

# Neurodevelopmental Pediatrics



Newsletter of the Neurodevelopmental Pediatrics chapter of the Indian Academy of Pediatrics





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## From the Editorial Team

Dear readers

It gives us all great pleasure in presenting the first step in a journey we hope to carry long and far. This is the first academically oriented and titled issue of the newsletterof the newly anointed IAP Chapter of Neurodevelopmental Pediatrics. Yes it is ambitiously titled and we intend to walk every inch of the talk. As with any nascent publication, it takes time to attract top notch researchers to be attracted to publish in our pages. That does not take away from the importance of the articles published here in. The focus of the journal will be two fold, and this is a topic we will return to in future too. One is to inform the practising Paediatrician of the basics and then some. of the ever expanding field of Developmental Paediatrics. Second and more onerous task is to inform the Developmental Paediatricians already working with these special children, of the very latest in cutting edge research in the field. We are therefore forced to put our feet firmly in both these boats. The glue that should keep them together is response and encouragement from our readers. In future we want to turn this into a zero advertisement journal funded only by subscriptions. So that makes your responsibility one of ownership as well!

Happy Reading

The Editorial Team

## Message From Chairperson

Respected Seniors and Dear Friends,

Welcome to the Annual Conference of the IAP Chapter of Neurodevelopmental Pediatrics NCDP and EMBICON 2016 in the city of Mumbai!

Your Chapter has achieved remarkable landmarks in the past few months. We have completed the first ever National Guidelines on Neurodevelopmental disorders- Autism Spectrum Disorder, ADHD, Learning Disability and Newborn Hearing Screening! These guidelines will appear in the Indian Pediatrics.

The Chapter has initiated the National IAP Fellowship of Developmental and Behavioural Pediatrics across the country and thus initiated a very important process of training pediatricians in this fast developing super-speciality!

This would not have been possible without the untiring efforts of all of you- especially our founders and mentors- Dr MKC Nair, Dr S SKamath, Dr Abraham Paul, DrJeesonUnni; Dr Chhaya Prasad and other office bearers, all the State Coordinators and Editor of this newsbulletin, Dr Santhosh R.

I would like to place on record the excellent services rendered by many of you in organising CMEs, Workshops and Advocacy Campaigns across the country throughout the year! You have made this Chapter a regular name among pediatricians in India!

On behalf of the Organizing Committee, I once again extend a hearty welcome to all of you and hope you have a memorable academic feast and awesome fellowship!

#### Dr Samir H Dalwai

MD, DCH,DNB, FCPS, LLB, Developmental Pediatrician, Chairperson, IAP Chapter of Neurodevelopmental Pediatrics, President, IAP Mumbai Branch, Chairperson, NCDP-EMBICON 2016.



Dr Samir H Dalwai MD, DCH,DNB, FCPS, LLB,



## Message From IAP Former President

#### Dear Fellow Academicians,

t gives me immense pleasure that the city of Mumbai is hosting the National Conference of the IAP Chapter of Neuro Developmental Paediatrics, the first one after recognition as a Chapter. Problems and challenges of children with challenges have always occupied the Academy's mind and is the main agenda for the Committee on Child Development and Disability.

The last year has seen many landmark achievements like the formal launch of the Fellowship programme for budding Developmental Paediatricians. I congratulate the excellent efforts put in by Dr Samir Dalwai and his dedicated team of members with great zeal and commitment towards the work they do. The much needed expansion of our regular newsletter into a fully academic publication is a welcome move. I congratulate all the office bearers for this splendid effort.

So see you in Mumbai!

Yours in Academy **Dr Sachidananda Kamath** Imm. Past President Indian Academy of Pediatrics



#### Dr Sachidananda Kamath Senior Developmental Paediatrician

and Immediate Past National President of IAP



## Message From Secretary

Respected Seniors and Colleagues, Greetings!

n behalf of the entire Team of IAP Chapter of Neuro Developmental Pediatrics I convey heartfelt warm wishes to all members and readers of this News Bulletin. Child Development is a complex process yet so magical and delightful. Child development does not mean helping parents to develop the child into an adult that the parents visualize them as, but it is more about bringing out the Best in the Child and help him / her achieve their Best Potential to be the person they are actually meant to be. Pediatricians play a very imperative role in this. It gives us immense pleasure in bringing this edition of the News Bulletin to you, compiled by Dr Santhosh Rajagopal, Editor News Bulletin. Most of us are dealing with Child Development Assessments in our routine practice and yearn to learn more every day. The articles published here have been brought to you by renowned experts in the field and I wish you a happy time reading.

I would like to express my sincere gratefulness to senior stalwarts of the Chapter Dr MKC Nair, Dr SS Kamath, Dr Abraham Paul, Dr Jeeson Unni, Dr Samir Dalwai and others for their constant motivation and timely advice for all activities.

The persistent mentoring support and guidance provided to all office bearers and members by the Chairperson, Dr Samir Dalwai is worth appreciating. He has taken the Chapter to newer heights by his perseverance, dedication and excellent leadership skills. On behalf of the entire Chapter I congratulate him for his brilliant work.

Under the Chairmanship of Dr SS Kamath Sir. and with Dr Samir Dalwai as the Convener, the IAP Committee on Disability / Child Development and Neuro - developmental Disorders has been working to bring about better policies and reforms for the cause. The National Consensus Meet on Developing IAP National Guidelines on Neuro Developmental Disorders (Autism, ADHD, Newborn Hearing Screening, LD) awas conducted in November 2015 and subsequently by ceaseless efforts of Dr Dalwai, the papers will be published in the IAP Journal (upcoming issue). Again. under his brilliant leadership skills, we were able to launch the IAP Fellowship Training Program in Developmental and Behavioral Pediatrics. Inspections were carried out by experts in the subject at aspiring centers and 7 centers across the country were finally accredited for running the



Dr Chhaya Sambharya Prasad, National Secretary, IAP - NDP training program. The first Batch of student Fellows have been selected and the program kick-started on 1<sup>st</sup> August 2016. We remain indebted to the Experts who agreed to spare their precious time to visit and inspect the centers for Accreditation for the Fellowship Program. Our sincere thanks to Central IAP Office Bearers and to all those who supported this movement.



The year had started on great academic note when the IAP Chapter of Neuro Developmental Pediatrics conducted the **TOT workshop** on 20<sup>th</sup> Jan 2016 on the topic Training and Dissemination of IAP NATIONAL GUIDELINES FOR MANAGEMENT OF NEURO - DEVELOPMENTAL DISORDERS: ASD, ADHD, SLD, NEWBORN HEARING SCREENING, the workshop attended by 43 enthusiastic Developmental Pediatricians from across the country. The previous day, 19th Jan, workshop on "STRATEGIES FOR MANAGING DEVELOPMENTAL DISORDERS IN OFFICE PRACTICE" saw 60 passionate participants with active interactions and dynamic discussions. These workshops were visited by the Honorable State Home Minister Telangana Shri Naini Narsimha Reddy; Honorable Speaker, Telangana Legislative Assembly Shri S. Madhusudana Chary; IAP President 2016 Dr Pramod Jog and Hon' Secretary Dr Bakul Parekh, Dr Ajoy, Chief Organizing Secretary Pedicon 2016 and they all blessed the

academic forum with their encouraging words. Dr P Hanumantha Rao hosted the two days workshop at Sweekaar Academy of Rehabilitation Sciences at Telangana and provided full support.

I also take this opportunity to welcome the 80 new members we have added to our Chapter this year through a special Membership Drive! Looking forward to a long lasting academic relationship with all!

#### May we all continue to work with dedication towards a single common cause - "For Attaining of Better health for All the Children, especially Children with Unique Needs"!

Last but not the least, I heartily congratulate ALL the Office Bearers, State Coordinators and Members who have been actively participating in the movement across the country creating awareness for children with developmental disorders and disabilities, by conducting National and State level Activities.

On BEHALF of the entire Team of IAP Chapter of Neuro Developmental Pediatrics, I heartily thank Dr Pramod Jog, Dr Bakul Parekh and the Central IAP Office Team for providing their timely guidance. I also take this opportunity to welcome Dr Anupam Sachdeva, President Elect 2017 wishing him a great tenure and assuring him that the Chapter will continue the sincere efforts and the good work started by our stalwarts.

#### Dr Chhaya Sambharya Prasad,

Developmental Paediatrician , Former Consultant at RIMH,Chandigarh and currently Secretary of IAP NDP Chapter. Consultant at Max Hospital Chandigarh

In Academic Service National Secretary, Chapter of Developmental Pediatrics, Indian Academy of Pediatrics 9356108559

## **Guest Editorial**

## Comprehensive Child Adolescent Care

omprehensive child care can be realized only if we follow a philosophy of child rights, a life cycle and family centred approach, with equity concerns addressed. The strategy should be to first focus on mortality morbidity reduction, then on prevention of childhood disability by giving special care for high risk newborns. The high risk new born is any neonate, regardless of birth weight, size, or gestational age, who has a greater than average chance of morbidity, mortality or poor developmental outcome later on. Risk factors include pre-conceptual, prenatal, natal or postnatal conditions or circumstances that interfere with the normal birth process or impede adjustment to extra-uterine environment. Neurodevelopmental follow up programs for high risk newborns should be supported by evidence based interventions and counselling for the parents, ultimately up-scaling the service models to the national level as has been envisaged in the Rashtriya Bal Swasthya Kariyakram (RBSK).

Developmental delay is diagnosed if a child does not achieve certain skills (or 'developmental milestones') by a predicted age. Developmental delay generally affects a child's gross motor skills, fine motor skills, communication, speech and language development and/or personal and social skills. A child's level of communication development may be the best indicator of a developmental delay. A language delay may be the primary problem or reflect delays in other domains (i.e., social, emotional, cognitive, motor or sensory). Hence the primary focus should be on early detection of developmental delay and speech delay in all babies especially the high risk babies using Trivandrum Developmental Screening Chart (TDSC: 0-6 years) and Language Evaluation Scale Trivandrum (LEST: 0-6 years) respectively.



**Prof (Dr.) M.K.C.Nair** Vice Chancellor Kerala University of Health Sciences





The UN child rights perspective emphasize on four basic rights; (i) The right to survival: right to life, health, nutrition, adequate standards of living; (ii) The right to protection: freedom from exploitation, abuse, neglect, armed conflicts; (iii) The right to development: right to education, leisure and recreation, early child care and development (ECCD), social security and (iv) The right to participation: freedom of expression, thought, conscience and religion. Hence parenting should involve not only the biological and the legal aspects, but also, the more important dimensions of care, protection, nurturance, understanding, guidance, mutual interaction and partnership occurring within the environment of a family. Since all the above aspects influence the role of a parent, how well a person is able to fulfil his/her duties and responsibilities along the above dimensions can be taken as a determinant of how one excels in the role of a parent. The art of bringing up children, requires understanding ourselves and our children, knowledge of their developmental needs, identifying and changing attitudes, behaviors and practices that promote the child's development as a physically and mentally healthy individual. More than that, it involves being able to do the right thing for the child, at the right age like;\

- 1. Delivery in a hospital with resuscitation facilities to avoid birth asphyxia.
- 2. Exclusive breastfeeding to prevent hypoglycemia and timely weaning.
- 3. Timely immunization following safe injection practices.
- 4. Developmental stimulation at home /

crèche/ anganwadi.

- 5. Early intervention for delay at District Early Intervention Centers.
- 6. Appropriate parenting / disciplining practices.
- **7.** Early Child Care and Development (ECCD) practices through anganwadis.
- 8. Preventing/treating diarrhoea using oral rehydration solutions (ORS).
- 9. Preventing pneumonia deaths by timely and appropriate antibiotics use.
- **10.** Improving or reopening the lines of communication with the adolescents.

ECCD is a comprehensive approach specially aimed at providing opportunities for the holistic development of children in the age group of 0-8 years. The strategies used are betterment of the children's (i) health, (ii) nutritional status, (iii) psychosocial development, (iv)early childhood education and (v) primary school education. It has been shown that ECCD programs, whether parent focused or child centered, help disadvantaged children directly or indirectly, to combat the detrimental effects of poverty on child development, especially during the crucial first six years of life. There is tremendous parental pressure for high educational success in adolescents, particularly among the most educated parents in India. This may be because, economic success and social up-liftment in life was always closely related to jobs, whose pre-requisite was only academic achievement. But in the recent times, with the advent of the information technology industry, there is increasing emphasis on skill development and attitude - ability for teamwork, even more than knowledge per se. While the "need" for inclusive primary education for all is the priority of the government, the private sector is increasingly catering to the "want" of parents for "sophisticated" exclusive schools and colleges for their children, resulting in undue stress and anxiety states in the adolescents. Comprehensive adolescent care would involve addressing scholastic issues, prevention of lifestyle related diseases, reproductive health problems, mental health problems and promotion of positive health in general including spiritual health. Pediatricians do have a significant role to guide the children, adolescents and their parents at every stage.

#### Prof (Dr.) M.K.C.Nair

## *Currently Vice Chancellor of the Kerala University of Health Sciences, Trichur*

Pioneering Developmental & Adolescent Paediatrician, Former National President of the IAP,

## Editorial

# UP CLOSE WITH AUTISM

rom being attributed to non-responsive parents to its present nuanced understanding, the putative causation of Autism Spectrum Disorder ( for the moment I am ignoring the academic debate over the semantics of nomenclature in DSM V ) has changed colours immeasurably. In this issue's lead article my friend and respected senior colleague Dr Anjan takes a closer look at the Neurobiology and genetics of Autism. Some of you might complain it's all Greek and Latin, but these kind of in depth look is what is needed lest we Paediatricians lose our way in the labyrinth of alternative therapies and behavioural therapies which by themselves of course are extremely important. For one the review places Autism right at the centre of scientific research and advances, not in the periphery of Psychological disorders where it has wrongly belonged. But the average practitioner might end up asking "What is in it for me?". Well for starters this is the information age and it does not hurt if you are slightly more knowledgeable than the parent. More importantly it gives us a reference framework which in future might validate, refute and even quide therapy.

For me personally two points merit mention. One the suggestion that the abnormal processing in different parts of the brain might not be limited to the child at hand but might also be present in varying degrees in their parents. Of course the original Kannerian construct of refrigerator mothers were explained at a later date by the theory that they themselves might have been Autistic. The explanation apart, could this be the reason that we find our parents understanding their children with Autism more than us, trained professionals? I never tire of mentioning that my parents have taught me more than many books. Indeed it's true and the review unwittingly highlights that Autism requires strategies that target whole families than the proband child alone.

The second point that caught my eye was the one on longitudinal studies and the changes the brain in children with ASD undergoes. If we can generalise



Dr Santhosh Rajagopal Editor In Chief

it more and pin point the measurable changes, it could strengthen the case for early intervention (not that it is any weak now). What would be more interesting to see is whether therapy changes these. Then finally, the outcome measures for putative treatment strategies would radically change. From disputed psychological scores they would be visible on the screen. Indeed, the NIRS studies quoted in the article highlights how maternal (parental) interventions are crucial in brain development. Interestingly the article on bonding by our senior colleague Dr Nandini Mundkur presses the point right home. So will Neuroimaging one day become what the Chest X-ray is to Pneumonia treatment? We are not there yet. But watch this space.

Meanwhile in our country regular screening and diagnosis continues to be important. The Right to education article in this issue highlight how crucial it is for us to screen for children with special needs .And if one were too enthusiastic in diagnosing Autistic disorders, turn to the Case Report by my friend Dr Shambhavi .

Research needs to guide our actions including screening and diagnostic techniques, let alone treatment. Our failures should humble us into searchingeven more vigorously for the right answers.

#### Dr Santhosh Rajagopal

MBBS,DCH,PGD-DN,PGD-EPI,FRSPH (UK) Surveillance Medical Officer, WHO India.

## Perspective

## Attachment Bonding is the Mantra

The greatest joy in anyone's life is perhaps their children. Even as the young mother conceives her first child, the parent start to dream as to how the child will look, what they want it to be when he or she grows up, what school to sent to etc. Is there a role parent play in helping their child have a successful and happy life? Is it the three R 'of education or is it something else. A well research show the success in life is how you face challenges confidently, happily and have emotional stability. These qualities which helps a person to success also to bounce back from adversities.

When do we then lay foundation for these qualities? Is there a special mantra for this?

Research in child development does talk of a stress free pregnancy, listening to music, reading about children healthy diet are the first step towards this.

Once the child is born then attachment bonding is the mantra.

What is attachment bonding?

The main predictor of how well a child will do in school and in life will depend on the is the strength of the relationship he or she has with the caregiver., caretaker. This relationship impacts the child's future mental, physical, social, and emotional health. It is the nonverbal emotional communication between child and parent known as the attachment bond. While it's easiest to form this secure attachment bond with an infant, it can be formed at any time or at any age.

A landmark report, published in 2000 by The Committee on Integrating the Science of Early Childhood Development, identified how crucial the attachment bond is to a child's development. This form of communication affects the way your child develops mentally, physically, intellectually, emotionally, and socially. While attachment occurs naturally as you, the parent or caretaker, care for your baby's needs, the quality of the attachment bond varies.



*Dr. Nandini Mundkur, M.D* Centre for Child Development and Disabilities, Bengaluru

A secure attachment bond the child feel <u>feel</u> secure, understood, and be calm enough to experience optimal development of his or her nervous system. Your child's developing brain organizes itself to provide your child with the best foundation for life: a feeling of safety that results in eagerness to learn, healthy self-awareness, trust, and empathy.

Developing a secure attachment bond between you and your child, and giving your child the best start in life, does not require you to be a perfect parent. In fact, the 2000 study found that the critical aspect of the child–primary caretaker relationship is NOT based on quality of care, educational input, or even the bond of love that develops between parent and infant. Rather, it is based on the quality of the nonverbal communication process that takes place between you and your child.

As a parent, one follows all the traditional parenting guidelines, provide doting, around-the-clock care for the r baby, and yet still not achieve a secure attachment bond. One can tend to the child's every physical need, provide the most comfortable home, the highest quality nourishment, the best education, and all the material goods a child could wish for. You can hold, cuddle, and adore your child without creating the kind of attachment that fosters the best development for your child yet the child may not have a secure attachment and may suffer developmentally

What is needed for a happy, emotionally stable child is to engage in a nonverbal emotional exchange between the child and with their primary caretaker in a way that babies communicates their needs that makes them feel understood, secure, and balanced. Children who feel emotionally disconnected from their primary caregiver are likely to feel confused, misunderstood, and insecure. . It is a tie that binds them together, endures over time, and leads the infant to experience pleasure, joy, safety, and comfort in the caregiver's company. The baby feels distress when that person is absent. Soothing, comforting, and providing pleasure is primary elements of the relationship. Attachment theory holds that a consistent primary caregiver is necessary for a child's optimal development

While it's easiest to form a secure attachment bond when your child is still an infant—and reliant upon nonverbal means of communicating—you can begin to make your child feel understood and secure at any age. Children's brains continue maturing well into adulthood (until their mid-20s). Moreover, because the brain continues to change throughout life, it's never too late to start engaging in a nonverbal emotional exchange with your child. In fact, developing your nonverbal communication skills can help improve and deepen your relationships with other people of any age.

It is not attending to the child's survival needs of feeding, changing diapers bathing or taking them to play centres, it is about picking up the cues of the child being happy or not, what does that cry mean, understanding the distress and the support he or she needs.

It is not about feeding the child quickly so that you can leave for your office, but finding time to hang out with your kid and have fun. It is about following your child's lead and having fun



Why there is so much confusion about bonding and the secure attachment bond?

Dr you mean to say merely attending to the child's need is not establishing attachment bonding.

Story of the mother working from home , smiling while feeding the baby

• Yes however attending to the child's needs is the time one can use to establish attachment

• .One is a connection based on the care a parent provides for infant child, while the other is based on the quality of nonverbal emotional communication that occurs between parent and child.

• Both types of parent-child interaction can occur simultaneously. While feeding, bathing, or otherwise caring for your child, you can also build the emotional connection by recognizing and responding to your child's nonverbal cues. (Pictures or video to show attachment)

• Before experts understood the radical changes going on in the infant brain during the first months and years of life, both the caretaking process and the attachment process looked very similar. Now, though, they are able to recognize and painstakingly record an infant's nonverbal responses to highlight the process of attachment in infants.

## What prevents a parent from creating a secure attachment bond

Obstacles to creating a secure attachment may first appear when your child is an infant. You may deeply love your baby, yet be ill-equipped to meet the needs of an infant's immature nervous system. Since infants cannot calm and soothe themselves, they rely on you to do so for them. However, if you're unable to manage your own stress, to quickly regain your calm and focus in the face of life's daily stressors, you'll be unable to calm and soothe your baby.

Even an older child will look to you, the parent, as a source of safety and connection and, ultimately, secure attachment. If, however, you are frequently depressed, anxious, angry, grieving, pre-occupied, or otherwise unable to be calm and present for your child, his or her physical, emotional, and/or intellectual development may suffer. If either the primary caretaker or the child has a health problem, nonverbal communication between the two may be affected, which in turn can affect the secure attachment bond.

## How an infant's well-being can affect the secure attachment bond

Experience shapes the brain and this is especially true for newborns whose nervous systems are largely undeveloped.

• When a baby experiences difficulty in the womb or in the birth process—during a caesarean birth, for example—his or her nervous system may be compromised.

• Adopted babies or those who spend time in hospital neonatal units away from a parent may have early life experiences that leave them feeling stressed, confused, and unsafe.

• Infants who never seem to stop crying whose eyes are always tightly closed, fists clenched, and bodies rigid—may have difficulty experiencing the soothing cues of even a highly attuned caretaker.

Fortunately, as the infant brain is so undeveloped and influenced by experience, a child can overcome any difficulties at birth. It may take a few months, but if the primary caretaker remains calm, focused, understanding, and persistent, a baby will eventually relax enough for the secure attachment process to occur.

## How an older child's well-being can affect the secure attachment bond

A child's experience and environment can affect his or her ability to form a secure attachment bond. Sometimes the circumstances that affect the secure attachment bond are unavoidable, but the child is too young to understand what has happened and why. To a child, it just feels like no one cares and they lose trust in others and the world becomes an unsafe place.

- A child gets attention only by acting out or displaying other extreme behaviours.
- Sometimes the child's needs are met and sometimes they aren't. The child never knows what to expect.
- A child is hospitalized or separated from his or her parents.
- A child is moved from one caregiver to another (can be the result of adoption, foster care, or the loss of a parent).
- A child is mistreated or abused.

## How a caretaker's well-being can affect the secure attachment bond

The feelings you experience as a primary caretaker can shape the developmental process rapidly occurring in your child's brain.

If you are overly stressed, depressed, traumatized, or unavailable for whatever reason, you may not have the awareness or sensitivity to provide the positive emotional mirroring a child needs for secure attachment.

Sometimes even a healthy, caring, and responsible caretaker may have trouble understanding and initiating a secure attachment bond with their child. If, as a child, you didn't experience a secure attachment bond with your own primary caregiver, you may be unaware of what secure attachment looks or feels like. But adults can change for the better, too. Just as you can strengthen yourself with exercise and a healthy diet, you can also learn to manage overwhelming stress and deal with emotions that may interfere with your ability to create a secure attachment bond.

## Repair of the secure attachment bond is always possible

You don't have to be a perfect parent to build a secure attachment bond with your infant—no one is able to be fully present and attentive to a child 24 hours a day. Because the brain is capable of changing, repair is always possible and may even strengthen the secure attachment bond.

If you notice there's a disconnect between you, when you've missed or misinterpreted your child's cues, and attempt to repair it by continuing to figure out what your child needs, the secure attachment process will stay on track. The effort involved in repair can even deepen trust, increase resiliency, and build a stronger relationship.

#### Distractions of daily life

Cell phones, computers, TV, and countless other distractions of daily life can prevent you from paying full attention to your child. Responding to an urgent email during meal time, texting a friend during play time, or just zoning out in front of the TV with your child are all ways parents miss out on opportunities to make eye contact with their child and engage in the secure attachment process. Without eye contact and your full attention you'll miss your child's nonverbal cues.

## Nonverbal communication tips for secure attachment

Nonverbal cues are sensory signals communicated by a certain tone of voice, a particular touch, or a particular facial expression. A child's primary caretaker brings all of these unique qualities together creating a sense of recognition, safety, and comfort for a child. Even when a child is old enough to talk, nonverbal communication remains key to building and maintaining a secure attachment.

**Eye contact** – You look at child affectionately and he or she picks up on the positive emotion conveyed by this nonverbal signal and feels safe, relaxed, and happy. If you're depressed, stressed, or distracted, you may not look directly into your child's eyes at all. Maintaining eye contact also plays an important role in sustaining the flow of conversation between you and your child.

**Tone of voice** – Even if your child is too young to understand the words that you use, he or she can understand the difference between a tone that is harsh, indifferent, or preoccupied and a tone that conveys tenderness, interest, concern, and understanding. When talking to older children, make sure that the tone you use matches what you're saying.

**Touch** – The way you touch your child conveys your emotional state – whether you're attentive, calm, tender, relaxed, or disinterested, upset, and unavailable. The way you wash, lift, or carry your baby or the way you give your older child a warm hug, a gentle touch on the arm, or a reassuring pat on the back can convey so much emotion to your child.

**Body language** – Talk to your child with your arms crossed and your head back and your child will see e you as defensive and uninterested. But sit with a relaxed, open posture, leaning towards your child and your child will feel what he or she is saying matters to you. The way you sit, move, and carry yourself communicates a wealth of information to your child.

Pacing, timing, and intensity – The pacing, timing, and intensity of your speech, movements, and facial expressions can reflect your state of mind. If you maintain an adult pace, or are stressed or otherwise inattentive, your nonverbal actions will do little to calm, soothe, or reassure your child. You need to be aware of your child's preferences for pacing and intensity, which are often slower and less forceful than your own. Facial expression – Your face is able to express countless emotions without you saying a word. If your expression is calm and attentive when you communicate with your child, he or she will feel secure. But if your face looks distressed, angry, worried, sad, fearful, or distracted your child will pick up on these negative emotions and feel stressed, unsafe, and unsure.

Research has shown that babies and caregivers demonstrate an instinct to attach. Babies instinctively reach out for the safety and security of the safe haven they have with their primary caregiver, while parents usually instinctively protect and nurture their children. Children who start their lives with the essential basis of secure attachment fare better in all aspects of functioning as their development progresses.

From a behavioural perspective, attachment is represented by a group of instinctive infant behaviours that serve to form the attachment bond, protect the child from **fear** and harm, and aid in the infant's protected exploration of the world. These behaviours include:

- reaching
- crying
- grasping
- smiling
- vocalizing
- clinging
- sucking
- moving

All of these behaviours assist in facilitating the maximum physical and emotional development of the child. These particular behaviours may vary from one culture

#### Infancy cues from the child

Several milestones occur over the course of their first year as infants form an attached relationship with their primary caregiver. These milestones include the following:

- In the first two months of life, even though infants show little observable preference for a particular care-giver, the warm, sensitive, and reliable responses of the caregiver to the child set the stage for the developing attachment relationship.
- From two to seven months, infants tend to interact differently with primary caregivers than they do with strangers but in general still do not display solid preferences.



- By four to six months of age, infants begin to develop expectations of how their primary caregiver will respond to them when they are distressed.
- Between seven months and one year, infants show a definite preference for their primary caregiver. They start to exhibit a wariness of strangers and symptoms of **separation anxiety**.

#### **Toddlerhood**

From 12 to 18 months, as they start to walk and crawl, children use their attachment figure as a secure base from which to go out and discover the world and as a safe haven to which to return when frightened or alarmed. Children with secure histories have been shown to be more determined, enthusiastic, and competent in problem-solving as toddlers.

#### Preschool

During this time, the attachment relationship is characterized by an increased tolerance for separation and an ability to cooperate with others. The child is learning to balance his or her need for independence, self-discipline, and exploration and the need for love and protection from the primary caregiver. However, as **preschool** approaches, children are still susceptible to a variety of dangers. Therefore, attachment behaviours, such as wanting to stay close to the primary caregiver and displaying occasional separation anxiety are adaptive processes, not regressive ones.

#### School age

School-age children with a history of secured attachment histories demonstrate an ability to be more goal-oriented and often display positive leadership skills. Numerous long-term studies have shown that in the following areas securely attached children do better as they grow older:

- self-esteem
- autonomy
- ability to manage impulses and feelings
- long-term friendships
- positive relationships with parents, caregivers, and other authority figures
- effective coping skills
- trust, intimacy, and affection
- positive and hopeful belief systems
- academic success in school

Therefore attachment bonding is the mantra to help a child succeed.

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## Perspective

# Right To Education (RTE) Act in light of Child Development

hild Development is the acquisition of new skills and new functions. A child during development learns motor skills (sitting, standing, walking), and communication skills (first nonverbal, then verbal) in a graded, oneafter -the -other, step-by-step manner; academic skills like reading, writing and mathematics are also acquired in a step by step manner. If the previous step is not perfected, the subsequent step can never be perfect. If alphabets are not mastered, words can never be mastered.

Sounds logical? Yet, year after year, our Education System was focused on "Pass Or Fail". The tragedy is - "Pass" is an arbitrary and mere 35%- which means that the child's ability/skill level/knowledge is only 35% for that level- which needless to say, is far from perfect. Yet, s/he is presumed suitable to receive instruction for the next level assuming that the previous level has been mastered.

This is a bit like completing the first floor of a building up to, say 350 sq feet and attempting to build the second floor of 1000 sq feet! No one in their right mind would even attempt that! Yet, year after year, parents are focused only on seeing that the child "goes to the next class"! They seem to be unaware that if the previous level is not mastered, the next level is doomed to fail! Passing seems to be the only important thing.

In this social quest for passing and going to the next level, we have forgotten the essence of educationacquiring adequate skills and knowledge. Any Examination is intended to ascertain whether the child has achieved this competence, and is ready



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to move to the next level to receive and learn the next level of education. If yes, we go ahead; if no, we need to wait, practice and learn more- till we master it. Once we do, then we may go ahead. If a child can stand independently, then s/he is ready to learn to walk.

However, Examinations soon became an end, rather an industry, in itself. Everything was focused on the quest for marks- the primary objective of learning and mastery of one level after another- was soon forgotten and lost. Thus, 'passing' and moving into the next grade became almost an annual religious ritual- it HAD to be done! If it didn't, you were the new apostate. The pariah. The outcast. Hence, come heaven or hell, your child HAD to pass.

Caution: Unless we bring primary education is sync with natural development of every child, no Act will help.

The RTE Act was brought in to rectify this anomaly and to ensure that sequential learning happens, in a step by step, piece-meal manner. Bite what you can chew. Chew it well. Swallow. Here, have another bite!

Hence, we need a clear focus on i) small nuggets of learning, ii) regular, continuous comprehensive



evaluations to ascertain mastery of the current and readiness for the next level, iii) taking remedial actions for those who were not coping TO HELP THEM LEARN, and of course, iv) doing away with detention ONLY IF the child had mastered the level for that grade/year and found to be appropriately suited to learn in the next grade/year.

This unfortunately failed because we committed two fatal errors here-

One, we did not realise the religious proportion the ritual of examination had taken by now. Hence, even if the frequency would change, the fervor for ritual did not! Kids who were toiling away and suffering towards the end of the year to "catch up" were now toiling every day and night!

Two, the assumption that every child can do better may be sound philosophy but in the case of children with some concerns or special needs this can be done ONLY IF backed by extremely well developed, well organised, meticulous detailed attention to every child's learning individually. Summarily dismissing them to "Remedial Education" without most of the country even understanding what is the multi disciplinary effort that this takes, leave alone the organising and implementation of it all, with standardisation across this vast country with its limitations, was a huge task fraught with challenges. Setting up a Sarva Shiksha Abhiyan and allocating enormous financial budgets to the same was like throwing boulders into the sea to build a bridge across it, hoping some will stick.

The unfortunate part is not that this has been an abysmal failure. The tragedy is that it has taught us nothing.

#### Unless we realise that the primary aim of education is to aid natural development of every child, no Act will help.

Having worked at New Horizons Child Development Centre with children with some or the other special need, their parents, their schools and all these stake holders' daily struggles, one realises that the devil is in the detail. No two children are the same: two special children even less so. Hence, any attempt to ameliorate the situation of children with concerns and special children can have only superficial benefits unless one attempts to move the entire mountain. And at the base of this mountain is the fact- that every child learns in a different way, at a different pace. The majority can indeed be lumped together. But not all. So we have been prioritizing on the majority and throwing alms to the others left behind- in the assumption that, "Look here- this is the best we can do for you. Thanks

to increased awareness, we are anyways doing so much now. So take it or leave it. (Our conscious is hereby unburdened.)"

This has to change. Unless you are prepared to walk the last mile, there will only be decorative and declarative improvements. Acts will come and go, policies will keep being tossed around. Low hanging fruit will be plucked. In a country of vast populace, even these numbers will be impressive. However, an even larger number will continue to be excluded. Parents will continue to be distressed and schools pressed; the innocents will be as nonplussed as ever.

This requires for a paradigm shift in the way we look at the organisation of education. The only way out is for educationists to begin this movement syllabus and conduct examinations for. If we can do this for our own biological kids at home, why not for those at school- as far as their education is concerned.

Once schools start looking at and appreciating children as individuals, it will be easy to look for solutions to their concerns. Classroom management strategies will help; these will see a smart teacher put a child with difficulties along with a group of bright ones who will help the formerin fact this will keep the bright ones from getting bored and keep them engaged. Getting children to learn cooperative learning and do projects together will also relieve overburdened moms from doing their child's project at home, or outsourcing it! Prioritizing the role each child plays in taking the whole class ahead may be appreciated by parents,



of recognizing the need to focus **at an individual level**. Every Developed nation who has achieved success in this sector has done so by focusing on an individualized approach. This "lumpenisation", "categorisation" has to stop. Even 'Special Needs' is a Label. 'Differently abled' is only a better label than 'disabled'- it doesn't do much to enable each child.

This is possible if we recognise the value and potential of each and every child's life; If we look at classrooms as a collection of different young people with different learning skills and potential and not merely as a factory to churn out marks, or pass vs. fail every year. Educationists need to embrace this challenge that we have, say, 300 children with us this year who we are individually responsible for; and not 5 'divisions" that we have to provide teachers for who will completely their rather than dumping them with marks on report cards. Of course, this will take time and patience, as today's parents have got hooked on to the ritualistic examination and marks culture.

But ultimately, that really is the key. Though we blame the Education system and the schools so easily, eventually this is a free market economy. The buyer gets what he pays for. Unless parents are gently and gradually made aware of this tremendous failure in the making and nudged towards change, the education system

will not change. If there are parents who chose a preschool who "teaches" "academics" over one that indulges in developmentally-appropriate, non formal education and play, the former will prosper at the cost of the latter.

Actually, at the cost of our children.

So, caveat emptor applies. Buyer, beware! Parents, it is time for you to make that leap of faith. Before it is too late!

#### Dr Samir Dalwai

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## **SILENT ABUSE**

#### - CHILDREN WITH SPECIAL NEEDS

The only reason why <u>child abuse</u> is alive today, is because we as adults fail our children when we fail to listen to them. Listen to a child today! Heather Mc Clane

19% of the world's children live in India. One out of every two children under three years of age is malnourished; nearly 1.8 million infants die each year, most from preventable causes; discrimination against the girl child continues, and is perhaps most visible in the declining child sex ratio. Children, who suffer from neglect, abuse, developmental delays, and speech and language disorders in the first vears of life, suffer psychological and emotional damage from which they may never fully recover. This may prevent them from reaching their full potential as older children, adolescents and eventually as adults. Those subjected to violence, abuse or exploitation may endure psychosocial trauma that can affect them throughout their lives. And children with developmental disorders may never be able to even speak about the abuse they may have undergone. We learned doctors are well aware that a society struggles to develop if its children are challenged physically or intellectually while growing up. Also children who grow up as malnourished, poorly educated and ravaged by diseases, burdened by psychological suffering of abuse create an emotional encumber on the society. Traditional practices, lack of opportunities, poverty, illiteracy, and ignorance are the barriers for protecting children of our society, and within such group the most vulnerable section is always the children with developmental disorders and disabilities.

The problem of abuse in children in our country is gigantic. Children are vulnerable in every sphere and strata of our country. Children living on streets, children in Orphanages, Juvenile Homes, Brothels, children working at construction sites, factories, mines, engaged in child labour form an immeasurable population. According to WHO, one in every four girls and one in every seven boys in the world are sexually abused. And estimated that 4.0 million children between 0-14 yrs of age suffer from abuse or neglect and require health and / or social care. Considering overall poverty- deprivation scenario, and number of children with disabilities, such estimates are bound to be higher in India.



Dr Chhaya Sambharya Prasad, National Secretary, IAP - NDP

Nearly 26 million people are suffering from various types of disabilities and more than one million suffering from intellectual disability [Disability Data NSSO Punarbhava 2011]. The data also suggests that nearly 2 million children below the age of 6 years are suffering from disabilities including intellectual disability.

Children with Developmental Disorders and Disabilities are children who require extra support for their Physical, Intellectual, Emotional, Communicative, Behavioural and Social Development. But due to ignorance, lack of knowledge and societal support, the families of children with special needs experience great stress and find themselves unable in dealing with day to day challenges. Unpreparedness to handle the care of a child with disability, including acceptance of that child as being "different," creates more hurdles in communicating empathetically with the child. Families may face financial limits and / or non availability of time for medical/educational activities of these children. A child with 'difficult to handle behaviour patterns', or communication difficulties, may become a target for physical abuse. Children who are unable to communicate their needs may experience greater instances of neglect. All of these can result in increased vulnerability to abuse. At the same time, a child with disability may develop more extensive relationships of trust with greater numbers of people visiting their home, and be unable to distinguish when boundaries are being crossed, resulting in potential sexual abuse.

There is a vicious cycle that forms: Abuse predisposing to Disability in Children; Disability predisposing to Abuse in Children



#### • STIGMA & SOCIAL EXCLUSION

Children who are physically and / intellectually challenged are usually deterred from attending social gatherings to avoid embarrassment to parents and family. This kind of Social Exclusion may lead to an increase in the behavioral problems. Families do not anticipate that segregating the child from social gatherings will not allow social skills to develop normally and when these children do behave inappropriately, they end up getting negative response from parents and family in the form of thrashing, shouting, and further exclusion. A large numbers of children with disabilities remain out of school. Teachers may refuse to allow such a child to continue in their class due to various reasons such as inability to follow instructions, inability to communicate, hyperactivity, disturbance of class atmosphere, etc. When they do not attend schools, they are more vulnerable / prone to abuse in any form. Even though the Sarva Shiksha Abhiyan (SSA) has made a concerted effort to promote the inclusion of children with special needs, the system faces challenges in identifying these children and responding to their needs. There is still a big dearth of special educators in schools who can adequately identify and respond to the needs of these children but the challenge is huge. The peers in a mainstream school do not have enough awareness and capacity to empathize with a child with special needs and find it difficult to accept them.

## • Disciplinary Methods used for children with Special Needs

Disciplinary methods used for children with disabilities may be more PUNITIVE and is usually accompanied by a lack of respect. Family members may feel that a child who is mentally and physically challenged may not have the capacity to feel a sense of loss of dignity and hence higher frequency of corporal punishment may occur. Many parents start to believe that their special child only listens to them when they hit, or shout, or a certain uncle in the family intervenes to discipline them. It is hard for parents to believe that adequate training of ADL's and Behavior Modification Therapy may help in curbing social behavioral concerns.

#### ROLE OF A PEDIATRICIAN

• Recognizing Abuse in children with Disabilities is a difficult and tricky task. Pediatricians, especially Developmental Pediatricians at Child Development Centers should incorporate in their routine assessments, methods to identify any signs of abuse in children with disabilities. Recognition can be done by considering the presenting symptoms, taking a detailed medical, behavioral and social history, physical examination of the child, asking for a feedback from school and by keeping a High Index of Suspicion

#### Signs of Physical Abuse –

- a) History of repeated falls / fracture / injury (including head injury)
- b) Unexplained bruises / redness over multiple sites of the body
- c) Bruises in these sites suggest abuse Head / face / neck; Genitalia; Inner thighs/limbs; Back; Buttocks; Chest
- Burns suggesting abuse Circular marks from cigarette butt; "Glove and stocking" distribution burn marks; Friction burns; Scalds; Chemical burns –
- e) Sites of Burn suggesting Abuse dorsum of hands / feet / buttocks / face / multiple sites
- f) Family showing a delay in seeking medical help
- g) Inconsistency in history provided by family members / caregivers.
- Poor corroboration of history with physical findings / Poor justification with developmental status.
- Pointers in Behavioral History
- a) Fear or Aversion of certain people or places which were not present earlier. Children with disabilities may exhibit these because of Sensory Processing Disorders, but it is less likely that the child suddenly develops the symptoms which have never been noticed before.
- b) Loss of appetite, sudden changes in eating habits.
- c) Sudden changes in Sleep Pattern.
- d) Certain Behaviour manifested during play, writing, drawings or dreams including sexual or frightening images.
- e) Sudden mood swings: rage, fear, anger, insecurity or withdrawal.
- f) Recurrent abdominal pain without identifiable etiology.

- g) Sudden appearance of bed-wetting, thumb sucking / other age inappropriate behaviour which were not present earlier.
- h) The child exhibiting Adult-like sexual activities with toys or other children
- i) The child using new words for private body parts.
- j) Showing resistance to bathing, toileting, or removing clothes even at appropriate situations.
- Signs of Emotional Abuse and Neglect
- a) Child appearing fearful of the family member or caregiver present; exhibiting severe feeding problems (it could be sensory issue), poor growth and stunting, severe behavioral problems, performing poorly at school ( could be due to intellectual challenge), substance abuse in older adolescents and adults, signs of social maladjustment.
- b) Signs of Neglect in an otherwise Healthy Child with Special Needs – Severe Behavioral problems; History of recurrent illnesses but poor medical care; on observation there may be poor parental interaction; lack of empathy towards the child; poorly dressed in shabby clothing's, may appear unhygienic. Many parents are busy working and the child may be left at home with a maid or caretaker who may not have enough knowledge about Caregivers Skills. Such caregivers can inflict severe physical and emotional injuries on the child in an effort to make them sit quietly.

## How can you know for sure whether a child with disability has been undergoing Abuse?

ASK!!! Most adults who have disabilities state that although they have been abused many times in their life, NO ONE ever asked about this aspect of their lives. Also, please be sure that you have something to offer if you decide to ask this question, such as Time to listen to their story, suggestions for help such as a GOOD referral to a Clinical Rehabilitation Psychologist / therapist, Groups, Videos, etc. Don't just ASK then leave them in the memory of the tragedies they have already survived.

## What makes abuse <u>different</u> with this population?

It is a bigger "secret". It is more extensive. Disability services agencies are not yet fully "on board" in conducting outreach, information & referral or direct services and require more "Hands on Training".

#### Key Points-

Pediatrician's commitment to Child Protection is the cornerstone of 'Effective Response'. Pediatricians should assess / suspect Abuse with the same thoroughness & attention as they would do with a life threatening condition; Poor management after disclosure can increase psychological damage; Doctors / Professionals should believe, support,

reassure, treat and ensure rehabilitation of victims of child abuse – [Child Protection Companion RCPCH 2006]

Record keeping and documentation of every case should occur. Follow up to assess outcome is essential. The entire staff at hospitals / child development centers should be TRAINED to provide effective and sensitive services to children with disabilities.

There is a need for existing child protection policy and services to become child friendly. People with disabilities should be included for planning of service delivery procedures, protocols and policies. Showcasing success stories of people with disabilities can challenge these deep rooted negative perceptions.



• The early years for a child's life are crucial for cognitive, social and emotional development. Therefore it is important that we take every step necessary to ensure that a child grows up in a safe environment where his/her social, emotional and educational needs are met. Children, who grow up in an environment where their developmental needs are not met, are at an increased risk for compromised health and safety, developmental delays and learning problems.

• Children who are Differently Abled need us, need our support. They can excel beyond imagination if given the right opportunity and training. Shrouding cases of abuse in these children would amount to Bigger Crime.....Bring them to Light!

#### Dr Chhaya Sambharya Prasad,

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## Lead Article

## RECENT ADVANCES ON NEUROBIOLOGY ON AUTISM SPECTRUM DISORDER (ASD)



Dr. Anjan Bhattacharya, FRCPCH, UK Head, Child Development Centre, Apollo Gleneagles, Kolkata

#### INTRODUCTION

Autism Spectrum Disorder ASD is now recognized as a disorder of prenatal and postnatal brain development. Although ASD is primarily a genetic disorder involving multiple genes, insights into underlying mechanisms will require a multidisciplinary approach<sup>1</sup>.

Advances in brain imaging research in autism spectrum disorders (ASD) are rapidly occurring, and the amount of neuroimaging research has dramatically increased over the past 5 years. In this article, advances during the past 5 years and longitudinal studies are highlighted. I have also taken help of a review that highlights a selection of recent advances from more than 200 original research publications in the past 12 months during its writing<sup>2</sup>.

The amygdala and hippocampus are key components of the neural system mediating emotion perception and regulation and are thought to be involved in the pathophysiology of autism. Although some studies in children with autism suggest that there is an enlargement of amygdala and hippocampal volume, findings in adolescence were sparse.

The abnormal enlargement of the amygdala and hippocampus in adolescents with autism adds to previous findings of enlargement of these structures in children with autism. This may reflect increased activity of these structures and thereby altered emotion perception and regulation. These results could therefore be interpreted in light of developmental adaptation of the autistic brain to a continuous overflow of emotional learning experiences<sup>2</sup>.

Autism spectrum disorder (ASD) is increasingly viewed as a disorder of functional networks, highlighting the importance of investigating white matter and interregional connectivity. Qualitative abnormalities of social interaction and social communication cluster with stereotyped repetitive interests and behaviors within individuals, become observable during the first year of life, and usually cause lifelong impairment, for reasons we still do not understand. Neuroimaging has the potential to help elucidate what has gone wrong, what continues to go wrong, what has gone right, and what can be improved in brain development in autism spectrum disorders (ASD)<sup>3,4,5</sup>.

One recent study<sup>6</sup> used diffusion tensor imaging (DTI) to examine white matter integrity for the whole brain and for corpus callosum, internal capsule, and middle cerebellar peduncle in children with ASD and typically developing (TD) children.

Children with ASD had reduced FA and increased radial diffusion for whole brain white matter and all three segments of the corpus callosum and internal capsule, compared to TD children. Increased MD was found for the whole brain and anterior and posterior limbs of the internal capsule. Reduced axial diffusion was found for the body of corpus callosum. Reduced FA was also found for middle cerebellar peduncle.

#### Figure 1



Representative slices showing the region of interest (ROI) placement (rectangle box) in the genu, body and splenium of the corpus callosum (A-C), genu and anterior and posterior limbs of the internal capsule (D) and middle cerebellar peduncle (E). Note: ROIs were drawn in native space on BO images on three representative slices that were selected to allow positioning of ROIs in the body, genu, and splenium of the callosum and genu, anterior and posterior limbs of the internal capsule in both hemispheres. Axial slices showing maximal thickness of corpus callosum (for body, genu and splenium separately) and internal capsule were identified and then ROIs were placed on three contiguous slices. For the corpus callosum, two ROIs (70µl each) were placed on each slice (reference slice and slices inferior and superior to the reference slice) for body and splenium and one for the genu. For the internal capsule, on each of the three contiguous slices (reference slice and

slices inferior and superior to the reference slice), one ROI (70µI) was placed on the genu and anterior and posterior limbs of the internal capsule in each hemisphere. Left and right middle cerebellar peduncles were selected from one slice showing maximal thickness, with a volume of 158µI each. All ROI placements were confirmed by viewing them on sagittal images for any partial volume effect.

These findings suggest widespread white matter compromise in children with ASD. Abnormalities in the corpus callosum indicate impaired interhemispheric transfer. Results for internal capsule and middle cerebellar peduncle add to the currently limited DTI evidence on subcorticocortical tracts in ASD. The robust impairment found in all three segments of the internal capsule is consistent with studies documenting impairment of elementary sensorimotor function in ASD.

#### Figure 2



Fractional anisotropy (FA), mean diffusion (MD), axial and radial diffusion (mean $\pm$ sem) for whole brain white matter. Note: ASD = Autism Spectrum Disorder. \*p<0.05 (corr.); \*\*p<0.005 (corr.).





Fractional anisotropy (FA), mean diffusion (MD), axial and radial diffusion (mean $\pm$ sem) for the genu, body and splenium of the corpus callosum; anterior limb (AL), genu and posterior limb (PL) of the internal capsule bilaterally; and middle cerebellar peduncle (MCP) bilaterally. Note: ASD = Autism Spectrum Disorder. \* p<0.05 (corr.); \*\* p<0.005 (corr.)

## Key Findings from the last 5 years longitudinal studies

- 1. The similarity is in activation of bilateral amygdala, and the difference is significantly increased in the activation of the left anterior insula and anterior cingulate gyrus in ASD in response to pictures of one's own interest<sup>7</sup>.
- 2. The anterior insula and anterior cingulate gyrus are key nodes of the salience neural network, which appears spatially restricted at the structural level<sup>8</sup>. But
- 3. Over-connected within itself at the functional level in ASD<sup>9</sup>.
- 4. Dysfunction of the salience neural network seems to be involved in socio-emotional impairment as well as restricted repetitive behaviors and interests<sup>9,10</sup>.
- 5. Children with ASD who have exaggerated negative responses to sensory stimuli have heightened functional activation in sensory processing areas, including primary sensory cortices, and in emotional processing and regulating areas of the brain including the amygdala and prefrontal cortex<sup>11</sup>. These brain regions are significantly over-reactive to sensory stimuli, even after individual differences in anxiety are controlled for.
- Different age-related changes in gray and white matter volumes in the Heschl's gyrus are present<sup>12</sup>. The transverse temporal gyri (also called Heschl's gyri or Heschl's convolutions) are found in the area of primary auditory cortex buried within the lateral sulcus of the human brain, occupying Brodmann areas 41 & 42. It is the first cortical structure to process incoming auditory information.



TRANSVERSE TEMPORAL GYRUS



Section of brain showing upper surface oftemporal lobe.("Transverse temporal gyri" visible at center left.)

- Atypical sensory processing may be related to focal cortical dysplasias in ASD<sup>13</sup> and to atypical microstructure in the inferior longitudinal fasciculus and splenium of the corpus callosum<sup>14</sup>.
- 8. As autistic traits increase, habituation and adaptation in the brain to repeated stimuli decrease<sup>15</sup>.
- 9. Parents of ASD children may also have increased activation of the amygdala and fusiform gyrus in response to faces<sup>16</sup>.
- 10. When children with ASD perform a set-shifting task, magnetoelectroencephalography results suggest abnormal temporal organization and dynamics in distributed large-scale neural assemblies, preventing the global brain interactions needed for efficient performance of the task<sup>17</sup>.
- Precise temporal orchestration of network functioning, essential for accurate higher-order sensory processing and appropriate behavioral response<sup>18</sup>, may be disrupted in ASD by cortical dysfunction and abnormalities of structural connectivity, including myelination<sup>19,20,21</sup>.
- 12. Maturation of cognitive control performance and brain circuitry appears atypical in ASD during adolescence<sup>22</sup>.
- 13. Functional connectivity appears to increase between brain regions supporting reactive 'lastminute' cognitive control (i.e. anterior cingulate cortex and ventrolateral prefrontal cortex) in young people with ASD, rather than between brain regions supporting proactive cognitive control (i.e. dorsolateral prefrontal and parietal cortices)<sup>23</sup>.

14. Modulation and normal differentiation of brain states may also be impaired<sup>24</sup>.

#### **MINICOLUMNS of CORTICAL TRACTS**

- 15. MRS studies have found 5% reduction in minicolumn width in cortical areas M1, V1, and frontal association cortex
- 16. Changes in minicolumnar organization are also seen in other cortical regions in ASD
- 17. A reduction in minicolumn width reflects changes in GABAergic systems that alter lateral inhibition or underlie excess local cerebral connectivity at the expense of long distance connectivity
- 18. The conclusion from these studies suggest that in ASD, such alterations promote abnormal connectivity at local level in preference to the long fibre connectivity needed for normal functioning
- 19. fMRI finding suggest skill deficits of ASD are accompanied by reduced neural activity in regions that normally govern the specific functional domain
- 20. Whereas deficits in social perception and/ or emotional engagement and arousal are associated with reduced activity in the fusiform gyrus

#### Figure 4



Control





Lateral

Figure 4: Hypoactivation of fusiform gyrus on facial recognition

21. IFG, Inferior frontal gyrus remains hypoactive during facial expression imitation;

- 22. PSTS, posterior superior temporal sulcus remains hypoactive during perception of facial expressions and eye gaze tasks;
- 23. SFG, superior frontal gyrus remains hypoactive during theory of mind tasks, i.e., when taking another person's perspective;
- 24. Amygdala shows hypoactivity during a variety of social tasks and
- 25. FG, fusiform gyrus, also known as the fusiform face area is hypoactive during perception of personal identity

#### Figure 5



## Lateral



## Medial

#### VISUOMOTOR and EARLY ONSET

- 26. Abnormal integration of information in distributed brain networks may underlie many core clinical features of ASD, but there is additional evidence of basic neural dysfunction in primary sensory and motor cortical areas and in the thalamus, well before the stage of higher-order integration<sup>25,26</sup>.
- 27. Basic deficits in visual motion processing in individuals with ASD seem to be related to specific dysfunction in primary visual areas where motion is first detected<sup>27</sup>. This is an

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excellent example of dysfunction in primary sensory cortex in autism.

#### LANGUAGE DYSFUNCTION

- 28. Different microstructural changes may differentiate language impairment in ASD from other language disorders. Non-ASD children with specific language impairment have atypically increased radial diffusivity in the arcuate fasciculus, indicating an alteration in microscopic architecture that results in a net increase in water diffusion perpendicular to the white matter tract fibre<sup>28</sup>.
- 29. ASD children with language impairment have increased mean axial diffusivity, pointing to white matter microstructural changes that result in a net increase in water diffusion parallel to arcuate fasciculus fibers<sup>28</sup>.
- 30. Impaired language processing in ASD is also associated with decreased functional synchronization within the language neural network, atypical distribution of the work involved in processing language, differences in how specific language regions of the brain are recruited, but also some positive changes in age-related maturation of the network<sup>29</sup>.

## LONGITUDINAL BRAIN IMAGING STUDIES OF IDIOPATHIC AUTISM SPECTRUM DISORDERS

#### Infancy and early childhood

- Longitudinal neuroimaging studies of ASD during very early childhood are conducted in two different types of samples: infants at high risk of developing ASD (because they have an older sibling with ASD) recruited before it is known whether or not the infants will develop ASD, and very young children with ASD recruited shortly after they are diagnosed.
- The mean brain volume of high-risk infants who develop ASD is normal at 6–9 months of age, but it is increased by 12–15 months of age<sup>41,43</sup>.
- 3. Mean rate of brain growth is faster between 6 and 24 months.
- 4. The mean volume of extra-axial fluid (in the subarachnoid space) is increased by 6 months of age, particularly over the front of the brain, and it is still increased at 18–24 months of age.
- 5. More fluid at 6 months of age predicts more severe core features of ASD at 24 months of age.

- Extra-axial fluid and increasing cerebral volume independently contribute to the abnormally increased head circumference observed during the first 2 years of life in some infants who develop ASD<sup>41</sup>.
- But in a very large prospective study of head circumference in high-risk infants during the first 3 years of life, rate of head growth did not predict which infants developed ASD<sup>44</sup>.
- 8. In young children scanned after they are diagnosed with ASD, mean cerebral volume and total gray and white matter volumes are increased<sup>34,40</sup>, with the most robust effect in the temporal lobe.
- 9. The growth rate of cerebral volume between 1.5 years and 4.5 years of age was atypically increased in one study, but was normal in another study.
- 10. A recent cross-sectional study of young children with ASD found no increase in mean total brain, total tissue, or total white matter or gray matter volumes<sup>45</sup>.
- These results, along with the mixed findings of longitudinal studies of head circumference during infancy and early childhood, question whether 'early brain overgrowth' in ASD truly exists<sup>46</sup>.
- 12. True brain overgrowth, that is, an abnormally enlarged brain, and abnormally rapid rate of brain growth during the first years of life seem to occur in a very small subgroup of ASD children, sometimes in association with general body overgrowth<sup>47</sup>.
- 13. Increased head size is a weak indicator of affected status in simplex families<sup>48</sup>.
- 14. Mean amygdala volume is increased bilaterally in young children with ASD between 2 and 4 years of age and 1–2 years later<sup>38,39</sup>.
- 15. The increase in the right amygdala is out of proportion to total cerebral volume. By 6–7 years of age, volumes of right and left amygdalae appear increased, predominantly due to expansion of the laterobasal subregion<sup>49</sup>.
- 16. Rate of amygdala growth appears atypically increased in some young children with autism<sup>38,39</sup>.
- Larger amygdala size is associated with more severe core features of ASD and worse 2-year developmental course and outcome in some studies<sup>49,50,51</sup>, but with better joint attention in one study<sup>38</sup>.
- 18. Mean fractional anisotropy, a measure of white

matter integrity, is increased at 6 months of age in high-risk infants, but by 24 months of age it has normalized in some tracts and decreased in other tracts<sup>51</sup>.

- 19. The longitudinal trajectory of fractional anisotropy between 6 and 24 months of age is atypical in 80% of the white matter tracts examined in high-risk infants, suggesting widespread involvement. At the whole-brain neural network level, network inefficiency appears decreased at 24 months of age in high-risk infants who develop ASD<sup>53</sup>.
- 20. The topography of the structural networks appears reduced in spatial extent and number of connections. Connections that do exist are weaker than in infants who do not develop ASD.
- 21. The differences in network efficiency are located primarily in posterior (occipital and temporal) regions of the brain involved in processing auditory, visual, language, and nonverbal social stimuli, rather than in frontal regions.
- 22. Greater network inefficiency is associated with greater severity of core features of autism<sup>53</sup>. This is the first study of neural networks in ASD in very young children with ASD. It is important because it points to the role of posterior brain regions early in the disorder.
- 23. Longitudinal studies of brain chemicals in children with ASD show stable, normal concentrations of brain lactate at 3–4, 6–7, and 9–10 years of age<sup>54</sup>.
- 24. Mean concentrations of N-acetylaspartate, choline, creatine, and glutamine + glutamate are decreased in children with ASD at 3–4 years of age, but normal by age 9–10 years<sup>55</sup>.

#### Later childhood, adolescence, and adulthood

- 1. Mean total cerebral volume appears modestly increased in early childhood but then it decreases in idiopathic ASD in contrast to typical development. The ASD and typically developing growth curves cross during early adolescence. The ASD curve then declines more than the typical curve into young adulthood<sup>30</sup>.
- 2. Decreasing total cerebral volume in ASD from late childhood into adulthood appears mainly due to a reduced rate of lobar white matter volume growth<sup>30</sup>.
- 3. The growth curve of total corpus callosum volume is similar in idiopathic ASD and typical development, although there may be some localized volumetric decreases<sup>30,31,32</sup>.

- 4. At the subregional level, preliminary tensorbased morphometry results show a reduced rate of white matter growth in late childhood and early adolescence in posterior lobes, particularly left parietal, bilateral temporal, and left occipital regions<sup>35</sup>.
- Tensor-based morphometry results do not detect significant ASD–control differences in age-related change in gray matter between late childhood and adolescence<sup>35</sup>.
- 6. When larger samples are examined using traditional volumetric and cortical thickness approaches, decreased growth of right Heschl's gyrus gray matter<sup>12</sup>, decreased occipital lobe cortical thickness<sup>33</sup>, and increased volumetric growth of the caudate nucleus<sup>37</sup> and the brainstem<sup>42</sup> are reported.
- 7. When regional cortical gray matter volumes are comprehensively examined from late childhood through young adulthood, more striking differences in ASD are found<sup>30,42</sup>.
- 8. At the lobar level, posterior rather than frontal lobes gray matter appears most affected, with the most robust effect in the occipital lobe followed by the parietal lobe.
- Overall, mean cortical thickness is somewhat increased during childhood in ASD, has a steeper decline during adolescence with the ASD curve crossing the typical development curve leading to decreased mean cortical thickness in adulthood<sup>42</sup>.
- 10. When intelligence quotient (IQ) is controlled, the evidence suggests a posterior-to-anterior developmental gradient: thicker occipital lobe cortex during childhood is followed by excessive thinning in some frontal lobe regions during adolescence, and by cortical thinning in some parietal areas and widespread cortical thinning in the frontal lobes in adulthood<sup>42</sup>.
- 11. Mean amygdala volume and rate of growth appear normal in older children with ASD followed for 2 years<sup>31</sup>.
- 12. A recent large cross-sectional study of ASD individuals 6–65 years of age also found no significant ASD–control difference in mean amygdala volume<sup>56</sup>.
- 13. Age-related changes in size of the amygdala from young to mid-adulthood in ASD can only be inferred from a large cross-sectional study: amygdala volume seems to increase in typical adults but not in adults with ASD<sup>57</sup>.
- 14. The clinical meaning of altered developmental trajectories of brain volume during late

brain development and maturation in ASD is not known. Results of studies examining longitudinal growth trajectories of white matter microstructure during this period in ASD are pending<sup>58</sup>.

- 15. Elevated levels of brain lactate may develop in localized areas of the brain in some ASD adults<sup>59</sup>.
- 16. Brain lactate is elevated in mitochondrial disorders, some cases of bipolar disorder, and transiently by subtle hyperventilation and caffeine<sup>53</sup>.

#### AUTISMSPECTRUMDISORDERSASSOCIATED WITH SPECIFIC GENETIC DISORDERS

Young children with fragile X syndrome (FXS) have much larger caudate volumes, smaller amygdala volumes, and similar global brain volumes compared to children with idiopathic ASD, and rates of brain growth are similar and normal between 2-3 and 4-5 years of age. Brain-behavior correlations are different; caudate volume robustly correlates with compulsive and ritualistic behavior in young children with idiopathic ASD, but with self-injurious behavior in young children with FXS<sup>60</sup>. Tuberous sclerosis complex (TSC) with ASD is characterized by smaller corpus callosum volume and greater abnormalities of white matter microstructural integrity in the corpus callosum and arcuate fasciculus compared to TSC without ASD<sup>61</sup>. At the level of whole brain functional neural networks, TSC is characterized by global underconnectivity and altered network topology, regardless of whether or not autism is present<sup>62</sup>. In contrast, ASD, regardless of whether it is idiopathic or associated with TSC, is characterized by decreased long-range connectivity, a proportional increase in short-range connectivity, and evidence of decreased functional specialization and excessive degeneracy within the network<sup>60</sup>. Neuroimaging studies of individuals with different types of 16p11.2 copy number variations with and without autism are underway<sup>63,64</sup>.

## HETEROGENEITY, VARIABILITY, AND MULTIPLE PERSPECTIVES

There is substantial individual variation in all brain measures<sup>15</sup>. Small control samples used in the majority of neuroimaging studies of ASD may not adequately represent the distribution of normal variation against which ASD measures are compared<sup>65</sup>[This is one of the first imaging studies to plot the distribution of fMRI measures of a very large number of typically developing individuals]. Large variability in how a construct, such as theory of mind, is defined and operationalized and how its brain correlates are measured are also problematic<sup>66</sup>. Different types of imaging, image analysis methods, and clinical measures applied within the same individuals may be essential to best understand what is going on in ASD<sup>67,68</sup>. Tremendous biological complexity lies below what appear to be simple measures of brain structure and function<sup>69,70</sup>. Increased consideration of the clinical heterogeneity of ASD has led to characterizing individuals in imaging studies along quantitative dimensions of specific behaviors in addition to diagnosis and diagnostic algorithm scores<sup>11,12,17</sup>. The creation of large publically available ASD neuroimaging databases such as the Autism Brain Imaging Exchange (ABIDE) and the National Database for Autism Research (NDAR), support efforts to replicate results in independent samples<sup>8,72,73</sup>.

#### **CROSS DISORDER GENES**

Genome wide association studies (GWAS) have shown how cross disorder genes interact as depicted in the figure 6 below:

Figure 6



Genes shared among	N genes
6 disorders	0
5 disorders	15
At least 4 disorders	20
At least 3 disorders	28
At least 2 disorders	39

This topic merits a fuller discussion, may be, in a future article.

#### Near-InfraRed Spectroscopy (NIRS)

NIRS studies conclude, "the earlier right structural maturation in fetal epochs seems to be paralleled by a right functional development" (p. 1). A

functional magnetic resonance imaging (MRI) study of 1- to 3-day-old newborns reports that music evokes right hemi- spheric activation in the auditory cortex. Using NIRS with 2- to 6-dayold neonates, Telkemeyer et al. (2009) observe, "responses to slow acoustic modulations are lateralized to the right hemi- sphere" (p. 14726). This same optical brain imaging technology reveals that prosodic processing of emotional voices in 3-month- old and 4-month-old infants activates the right temporoparietal region. Grossmann et al. (2010) report that 7-month-old infants respond to emotional voices in a voice-sensitive region of the right superior temporal sulcus, and happy prosody specifically activates the right inferior frontal cortex.

Caregiver's use of infant-directed speech is critical for the development of the posterior areas of the right hemi- sphere that process prosodicemotional functions to infants, is higher in pitch, has a wider pitch range, and exhibits exaggerated pitch contours. In addition, it is shorter, slower, and separated by longer pauses than adult speech. Developmental neurobiological research demonstrates that maternal infant directed speech activates the right temporal area of 4- to 6-monthold infants, and that this activation is even greater in 7- to 9-month-old infants. In 11-month-old infants, the voice of a woman's infant-directed speech (i.e., with some- what exaggerated prosody) elicits a right-lateralized event-related.

In the right amygdala, right anterior cingulate, and right orbitofrontal cortex, these three systems interconnect with each other and with arousal regulating bioaminergic neuro- modulatory dopaminergic, noradrenergic, and serotonergic nuclei in the brainstem and midbrain, as well as with neuroendocrine nuclei in the hypothalamus, the "head ganglion" of the autonomic nervous system, and therefore each inputs the stress regulating hypothalamic–pituitary–adrenocortical (HPA) axis.

At 2–3 months the right basolateral amygdala, which densely connects with higher cortical areas, begins a critical period of growth, initiating the infant's burgeoning intersubjective functions. From 3 to 9 months, the anterior cingulate, a cortical-limbic structure associated with responsivity to social cues comes online, giving the infant even greater capacities for intersubjectivity and for receiving non-verbal communications of "good-enough" caregiver interactive regulation. From 10 to 12 months of age the regulatory center in the orbitofrontal cortex, the attachment executive control system, begins its developmental growth

period, which spans until the end of the second year (Schore, 2000). With optimal relational attachment experiences, the vertical axis that connects the right orbitofrontal cortex with subcortical areas is well developed, allowing the right orbitofrontal cortex to regulate the right amygdala.]

#### CONCLUSION

In-vivo neuroimaging in ASD has the potential to discover reliable and replicable clinicopathological associations across the lifespan. Such discoveries will help the field move from understanding ASD as clinical syndrome to understanding ASD as the common expression of a variety of different neurodevelopmental diseases with at least somewhat different pathological mechanisms.

#### **KEY POINTS**

- True brain overgrowth, that is, an abnormally enlarged brain, and an abnormally rapid rate of brain growth during the first years of life occur in only a small minority of children who develop ASD.
- Longitudinal neuroimaging studies of the brain in ASD show dynamic changes from infancy through young adulthood.
- Abnormalities in primary sensory cortices appear to be involved in ASD, in addition to neural network dysconnectivity and dysfunction.
- Long nerve tract connections are compromised giving way to local minicolumns to develop
- Genes play a critical role but with cross border genes, the subject still remains complicated enough to be of any practical use in clinical practice
- Higher modules of neuroimaging techniques are enabling us in pin-pointing brain centre for minute functionalities hitherto unimaginable to decipher
- These facts certainly makes neurobiology of ASD an interesting read

#### ACKNOWLEDGEMENT

This article is largely a reproduction from the meticulous work done by References 1,2 and 7 along with the other references used. I also thank Dr. Lokesh Lingappa, Consultant Paediatric Neurologist at Rainbow Hospital, Hyderabad for some of the material and his personal communication with University College of London in the sections on Minicolumns, fMRIs, Cross Border Genes and NIRS.

There is no conflict of interest known to me. This is not a funded project. No money changed hands in putting it all together. It is written with the good

#### faith and for the academic purposes only.

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## Walking the Talk

## POOR SCHOLASTIC PERFORMANCE PROGRAM - 2007 - 2015 Lessons learnt

#### Aims and Objectives:

This program was aimed at enhancing awareness among pediatricians regarding approach to and management of children presenting with poor scholastic performance which affects nearly 20% of school children in our country. These trained pediatricians in turn conducted awareness programs for the public at large, parents, school managements and teachers so that the problems of this 'invisible handicap' are dealt with on a war footing by every one dealing with children in our country.

Advocacy involving the Human Resources Ministry, Education Ministry of the Centre and the State Governments and all the School Boards was also part of the program.

#### Workshops and follow-up

The IAP PSPP was included in the IAP Action Plan 2007 and 2011 and this gave the program a boost. The module was prepared by experts from the then Childhood Disability Group. Zonal workshops were conducted and the program was then rolled out at the district and city branch level - multiple un - sponsored sessions were held all over the country during all the years since its inception in 2007. A good awareness of approach to poor scholastic performance and its co-morbid disorders have been generated among pediatricians, school administrators, teachers, parents and the public .

1. All delegates at the nation wide workshops were given CD of all the presentations which they would use for sensitising pediatricians, public and schools in their vicinity.

If the child is performing poorly in studies, the following protocol was t be followed uniformly by all pediatricians.

i. Examine for Physical problems-specifically -Vision, Hearing, Speech, Epilepsy, Hypothyroidism, Avitaminosis, Anemia, Chronic disorders as asthma causing absenteeism, Medications causing poor attention, etc.



Dr Jeeson C Unni Senior Paediatrician based in Cochin,pioneer in the field of Develeopmentalpediatrics and chief motivator and mover behind the Poor Scholastic Performance programme of the IAP

ii. A developmental history for global delays in development (Mental Retardation or Autism) or Specific delays in Development (Speech Delay). Consider lead, mercury and manganese poisoning as a cause.

iii. Psychiatric disorders as ADHD, Conduct Disorders, Oppositional Defiant Disorder, Obsessive Compulsive Disorder.

iv. Educational history- ensuring adequate opportunities to learn, adequacy of Readiness skills, Study skills and Efforts at learning.

v. Family history looking specifically at issues which would interfere with learning (remember that children from functional families also have learning problems).

vi. Referral services – assessment of IQ, specific learning disability, attention deficit hyperactivity disorder; and for remediation to the special educator, psychologist

for conduct disorders, anxiety, obsessive compulsive disorder, psychiatrist for depression, severe OCD, etc.

vii. Emphasis was on the need for a multi-disciplinary approach.

2. A booklet with all this material was circulated

3. LOCAL ACTIVITIES - Local branches, after the awareness program, conducted school and public awareness programs on the issue

4. School and community screening programs to assess the magnitude of the problem, though planned, could not be undertaken because a uniform assessment tool was not available



5. PUBLICITY- Publicity in various media regarding the problems of children with SLD and IAP's interest in helping these children was conducted.

#### ADVOCACY

The IAP National Presidents 2007 Dr Naveen Thacker and 2015 Dr S S Kamath along with the members of our group submitted the IAP Advocacy Document on Learning Disorders to all organisations dealing with childhood disability in India during both these years. The concerns of the Academy and the Childhood Disability Group (Now IAP Neurodevelopment Chapter) were recognised by the Ministry of Social Justice and Empowerment Govt of India, RCI and the committee dealing with the Amendment of the Persons With Disability Act 1995.

We humbly presented our case and requested that an amendment be made in the Persons With Disabilities Act so that

1. Learning Disorder (LD) be recognized as a disability in the PWD Ac

This should make it possible to provide educationsl support for all children with Learning Disorders in the country by

a) providing funds for and ensuring that all schools have adequately equipped resource rooms

b) Providing trained special educators - sufficient number to cater to the requirements of each school

c) Centres for referrral and therapy for moderate and severe LD at district and taluk level.

d) Educational grants to private institutions providing diagnostic and remedial care for LD

e) Medication for ADHD - Methylphenidate and Attenterol - be made available at pharmacies at affordable price

2. Provisions for SLD in National Policy of Education and State Education Acts

3. The Disability Board in every district should include a pediatrician, psychiatrist, special educator or an educational psychologist well versed with assessment of children with specific learning disability and aware of the provisions that could be availed by a child certified as having SLD

4. Clear cut criteria for diagnosis of Specific Learning Disability needs to be formulated and guidelines made available

5. Include private schools affiliated to the CBSE / ICSE also in the efforts

to include students with disabilities in regular schools. Compulsory seat reservation for students with disabilities in all regular schools, including those affiliated to the CBSE / ICSE.

6. Compulsory integration of SLD component in the B.Ed. programme at the National and State level. Regular teachers should be required to do the 6 months Foundation Course in Education of Children with Disabilities of RCI in distance mode. Teachers of children with special needs and regular teachers may also be trained in SLD under the Sarva Shiksha Abhyan.

7. SLD awareness and information dissemination across India by trainers, teachers, parents and medical fraternity.

The effort has resulted in LD being included as the 18th of the 20 disabilities proposed for inclusion in the PWD Bill for amendment. The Bill needs to be passed in the parliament as the new PWD Act. We need to reinforce our advocacy to ensure that LD is included.

## Walking the Talk

## **Hearing Loss in Neonates** Need for Early Detection and Intervention

#### Dr. Abraham .K. Paul

MD, DCH, FIAP, FNNF Con. Pediatrician, Cochin Hospital Convenor, New Born Hearing Screening Programme IAP Kerala WHO Lead Expert, New Born Hearing Screening Programme, South East Asia Region Cochin – 682016, Kerala 9846023388 abrahamkpaul@gmail.com



earing loss has considerable impact on the overall development of the infant language, cognition and development of social emotional competence. The first year of life is a critical period for brain development, especially development of the auditory pathway. Auditory experience during this period has profound influence on functional development of auditory system and lack of auditory experience can have detrimental effects. At birth, the brain has 100 billion neurons and they form about 50 trillion connections. The only way the connections can be strengthened is by stimulation both auditory and sensory. The connections that are not used or stimulated, wither away. This emphasizes the need for constant auditory stimulation right from birth for optimal development of auditory system, a prerequisite for optimal development of speech and language. (Fig. 1)

It established that unidentified hearing loss can adversely affect optimal speech and language development, acquisition of literacy and academic, social and emotional development. Neonatal hearing loss and its developmental consequences are measurable before the age of 3 years. If these are not remediated through early intervention, they impact the child for life. There is robust evidence that identification and remediation of hearing loss, when done before 6 months of age for newborn infants who have hard of hearing, enables them to perform significantly higher on vocabulary, communication, intelligence, social skills and behavior necessary for a successful later life. We have now readily available technology that provides rapid and ultimate identification of hearing loss in newborns and also included assistive listening devices (hearing aids, frequency modulated systems, cochlear implants) that can provide markedly improved hearing to the needy children. American Academy of Pediatrics (AAP) in 1999 advocated Universal New Born Hearing Screening Programme (UNHSP) and remedial intervention which is being practiced in most of developed countries. Significant bilateral hearing loss is present in 1 to 3 per 1000 newborn infants in the well baby nursery population and in 2 to 4 per 100 infants the intensive care unit population.

In a developing country like India, simple and practical preventive measures for Universal Screening need to be developed for this purpose. At present in majority of the hospitals in India, there is neither a universal neonatal screening nor a high risk screening for hearing, as a routine.

## Universal New Born Hearing Screening Programme (UNHSP)

American Academy of Pediatrics Task Force on newborn and infant hearing recommends UNHS by 3 months of age with intervention by 6 months of age. The joint committee on infant hearing (JCIH) position statement provides guidelines that include newborn hearing screening (NHS) soon after birth, before discharge from hospital or before 1 month of age, diagnosis of hearing loss through audiological and medical evaluation before 3 months, and intervention through interdisciplinary programme for infants with confirmed hearing loss before 6 months of age. This screening involves all newborns, with special attention to the hight risk group which include the following:

- i. Family history of hereditary childhood sensorineural hearing loss.
- ii. In utero infection such as cytomegalovirus, rubella, syphilis, herpes and toxoplasmosis.
- iii. Craniofacial anomalies, including those with morphological abnormalities of the pinna and ear canal.
- iv. Birth weight less than 1500 gms.
- v. Hyperbilirubinemia at the serum level requiring exchange transfusion.
- vi. Ototoxic medications, including but not limited to the aminoglycosides.
- vii. Bacterial meningitis.
- viii. Mechanical ventilation lasting 5 days or more and
- ix. Stigmata or other findings associated with the sensori-neural and / or conductive hearing loss.

## Centralized New Born Hearing Screening Programme (CNBHSP)

At present few hospitals in our country do hearing screening for newborns born in their hospital and in some instance, babies that are brought for hearing screening to their tertiary hospitals. In a developing country like India, a hearing screening equipment facility in every hospital with a maternity unit may not be a viable proposition.

A Centralized New Born Hearing Screening Programme with a two stage screening protocol with otoacoustic emission (OAE) as the first screening, followed by auditory brain system response (ABR) for those who failed the first screening will be more practical. In this 2 tier screening programme (the second tier being the more expensive ABR), ABR will be required only for a selected few - thus making the programme more practical and viable. The trained personnel can report to a particular hospital at a particular time and day of the week. This protocol will make the screening cost effective and acceptable, avoiding the need for transporting the neonates to a screening facility and thus significantly preventing dropouts. The overall practicability will make it relevant for our country; making it a potential model screening programme. Personnel with basic knowledge in computer and good communication skills may be given basic training in hearing screening and entrusted the task of screening. (Fig. 2 & 3).

The treating pediatrician can appraise the parents of the infants about the procedure and its need. As per guidelines, the neonate gets screened before discharge from the hospital. If there is an abnormal result, repeat test is done on the day of the infant's next scheduled visit for immunization. If the repeat test also is abnormal, the baby is referred for ABR. Babies with abnormal ABR are referred for comprehensive evaluation and remediation. The evaluator can record the medical history from the discharge card / inpatient file of the infant, to identify the subsequent scheduled follow up visit. OAE screening will take only about 3 -4 minutes, if the baby is in the natural sleep. Older babies may require sedation. Babies requiring repeat test may be given specific dates by the hospitals for the scheduled follow up visits, so that it will coincide with the visit of the screener. The Centralized NBHSP is in practice in the city of Cochin since 2003 and is functioning well giving excellent results.

OAE, ABR and automated ABR (AABR) testing have all been used in newborn hearing screening programmes. ABR assesses auditory functions from the eighth never through the auditory brainstem. Both tests are necessary to differentially diagnose on infant's hearing impairment. OAEs are used to assess structural integrity and are physiologic measurements of the response of outer hair cells of the cochlea to acoustic stimuli. They serve as a fast objective screening test for normal cochlear function. OAE tests are used to assess the outer, middle and inner ear portions of the auditory system. ABR testing helps in assessing the whole system, from periphery to the auditory never and brain system. If an infant has normal OAE and abnormal ABR, he may be having auditory neuropathy or auditory dyssynchrony. The ABR and OAE are tests of structural integrity of the auditory pathway and not tests of hearing; therefore, even if ABR and OAE test results are normal, hearing cannot be considered definitely normal until a child is mature enough for a reliable behavioral audiogram.

All infants, regardless of the newborn hearing screening outcome are recommended to receive ongoing monitoring for development of ageappropriate auditory behaviours and communication skills. Any infant who demonstrates delayed auditory and / or communication skill development, even if he or she passed newborn hearing screening should receive an audiological evaluation to rule out hearing loss. These are also communicated to the parents by the pediatricians.

UNHSP has become a national practice in most of the developed countries. The identification of all newborns with hearing loss before 6 months has now become and an attainable realistic goal in almost all the developed countries. The prevalence of permanent congenital hearing loss (PCHL) is higher than other neonatal screenable conditions put together. Even though the incidence of PCHL is more than 10 times in the high risk group as compared to the well baby nursery population, high risk screening is not enough, given that as many as 50% of infants born with hearing loss have no known risk factors and hence UNHS is needed.

#### Centralized New Born Hearing Screening Programme – Ernakulam District

Even though new born hearing screening is practiced in some hospitals in India, to our knowledge, this is the first project in India covering all newborns in a city.

The Centralized newborn hearing screening programme, an ambitious project taken up by IAP Cochin Branch and Child Care Centre in January 2003 is yielding excellent results.

Now IAP Cochin Branch in association with the District administration, National Health Mission and State Health Department has initiated a project "Hearing Friendly Ernakulam District" in August 2014. All the babies born in the 91 hospitals in the district are being screened with the help of 8 OAE machines and 8 screeners. The programmed is being monitored by a Co-ordinator. So far 1, 01,688 newborns were screened and 162 newborns are confirmed to have hearing deficit and are on treatment with hearing aids.

#### PROTOCOL

- 1. A trained person visits all major hospitals on a particular day of the week regularly.
- 2. Baby preferably screened before discharge from the hospital.
- 3. If by chance the screening is missed, do the screening at the first immunization visit at 6 weeks.
- 4. Babies are screened by Portable handy equipment OTOPORT (Time taken 1 to 2 minutes).
- 5. If abnormal result, test repeated after two weeks.
- 6. If again abnormal, BEARA Test done for confirmation and quantification of HearinIf BEARA Test abnormal, perform comprehensive hearing evaluation.
- 7. If confirmed hearing loss, usage of Hearing Aid recommended at the earliest along with intensive communication and speech therapy.

Hearing Aids can be fitted even as early as two months of age

8. Cochlear implant in selected cases (profound hearing loss and infants who do not improve with hearing aid for 6 months)

#### **SCREENING PROCEDURE & THE TEAM**







#### The Equipment OTOPORT LITE OAE Screener



#### Sticker Attached to Baby Card Screening Report Card for Patients

SOME EARLY SYMPTOMS IN A CHILD T SUSPECT HEARING IMPAIRMENT (for parents or caretakers)	NEWBORN HEARING
0-4 months	SCREENING PROGRAMME
<ol> <li>Child does not respond to loud sounds.</li> </ol>	A project of
<ol> <li>Does not attempt to search for sound with eye</li> </ol>	and/ or IAP Cochin Branch
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9 - 12 months	the second second
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<ol><li>Does not attempt to attract attention by spee</li></ol>	ich. T T
1-2years	Phone :
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11. Does not follow simple commands at normal lo	budness Bhavya :99953 68990 - (Audiologist &Co-ordinator)
level or even at slightly loud levels.	Usha : 96569 33178 Remva : 9744496120
If the parents notice absence of any of these,	accord- Megha : 96562 48456 Sandya : 9961909315
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old, to prevent disabilities in speech, language and cognition in the child's development.

- 3. A two stage screening protocol with otoacoustic emissions (OAE) as the first screen, followed by auditory brain system response (ABR) for those who fail, is more practical. This will obviate the need for more expensive and time consuming test like ABR for the majority of infants, thus making it more practical, viable and replicable.
- 4. Pediatricians have to take a proactive role in developing newborn hearing screening programme in their respective city / town and in the initiation of follow up programmes.

#### Conclusion

Pediatricians should take a proactive role in developing NBHSP and also in the initiation of follow up programmes to provide a continuity of care for these infants; pediatricians should be the team leaders in the multidisciplinary approach to management of hearing impaired children. They can also play a major role in promoting acceptance of hearing aids, encouraging constant usage of aids and providing information regarding early intervention services.

#### Recognition from WHO for IAP Cochin Centralized New Born Hearing Programme

WHO Collaborating agency New Delhi appreciated the Centralized New Born Hearing Programme of IAP Cochin and is planning to replicate this Cochin Model in South East Asia Countries.

#### Points to Remember

- 1. The incidence of bilateral congenital hearing loss in general population is 1 to 3 per 1000 and is 10 times more in neonatal intensive care units. This incidence is more than other neonatal screenable disorders put together.
- 2. Hearing loss, it present, should be identified and remediated before the baby is 6 months

## **Case Files**

# An interesting case of a 7 year old with language delay

7 year old girl was referred for a comprehensive developmental and psychometric assessment at Child Development Clinic at BLK Super Speciality Hospital, New Delhi.

She belonged to a Maharashtrian family residing in Delhi and was the only child born out of a non consanguineous marriage. She was born at term gestation through emergency Caesarean section done in view of fetal distress. At the time of birth she was reported to have delayed cry and required neonatal intensive care stay for about 4 days. She did require oxygen support for first 24hours and no seizures were reported.

Developmentally she attained her motor milestones appropriate for age but had delay in acquisition of language milestones. She started speaking single words by 3 years of age and making brief sentences by 5 years of age. At this stage she was assessed and diagnosed to have mild- moderate Autism Spectrum disorder (CARS Score of 31.5) by a child psychologist and same was reiterated by a speech therapist. She was also started on speech therapy which was continued for couple of months but was later stopped by parents as no improvement was seen.

Presently they reported with following concerns that child had poor language content and spoke in a different tone. She could answer and hold brief conversations at home but was facing difficulty in social setting outside school. She was keen to play with other kids as per mother but was not included in social play groups. She was attending Kindergarten grade in regular school as she was not able to cope up at higher grade level.

At this point she was seen by Paediatric neurologist and MRI brain was advised which revealed focal cortical dysplasia of left inferior temporal lobe. Clinically no focal neurological deficit was reported nor a history of seizures. EEG was also normal. A provisional diagnosis of Auditory verbal agnosia was also considered at this stage.

After a detailed assessment by a team of developmental paediatrician and clinical



Dr Shambhavi Seth Developmental Paediatrician BLK Super Speciality Hospital Max Hospital, Bright Beginnings Child development centre New Delhi

psychologist it was noted she seemed selectively responding to auditory stimuli when presented in a specific tone. She had both receptive and expressive language delays but she responded better if similar vocabulary of words which her parents used were spoken. She was keen to participate in conversation and often looked for parent's reaction when faced with a challenge. It did not look like a typical case with autistic features alone.

On psychometric testing she had average nonverbal composite score but low verbal scores on Differential Ability Scale (DAS 2<sup>nd</sup> edition). She also had a secondary learning disorder across all academic areas. Her overall DQ was 70. A detailed audiological testing was decided although a BERA done earlier was reported as normal. The ASSR (Auditory Steady State response) test was done and moderate-severe high frequency hearing loss was reported.

It was decided to go for hearing aid (RIC receiver in canal) trial in view of high frequency loss. She is three weeks into follow up now and she is doing much better and her communication has improved significantly. Currently she is undergoing speech interventions with the hearing aid and also started on remedial tutoring.

It was an interesting case which had varied diagnostic impressions from autism spectrum to neurological language impairment to auditory loss. Although a normal BERA was reported still a detailed clinical examination helped us to clinch a diagnosis of high frequency hearing loss.

## Activity Log

## Child Care Centre distributed booklets on Learning Disabilities to create awareness among Teachers in the District

hild Care Centre conducted awareness programmes for school teachers in the district on Learning Disabilities (L.D.) in children (present in about 10% of school children). As first step, a booklet on Learning Disability was distributed to all Govt. and aided schools which contains details about the condition and also pointers to the disorder which will enable teachers in the school to suspect / detect the problem.

The copies of booklet prepared by Child Care Centre, was handed over to the District Collector, Sri. M.G. Rajamanickam .IAS by Dr. K.C. George, President, IAP Cochin Branch, Dr. Abraham .K. Paul, Executive Director, Child Care Centre, Dr. Sivaprasad, Secretary, IAP Cochin and Dr. Rohin Abraham, Treasurer, IAP Cochin. This will be distributed to all schools through the D.E.O.

The booklet deals with causes of poor school performance, methods of evaluation and remedial measures. The information gained by teachers through this booklet will enable them to suspect / detect the condition and do remedial measures. Child Care Centre plans to conduct a workshop for teachers on Learning Disability as the next step.

Child Care Centre, doing yeomen service in the field of Learning Disability since last 20 years is a joint venture of Ernakulam District Council for Child Welfare and Indian Academy of Pediatrics, Cochin Branch with District Collector as the Chairman.



Booklets on Learning Disability handed over to District Collector Sri. M.G. Rajamanikiam I.A.S for distribution among Teachers in the district of Ernakulam by Dr. Abraham K. Paul, Dr. K.C. George, Dr. Sivaprasad and Dr. Rohin Abraham.

### **CME in Hisar**

CME for awareness of Teachers and doctors (Pediatrician) in and around Hisar (Haryana) was conducted on 31st july 2016. This was a full day programme with morning session dedicated for teachers and evening session dedicated for pediatrician.

This CME was organised by dr Harsh bhayana along with members of hisar IAP branch. The faculty of this CME was dr chaya prasad from chandigarh and dr shambhavi from delhi

This CME was attended by approximately 35 pediatrician and a total of 60 teachers . Teachers showed a keen interest in all the topics and it was a great interactive session with them where they shared there issues with the faculty and local pediatricians For almost all pediatrician there it was a new topic. Everybody participated in the event showing keen interest. they also shared there difficulties while seeing these patients in OPD. Pediarician session continued till late in evening with good attendance till the end.



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## Workshop for parents in BL K Hospital

DR SHAMBHAVI SETH Organized workshop for parents with children with autism in association with IAP Central Delhi branch at BL Kapur Hospital in January 2016. It was attended by more than 100 parents. A parent support group was also formed at the meet by the name of "Comrades for autism". National Trust also participated in this event and gave information on different insurance schemes for children with disabilities available through Ministry of Social Justice and Empowerment.



## **Workshop on Bayley Scales**

Dr Shambhavi organized workshop on Bayley scale of Infant development (3<sup>rd</sup> edition)- scoring and administration in association with Pearson academy, India at BL Kapur memorial hospital, New Delhi in April 2016.



### **CME** in Bhubaneswar

A CME on Neurodevelopmental disorder was organised at IMA House Bhubaneswar on 13th March 2016 in association with NHM Odisha. Dr Chhaya Prasad and Dr Leena Srivastava along with Dr Mahesh Prasad Mohanta Odisha coordinator, Dr Aditya Mohapatra, NHM Consultant, Dr Debashis Panigrahi, Dr Subrat Majhi, Dr Rabi Satpathy and Dr Vidya Patwari were the faculties. The CME was attended by 103 participants, which included Pediatricians, DEIC Medical Officers and clinical psychologists. The CME was given 4 credit hours by Odisha Medical council.



Booklets on Learning Disabilities to create awareness among Teachers in the District

## **World Prematurity Day**

Dr.Lata Bhat organised meeting of follow up of preterm babies with their parents on world prematurity day 17<sup>th</sup> November 2015 and did their developmental screening and counselled parents accordingly.



## **CME at Aster Medicity**

The IAP Neurodevelopment Chapter CME,organised by IAP Neurodev Ch, IAP Cochin Branch and Dept of Child Health Aster Medcitywas held at Aster Medcity on 21.8.16. The CME was inaugurated by IAP Preswident 2015, Dr S S Kamath, Keynote address was by Chapter Chairperson Dr Samir Dalwai and the Parent Awareness Booklet of Aster Kind the Neurodevelopment Centre of Aster Medcity that was inaugurated that day - was released by Dr Beena Koshy. 60 delegtaes attended the CME.



## Webinar on Human milk banking

IAP NDP member Dr Lata Bhat addressed a webinar on human milk banking .



## Symposium on 'Autism Spectrum Disorder'

Over 100 doctors from the Tricity and organizations like the Indian Academy of Pediatrics and Indian Medical Association attended the Symposium on Autism Spectrum Disorder" held at Max Super Speciality Hospital Mohali in observance of World Autism Awareness Week in April 2016. Role of Pediatricians was stressed upon in picking up red flags and early signs of Autism. Timely Early Identification and appropriate Early Intervention were discussed by Dr Chhaya Prasad, Developmental and Behavioral Pediatrician, Senior Consultant, Max Hospital, Children with Autism should be helped to accommodate in the mainstream education to give them a better learning environment and not segregate them in special schools, she added. Dr Pratibha Singhi, H.O.D & Professor, Chief Pediatric Neurology, Dept of Pediatrics, PGIMER, Chandigarh, and Prof O N Bhakoo, Former Head. Department of Pediatrics, PGIMER Chandigarh chaired the scientific sessions. Dr Singhi remarked that "Early Diagnosis is the key to managing Autism in children and awareness amongst Professionals and Parents is extremely important." Latest global surveys suggest that 1 in every 68 children are being diagnosed with autism spectrum disorder (CDC 2014). Role of Parents in understanding the Spectrum of Autism and being an integral part of the Interventions is very important. Striking a positive note, Dr ON Bhakoo said that "With the Indian Govt. becoming more pro active and expecting the doctors to report every case of child with developmental delay, the role of doctors, especially pediatricians becomes more pertinent that they get skilled in the standardized process of Identification, Diagnosing and Reporting the case.

## Activity Log

## Workshop on Learning Disabilities at IMA House, Kochi on 16-17 October 2015 Organized by Child Care Centre, Kochi

Child Care Centre, Cochin organized a **Two Day** Workshop on Learning Disabilities at IMA House, Kochi on 16<sup>th</sup> & 17<sup>th</sup> October 2015 at 9.00 a.m. The workshop focused on remediation of writing and Mathematics disorder.

The expert team from Alpha to Omega Learning Centre, Chennai lead by Ms. Laitha Ramanujan & Ms. Rathi Viswanathan conducted the workshop.

The inauguration was done by Dr. M.K.C Nair, Vice Chancellor, Kerala University of Health Sciences. He stressed the need for early identification and remediation of the problem, so as to mainstream these children in the most effective way. Dr. M. Narayanan, President, IAP Cochin Branch gave the presidential address Dr. Abraham K Paul, Executive Director, Child Care Centre welcomed the gathering . Ms. Lalitha Ramanujan did the felicitation and Dr. Vivin Abraham, Secretary, IAP Cochin Branch proposed vote of thanks.

This was the first of the series of workshops. Child Care Centre is planning to organize for the benefit of the Learning Disabled children.



CITY EXPRESS Kochi, Thursday, 24 September, 2015

## '171 Babies Have Hearing Defects'

#### **Express News Service**

Kochi: Newborn Hearing Screening Programme initiated by IAP Cochin has covered one lakh babies and out of them 171 were detected to have been born deaf in Ernakulam district.

Out of 91 hospitals in the district, the centralised Newborn Hearing Screening Programme caters to 78 hospitals whereas other 13 hospitals have their own in house facility. The programme is carried out by eight screening personal, eight portable machines and a co-ordinator.

So far 1,21,000 babies have been screened and 171 babies have been confirmed to have hearing problems. They are on remedial treatment programme initiated by IAP Cochin Branch in association with National Health Mission, Directorate of Health and Dist- Administration. This screening model is in accordance with the International guidelines stipulated by American Academy of Pediatrics and Joint committee on Infant Hearing (USA).

Early identification and intervention will oblivate the need for expensive Cochlear implant surgery in majority of cases. With the implementation of the programme in the whole district, about 2,400 babies are screened per month.

## Album

















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## Album

















# Visit the **CogniCare**™

# Journey plan contemplated for the CogniCare World

• CogniCare under the umbrella of **BrioBliss Life Science** will closely work with **'Developmental Pediatrics'** across the country.

- The above togetherness includes, scheduled interface to share the experience by way of **CME through IAP** connecting all zones of the country and network of cities.
- CogniCare is examining **'Study grant'** to developmental pediatrics to promote Research and Development in this specialization.
- CogniCare in India is endorsed by over 100 doctors and over 2000 children have shown marked and measurable improvement in cognitive factors. This data is based on actual usage study in the past three months. *Indian Clinical Studies* are also initiated. This Study will be multi centric involving 300 Children facing neurological challenges. These Clinical Studies will supplement US Studies on L-Carnosine by Dr. Michael G. Chez in children with ASD.
- CogniCare has drawn plans to enhance Research on child development where Developmental pediatricians, Child Development Centers and IAP join together and work for child development.
- Neurological Disorders are addressed using the approach of evaluate, counsel and treatment. Science strongly advocates 'Child Engagement Program' for child development by the parents along with current approaches.
- **Appeal to Doctors**: Join and support the CogniCare world and make a difference in the development of Angelic Child and bring out specific skill in them to showcase the world. In the process Parents of the Angelic Child feel and enjoy the Bliss.



## L-Carnosine Syrup & Tablet

## **Regulates Neuronal Signalling & Improves Cognition**

## ...Improves Cognitive Function, without INSOMNIA, WEIGHT GAIN, AGITATION



## Patented in USA, Now in INDIA

**Improves Cognition** 

