



JUNE 2020

Centre for Advanced Research and Excellence in Autism
and Developmental Disorders

St. John's National Academy of Health Sciences



Newsletter Vol. 1 Issue 1

Patron

Rev. Dr. Paul Parathazham
Director, SJNAHS

Advisors

National:

Prof. Shoba Srinath
Prof. Swarna Rekha-Bhatt
Prof. Dominic Misquith

International

Prof. Lonnie Zwaigenbaum

Core Team:

Dr. M.V.Ashok (Head, CAREADD)
Dr. Vijaya Raman
(Research Lead - Behavioural Sciences)
Dr. G.R.K. Sharma
(Research Lead - Neurosciences)
Dr. Aruna Korlimarla
(Research Lead - Genetics)
Dr. Shyam Rajagopalan
(Research Lead - Computational Sciences)

Research Associate

Dr. Sowmyashree Kaku

Research Staff

Ms. Angelin Grace R.
(Manager - Administration)
Ms. Roopa N. (Manager - Data)
Ms. Srividhya D.
(Senior Research Fellow - Genetics)
Ms. Bhavana Kumaraswamy
(Senior Research Fellow - Clinical Psychology)
Ms. Priyanka Srikantapuram
(Junior Research Fellow - Psychology)
Ms. Manjula W. J.
(Nursing Research Fellow)
Sandesh P. (Administrative Assistant)
Veronica Mary (Housekeeping)

ComDEALL @ CARE-ADD

Early Intervention Therapists

Ms. Supreetha Santhosh
Ms. Satyalakshmi P. S.
Ms. Athira N. D.

Consultants

Dr. Vanitha S. Rao
(Special Education & Neurocognition)
Ms. Nirupama Srikanth
(ComDEALL Early Intervention Program)



The Centre for Advanced Research & Excellence in Autism and Developmental Disorders (CARE-ADD) is a multi-disciplinary research centre that aims to trace the biological underpinnings of Autism and related developmental disorders, while also exploring cost-effective interventions.

The translational output includes the development of tools & technologies for early detection and intervention for Autism and related developmental disorders; and long-term plans are to develop scalable models of care for public health in the State.

The centre will provide screening, assessments, therapy, education and parent training-programmes to address current issues. The centre also envisages developing nationwide research networks and training a wide variety of professionals.

CARE-ADD has been developed through a generous donation by a philanthropist. We are indeed grateful for this visionary support.

Vision

Autism spectrum disorders include children with challenges in social communication and in regulating their behaviours, movements and routines. They may have varying degrees of intellectual difficulties besides a number of challenging behaviours and neurological abnormalities. They may have many a potential that fails to develop for lack of early identification and intervention. Their numbers are growing across the country. And as of date, for many families, a diagnosis of autism translates into a lifelong challenge.

The Centre for Advanced Research and Excellence in Autism and Developmental Disorders, CARE-ADD for short, reflects all that the acronym says – ‘Adding to Care’ and much more. It has clinical and research tracks with training running through both of them. Training and capacity building in health care and related research is the chief mission of our Institution. We hope to take this forward through short term certificate courses as well as longer term Fellowship programs. The Clinical track at CARE-ADD involves developing care models for Early Identification and Early Intervention that can be upscaled to public health settings in the State of Karnataka. We intend using technology to do so along with task shifting processes involving Nurses. The research track includes exploring genetics and neural signals in understanding brain developmental trajectories in children-at-risk for the condition. We will begin with children as young as 9-12 months old, a group that we have been identifying already as part of our ongoing studies. We also hope to develop models of rehabilitation for teenagers and young adults with Autism, a growing number without any recognised paradigms of care.

We intend to achieve our goals through several intra-mural and extra-mural collaborations. We believe that all wings of SJNAHS will work with us actively on shared pursuits. We already have assured collaboration with Com DEALL Trust, a pioneer in developing manualised early interventions for the condition (Page 5). We have initiated discussions to complete collaborative agreements with four leading Institutions in the city. We have begun the process of putting together a board of advisors and are delighted to have eminent persons on this already (Page 4). And our strength comes, as always, from the large informal networks with autism centres that we are fortunate to have across the city; this has resulted in two global autism conventions already this decade.

Above all, we intend to have a close working partnership with families that we serve. We have already conducted a formal meeting last December (Page 4). The Autism Society of India (as well as many individual families) has expressed support. We have had webinars with families through our city wide partners in care in April (Page 7). Families have supported our survey conducted along with our partners, to understand new needs and challenges during the ongoing pandemic. We sincerely aim to have families guide us and monitor our research too.

We wish to create a centre that will be abuzz with multidisciplinary teams, with students of various backgrounds from across the city, all coming together, to care for and understand autism. We seek support of all stakeholders in public health in planning models of care. And we hope, once the covid crisis is mitigated, that we can have visits by the city’s highschool students, not only for them to understand autism, but energise us too!

Dr. M. V. Ashok
Head, CARE-ADD

The Beginning

The Centre for Advanced Research and Excellence in Autism and Developmental Disorders (CARE-ADD) was inaugurated on 9th August 2019 by Most Rev. Fr. George Antonysamy, Chairman of the Governing Board of St. John's National Academy of Health Sciences (SJNAHS). The creation of this centre nestled within St. John's Medical College Hospital's *Unit of Hope*, is the result of the vision of many years of dedicated study and multidisciplinary work in autism and related disorders.

Dr. M. V. Ashok, Head of CARE-ADD, introduced the centre as an Institution that Adds Care and much more to autism research, training and capacity building. The Clinical track uses technology and task shifting processes to develop care models for Early Identification and Early Intervention to be upscaled to all units of public health in the State of Karnataka. The Research track includes exploring genetics and neural signals in understanding brain developmental trajectories in children-at-risk for the condition.

The services at CARE-ADD begin with children as young as 9-12 months old, a group that has already been identified as part of ongoing studies. The goal is to eventually also develop models of care and assistance for independent living. We would also seek to upscale such models into statewide public health settings.



Most Rev. Fr. George Antonysamy at the inauguration of CARE-ADD in the Unit of Hope, SJMCH



The work at CARE-ADD is based on active collaboration with other streams of healthcare and also with other organizations that work with Autism and other developmental disorders. In this endeavour, we are already collaborating with ComDeall, a pioneer in developing manualised early intervention for Autism. The core team includes Dr. Vijaya Raman, Professor of Clinical Psychology, Professor Dr. G R K Sarma from Neurology, Dr. Aruna Korlimarla from Molecular Medicine, St. John's Research Institute and Dr. Shyam Rajagopalan, a Computational Scientist (Machine Learning).

Board of Advisors

On 21st February 2020, CARE-ADD felicitated and appointed its Board of Advisors. During the event, the importance of not forcing a diagnosis, but rather conducting developmental surveillance and starting early intervention was discussed. The Board of Advisors expressed their shared vision of using a multi-disciplinary approach and taking into consideration the astute observations of parents to respond to the needs of children with autism.



Felicitations of the Board of Advisors

Prof. Shoba Srinath, Former Head and Senior Prof (Retd.), Department of Child and Adolescent Psychiatry, NIMHANS, Bangalore, *Prof. Swarna Rekha*, Former Head, Pediatrics and Founding Lead of the Unit of Hope (St. John's Centre for Children with Special Needs, St. John's National Academy of Health and Allied Sciences), *Prof. Dominic Misquith*, Former Head, Community Health, St. John's Medical College and Founding Member of Unit of Hope, SJNAHS, and *Prof. Lonnie Zwaigenbaum*, Professor and the Director of Autism Research in the division of Developmental Pediatrics in the Faculty of Medicine and Dentistry at the University of Alberta, Canada were appointed as CARE-ADD's Board of Advisors.

Public Awareness Programme



CARE-ADD conducted a Public Awareness Programme on account of World Disability Week, on 2nd December 2019 in the Unit of Hope. The programme was attended by 50 families of autistic children and professionals from various institutions working in Autism research and care. Parents were informed about the facilities available and what the centre hoped to accomplish. They were also

encouraged to provide insight on what research they felt was essential to aid professionals in their care-giving.

The event was an effort to introduce the centre to the city. For the professionals at CARE-ADD, it was an opportunity to understand research priorities from the perspective of families and have their work vetted for its relevance and the meaning of its findings. Rev. Dr. Paul Parathazham, Director, St. John's National Academy of Health Sciences, Dr. Rajini Parthasarathy, Deputy Director of Health Sciences (Mental Health), Mr. Basavaraju, Commissioner of Disabilities were the chief guests for the programme.

AOSI workshop

AOSI – Autism Observation Scale for Infants (Bryson, Rombough, McDermott, Brian & Zwaigenbaum (JADD, 2008)) is a semi structured play-based observation modelled after ADOS for infants aged 6-18 months. Training for this research tool was conducted by Prof. Lonnie Zwaigenbaum during his visit to Unit of Hope, SJNAHS on the 20th and 21st of February 2020.



Eight trainees – Dr. Sowmyashree Mayur Kaku (CARE-ADD), Ms. Saritha (CARE-ADD), Dr. Meera SS (NIMHANS), Dr. Shashidhar (SJMCH), Dr. Madhumita Bhattacharya (CIP, Ranchi), Ms. Archana Sharma (GMC, Chandigarh), Dr Swati Shelke (Nair Hospital, Mumbai) and Dr. Chitra Murali (St. Philomena's Hospital) participated in the hands-on training with Prof. Lonnie which included assessment and observation of infants along with active discussion and observership by other staff and faculty of CARE-ADD and SJNAHS.

ComDEALL at CARE-ADD

Centre for Advanced Research & Excellence in Autism & Developmental Disorders (CARE ADD) in association with The ComDEALL Trust, Bangalore has started an *Early Intervention Program for children with Autism*. The Communication DEALL (Developmental Eclectic Approach to Language Learning) program aims at maximizing the child's potential through intensive preschool intervention. As of now intensive early intervention is the most promising approach for alleviation of developmental disabilities. Intervention is long term in nature and has to be provided on a continuous basis over a prolonged period of time.

Highlights of the Early Intervention Programme:

- Intensive early intervention targeting the sensory perceptual, motor and communication issues in Autism Spectrum Disorders by an interdisciplinary team of Speech language pathologist, Occupational/Physiotherapist, Educator/Developmental Psychologist.
- The program is developed within a broad-based developmental profile and is eclectic in nature.
- Intervention is profile based through a team approach addressing child's strengths and limitations.
- Small and large group intervention with individual monitoring in a supportive, predictable environment.
- Parental empowerment is integral to the program



ComDEALL Team at CAREADD, SJNAHS
Supreeta, Athira, Sathya Lakshmi -*Early Intervention Therapists*
Nirupama Srikanth - *Coordinator*
Dr. M.V. Ashok, Dr. Vijaya Raman

As part of the clinical services offered at CARE-ADD, ComDEALL is multidisciplinary, comprehensive and provides holistic care. The program has been developed by *Dr. Prathibha Karanth*, a pioneer in the field of speech and language pathology in India with over 40 years of experience and long standing interest in language disorders both in adults & children. The development and continuous fine tuning of the program is the result of her vast clinical experience & research interests. The program is an indigenously developed program, viable, self-sustaining model which aims at bridging the gap between the lack of adequate early intervention services in India and the large number of children with Autism Spectrum Disorder.

Indo-Canadian Autism Network, February 2020

The I-CAN (Indo-Canadian Autism Network) group was launched in July 2019. This is a group formed by five experienced clinicians and researchers from Canada and a dozen centers from India that are focused on clinical and/or research activities in the area of autism. Some of these centers in India were already partnering with the Canadian members since 2010. Dr. Ashok MV from CARE-ADD was invited to be part of this network in July 2019. The first meeting held in Hyderabad involved sharing experiences and deciding on the goals of the network. The second meeting also held in Hyderabad in February 2020 has led to better delineation of the vision of this network. A two-day training program in clinical assessment approaches to assessments and interventions were also conducted in this meeting where three persons from CARE-ADD and Child Psychiatry teams of St. John's participated. The network has resolved to continue with bimonthly meetings and also explore autism specific academic activities including research. CARE-ADD particularly seeks support from this network for evolving models to work with Teenagers and Young Adults with ASD. The entire list of organisations involved and their Leads in this network are listed below:

*I-CAN member Agencies and Leads (I-CAN Annual Report)**

ACTION FOR AUTISM, NEW DELHI	DR. NIDHI SINGHAL
ALL INDIA INSTITUTE OF MEDICAL SCIENCES, NEW DELHI	DR. SHEFFALI GULATI
CENTRE FOR CHILD DEVELOPMENT AND DISABILITIES, BANGALORE	DR. NANDINI MUNDKUR
FERNANDEZ FOUNDATION, HYDERABAD	DR. PRAMOD GADAM
FERNANDEZ HOSPITAL AND FOUNDATION, HYDERABAD	DR. DEDEEPPYA PUSKUR
GOA MEDICAL COLLEGE, GOA	DR. MIMI DA SILVEIRA
LATIKA ROY MEMORIAL FOUNDATION, DEHRADUN	JO CHOPRA-MCGOWAN
LONDON LEARNING CENTRE, NEW DELHI	DR. SUPRIYA MALIK
NATIONAL INSTITUTE OF MENTAL HEALTH AND NEUROSCIENCES (NIMHANS), BANGALORE	DR. K JOHN VIJAY SAGAR
NATIONAL INSTITUTE OF MENTAL HEALTH AND NEUROSCIENCES (NIMHANS), BANGALORE	DR. S.S. MEERA
SETHU CENTRE FOR CHILD DEVELOPMENT, GOA	DR. NANDITA DE SOUZA
CARE-ADD AND ST. JOHN'S MEDICAL COLLEGE HOSPITAL, BANGALORE	DR. ASHOK M.V
UMMEED CENTER, MUMBAI	DR. KOYELI SENGUPTA

*borrowed from I-CAN Annual Report, courtesy, Dr. Vikram Dua

As per the annual report of the network being prepared by Dr. Vikram Dua, "the I-CAN project is lead by Dr. Vikram Dua, from the University of British Columbia (U.B.C.), who along with Dr. Dan Goldowitz, from U.B.C., and Dr. Lonnie Zwaigenbaum, from the University of Alberta, have been the primary Canadian coordinators for the project activities, including the

program planning for I-CAN (Feb 2020)". "Other key Canadian partners have also been critical to I-CAN 2020's success. Dr. Jessica Brian and her colleagues Erin Dowds and Kate Bernardi from Holland-Bloorview in Toronto have brought their Canadian-grown knowledge of the Social ABC's to I-CAN, and Kavita Kamat, from posAbilities in Vancouver has brought expertise in Behavioural Analysis and parent-training. As I-CAN grows, it is expected to expand Canadian clinical expertise from other identified areas of need, such as adults and aging, girls and women, and neurobiological research".

Dr. Sowmyashree Mayur Kaku attended the workshop on Psychiatric comorbidities in ASD conducted by Prof. Vikram Dua and the half-day plenary talks on early identification of ASD, building collaborations and psychiatry in Autism. The workshop emphasised the need for meticulous behavioural analysis and documentation, its role in psychopharmacology and follow-up. Participating in the live case conference with children from extreme ends of symptom spectrum and being able to share the challenges professionals face while dealing with families was enriching. Dr. Suhas Chandran attended the workshop conducted by Dr. Kavita Kamat on addressing challenging behaviour and teaching adaptive skills to children with Autism. The session provided hands-on experience in creating a function-based plan to address problem behaviours. The lessons on gathering behavioural data and tracking the family's progress in behavioural management were innovative and provided a new perspective. Ms. Bhavana Kumarswamy attended the Social ABC workshop conducted by Dr. Kate Bernardi. The sessions emphasised the importance this intervention gives to parent-child relationships considering it simultaneously targets language, social and emotional skills. This was an opportunity to be observant and respectful of the parent-child dyad, appreciate how they share emotions and how clinicians can intervene to enhance the quality of engagement.

EMERGING FROM CRISIS

A three part Webinar as families share their time during the pandemic lockdown

In order to understand the effect of the lockdown and managing individuals with Autism during this period, Academy for Severe Handicaps and Autism (ASHA) along with professionals from CARE-ADD, Sunshine Autism Trust and Spastics Society of Karnataka (SSK), Bangalore held a 3 part webinar on 13th, 15th and 17th April 2020, titled "Emerging From a Crisis - Autism: Opening Up During Lockdown". The sessions were moderated by experts in the field which included special educators, doctors and therapists. Predictability in routine is important for individuals with Autism and it is difficult for them to understand something as sudden and unprecedented as this lockdown, pointed out Dr.Nalini Menon of SSK.



Parenting a child with autism is "a journey where we grow together with our child"

Ms.Jayashree Ramesh of ASHA believes that it was not just families but even institutions that were caught unawares. They expected individuals with Autism to have their meltdown moments and reached out to families to understand how they were coping. Professionals working in the field of Special Education recognise the need to collaborate with families to ensure the holistic development of individuals with autism. The lockdown has been an opportunity for professionals to better understand the perspective of parents. Dr. Nalini found it reassuring that families were adjusting rather well and said that most children were excited to have the undivided attention of their entire family throughout the day. "At this time of crisis, not just families but also children with Autism demonstrated the ability to adapt", says the mother of a 16-year-old with Autism. Dr. Ashok, Head of CARE-ADD, said that this 3-day webinar was an effort to showcase this positivity and commitment. 9 families came forward to share their 'lockdown experience' and it was mutually beneficial to both parents and professionals. Despite the organisers' efforts to involve both parents, it was the mothers who came forward to participate in the webinar. The fathers perhaps chose to help behind the scenes, suggests Ms.Jayashree. Many of the mothers who participated were Special Educators and it was the first time they were sharing videos of their children on a public forum. Respecting the privacy of families, the organisers ensured that the sessions were not recorded nor were videos of the children made available for download. Ms. Soumya Kuduvalli of Hope - The early intervention centre and Ms. Suchita Somashekaraiah of Shristi Special Academy were also among the professionals who contributed to the webinar series.

Dr. Vanitha Rao of Sunshine Autism Trust felt that the webinar created a space for mutual learning between families. The mother of a 3-year-old found herself in tears, overwhelmed and emotionally drained, but she left the webinar feeling highly inspired. For others like the mother of a 21-year-old, it was an opportunity to reach out to younger parents and reassure them that the "journey is difficult but not as difficult as one assumes it will be." She adds that parenting a child with autism is, "a journey where we grow together with our child". The participating families impressed everyone with the innovative methods they employed to keep their children occupied. The exchange of ideas was important, but more impressive was the positivity and willingness to go the extra mile to care for their child. There is however a large section of families that are not as invested in their child. Professionals like Ms. Jayashree are reaching out to such families and trying to offer their support. While programmes that are conventionally held in April every year as part of Autism Awareness Month could not occur this year, the webinar has been a unique platform for families and professionals to interact with and appreciate each other's perspective in care-giving. It may have opened up a new route for reaching out to families.

Announcements

OPEN Autism (Obstetrics, Placenta, Epigenetics and Neurodevelopment in Autism) symposium

CARE-ADD is currently involved in research of the placenta from genetic, obstetric, epigenetic and clinical perspectives. As part of understanding how these come together and contribute to the neurodevelopment and evolution of Autism, we are conducting a virtual symposium in July. Experts from various backgrounds will be invited to speak and facilitate scientific brainstorming, explore the feasibility of placental research and provide a platform to present our data and experience to date in this area. This symposium will be a foundation for conceptualizing OPEN Autism research, the summary of which will be presented at our Special Interest Group in August. Please note that this is a closed group symposium. Participation requires prior registration. Details will be announced shortly.

Special Interest Group (SIG) at International Society for Autism Research (INSAR)

Team CARE-ADD is happy to share that our application to conduct a Special Interest Group at the INSAR annual meeting (2020) has been selected from a pool of more than 200 competitive applications from around the world. Titled OPEN Autism (Obstetrics, Placenta, Epigenetics and Neurodevelopment in Autism), the SIG will facilitate understanding of potential challenges in using placenta in Autism biomarker research and its potential epigenetic impact. Other goals include developing a study model for placental research through a panel discussion and deliberating possible research avenues. The group meeting can facilitate the conceptualization of a unique bio repository that can benefit researchers across the world. The virtual presentation is scheduled for August 21st, 2020 at 6.30pm IST. Contact us if you would like to attend the SIG or learn more. *Divya Swaminathan*, a member of the team has received the travel grant award.

Team CARE-ADD's posters published at INSAR 2020:

Scaling Challenges of ASD Screening Technology Solutions to Remote Regions in India

Shyam Sundar Rajagopalan¹ & Ashok Mysore V¹

¹Centre for Advanced Research & Excellence in Autism and Developmental Disorders (CARE-ADD), St. John's National Academy of Health Sciences, Bangalore, India.

Leave Empty

This space will be automatically filled with a QR code and number for easy sharing

Background

- As Technology based solutions have tremendous potential for early diagnosis and intervention in professional scarce settings, there has been a lot of focus on this across the country.
- Challenges exist in scaling technology solutions across all primary care in resource poor settings

Objective

To list the challenges in scaling remote ASD screening technology solutions across primary health care centres in India

Methods

Focused discussions

- With independent child mental health professionals specialized in ASD diagnosis
- With a computer software architect from a leading multinational software organization
- Towards delivering end-to-end technology system for ASD screening, deployment practices, security, monitoring system health and socio economic conditions

Center for Advanced Research & Excellence in Autism & Developmental Disorders

Results

Administration – Parent questionnaire and semi-structured play activity video recordings

- Installation & maintenance of recording setups, noisy data and quality of recording
- Training local resource person to administer semi-structured video recordings in local language and context, besides managing child's behaviour
- Absence of expertise to control video recordings. Cost of training and sending of outstation personnel
- Power outages leading to multiple sessions. Challenges in stitching videos and motivational issues for interruptions
- Smartphone penetration is low in India (estimated to be ~31% by 2022 [1]) and the quality of recordings from smartphone from naturalistic unconstrained settings has more challenges for analysis

Secured video storage system - Large sized videos and storage capacity with backup for preventing data loss

- Increased infrastructure and power costs
- Need stricter access control systems to ensure participants privacy

Secure video transmission to a server

- Rural areas with network bandwidth constraints, connection drops and partial transfer
- Physical transmission using external devices is not scalable

Behaviour quantification and report generation

- Accuracy and Interpretability of advanced video analysis using AI/ML algorithms

Report delivery to primary caregivers

- Time to deliver & mode of delivery

[1] <https://www.statista.com/statistics/321487/smartphone-user-penetration-in-india/>

Conclusions

- Challenges in scaling technology have been listed
- App based questionnaires are limited by ambient level of awareness and language/translation issues
- Remote screening methods using videos need effective implementation solutions
- It is ideal to involve multiple stakeholders in discussions from the outset

Contact

shyam.careadd@stjohns.in : ashok.careadd@stjohns.in

Will be covered by controls if you define slides

Development of Early Screening for Communication and Social Skills (ESCoMS) Instrument: Sensitivity and Specificity

D. Swaminathan¹, S. Nagaraj², K. Iyengar², D. Purkayastha², M. Lewin³, F. Naaz Fathima⁴, T. Agrawal⁴, V. Raman², D. Misquith⁵, and A. M. Visweswariah²

(1)Psychiatry, St. John's Medical College Hospital, Bangalore, India, (2)Psychiatry, St John's Medical College Hospital, Bangalore, India, (3) Pediatrics, St John's Medical College Hospital, Bangalore, India, (4)Community Health, St John's Medical College Hospital, Bangalore, India, (5) Retired Community Health, St John's Medical College Hospital, Bangalore, India

INTRODUCTION

There is an increase in the number of children diagnosed with ASD and related conditions over the last two decades. Studies have shown that symptoms of autism begin during infancy and can be identified in those as young as 6 months of age. There is a need for a reliable screening tool for autism in those below 18 months in the Indian context.

OBJECTIVE

To develop an instrument to screen infants between 9 and 18 months for Autism Spectrum Disorder (ASD) using mixed methodology.

METHODOLOGY

Three Phases. The first two are described here.

Phase I
• Develop items through qualitative methods

Phase II
• Discriminate validation and instrument construction

Phase III
• Explore predictive validation

PHASE I

Collation of items from literature: 106 articles focused on signs and symptoms of ASD below 24 months were examined for frequency and concordance. A final list of 43 distinct items were created (List A)

11 groups discussions (FGDs) with Speech Language Pathologists, Occupational Therapists, Special Educators, Mental Health Professionals and Pediatricians were conducted. 9 out of the 11 groups were homogenous. Minimum membership was Four. After open discussion the group members individually rated the items from List A on a five point likert scale (Strongly Agree, Somewhat Agree, Somewhat Disagree, Strongly Disagree, and Unsure)

The FGD transcripts were analysed for themes and coded. 24 items other than list A were generated (List B).

List A and List B were merged to form a list of 67 items, 5 items were eliminated due to low frequency of endorsement by the professionals. Remaining 62 items were reexamined for frequency and nature of endorsement. Items strongly endorsed by at least 7 groups from List A and those items figuring in at least 7 groups in FGDs were pooled together, resulting in the final list of 33 items.

These 33 items were subjected to ranking by a set of fresh 25 Professionals in order of importance of the red flags for autism in 9 to 18-month infants., resulting in 27 items (Draft 1 of the instrument).

PHASE II

27 items were administered to parents of children between 2-5 years, with a clinical diagnosis of autism (n=250) and those with typically developing children (n=220). Children with autism were drawn from centers across the city. Controls came from five play schools.

Parents were asked to answer the 27 polar questions retrospectively based on the child's behavior when they were below 18 months..

RESULTS

The collated data was analyzed using Statistical Package for Social Sciences (SPSS). Sensitivity and Specificity were determined for a variety of totals. Receiver Operating Characteristic Curve (ROC) was generated. Chi Square analysis was used to analyse each of the 27 items; 3 items which did not have significant statistical difference between the two groups were eliminated from the final instrument.

ROC for different cutoff scores

Each point represents sensitivity and 1-specificity value for different cut off scores. Since the reference line is near 1.00 and the area under the curve is 0.9779 for the total score making the tool is highly sensitive and specific.

For the 24 items which were validated, the cut of score was set as 14 with 90% specificity and 90% sensitivity using the Youden's Index. Further those with any history of regression in motor and cognitive milestones are deemed to be positive regardless of their endorsement of other items.

CONCLUSION

Literature indicates delayed identification of children with ASD in India. It is expected that this tool can help early identification of children. We are currently exploring the predictive validity of this tool in phase 3 of the study.

DIMENSIONS INCORPORATED IN THE INSTRUMENT	
Language & Communication	8 Items
Social skills	9 Items
Sensory Issues	3 items
Repetitive Behavior	1 item
Regression	2 items- 1 about verbal and another about non-verbal regression of skills
Sleep	1 item

ACKNOWLEDGEMENT

Funding Agency: Indian Council for Medical Research (ICMR)

Advisory Committee:
 Dr.Nachiket Shankar, Associate Professor, Dept of Anatomy.
 Dr.Ramesh Arumugam, Associate Professor, Dept of ENT.
 John Micheal Raj. A., Lecturer, Dept of Biostatistics

CONTACT INFORMATION

Divya Swaminathan
 Email: divya.careadd@stjohns.in

Corresponding Author:
 Dr. Ashok Mysore Visweswariah
 Email: ashok.careadd@stjohns.in

SCAN ME