals for early identification of ASD. In this regard, this study has been undertaken.

This study has been supported under the prestigious Reeta Peshwarai Fellowship 2014, the same year when the fellowship was instituted in by the Indian Vision Foundation, New Delhi.

While I hope this scale will find its users for early identification of ASD, it requires more research. I would be happy to see normative data on this scale. At the next level, it would be good to see how this scale fares in differentiating children with ASD from those with pure intellectual disability/global developmental delay and those with pragmatic language disorders. There could also be studies on comparing its efficacy with other scales developed outside India for early identification of ASD. Prospective studies to examine the predictive validity of this scale will provide the ultimate evidence. I hope more young researchers cutting across the disciplines would be interested in the area of early identification and intervention for ASD.

Acknowledgements

"Let us be grateful to the people who make us happy; they are the charming gardeners who make our souls blossom." **— Marcel Proust**

I thank the India Vision Foundation, New Delhi for awarding me the prestigious Reeta Peshawaria Fellowship for the year 2014. I deem the fellowship with great honour and respect because Dr Reeta Peshawaria, in whose name the fellowship instituted, was my teacher at NIEPID; an acclaimed academician, researcher and clinician in the field of intellectual and developmental disorders (ID) including autism spectrum disorder (ASD). Her work besides others' in the area of ID and ASD has immensely influenced this work.

I also take this opportunity to thank my teachers starting from those who taught me at NIEPID and those at the Central Institute of Psychiatry, Ranchi whose clinical acumen, multidisciplinary perspectives, scientific rigour and value-based education have shaped my clinical and research interests that are the bedrock of my current study.

The work carried under the fellowship i.e. developmental a scale for early identification of ASD would not have been possible without the generous, practical support of the following therefore my sincere gratitude to them all:

Parents and their children with ID and ASD; and children without ID and ASD	For active participation
Institutes' Ethics Committee, University of Hyderabad	For the primary ethical approval of the study
Ms E.V.K. Bhagya Lakshmi and Mrs Bindu N. Shah (Ambika Shishu Kendra, Kurnool); Shri. Sunil Kumar (NIPCCD, Lucknow); Mrs Alakananda Bandopadhyay & Mrs Sucharita Dutt (NIEPID Regional Centre, Kolkata); Dr Himangshu Das (Society for Advanced Studies in Rehabilitation, Faridabad); Dr Lalitha Subramaniam (Sree Ramachnadra Medical College, Chennai), Dr Bala Bhaskar (NIEPD, Chennai), Dr Mousumi Bhaumik (MSMDC, New Delhi)	For motivating the parents and families of children with ID and ASD to participate in the study.
Jyothi Preetham Kumar	For motivating the parents and families of children without ID or ASD in the community to participate in the study
Professor JL Matson and his team	For sharing BISCUIT (a scale for ASD) to use as gold standard in this study

Dr Vincent Guinchat	For allowing me to identify early behavioural indicators of ASD from his review article
All experts (see, appendix 8)	For their advise and encouragement
Mrs Alakananda Bandopadhyay & Mrs Sucharita Dutt; Dr Mousumi Bhaumik Dr Himangshu Das; and Dr Lalitha Subramaniam	For helping with the translation of the tools and informed consent forms into Bangla, Hindi and Tamil, respectively
Dr Binukumar B., Department of Biostatistics, NIMHANS	For statistical analysis
My teachers at NIEPID and the Central Institute of Psychiatry	For their inspirationn and encouragement for this study and in all academic activities that I pursued
My family	For their constant support and unconditional love and unbiased critique

Chapter 1: Introduction & Review of Literature

Autism is one of the severe developmental disorders. It qualitatively affects the development of socio-communication skills and is associated with restricted interests and repetitive behaviors. Although often associated with some degree of intellectual disability, autism differs from intellectual disability in certain ways in that its social interaction and communication development most severely affected whereas other areas, such as nonverbal cognitive abilities, may be within normal limits (Volkmar & Lord, 2007, p1). The nature of autism is such that sociocommunication deficits and limited interests overshadow the cognitive levels of the individual and interfere with adaptation skills of the individual (American Psychiatric Association, 2013).

A). Magnitude of the problem

There are no epidemiological studies on autism in India, but it is estimated that the prevalence figures may not be very different from the rest of the world. Extrapolating the global prevalence rates, it is estimated that there would be nearly two million people with autism in India (Directorate General of Health Services, 2011). Nearly 20-30% of the population may suffer from comorbid intellectual disability while conditions such as ADHD and epilepsy are also common (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003).

A few children seems to develop autism after some period of normal development, but current understanding is that autism is generally present from birth (Bryson, Rogers, Fombonne, 2003; Volkmar, Chawarska, & Klin, 2005), and intense therapy given in the first three years of age helps improve the condition significantly (Landa & Garrett-Mayer, 2006; Barbaro & Dissanayake, 2009). Somewhat paradoxically, however, our knowledge of autism as it is expressed in infancy is quite limited (Volkmar, Chawarska, & Klin, 2008). There are no biological models which will explain the entire range of psychopathology of autism (Brian et al., 2008). This scenario may possibly explain why autism is usually not diagnosed until the age of 3 years. Since there are no biological markers for autism (Bishop, Luyster, Richler, & Lord, 2008; World Health Organization, 2011), a diagnosis of ASD is made on the basis of a behavioral profile, which is characterized by both the absence of typical behaviors as well as the presence of atypical behaviors. Hence there is a scope to understand the condition from a behavioural and developmental perspective (Kishore & Basu, 2011, 2014).

B). Nosological system

According to the criteria outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV; American Psychiatric Association, 1994) and the *International Classification of Diseases* (ICD-10; World Health Organization, 1992), in order to receive a diagnosis of autism, a child must have shown abnormalities in social interaction, language as used in social communication, or symbolic/imaginative play before the age of 3 years. As per ICD-10, when all of the above criteria for autism are not met, the child may be given a diagnosis of Asperger syndrome or Pervasive Developmental Disorder-Not Otherwise Specified (Volkmar, Chawarska, & Klin, 2008). Together these three conditions are known as autism spectrum disorders (ASD) and DSM-5 places them under the domain of neuordevelopmental disorders (American Psychiatric Association, 2013; Geschwind, 2009). Across all the diagnostic entities, onset of at least 36 months is mandatory before a diagnosis of autism, but many behavior criteria are rare (i.e., stereotypes) or are not appropriate (i.e., language communication) under the age of 2 years. There could be several, non specific developmental or behavioural problems during early age (Guinchat et al., 2012). Therefore, there is a scope for close monitoring and surveillance of children who show atypical behaviours and developmental problems during early stages, though such atypicalities are not to the level of a syndrome. By inference, there is a scope for development of tools focusing on atypical behaviours and developmental concerns during infancy and early childhood.

C). Autism during infancy and early years

Most of our understanding about the initial manifestation of autism comes from parental reports and home videos taken on birthdays of the affected children or during family celebrations (Volkmar, Chawarska, & Klin, 2008). There is consistent evidence that the vast majority of parents of children with ASD first notice abnormalities during the course of the first 2 years of life (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Chawarska et al., 2007). But early identification by parents did not always result in early diagnosis and intervention. Independent of initial concern, children with ASD received a diagnosis and intervention only at around four years of age. So there is a huge gap between early identification and diagnosis of autism, and this phenomenon is universally observed (Chawarska et al., 2007; Kishore & Basu, 2011; Daley, 2004).

Among the most common and often first noted concerns are delays in speech and language development, followed by an abnormal social responsivity level, medical problems, and nonspecific difficulties related to sleeping, eating, and attention (Chawarska, et al., 2007).

Infants who were later diagnosed with ASD were less likely to look at and seek other people, and they were less likely to smile and vocalize at others in the first 6 months of life (Maestro et al., 2002). Such problems continued well into the second half of the first year (Osterling et al., 2002). Notably, in young children, the appearance of stereotyped behaviors, motor mannerisms, and unusual interests rarely trigger parental concerns, most likely because of their relatively mild manifestations in infancy or a later onset or it is considered that they will disappear with age (Volkmar, Chawarska, & Klin, 2008). Zwaigenbaum and colleagues (2005) identified several features at 12 months that are likely to differentiate siblings with ASD from those without social disability. Among the features were poor eye contact, limited social interest and smiling, limited use of gestures, poor response to name, poor imitation, and delays in receptive and expressive language. These infants also exhibited temperamental abnormalities, including initial passivity in early development followed by the emergence of a tendency for extreme distress reactions by 12 months. Difficulties in disengagement of visual attention were also noted. Studies such as these constitute the first step toward establishing clear diagnostic criteria for ASD in the first year of life, although extensive studies are needed to establish both sensitivity to and specificity of the identified abnormalities.

Regression is usually reported in 20–35% of cases and can involve the loss of words, vocalizations, nonverbal communication skills (e.g., eye contact, gestures), imitation, or pretend play (Luyster et al., 2005). The perception of regression appears to be specific, though clearly not universal, to ASD. Nonspecific concerns related to feeding, eating, and sleep are reported in autism (Chawarska et al., 2007). Since information on early development is crucial to identifying autism, we need to depend on several sources such as home videos of infancy, and retrospective accounts of parental concerns about the child's development and so on. Though parental ability to detect and report on the more subtle and contextualized symptoms of ASD is often debated (see Zwaigenbaum et al., 2007), subsequent studies have confirmed that parental concerns may be useful in predicting specific risk factors when social and environmental factors are also taken into account. Asking parents open-ended questions about their child and appreciating their concerns may constitute a valid resource to identify young children in need of closer monitoring and surveillance with regard to ASD. Their experiences underline the necessity to improve the appraisal of non-specific warning signs, which should be

integrated into the early-screening strategies for autism (Guinchat et al., 2012). Further study into these additional variables may help to identify and target very early treatments for at risk children, and provide for optimal outcomes (Matson, Rieske, & Tureck, 2011; Turygin, Matson, Williams, & Belva, 2014). Therefore, till the time we have robust, viable methods of screening we may have to depend on the information provided by parents regarding early development of autism (Kishore & Basu, 2011).

Symptoms of ASD in the Second and Third Years of Life

Several factors have contributed to a much larger body of data on autism as it manifests after the first birthday and before age three. Recent studies suggest symptoms of autism center on areas of social interaction and communication and are often accompanied by delays in multiple areas of functioning, including motor and nonverbal cognitive development (Bishop, Luyster, Richler, & Lord, 2008; Chawarska & Volkmar, 2005). In the social domain, the most frequently reported symptoms are diminished eye contact, limited interest in social games and turn-taking exchanges, low frequency of looking referentially at parents, and preference for being alone (Cox et al., 1999; Stone et al., 1999). A limited range of vocal and motor imitation and symbolic play skills (Cox et al., 1999), facial expressions and infrequent instances of sharing affect (Stone et al., 1999) could be noted as compared with the children's overall developmental levels. In the area of communication, the most striking differences relate to early emerging social communicative exchanges through nonverbal (e.g., use of gestures or gaze to communicate interest or joint attention) and vocal or verbal means. The child's responsivity to speech in general, and to his or her name in particular, continues to be limited (Paul, Chawarska, Klin, & Volkmar, 2007). Vocalizations may take on an abnormal quality (Sheinkopf, Mundy, Oller, & Steffens, 2000). Stereotypic and repetitive behaviours reach clinical threshold in a vast majority of children by the age of 4 (Lord, 1995).

Adaptive skills are usually delayed beyond what would be expected based on the developmental level (Stone, Ousley, Hepburn, Hogan, & Brown, 1999). But we do not know how specific they are to ASD. However, difficulties in adapting to new situations, interest in visually repetitive phenomena (e.g., ceiling fans), and overattention to the nonsocial environment (e.g. focusing on alphabet letters on blocks or small details of play materials instead of people holding them) are potential candidates (Volkmar, Chawarska, & Klin, 2008). Overall, the review reiterates the findings obtained by Kishore and Basu (2011) that

behavioural abnormalities and atypical developmental pattern could be seen across all core domains of ASD viz. the socio-communication and limited interests, but with a wide variation across individuals. It further implies that we cannot afford to focus only on a few symptoms of ASD during early childhood..

C). Tools available for assessment

At present, specific tools are available for infants and toddlers. There are at least twelve scales for early identification of autism spectrum disorders. They are: Pervasive Developmental Disorders Screening Test-II, Screening Tool for Autism in Two-year-olds, First Year Inventory, Communication and Symbolic Behavior Scales Developmental Profile, Revised Psychoeducational Profile, Parent Concern Checklist, Early Screening of Autistic Traits Questionnaire, Young Autism and other developmental disorders Checkup Tool, Preschool Imitation and Praxis Scale, Social Communication Questionnaire, Checklist for Early Signs of Developmental Disorders, Autistic Behavioural Indicators Instrument, and Baby and Infant Screen for Children with aUtIsm Traits. But a comprehensive review indicates that none of the existing tools are suitable for identification of autism during infancy (see, Brian et al., 2008; Matson, Rieske, & Tureck, 2011; World Health Organization, 2011).

D). Need for the study

Universal screening procedures are impeded by the varying patterns of onset of autism. More generally, well-documented diagnostic instruments may work well after age 3–4 years or past a certain developmental level, but their use is not clearly established for infancy (Chawarska et al., 2007). Only trained clinicians are able to detect autistic children under the age of 2 (Klin, Lang, Cicchetti, & Volkmar, 2000). But large number of children and infants are also seen by other professionals such as special educators, psychologists, and community workers (e.g. anganwadi workers), who may need appropriate screening tools to identify children at-risk for autism. Hence, there is a scope for development of a scale for identifying autism during infancy and early childhood, particularly in Indian context. The objective of the present study was to development of a tool to identify autism based on the early developmental and behavioural pattern in children later diagnosed with autism.

Chapter 2: Method

Research design: This is a post-facto research design, with survey method.

Tools

1. Socio-demographic and clinical data sheet: A data sheet was prepared to collect optimum data regarding the socio-demographic and clinical details of the case (Appendix 1).

2. Baby and Infant Screen for Children with aUtIsm Traits (BISCUIT; Matson, Boisjoli, & Wilkins, 2009). This is a standardized scale designed to be completed by parent/caretakers of infants and toddlers ages 17-37 months. The scale comprises of four components: *Baby and Infant Screen for Children with aUtIsm Traits - Part 1*(BISCUIT-Part 1), *Baby and Infant Screen for Children with aUtIsm Traits - Part 2* (BISCUIT Part2), *Baby and Infant Screen for Children with aUtIsm Traits - Part 3* (BISCUIT-Part 3), and the *Baby and Infant Screen for Children with aUtIsm Traits – Observation* (BISCUIT-O). The BISCUIT-Part 1 is an informant-based measure designed to assess symptoms of Autistic Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) in infants and toddlers. The purposes of this measure are to aide in the diagnosis of ASD, as well as, provide a means for treatment monitoring in the toddler years. The rating scale consists of 62 items that are read to a parent/caretaker. The parent/caretaker is instructed to rate each item by comparing the child to other children his/her age with the following ratings: 0 = "not different; no impairment;" 1 = "somewhat different; mild impairment;" 2 = "very different; severe impairment." The BISCUIT-Part 2 assesses symptoms of emotional difficulties that commonly occur with ASD. The BISCUIT-Part 3 assesses challenging behaviors that commonly occur with ASD. The BISCUIT-O provides supplemental information obtained from the BISCUIT Parts 1-3. The measure consists of 13 items and aids in providing information on behavior based on clinical observations such as: response to name, interest in peers or others, eye contact, pretend play, and engagement in reciprocal play. Items are rated to extent that the behavior is observed or is a problem during the observation: 0 = "not a problem or impairment; not at all;" 1 = "mild problem or impairment;" or 2 = "severe problem or impairment." Specific cut-off scores are proposed to diagnose ASD. In this study, all parts except BISCUIT Part 3 were used. A score of 21 or above is said to indicate at-risk for ASD (p.9).

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3. **Developmental Assessment**: The general development was assessed using the Developmental Screening Test (DST; Bharatraj, 1977) and the adaptive behaviour by the

Vineland Social Maturity Scale (VSMS; Bharatraj, 1992). These scales are extensively used in India for developmental assessment and are known to complement intellectual assessment well.

Sample

The sample consisted of 190 children who were below six years, and had an ICD-10 primary diagnosis of autism (n= 100) or global developmental delay suggestive of mental retardation (n= 40); and typical development (n= 50). Gender of the child and socio-economic status of the family was no bar. The clinical groups (autism and mental retardation) was recruited from various organizations across the country, who have been working in the field of developmental disabilities, and gave consent to participate in the study. List of organizations, which participated in the study is given in **Appendix 2**

Procedure

Ethical approval was obtained primarily from the Board of Ethics, University of Hyderabad, where the work was planned and initiated; and necessary permissions were also obtained from local organizations before data collection. The study was carried out in several phases as following:

1. Item pooling: A comprehensive review by Matson et al. (2011) indicates that we would be biased in usual screening of autism when we focused on features specific to autism. The available research shows a marked overlap between core symptoms of autism, challenging behaviors, and some specific types of psychopathology. The extreme clinical heterogeneity of autism requires us to define symptoms that are not necessarily included in the standard definitions of autism. Hence best practice for early identification and diagnosis of autism is that instruments should go well beyond measuring core symptoms of autism. Keeping this in view items were pooled from several sources, with an understanding that all items are not specific to autism (Boyd et al., 2010; Brian et al., 2008; Bryson et al., 2004; De Giacomo, & Fombonne, 1998; Gillberg et al., 1990; Guinchat et al., 2012; Mitchell et al., 2006; Volkmar, Chawarska, & Klin, 2008; Volkmar, Chawarska, & Klin, 2005; Wetherby et al., 2004; Wetherby et al., 2007; Young et al., 2003; Zwaigenbaum et al.2009; Zwaigenbaum, 2010). But the following four sources are credited for the item pool as they have included all major, important studies on early manifestation or identification of ASD: Guinchat et al. (2012), Volkmar, Chawarska, and Klin (2008), Volkmar, Chawarska, and Klin (2005), and Zwaigenbaum (2010).

2. **Objectively wording the items**: The pooled items were worded in objective terms. Ambiguous descriptions were avoided. When symptoms appeared across several domains, they

were retained only in one domain. Since this study did not focus on domain-specific item categorization, further procedures were not planned to see whether particular item fits into specific domain or not.

3. Establishing validity and reliability: Face validity and content validity were obtained by giving the item pool to a panel of 15 experts from diverse fields such as Clinical Psychology (n=7) Psychiatry (n=2), Speech Pathology (n=2), Paediatrics (n=1) and Special Education (n=3), who have extensive experience in working with children with ASD. According to their suggestions, few items were reworded. But the panellists agreed that all the items were relevant and the item-pool was comprehensive. Therefore, all the items pooled were retained for field trial. Interrater reliability was established with a mixed group of 20 children aged 6-36 months. The group included 10 children with developmental delay, six children with hearing, speech and communication deficits and four children with autism spectrum disorders. Data for interrater reliability was collected from only one centre i.e. the Ambika Shishu Kendra, Kurnool, Andhra Pradesh for the centre was actively willing to participate in the study. The interrater reliability for the overall scale was satisfactory (r= .79; p <.01). Final list is given in table 2.1

Table 2.1. Final list of pooled items.

	Items
I	**Perception**
A	**Visual**
1.	No reaction to light/visual stimuli
2.	Slow/delayed reaction to light/visual stimuli
3.	Abnormal fixation to light/hand/visual stimuli – specify
4.	Hypersensitivity to light – shielding of eyes/closing of eyes/frequent blinking/refusal to come out in sunlight/brightly lit room
B	**Hearing**
5.	No reaction to noises/sounds
6.	Slow/delayed reaction to noises/sounds
7.	Abnormal reaction to certain noises/sounds by shouting/screaming/closing ears/banging ears/hitting self – specify
8.	Hypersensitivity to noises/sounds - specify
C	**Olfactory**

9.	No reaction to pungent/putrid odors/fragrances
10.	Abnormal reaction to specific odors/fragrances – specify
11.	Repetitive smelling of objects/persons/food – specify
12.	Hypersensitivity to certain/everyday odors/fragrances – specify
D	**Oral (taste)**
13.	No reaction to any taste/texture
14.	Selectivity – preference for/dislike of taste/texture of food – specify
15.	Oral Hypersensitivity for taste/texture of food – specify
16.	Persists to orally explore all/certain objects – specify
C	**Tactile**
17.	Does not like to be touched/cuddled
18.	Repeated need for touching/tactile stimulation – specify
19.	Insensitive to pain
20.	Hypersensitive to slight touch/painful stimuli
21.	Preference for repetitive textures/water
22.	Hypersensitive to water/paint/liquid/jelly textures
23.	Preference for certain types of clothes – specify
24.	Hypersensitive to certain types of clothes – specify
25.	Difficulty in bathing – water/soap on body/head/face; drying –texture of towel/specific body part – specify
26.	Warm/cold – insensitivity/hypersensitivity – specify
D	**Repetitive and restricted interests**
27.	Stereotyped movements - specify
28.	Swinging motion – to and fro/back and forth/side to side/standing/sitting/lying – specify
29.	Hand flapping
30.	Running aimlessly
31.	Jumping aimlessly
32.	Making strange gestures
33.	Head nodding
34.	Imitation of sounds/words/sentences - Echolalia
35.	Staring
36.	Fiddling with hands

37.	Head turning
38.	Obsession with certain objects/toys – specify
39.	Repetitive pattern of play (making lines with toys, building towers etc.)
40.	Creeping, crawling, bear-like, bottom-shuffling
41.	Walking on toes
42.	Balance - standing on one foot/ frequent falling/ walking backwards
E	**Persistent preoccupation with parts of objects**
43.	Rotating car wheels
44.	Preoccupation with specific objects (cords/ napkin/cloth/ Caps/lids/buttons etc.
45.	Switching on/off of light/fan/other fixtures
46.	Opening/closing of door
47.	Banging of/dissembling-assembling of parts
48.	Other - specify
F	**Socio-communication**
49.	Regression in language – specify
50.	Stagnation in language
51.	Restricted language – telegraphic speech/ monotonous voice – specify
52.	Difficulty in initiating / maintaining/ terminating conversation – specify
53.	Unable to take cues from body language/facial expressions/intonation of speaker
54.	Unable to use - gestures/pointing/pulling the person
55.	Regression in non-verbal communication
56.	No/empty gaze/sees through things/people
57.	No eye contact
58.	Avoids eye contact
59.	Uses peripheral vision
60.	Impression of deafness
61.	No sense of danger/safety
62.	No response to name
63.	No reaction to social solicitation
64.	Poor reciprocity/disinterested in engaging with people
65.	Actively avoids social solicitation/interaction
66.	Slow to warm up to interaction
67.	Specific preferences for age/gender – specify

68.	Remains aloof/withdrawn/in his own world/oblivious of surroundings
69.	No specific reaction to separation from family members
70.	Difficulty in separation from family members/specific person
71.	Abnormal attachment to a specific person – specify
72.	No response to emotions (apathetic) – joy/sorrow etc – specify
73.	Appropriate response to emotions
74.	Inappropriate response to emotions - specify
G	**Play behavior**
75.	No interest in toys/games
76.	Specific interest in a particular toy/game - specify
77.	Repetitive play – specify
	Sensory integration
78.	Resistant to change in routine/ritual
79.	Anxious to change but able to adapt with repetition/over time
H	**Behavioral difficulties not specific to autism**
80.	Inattention
81.	Low attention span
82.	Restlessness
83.	Over activity
84.	Impulsivity
85.	Aggression-biting/hitting/pushing/pinching etc. – specify
86.	Calm/quiet behavior
87.	Too good behavior
88.	Unusual fears – specify
89.	Hyperventilation
90.	Avoidance of particular place/person/thing - specify
91.	Screaming/crying/whining
92.	Throwing things
93.	Banging head
94.	Rolling on the floor
95.	Self-mutilation
I	**Major physiological functions**
96.	Weaning of breast feed/bottle feed

97.	Vomiting
98.	Difficulty with chewing food - specify
99.	Preference for specific taste/texture of food – specify
100.	Preference for specific temperature of food – specify
101.	Resistance to use of toilets – specify
102.	Resistance to use of diapers
103.	Urinary incontinence
104.	Fecal incontinence
105.	Difficulty in falling asleep
106.	Waking up often in the night
107.	Early morning waking up
108.	Frequent nightmares/night terrors
109.	Bruxism
110.	Inadequate sleep during day – short sleeper/does not sleep
J	**Associated medical conditions/disorders**
111.	Nystagmus, wears glasses, complete/partial impairment– specify
112.	Wears hearing aids/cochlear implant– specify
113.	Frequent sickness/hospitalization– specify
114.	Epilepsy, metabolic disorders, genetic disorders– specify
115.	Food allergies/others – specify
116.	Overall developmental delay
117.	Subjective feeling that the child is different from other children
118.	Bizarre behaviors
119.	Hyper ability in certain skills - specify
120.	Other – specify

4. Translation

This scale along with BISCUIT was translated to Bengali, Hindi, Tamil and Telugu by using Sperber's (2004) guidelines, which are widely followed in biomedical research. Please see **Appendix 3** for the list of experts who coordinated vernacular translations.

5. Administering the scale on the target population

During this phase, 90 children with autism, 40 children with global developmental delay and 50 children with typical development were included. This sample also includes those who participated in the pilot study on the interrater reliability of the scale. Clinical diagnoses

were based on ICD-10 criteria. Qualified special educators, speech therapists, psychologists participated in data collection under the supervision of the experts in the respective organization that has agreed to participate in the study. Initially the purpose of the study was explained to the prospective participants by giving a flyer and further clarifying the doubts, if any. Then informed consent was obtained. The flyer and informed consent form are as given in **Appendix 4**. Then the scale was administered on all of them individually by collecting information from the mothers and also by direct observation. When the mothers were not sure of information, the same was cross-checked with their respective spouses and other family members involved in care-giving of the index child.

Statistical Analysis:

Data were analyzed using the Statistical Package for Social Sciences for Windows (SPSS 16.0). Descriptive statistics such as percentages, mean and standard deviation were applied to understand the characteristics of the sample. Chi Square, Cravmers V, Pearson's r, factor analysis with Varimax rotation, Binary logistic regression analysis, Receiver Operating Characteristic (ROC), and Canonical disciminant analysis was applied as per their basic assumptions. Adopting Steiner's guidelines (2003), Chronbach α values in the range of .50 to .90 were set as criteria to denote good internal consistency. Diagnostic efficiency statistics were calculated by using a calculator based on Excel programme by DeFife (2004). Since the sample size was small in the global developmental delay group and the typically developing groups, both groups were merged to form a reference group called, no-autism group.

Chapter 3: Results

Descriptive analysis indicates that there were 53 males (60%) and 37 females (40%) in the no-autism group; and 78 males (78%) and 22 females (22%) in the autism group. Majority in both groups belonged to middle socio-economic status (85%), followed by low economic status (10%) and high economic status (5%). Additional data such as age, and parental details are tabulated as following.

Table 3.1. *Showing the socio-demographic variables of the study groups.*

Age	Category	N	Minimum	Maximum	Mean	SD	t df=188
Child's age (in months)	No-Autism	90	4	84	36.99	19.52	5.74**
	Autism	100	10	84	51.24	14.56	
Fathers' age (in years)	No-Autism	90	22	52	32.01	5.76	5.46**
	Autism	100	27	49	35.99	4.24	
Mothers' age (in years)	No-Autism	90	19	45	26.26	4.94	8.08**
	Autism	100	24	44	31.42	3.82	
DQ	No-autism	90	12	106	74.16	30.49	9.71**
	Autism	100	2	106	38.17	19.98	
SQ	No-autism	90	8	110	75.82	29.67	9.78**
	Autism	100	2	110	39.35	21.58	

** $p < .01$

Table 3.1 shows that there were significant differences between the autism and no-autism group in terms of the age, parents' age, DQ and SQ.

Table 3.2 *Showing family and demographic variables*

Family demographic variables		No-Autism (n)	Autism (n)	
Father 's occupation	Govt. Sector	11	15	22.77** df=5
	Private sector	30	46	
	Business	13	21	
	Skilled labourer	9	11	
	Seasonal labourer	21	2	
	Others	6	5	
Mothers' s occupation	Govt. Sector	2	5	9.28 df=5
	Pvt. Sector	3	9	
	Business	0	3	
	Skilled labourer	3	2	
	Housewife	77	78	
	Seasonal labourer	5	2	
	Others	0	1	
Domicile	Urban	73	78	2.87 (df=2)
	Semi-urban	10	17	
	Rural	7	5	
Family history of disability	Nil	86	96	.02 (df=1)
	Yes	4	4	
Disability in the family	Mental retardation	3	0	6.56 (df=2)
	Polio	1	0	
	Nil	86	100	
Family history of chronic illness	No	89	96	1.54 (df=1)
	Yes	1	4	
Birth order	1	52	74	15.35 (df=3)
	2	24	25	
	3	13	1	
	9	1	0	
Number of siblings	Nil	33	43	7.38 (df=4)
	1	37	45	
	2	19	10	
	3	0	2	
	8	1	0	

$^{**}p<.01$

Table 3.2 indicates that both groups differed in terms of fathers' occupation, though in both groups majority were working in private sector. Low-paid workers such as seasonal labourers were high among the no-autism group. But there were no group differences with reference to

mothers' occupation, domicile, family history of disability, family history of chronic illness, birth order and number of siblings. In autism group 43% of the children were single children and another 45% had only one sibling.

Table 3.3 *Showing personnel and place involved in autism diagnosis (N=100).*

		n	%	χ^2
Professionals who diagnosed	Psychiatrist	29	29.0	117.36** (df=6)
	Paediatrician	28	28.0	
	Psychologist	28	28.0	
	Speech Therapist/ Audiologist	2	2.0	
	Occupational Therapist	1	1.0	
	Special Educator	1	1.0	
	Others	11	11.0	
Place of diagnosis	Hospital-based	71	71	77.52** (df=3)
	Centre-based	17	17	
	Community-based	2	2	
	Others	10	10	

***p<.01*

Table 3.3 shows that almost equal number of psychiatrists, paediatricians and psychologists were involved in autism diagnosis and majority of the diagnostic evaluations were conducted in hospital-based setting.

Table 3.4. *Early concerns of mothers of children diagnosed with autism (N=100)*

	n	%
Speech delay	41	41.0
Poor eye contact/ visual tracking	16	16.0
Behavioural problems	13	13.0
Nothing specific	6	6.0
Slow activity	6	6.0
Poor auditory responses	4	4.0
Attention deficits	2	2.0
Problems with expressive speech	2	2.0
Lack of interest	2	2.0
Poor response	2	2.0
Delayed crawling	1	1.0
Delayed neck control	1	1.0
Speech regression	1	1.0
Delayed rolling over	1	1.0
Problems in sitting	1	1.0
Microcephaly	1	1.0

Table 3.4 shows that majority of the mother had concerns related to speech problems (41%), Poor eye contact/ visual tracking (16%), behaviour problems (13%), and specific cognitive and motor problems.

Table 3.5. *Showing test items with high internal consistency as measured by chronbach alpha*.

S.No.	Item No.	Abnormality	Chronbach
1.	80	Does not pay attention to the task	0.74
2.	81	Low attention span	0.74
3.	65	Actively avoids social solicitation/interaction	0.72
4.	66	Slow to warm up to interaction even with familiar people	0.72
5.	79	Anxious to change though adapts with repetition over time	0.72
6.	64	Poor reciprocity/disinterested in engaging with people	0.71
7.	83	Over activity	0.71
8.	63	No reaction to social solicitation	0.70
9.	58	Avoids eye contact	0.68
10.	82	Restlessness	0.67
11.	49	Regression in verbal language	0.66
12.	52	Difficulty in initiating / maintaining/ terminating conversation	0.65
13.	71	Abnormal attachment to a specific person	0.65
14.	72	Apparently no display of emotions	0.65
15.	53	Inability to take cues from body language or facial expressions or intonation of speaker	0.64
16.	68	Remains aloof/withdrawn and is oblivious of surroundings	0.64
17.	22	Hypersensitive to wetness (e.g. water/paint/liquid/jelly textures)	0.63
18.	30	Runs aimlessly	0.63
19.	50	Stagnation in language	0.62
20.	73	No response to others' emotions	0.62
21.	51	Restricted language such as telegraphic speech and monotonous voice	0.61
22.	29	Hand flapping	0.59
23.	31	Jumps aimlessly	0.59
24.	77	Repetitive play	0.58
25.	21	Preference for repetitive textures including water	0.57
26.	13	No reaction to any taste/texture	0.56

27.	56	No gaze and empty gaze and as if the child sees through things and people	0.56
28.	78	Resistant to change in routine/ritual	0.56
29.	55	Regression in non-verbal communication	0.55
30.	59	Uses peripheral vision to gaze	0.55
31.	34	Problems with imitation of speech and/or echolalia	0.54
32.	61	No sense of danger or safety	0.54
33.	70	Difficulty to separate from family members/specific person	0.54
34.	74	Inappropriate response to emotions	0.54
35.	84	Impulsivity	0.54
36.	27	Stereotyped movements	0.53
37.	32	Makes strange gestures	0.52
38.	69	No specific reaction to separation from family members	0.52
39.	62	No response to name	0.51
40.	14	Selective preference or dislike for certain taste and/or texture of food	0.50

Table 5 presents the items with high internal consistency. Adopting Steiners criteria (2003), 40 items were identified as having high internal consistency. They are- Item number 13, 14, 21, 22, 27, 29, 30, 31, 32, 34, 49, 50, 51, 52, 53, 55, 56, 58, 59, 61, 62, 63, 64, 65, 66, 68, 69, 70, 72, 73, 74, 77, 78, 79, 80, 81, 82, 83 and 84. Redundancy is ruled out as none of the items had α value of above .90.

Table 3.6. *Factor loading of the selected items with high internal consistency.*

	Component		
	1	2	3
t64	0.79		
t82	0.78		
t65	0.78		
t81	0.77		
t66	0.76		
t63	0.75		
t80	0.74		
t84	0.74		
t58	0.71		
t83	0.70		
t53	0.70		
t73	0.69		
t52	0.68		
t72	0.68		
t30	0.67		
t49	0.67		
t74	0.66		
t51	0.65		
t29	0.65		
t68	0.65		
t50	0.64		
t31	0.62		
t56	0.60		
t55	0.59		
t62	0.58		
t34	0.56		
t78	0.56		
t22	0.55		
t59	0.55		
t69	0.55		
t77	0.54		
t61	0.54		
t32	0.53		
t21	0.53		
t27	0.51		
t70	0.51		
t79		0.59	
t13			0.48

Table 3.6 presents the results obtained through Principal Component Analysis through Varimax with Kaiser Normalization Rotation. Forty items have shown loading on three factors, with factor 1 having the highest load, followed by factor 2 and 3. The item content indicates that factor 1 is socio-communication, factor 2 is resistance to change and factor 3 is sensory integration.

Table 3.7. *Factor variance of the 40 items selected from initial pool.*

Total Variance Explained						
Component	Initial Eigenvalues			Extraction Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	15.83	40.60	40.60	15.83	40.60	40.60
2	2.41	6.17	46.77	2.41	6.17	46.77
3	1.86	4.78	51.55	1.86	4.78	51.55
4	1.77	4.53	56.08	1.77	4.53	56.08
5	1.51	3.87	59.95	1.51	3.87	59.95
6	1.33	3.42	63.36	1.33	3.42	63.36
7	1.29	3.32	66.68	1.29	3.32	66.68
8	1.08	2.78	69.46	1.08	2.78	69.46
9	1.02	2.61	72.06	1.02	2.61	72.06
10	0.86	2.20	74.26			
11	0.78	2.01	76.27			
12	0.68	1.76	78.03			
13	0.67	1.72	79.75			
14	0.62	1.58	81.33			
15	0.61	1.55	82.88			
16	0.57	1.47	84.35			
17	0.53	1.37	85.72			
18	0.52	1.32	87.04			
19	0.50	1.28	88.32			
20	0.48	1.22	89.54			
21	0.40	1.04	90.57			
22	0.39	1.00	91.57			
23	0.34	0.87	92.45			
24	0.33	0.84	93.28			
25	0.33	0.83	94.12			
26	0.29	0.73	94.85			
27	0.26	0.67	95.52			
28	0.24	0.61	96.13			
29	0.23	0.58	96.70			
30	0.21	0.53	97.23			
31	0.17	0.45	97.67			
32	0.16	0.42	98.09			
33	0.14	0.36	98.45			
34	0.14	0.35	98.80			
35	0.13	0.33	99.12			
36	0.12	0.29	99.42			

37	0.09	0.22	99.64			
38	0.08	0.20	99.84			
39	0.06	0.16	100.00			

Table 3.7 shows the factor variance, which was obtained through Principal Component Analysis through Varimax with Kaiser Normalization Rotation. Rotation converged in 16 iterations. Factor 1(Socio-Communication) accounted for 40.60% variance, Factor 2 (Resistance to Change) for 6.17% variance and Factor 3 (Sensory Integration) for 4.78% variance. Cumulatively the three factors accounted for 51.55%.

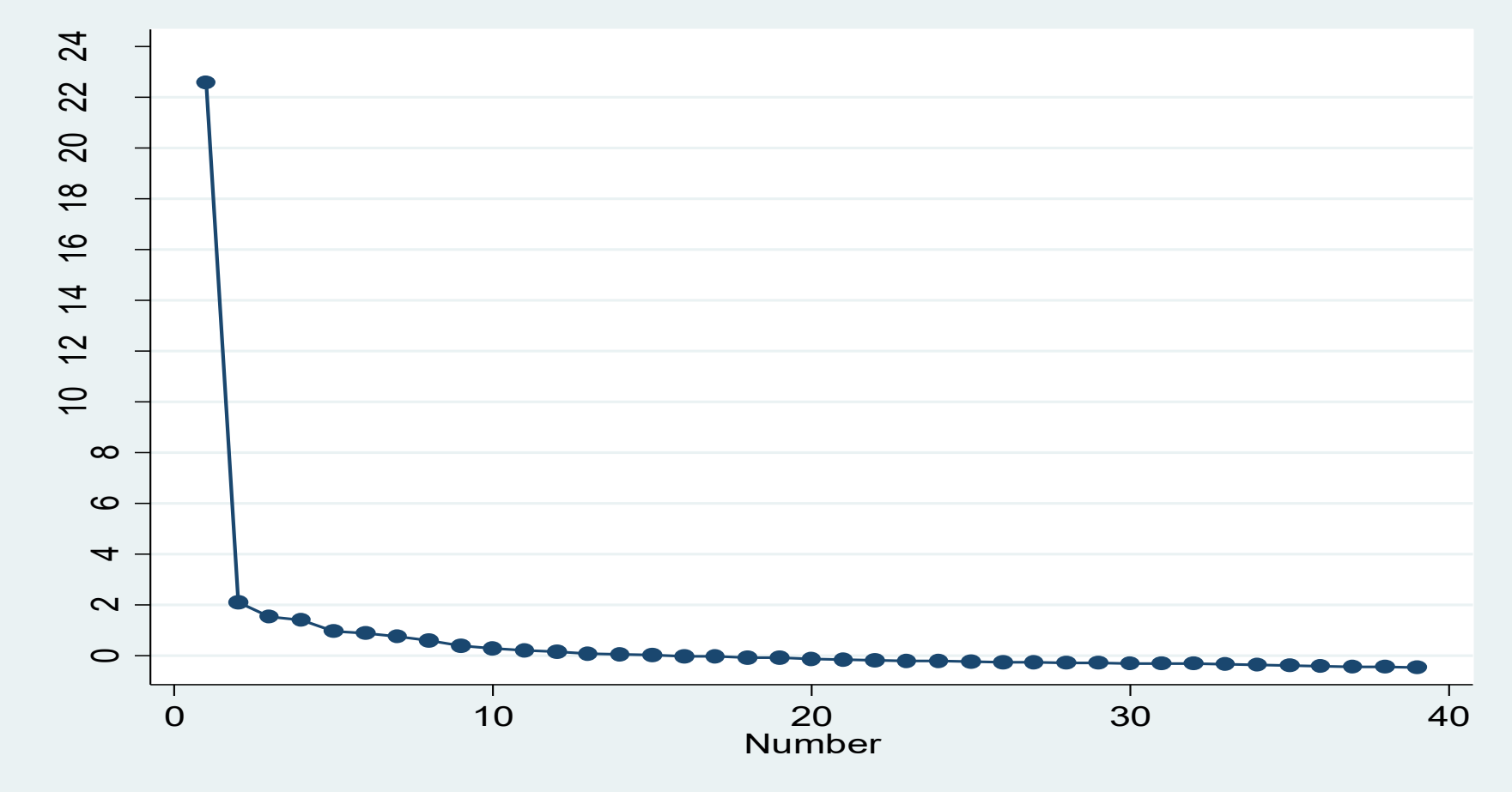

Figure 1: *Scree Plot showing the eigenvalue on factor analysis of 40 selected items.*

Table 3.8. *Showing association between test results and clinical diagnosis with cutoff-5 for the whole sample (n=190).*

		ICD-10 Diagnosis		Total	χ^2 (df=1)	Cramer's V
		No-Autism	Autism			
Test results with Cut-off 5	No-Autism	74	6	80	112.89**	.78**
	Autism	16	94	110		
Total		90	100	190		

***p<.01*

Table 3.8 indicates that there is a significant association between the test results and ICD-10 diagnosis, when cut-off 5 was adopted for classification of cases.

Table 3.9. *Showing association between test results and clinical diagnosis with cutoff-7 for the whole sample (n=190).*

		Clinical Diagnosis		Total	χ^2 (df=1)	Cramer's V
		No-Autism	Autism			
Test results with Cut-off 7	No-Autism	77	10	87	108.94**	.76**
	Autism	13	90	103		
Total		90	100	190		

***p<.01*

Table 3.9 indicates that there is a significant association between the test results and ICD-10 diagnosis, when cut-off 7 was adopted for classification of cases.

Table 3.10. *Showing association between test results and clinical diagnosis with cutoff-9 for the whole sample (n=190).*

		Clinical Diagnosis		Total	Chi-square (df=1)	Cramer's V
		No-Autism	Autism			
Test results with Cut-off 9	No-Autism	81	12	93	115.33**	.78**
	Autism	9	88	97		
Total		90	100	190		

***p<.01*

Table 3.10 indicates that there is a significant association between the test results and ICD-10 diagnosis, when cut-off 9 was adopted for classification of cases.

Table 3.11. *Showing association between BISCUIT Part 1 and clinical diagnosis with cutoff-21 for the whole sample (n=190).*

		Clinical Diagnosis		Total	Chi-square (df=1)	Cramer's V
		No-Autism	Autism			
BISCUIT Part 1	No-Autism	77	8	85	115.24**	.78**
	Autism	13	92	105		
Total		90	100	190		

***p<.01*

Table 3.11 indicates that there is a significant association between BISCUIT Part 1 and ICD-10 diagnosis.

Table 3.12. *Showing association between test results and BISCUIT Part 1for the sample (n=190).*

		BISCUIT Part 1		Total	Chi-square (df=1)	Cramer's V
		No-Autism	Autism			
Test results with Cut-off 9	No-Autism	78	15	93	112.84**	.77**
	Autism	7	90	97		
Total		85	105	190		

***p<.01*

Table 3.12 indicates that there is a significant association between the test results and BISCUIT Part 1 autism diagnoses.

Table 3.13. S*howing the canonical disciminant analysis of test results versus clinical diagnosis for the whole sample (n=190).*

		Clinical Diagnosis		Hit rate	Wilks' Lambda
		No-Autism	Autism		
Test results with Cut-off 9	No-Autism	81	12	88.9%	.393**
	Autism	9	88		

***p<.01*

Table 3.13 indicates that test, with a cut-off of 9, was able to identify 88.9% participants into autism or non-autism group correctly.

Table 3.14. S*howing the canonical disciminant analysis of* BISCUI Part 1 diagnosis *versus clinical diagnosis for the whole sample (n=190).*

		Clinical Diagnosis		Hit rate	Wilks' Lambda
		No-Autism	Autism		
BISCUI Part 1 diagnosis	No-Autism	77	8	88.9%	.393**
	Autism	13	92		

***p<.01*

Table 3.14 indicates that test, with a cut-off of 9, was able to identify 88.9% participants into autism or non-autism group correctly.

Table 3.15. *Showing Diagnostic Efficiency Statistics*.

Tests	Sensitivity	Specificity	Hit rate	Positive Predictive Valdidity	Negative Predictive Validity	Likelihood ratio
New Scale	.88	.90	.89	.91	.87	8.80
BISCUIT Part 1 diagnosis	.92	.86	.89	.88	.91	6.37

Table 3.15 shows that both the new scale and BISCUIT have same hit rate but the new scale has slightly lower sensitivity than the latter. However, the new scale seems to have better specificity, positive predictive validity, and likelihood ratio than BISCUIT.

Table 3.16. Showing diagnostic efficiency statistics for different cut-offs across various age groups.

S.No.	Age	Autistic	Non-autistic	AUC	Cutoff	SN	SP
I	< 24 months	2	30	.98	4.5	1.00	.83
	> 24 months	98	60	.92	5.5	1.00	.87
II	< 30 months	10	39	.94	4.5	1.00	.80
	> 30 months	90	51	.94	6.5	.90	.88
III	< 36 months	24	49	.91	4.5	.92	.82
	> 36 months	76	41	.94	6.5	.92	.85
IV	< 48 months	50	39	.91	4.5	.92	.85
	> 48 months	50	51	.94	8.5	.94	.92

Note: SN = Sensitivity; SP = Specificity

Table 3.16 shows diagnostic efficiency statistics of the new scale with different cutoffs across different age groups. The table clearly indicates that cutoff 5 (i.e. 4.5 rounded off to the nearest whole number) could be used as a cutoff for age groups below 48 months to identify autism. For those above 48 months, cutoff 9 (i.e. 8.5 rounded off to the nearest whole number) could be used as a cutoff on this scale.

Chapter 4: Discussion and conclusion

Early indicators of autism could comprise of behaviours and developmental manifestations that are not specific to autism. Therefore, we need to focus on both specific and non-specific behavioural and developmental issues in order to identify autism in early childhood (Matson et al., 2011). The scale developed in this study has 40 items with high internal consistency, and a factor loading on socio-communication. It also corroborate with mothers identifying speech problems, eye-contact/visual problems as early concerns in children with autism. The symptoms identified in the scale are largely confining to the earlier literature. The scale is given as Appendix-7.

The scale developed in this study shows high internal consistency; and diagnostic efficiency on par with BISCUIT. This scale can be used for screening children between 4 months to 84 months. If the children are below 48 months, a cutoff of 5, and if they are above 48 months, a cutoff of 9 is proposed to indicate autism. Those children identified positive by the test may be followed up for detailed assessment and appropriate intervention. Future studies may be planned to conduct longitudinal studies to examine the course and outcome of autism by using this scale.

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Appendix 1

Early Behavioural and Developmental Indicators of Autism
(A study supported under Reeta Peshwaria Fellowship 2014)
Socio-demographic and clinical data sheet

Identification data:

1. Name: _____ **S. No.**
2. Age : _____ **Date:**
3. Sex : 1. Male 2. Female
4. Education: _____

Demographic data:

5. Name of the father:
6. Age of the father:
7. Education of the father: 1. Primary 2. Secondary 3. Intermediate 4. Graduation 5. ≥ PG
8. Occupation of the father: 1. Govt. Employee 2. Pvt. Sector 3. Business 4. Skilled labourer 5. Seasonal/casual labourer 6. Others
9. Name of the mother:
10. Age of the mother:
11. Education of the mother: 1. Primary 2. Secondary 3. Intermediate 4. Graduation 5. ≥ PG
12. Occupation of the mother: 1. Govt. Employee 2. Pvt. Sector 3. Business 4. Skilled labourer 5. Housewife 6. Seasonal/ casual labourer 7. Others
13. Domiciliary: 1. Urban 2. Semi-urban 3. Rural
14. Monthly income (approximately): _____ pm
15. Number of siblings:
16. Birth order of the child:
17. Disabilities/impairments in the family or first degree relatives: 1. Yes 2. No
18. If yes, please specify the condition:
19. Chronic illnesses in the family or first degree relatives prior to the birth of the child: a. Yes 2. No
20. If yes, please specify the condition:

Clinical Variables:

21. Age of detecting abnormality/atypicality in child: _____
22. Main concern/atypicalities you have first spotted: _____
23. Age of child at the time of first contact with professionals:
24. ASD Diagnosis:_____ [core feature:_____]
25. Any other major medical diagnosis: 1. Yes [_____] 2. No
26. Age of child at the time of Diagnosis: _____
27. Professional who diagnosed ASD: 1. Psychiatrist 2. Pediatrician 3. Psychologist 4. Speech Therapist 5. Occupational Therapist 6. Special Educator 7. Others (specify)
28. Nature of consultations: 1. Hospital-based 2. Centre-based 3. Community-based 4. Others (specify)
29. Laboratory findings (if any): _____
30. IQ Level/ Level of general intelligence:_____
31. Scores of autism rating scales, if applied any:_____score on _____Scale
32. Any other specific, relevant information: _____

Developmental history

	Gross Motor (Delays or skipped)	**Age of development**	**Any regression**
1.	Neck holding		
2.	Rolling over		
3.	Sitting		
4.	Standing		
5.	Walking		
6.	Climbing stairs		
7.	Climbing on things (chair, table, window, etc.)		
8.	Running		
	Fine motor		
9.	Grasping		
10.	Releasing		
11.	Scribbling		
	Language -verbal		
12.	Responding to name		
13.	Follows commands/instructions		
14.	Cooing		
15.	Babbling		
16.	First Words		
17.	Talking in phrases		
18.	Talking in sentences		
19.	Independent in toileting		

	Any of the following were observed at any point of time during childhood?	**Yes/no**	**If yes, age when observed**
20.	Hypontonia – no muscle tone(like a rag doll)/low muscle tone (floppy)		
21.	Hypertonia – rigidity – general/specific body part		
22.	Predominant nature of play		
	a) Exploratory		
	b) Solitary		
	c) Parallel		
	d) Pretend		
	e) Imaginary		
	f) Games with rules		
	g) Video games/mobile apps		

Appendix- 2

List of the organizations/personnel facilitated/coordinated data collection

Name of the Organization	**Address for communication**
Ambika Shishu Kendra, Kurnool, Andhra Pradesh	Mrs. Bindu N Shah Director Ambika Shishu Kendra 44/86-C, Prakash Nagar Kurnool- 518004, AP, India
National Institute for the Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai	Dr. Bala Bhaskar Lecturer, Department of Adult Independent Living NIEPMD East Coast Road, Muttukadu, Kovalam Post Chennai - 603112, Tamil Nadu.
National Institute for the Mentally Handicapped (NIMH) Regional Centre, Kolkata	The Officer-in-Charge NIMH Regional Centre NIOH Campus BT Road Bon Hooghly Kolkata 700090
National Institute of Public Cooperation and Child Development (NIPCCD)- Regional Centre, Lucknow	Shri. Sunil Kumar Assistant Director NIPCCD- Regional Centre PO Gudumba, Kursi Road (Near Sports College) Lucknow- 226007
Society for Advanced Studies in Rehabilitation, Faridabad, Haryana	Dr. Himangshu Das Society for Advanced Studies in Rehabilitation Integrated Institute for The Disabled, B45, Dayal Bagh, Charmwood, Faridabad 121009, Haryana
Sree Ramachnadra Medical College, Chennai	Dr Lalitha. Subramaniam Asst. Professor of Clinical Psychology Sree Ramachnadra Medical College Intra College Rd, Potheri, Guduvancheri, Chennai-603 203 Tamil Nadu

Note: Normative data was obtained by the researcher in Kurnool, Andhra Pradesh; and by Ms. Swathikrishna Yadav. Consultant Health Psychologist in Vishakapatnam, Andhra Pradesh.

Appendix 3

List of experts who coordinated/directly involved in vernacular translations of the tools and IEC formats used for this study.

Language	Expert
Bengali	**Mrs. Alakananda Bandopadhyay &** **Mrs. Sucharita Dutt** National Institute for the Mentally Handicapped (NIMH) Regional Centre, Kolkata NIOH Campus, BT Road Bon Hooghly Kolkata -700090, West Bengal
Hindi	**Dr. Mosumi Bhaumik** NIMH Regional Centre, Lajpat Nagar, New Delhi 110024 & **Dr. Himangshu Das** Director Society for Advanced Studies in Rehabilitation Faridabad-121009, Haryana
Tamil	**Dr. Lalitha Subramaniam** Sree Ramachnadra Medical College Intra College Rd, Potheri, Guduvancheri, Chennai - 603 203, Tamil Nadu
Telugu	**Dr. M.Thomas Kishore** Associate Professor Dept. of Clinical Psychology NIMHANS Banaglore 560029, Karnataka

Appendix 4

Flyer for the participants and organizations

Name of the Study: Early developmental and behavioral indicators of autism

Background: Studies indicate that early identification leading to intervention 20 hours of weekly, individualized, language focused programmes are found to be effective in reducing autism spectrum disorders (ASD) by more than 80%. But across the globe, average age of detection is 2½ years and it is not until another two years that they receive proper assessment, diagnosis and intervention. In India, the average age of detection is same as any developed country but it is not before six years proper diagnosis and intervention is facilitated. In this context, early identification is very important in the management of ASD.

Aim: To identify developmental and behavioural indicators that facilitates early identification and intervention.

How it is proposed to be done?
We need to directly interact with parents of children with autism whose children are below six years of age. The parents will be asked questions related to the development of their child with ASD by using the following questionnaires:

1. Checklist developed as part of the study.
2. The Baby and Infant Screen for Children with *aUtIsm* Traits (BISCUIT)
3. Developmental Screening Test (DST)
4. Vineland Social Maturity Scale (VSMS)

How much time it may take?

It may take about 1½ to 2 hours for each parent; and another 30 minutes for debriefing about the results.

Are there any risks for the child or the parent?

No. There are no risks for either the child or the parent. But parents may not feel comfortable answering all the questions related to the development of the child, which is a kind of reviewing the atypicalities in the children. But parents have the freedom not to answer certain questions.

What are the rights of the parents?

1. Parents can opt out of the study at any point of time.
2. Guarantee for privacy and confidentiality of the information.

Who is funding the study?

The study is funded by the India Vision Foundation, New Delhi under the prestigious 'Reeta Peshawaria Fellowship 2014'. The fellowship is instituted by the India Vision Foundation, New Delhi after late Dr. Reeta Peshawaria, who dedicated her professional lifetime for the cause of developmental disorders, particularly, the intellectual disabilities and ASDs.

Do you have to stop any of your prescribed medications or treatment?
No. You **need not stop** any medicines or treatment programmes prescribed either by your physician or other consultants. You can continue with your regimen.

How this data will be used?
This data will be used solely for **research**. Your name and identity will not be disclosed to anyone other than the research team. The data will be kept confidential, and would be analyzed so as to be helpful in the implication for national health policies on early detection and prevention of depression in chronic illnesses.

Can you leave the study in middle?
This is only one time collection of information. In case you feel uncomfortable answering any questions you may choose not to complete the questionnaire.

Are any monitory benefits to the participants?
No. The study has no provision for monitory benefits for the participants. But a token amount will be considered covering the minimum cost of travel to the site of study; and refreshments will be provided during the study period.

Who is the researcher?
Dr. M. Thomas Kishore, Associate Professor of Health Psychology, Centre for Health Psychology, University of Hyderabad, Prof. CR Rao Road, Gachibowli, Hyderabad 500046. Ph: 91-8790118253; mtkpsy@gmail.com

Can we contact the researcher?
Yes. You may contact the researcher by any of the following: surface mail, email and phone (details are as given above) to get more information about the study or about ASD.

Appendix 5

Early developmental and behavioral indicators of autism
(A study conducted under Reeta Peshawria Fellowship 2014)

Informed Consent Form

This is to state that I have read the information sheet carefully and understood the details of the study. I have been given ample time by the Research Team to clarify my doubts and understand the procedure of the study and my role and extent of participation. I give my consent to participate in the study titled "Early developmental and behavioral indicators of autism" conducted by Dr. M. Thomas Kishore of the Centre for Health Psychology, University of Hyderabad, Hyderabad 5000 046.

1. I am willing to give the Socio-demographic information as required by the study.
2. I give my consent for the administration of the following questionnaires regarding my child with autism spectrum disorders
    a. Checklist developed as part of the study.
    b. The Baby and Infant Screen for Children with *aUtIsm* Traits (BISCUIT)
    c. Developmental Screening Test (DST)
    d. Vineland Social Maturity Scale (VSMS)

Date: Signature of the Subject

Name of the Subject

Address

Phone No

E-mail

Signature of the interviewer

Appendix 6

Ethical approval from the local body

Geeta Vemuganti <[redacted]> Mon, Aug 4, 2014, 10:13 AM

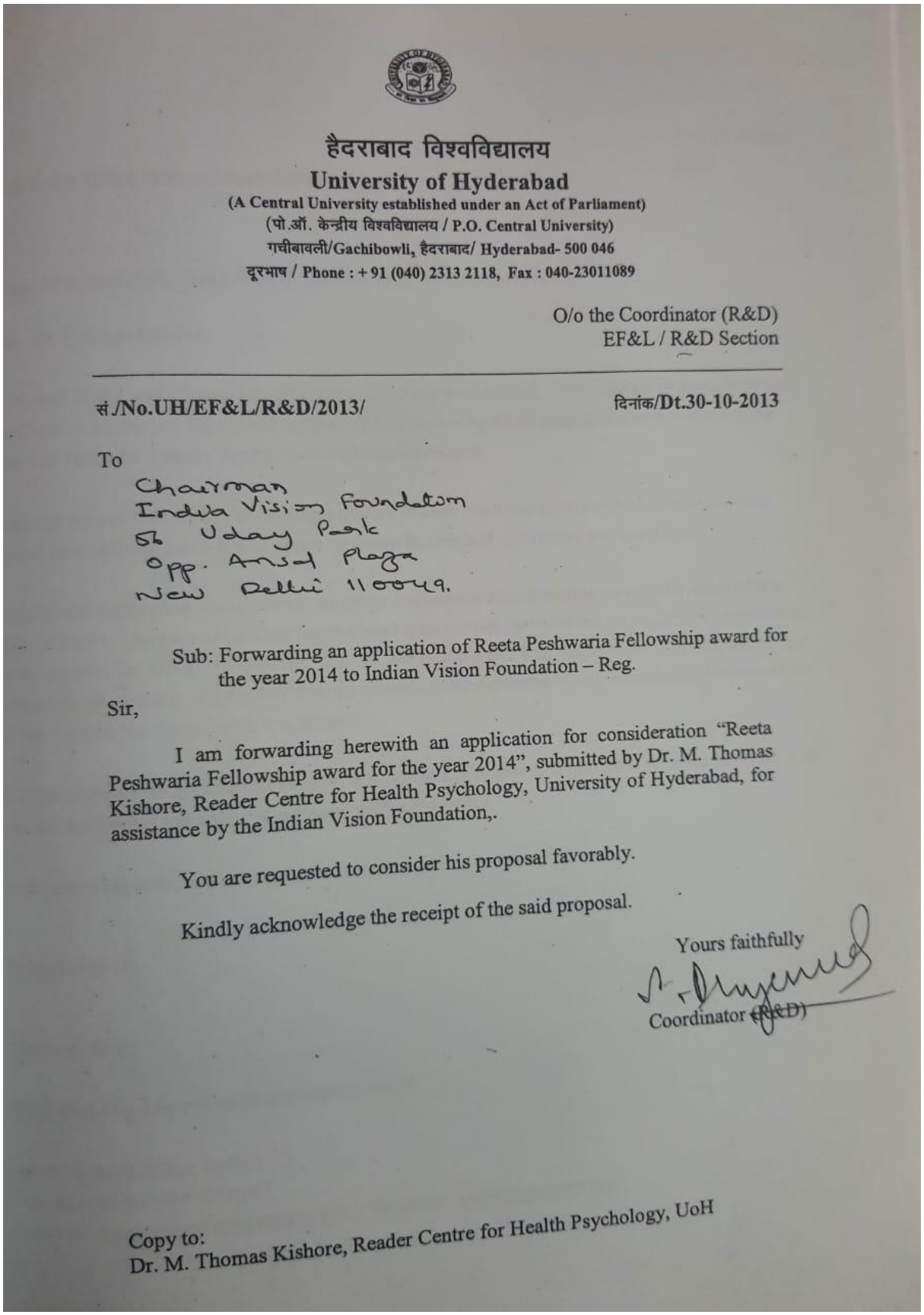
to Thomas Kishore

Dear Dr Thomas

While your proposal is approved in principle, as suggested at the IEC meetign, kindly submit the approval of all participating institutions. Outstation cases, pl see if you can have an IEC approval from there

Geeta

--
Prof Geeta K Vemuganti, MD, DNB, FAMS, FICP
Dean, School of Medical Sciences
University of Hyderabad
Prof C R Rao Road
Gachibowli
Hyderabad 500046
Phone: 91-40-23013279/23134781
Email: ****d@uohyd.ernet.in
****md@uohyd.ernet.in
***nti@gmail.com



हैदराबाद विश्वविद्यालय

University of Hyderabad

(A Central University established under an Act of Parliament)
(पो.ऑ. केन्द्रीय विश्वविद्यालय / P.O. Central University)
गचीबावली/Gachibowli, हैदराबाद/ Hyderabad- 500 046
दूरभाष / Phone : + 91 (040) 2313 2118, Fax : 040-23011089

O/o the Coordinator (R&D)
EF&L / R&D Section

सं./No.UH/EF&L/R&D/2013/ दिनांक/Dt.30-10-2013

To
Chairman
India Vision Foundation
54 Uday Park
Opp. Ansal Plaza
New Delhi 110049.

Sub: Forwarding an application of Reeta Peshwaria Fellowship award for the year 2014 to Indian Vision Foundation – Reg.

Sir,

I am forwarding herewith an application for consideration "Reeta Peshwaria Fellowship award for the year 2014", submitted by Dr. M. Thomas Kishore, Reader Centre for Health Psychology, University of Hyderabad, for assistance by the Indian Vision Foundation,.

You are requested to consider his proposal favorably.

Kindly acknowledge the receipt of the said proposal.

Yours faithfully

Coordinator (R&D)

Copy to:
Dr. M. Thomas Kishore, Reader Centre for Health Psychology, UoH

Appendix 7

Scale for identifying early behavioural and developmental indicators in autism

Note: Read each of the following statement carefully and see if it is generally noted in the child. If yes, score 1, and if no, score 0. Each item is described at the end if clarification is needed.

S.No.	Abnormality	Score
1.	Does not pay attention to the task	
2.	Has low attention span	
3.	Actively avoids social solicitation/interaction	
4.	Slow to warm up to interaction even with familiar people	
5.	Anxious to change though adapts with repetition over time	
6.	Poor reciprocity/disinterested in engaging with people	
7.	Overactive	
8.	Does not react to social solicitation	
9.	Avoids eye contact	
10.	Generally restless	
11.	Has a history of loss of verbal language	
12.	Difficulty in initiating / maintaining/ terminating conversation	
13.	Abnormal attachment to specific person (s)	
14.	Apparently does not display emotions	
15.	Cannot follow cues from body language or facial expressions of others	
16.	Remains aloof/withdrawn and is oblivious of surroundings	
17.	Hypersensitive to wetness (e.g. water/paint/liquid/jelly textures)	
18.	Runs aimlessly	
19.	No progress in language	
20.	No response to others' emotions	
21.	Restricted language such as telegraphic speech and monotonous voice	
22.	Flaps hands	
23.	Jumps aimlessly	
24.	Prefers repetitive play	
25.	Prefers repetitive textures including water	

26.	Does not react to any taste/texture	
27.	Has an empty gaze or gazes through things and people	
28.	Resistant to change in routine/ritual	
29.	History of loss of non-verbal communication	
30.	Uses peripheral vision to gaze	
31.	Problems with imitation of speech and/or echolalia	
32.	No adequate sense of danger or safety	
33.	Difficulty to separate from family members/specific person	
34.	Inappropriate response to emotions	
35.	Acts as if not mindful of consequences	
36.	Has stereotyped movements	
37.	Makes strange gestures	
38.	No specific reaction to separation from family members	
39.	No adequate response to name	
40.	Selective preference or dislike for certain taste and/or texture of food	
	Total Score	

Interpretation: This scale can be used for screening children between 4 months to 84 months. If the children are below 48 months, a cutoff of 5, and if they are above 48 months, a cutoff of 9 is proposed to indicate autism spectrum disorders.

Item description

Item .No.	**Description**
1.	Does not pay attention to the task: If any age appropriate task/activity is given the child does not pay adequate attention.
2.	Has low attention span: The child has low attention in general.
3.	Actively avoids social solicitation/interaction: In general the child actively avoids social solicitations/interactions such as cuddling, patting, reaching out, talking, etc. even with familiar people and situations. Or, similar behaviours noted with others though the situations are non-threatful.
4.	Slow to warm up to interaction even with familiar people: In general the child is slow to warm up when cuddled, patted, reached out to, talked to by familiar people in routine situations.

5.	Anxious to change though adapts with repetition over time: The child may show anxiety in the form of avoiding, crying or resisting when any change is brought in routine, though he may eventually adapt to this.
6.	Poor reciprocity/disinterested in engaging with people: The child apparently prefers objects to human beings. For example, when a toy is shown, the child is more interested in the toy rather than the whole activity of playing with another person
7.	Overactive: It appears as the child has more energy but subjective discomfort is not evident.
8.	Does not react to social solicitation: The child is apparently very cold and unresponsive to social interaction by others, both familiar and unfamiliar people, in general.
9.	Avoids eye contact: The child actively avoids eye contact even where eye contact is required and tenable.
10.	Restless: The child shows overactivity with apparent distress or discomfort. It may evident when any activity is initiated or otherwise.
11.	Has a history of loss of verbal language: The child has a history of typical verbal language development and lost it. parents/ caregivers usually report that the child has a loss of language for certain period at least
12.	Difficulty in initiating / maintaining/ terminating conversation: This is applicable only in case of children who are verbal. Despite having capacity to communicate verbally, the child shows difficulty in initiating / maintaining/ terminating conversation.
13.	Abnormal attachment to specific person (s): The child may show disproportionately more attachment with specific person or persons; and he may appears clingy and may cry or show restlessness when the specific person(s) leaves the child behind. Or, the child may appear lost when attached figures are not around.
14.	Apparently does not display emotions: Basic emotions such as anger, happiness or sadness are not usually seen.
15.	Cannot follow cues from body language or facial expressions of others: The child has problems in following body language or facial expressions e.g. Hand gestures communicating specific commands; facial expressions communicating specific emotions or intention.
16.	Remains aloof/withdrawn and is oblivious of surroundings: The child appears lost by

	self or is withdrawn. This may become more obvious when the child is alone or not actively engaged by an adult.
17.	Hypersensitive to wetness (e.g. water/paint/liquid/jelly textures): The child may react in an exaggerated fashion when comes in contact with wet substances. It may be noted while giving the child a bath or when the child has to feed self by mixing or holding loose, wet food with hands (e,g. *Dal-Rice, Sticky candies, etc*).
18.	Runs aimlessly: The child runs apparently without any goal.
19.	No progress in language: This is scored positive when caregivers report that the language reached a plateau or that there is no further improvement after a specific period of typical development.
20.	No response to others' emotions: The child does not react when the caregivers are laughing or sad or angry; this deficit could be seen even in play activities such as peek-a-boo.
21.	Restricted language such as telegraphic speech and monotonous voice: The child's language appears restricted to specific objects/events or too crisp to make a unfamiliar person understand the intention of speech.
22.	Flaps hands: The child flaps hands repetitively.
23.	Jumps aimlessly: The child jumps aimlessly.
24.	Prefers repetitive play: The child prefers same play or play material despite a variety of options are available.
25.	Prefers repetitive textures including water: The child shows high interest in touching specific objects or textures repeatedly.
26.	Does not react to any taste/texture: The child appears unmindful of the taste or touch.
27.	Has an empty gaze or gazes through things and people: The child looks at the speaker/caregiver very passively, with a blunt affect (i.e. no display of emotions on face)
28.	Resistant to change in routine/ritual: The child resists any change in routine such as those in daily activities.
29.	History of loss of non-verbal communication: The caregivers identify very clearly that gestures, facial expressions and/or movements that earlier used for communication are lost.
30.	Uses peripheral vision to gaze: The child looks at others or objects through peripheral vision i.e. the child do not give active eye contact.

31.	Problems with imitation of speech and/or echolalia: The child has problems in imitating speech of the caregiver/speaker. Or the child may repeat the command or question instead of answering or acting out.
32.	No adequate sense of danger or safety: The child does not understand danger as evident in running across street animals; touching hot/ live electrical appliances; going with strangers, poking self with objects etc.
33.	Difficulty separating from family members/specific person: It is somewhat similar to item 13. The child has shows restlessness or agitation when moved away from specific, familiar people. The occasion may be handing over the child to others for standby care; leaving the child in a crèche; when the caregivers are leaving the child behind at home, etc.
34.	Inappropriate response to emotions: The child shows some strange, inappropriate reactions instead of expected emotional reactivity to situations.
35.	Acts as if not mindful of consequences: This item is somewhat similar to item 32. But here the situations in which this behaviour is noted is not as grave and obviously dangerous as described in item 32. This item is coded positive when the child is unmindful of consequences his actions in general.
36.	Has stereotyped movements: The child may show varied, purposeless, repetitive behaviours such as whirling, posturing, cuddled-up, nodding, etc.
37.	Makes strange gestures: The child makes gestures that are not understandable or not relevant or appropriate for a given activity/situation.
38.	No specific reaction to separation from family members: This is somewhat opposite to item 13 and 33. The child apparently does not show any specific reactions in the event of separation from family members.
39.	No adequate response to name: The child does not respond when called by name. Note: The name has to be the one frequently used by the family members. Hence it may include a pet name as well.
40.	Selective preference or dislike for certain taste and/or texture of food: The child shows his dislike for certain taste and textures by making faces/gets irritated refusing to touch them; conversely his preference could understood when opposite behaviours are noted.

General tips for assessment:

1. The examiner is at the liberty to use wide variety of examples, situations and activities to elicit information regarding a particular event.
2. A skilful examiner may look for examples beyond those given in the description.
3. Process is more important than the outcome such as number of positive items.
4. Even when a child falls below the cutoff, it is important to note the behaviours that are coded positive and probe further whether any intervention is required.

Appendix 8

Experts who supported e with their valuable inputs at various stages of the project

Dr.	Alka Nizamie	Ranchi
Dr.	Anirban Basu	Kolkata
Dr.	Arun Singh	New Delhi
Dr.	B Binukumar	Bengaluru
Dr.	Bala Bhaskar	Chennai
Dr.	Beenapani Mahapatra	Hyderabad
Dr.	D.K. Menon	US
Dr.	Himangshu Das	Faridabad
Dr.	Jayanthi Narayan	Hyderabad
Dr.	Lalitha Subramaniam	Chennai
Dr.	Mallika Banarjee	Kolkata
Dr.	Masroor Jahan	Ranchi
Dr.	Mousumi Bhaumik	New Delhi
Dr.	Nachiketa Raut	Chennai
Dr.	Nibedita Patnaik	Hyderabad
Dr.	Omsai Ramesh, V	New Delhi
Dr.	Prasanta Kumar Ray	Kolkata
Dr.	Ram Lakhan	US
Dr.	Saroj Arya	Hyderabad
Shri.	T.C. Shiv Kumar	Hyderabad
Dr..	Suman Kumar	New Delhi
Shri.	Sunil Kumar	Lucknow
Dr..	Surrender kr. Dhalwal	Dehradun
Dr.	Tanmoy Mukherjee	Kolkata

Appendix 9

Permission to use gold standard scale and an article:

Permission
Inbox

Thomas Kishore <[redacted]> Tue, Mar 3, 2015, 12:59 PM

to vincent.guinchat

Dear Dr. Vincent Guinchat,

Reference: Guinchat, V., Chamak, B., Bonniau, B., Bodeau, N., Perisse, D., Cohen, D., & Danion, A. (2012).Very early signs of autism reported by parents include many concerns not specific to autism criteria. *Research in Autism Spectrum Disorders*, 6, 589–601.

I am working on a study to explore the early indicators in autism spectrum disorders. Most of the studies I have come across individually have been quoted in your study referred above and therefore, I would like to use as a major source in pooling items for including in the scale on early indicators:

I will be very grateful if I am given permission for the same. I will be very glad to clarify if you have any in this regard.

With regards,

Thomas

--

Dr. M. Thomas Kishore
Associate Professor of Clinical Psychology
Department of Clinical Psychology
M.V. Govindaswamy Center, 3rd Floor
NIMHANS, Bangalore - 560029, India
Phone: +91-80-26995180 (o)

GUINCHAT Vincent <[redacted]> Tue, Mar 3, 2015, 3:16 PM

to me

No problem.

Kindly yours

Thomas Kishore <[redacted]> Fri, Apr 4, 2014, 2:55 PM

to johnmatson

Dear Professor Matson,
I would like to inform you that I am working on a project to look at the early indicators of autism. As part of the study I plan to use BISCUIT Part-1 by translating it into vernacular languages (Telugu, Hindi, Tamil and Begali; all four are Indian languages). I would be very grateful if you would kindly give me permission for the same.
I will be very glad to answer in case you have any questions on the study.
With regards,
Thomas

--
Dr. M. Thomas Kishore
Reader in Health Psychology
Centre for Health Psychology
University of Hyderabad
Hyderabad 500046
...

Use of the BISCUIT
Inbox

Rachel Goldin <[redacted]> Fri, Apr 4, 2014, 8:12 PM

to me

Dear D. Kishore,

My name is Rachel and I am contacting you on behalf of Dr. Matson. Dr. Matson will provide you with the BISCUIT to use only for research purposes and under certain guidelines. First, if he provides you with the BISCUIT, all 3 parts of the measure, the bservation component, and the manual must be translated. Copies of the translated measure and manual need to be provided to Dr. Matson. Second, the measure must only be used for research and not for clinical purposes.

We would also like to invite you to participate in an international study using the BISCUIT we are currently conducting. Attached is a letter from Dr. Matson explaining the purpose of the study.

Please let me know if you can agree to Dr. Matson's guidelines for use of the BISCUIT for research and if you have have any further questions.

Additionally, please let me know if you are interested in participating in our international study or if you would like any more information on the study.
Thanks,
Rachel
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Louisiana State University

Appendix 10

Publication of the scale in the Indian Journal of Psychiatry

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Development of a scale for identifying autism spectrum disorder during early childhood

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Affiliations + expand

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Abstract

Context: Assessment forms an important part of the early intervention in autism spectrum disorders (ASD). However, there is not much choice with regard to tools and methods for early identification and assessment of ASD.

Aims: The aim is to develop a scale for identifying ASD during infancy and early childhood by mapping empirically supported skill behaviors and excess behaviors.

Settings and design: The study was conducted in community-based organisations and the local communities. Moreover, it employed a *post facto* research design, with survey method.

Materials and methods: Following the standard procedures to pool items and standardization, a scale was developed and administered to three groups of children (N = 190) including children with autism (n = 100), global developmental delay suggestive of mental retardation (n = 40) and neurotypicals (n = 50) in the age range of 1.5-6 years. The ICD-10 Classification of Mental and Behavioural Disorders and Baby and Infant Screen for Children with aUtism Traits (BISCUIT) were the gold standards to diagnose ASD.

Statistical analysis used: Descriptive statistics (frequency, percentages, median, and quartile deviation), Pearson's correlation, Cronbach's α, factor analysis, and binary logistic regression analysis with receiver operating characteristic curve were performed.

Results: The new scale also demonstrated a high diagnostic efficiency by yielding a hit rate of 0.89, specificity of 0.90, and sensitivity of 0.88.

Conclusions: The new scale can be used for early identification of ASD in the Indian population, though further validation with large population is required.

Keywords: Autism spectrum disorder; Baby and Infant Screen for Children with aUtism; India; early childhood; identification.

Note: The above is a snapshot of the information available on PubMed where full text links are also available. See, https://pubmed.ncbi.nlm.nih.gov/30581209/

Early identification of autism spectrum disorder

M. Thomas Kishore

Autism is a neurodevelopmental disorder characterized by significant impairments in socio-communication, social interactions, restricted or inflexible interests and repetitive behaviours. Currently, it is considered a spectrum disorder because the cluster of symptoms and the severity vary across the individuals. Some individuals may have additional neurodevelopmental conditions like intellectual disability, ADHD, and Expressive Communication Disorder. The nature of autism is such that socio-communication deficits and limited interests can overshadow the cognitive abilities and interfere with the adaptive behaviour of the individual (American Psychiatric Association, 2013). There is no cure because it is a neurodevelopmental condition. However, the impact of autism spectrum disorder (ASD) can be minimized by early identification and intervention (Landa & Garrett-Mayer, 2006; Barbaro & Dissanayake, 2009).

There are no epidemiological studies on autism in India, but it is estimated that approximately one in every 100 children under 1-15 years of age has ASD (Chauhan et al., 2019). According to a conventional estimate, the prevalence rates of ASD may not be very different from the rest of the world and there might be nearly two million people with ASD in India (Directorate General of Health Services, 2011). A few children seem to develop ASD after some period of normal development, but the current understanding is that autism is generally present from birth (Bryson, Rogers, Fombonne, 2003; Volkmar, Chawarska, & Klin, 2005).

B). Current diagnostic systems

The two major existing diagnostic frameworks for ASD, DSM-IV and ICD-10, both describe three defining dimensions of ASD as follows: 1) deficits in social reciprocity, 2) deficits in communication and 3) presence of restricted, repetitive behaviours and interests. However, ASD definitions in both new systems, DSM-5 and ICD-11 have undergone two important changes- one, the concept of 'autism spectrum disorders' whereby the three conditions are formerly known as Childhood autism, Asperger syndrome and Pervasive Developmental Disorder-Not otherwise specified are now considered a single disorder. Second, the condition is identified mainly by two domains: (1) social communication/ social interaction and (2) restricted, repetitive behaviours and interests (Lord & Jones, 2012). The new diagnostic criteria in DSM-5 and ICD-11 propose three principles in defining diagnostic features within the social dimension: social-emotional reciprocity; nonverbal communicative behaviours used for social communication; deficits in developing and maintaining relationships. To receive a diagnosis of ASD, an individual must show difficulty either in understating or using at least one skill within each of the three levels. However, the challenges are, that these levels are not empirically

defined; and we do not have a clear understanding of the early manifestation of behavioural deficits across these levels. These issues have implications for early identification because it is difficult to identify many of these deficits under the age of 2 years let alone attribute them to ASD (Volkmar, Chawarska, & Klin, 2008). Adding to the complexity of early identification, there could be several, non-specific developmental or behavioural problems during early age (Guinchat et al., 2012). Therefore, there is a scope for close monitoring and surveillance of children who show atypical behaviours and developmental problems during the early stages. In other words, there is a scope for the development of tools focusing on atypical behaviours and developmental concerns during infancy and early childhood (Kishore & Basu, 2011, 2014).

C). Autism during infancy and early years

Most of our understanding of the initial manifestation of autism comes from parental reports and home videos taken on birthdays of the affected children or during family celebrations (Volkmar, Chawarska, & Klin, 2008). There is consistent evidence that the vast majority of parents of children with ASD first notice abnormalities during the course of the first 2 years of life (Chawarska et al., 2007). But early identification by parents did not always result in early diagnosis and intervention. Independent of initial concern, children with ASD received a diagnosis and intervention only at around four years of age. So there is a huge gap between early identification and diagnosis of autism, and this phenomenon is universally observed (Chawarska et al., 2007; Kishore & Basu, 2011; Daley, 2004). Let us look at some of the early behavioural deficits identified in children who later received a diagnosis of ASD:

Before 2 years
Less likely to look/smile/vocalize at and seek other people by 6 months of life
Poor response to name
Poor imitation
Difficulties in disengagement of visual attention
Delays in receptive and expressive language.
Temperamental difficulties with initial passivity followed by extreme distress reactions by 12 months.
Regression of words, vocalizations, nonverbal communication skills

3-4 years
Diminished eye contact
Limited interest in social games and turn-taking exchanges
Low frequency of looking referentially at parents
Preference for being alone
A limited range of vocal and motor imitation and symbolic play skills; and facial expressions
Infrequent instances of sharing affect
Difficulty using gestures or gaze to communicate interest or joint attention
Responsivity to speech in general, and to his or her name in particular, continues to be limited Vocalizations may take on an abnormal quality
Stereotypic and repetitive behaviours reach clinical threshold
Adaptive skills are much delayed than their current level of intellectual and developmental level Difficulties in adapting to new situations
Interest in visually repetitive phenomena
Over-attention to the non-social environment

Overall, the review indicates that behavioural abnormalities and atypical developmental patterns could be seen across all core domains of ASD viz. social reciprocity and social communication, but with a wide variation across individuals. Therefore, we need to focus on all of these domains to identify ASD during early childhood (Kishore and Basu, 2011). Though, it may not always be possible for identifying ASD only through behavioural observation. Hence there is a need for systematic efforts such as assessment with appropriate tools.

C). Tools available for early identification of ASD

There are at least twelve scales for early identification of autism spectrum disorders in infants and toddlers. They are: Pervasive Developmental Disorders Screening Test-II, Screening Tool for Autism in Two-year-olds, First Year Inventory, Communication and Symbolic Behavior Scales Developmental Profile, Revised Psychoeducational Profile, Parent Concern Checklist, Early Screening of Autistic Traits Questionnaire, Young Autism and other developmental disorders Checkup Tool, Preschool Imitation and Praxis Scale, Social Communication

Questionnaire, Checklist for Early Signs of Developmental Disorders, Autistic Behavioural Indicators Instrument, and Baby and Infant Screen for Children with aUtIsm Traits. But a comprehensive review indicates that none of the existing tools is suitable for the identification of autism during infancy (see, Brian et al., 2008; Matson, Rieske, & Tureck, 2011; World Health Organization, 2011). The challenges will increase further with cultural diversity where the notions of social reciprocity and accepted levels of social and 'normal' communication patterns are solely defined by societal and cultural norms.

D). Development of a new scale for early identification of ASD

Universal screening procedures are impeded by the varying patterns of onset of ASD. More generally, well-documented diagnostic instruments may work well after age 3–4 years or past a certain developmental level, but their use is not clearly established for infancy (Chawarska et al., 2007). Only trained clinicians are able to detect ASD under the age of 2 (Klin, Lang, Cicchetti, & Volkmar, 2000). But a large number of children and infants are also seen by other professionals such as special educators, psychologists, and community workers (e.g. Anganwadi workers), who may need appropriate screening tools to identify children at risk for autism. In this backdrop, a scale has been developed for the identification of ASD during infancy and early childhood, particularly in the Indian context (Kishore, Menon, & Binukumar, 2018). The scale has been standardised with 190 children (100 children with ASD; 40 children with global developmental delay; and 50 neurotypical children) in the age range of 1.5–6 years. The ICD-10 Classification of Mental and Behavioural Disorders and Baby and Infant Screen for Children with aUtIsm Traits (BISCUIT) were the gold standards to diagnose ASD. The scale has 40 items, with a heavy factor loading on socio-communication skills. Based on binary logistic regression analysis with receiver operating characteristic curve, it is proposed that a cut-off of 5 is indicative of ASD in children below 48 months and a cut-off of 9 is indicative of ASD in children between 48 and 84 months. The scale has good content validity, internal consistency and convergent and clinical validity. For more details about the scale, the readers may kindly refer to the manual.

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