SYMPOSIUM ON EARLY INTERVENTION

In collaboration with
Ummeed Child Development Centre, Mumbai &
In association with
Indian Academy of Paediatrics (Assam State Branch)





21st September 2022 at Shishu Sarothi, Guwahati
Guwahati

Introduction:

A Symposium on Early Intervention was organized by Shishu Sarothi on the 21st September 2022, in collaboration with Ummeed Child Development Centre, Mumbai and in association with the Indian Academy of Paediatrics (Assam State Branch) to discuss the importance of early intervention, based on tried and tested practices. The symposium was intended to explore opportunities for collaboration and support for ongoing EI services, and convergence with ongoing government schemes, so as to reach more children with developmental disabilities and families. It was also hoped that participants would form a network of professionals, government departments, organizations, and families to discuss, support topics related to Early Intervention.

The symposium was held in a hybrid mode with in-person and online participation of 32 stakeholders from 4 states in the North-East region. Participants included government and National Health Mission Assam officials, professors from Medical Colleges, practicing paediatricians, representatives from civil society organizations imparting early intervention services, universities and colleges offering courses on physio and speech therapy, as well as individual practitioners and professionals.

Inaugural Session:

In her welcome address Ms Ketaki Bardalai, Executive Director (Shishu Sarothi) welcomed participants and the IAP Assam State Branch for taking such keen interest in the program. She said that the idea of the symposium took shape from a need for highlighting the work of different organisations across Assam and NE region in Early Intervention and hoped that it would chart a path to work together. She acknowledged the support of Light for the World and Numaligarh Refinery Limited for supporting Shishu Sarothi 's Early Intervention services in different locations in Assam.

She shared that Shishu Sarothi held its first workshop on Early Intervention with the Paediatrics Department of GMCH, way back in 1992, with the help of technical expertise of Indian Institute of Cerebral Palsy, Kolkata to raise awareness among the medical fraternity, so that they did not miss the crucial period of early childhood of so many of the children coming to Shishu Sarothi in those days. Since then, there has been a gradual increase in the number of younger children - infants and high-risk babies - availing SS's services.

Over time with a steady increase in referrals of young children, Mr. Arman Ali, the then ED of Shishu Sarothi, redesignated the erstwhile Out Student Department (OSD) to an Early Intervention Unit, thus aligning the work with the mandate of Article 25 of the UNCRPD and the provisions of the RPwD Act 2016 too. She mentioned that the initiation of EI services at the Composite Regional Centre in Guwahati with its proximity to the GMCH, along with referral support of the Paediatrics Dept (NICU) led by Dr Gayatri Bezboruah, had seen a significant increase in number of young children - neonates and high-risk babies - availing the EI services at the CRC.

She regretted that the Mission Director, National Health Mission, Assam was unable to grace the symposium due to an urgent meeting and cited the potential of National Health Mission’s

Rashtriya Bal Swasthya Karyakram(RBSK) and its initiative to reach out to children with delayed development and disability, representing the 4th Dto be addressed at District Early Intervention Centres, that are being set up across the country. She felt that in view of the wide gaps in early intervention services for children, it would be a good idea to connect and converge with public health programs in Early Intervention of the National Health Mission and was hopeful that the symposium would lead to a concrete solution to take this forward.

She thanked Dr Vibha Krishnamurthy, Ashoka Fellow and Founder Director, of Ummeed Child Development Centre, for agreeing to come and speak about the importance of Early Intervention, including the 'why' and 'how' of it. She was grateful for Ummeed's support in organising the symposium as part of their collaboration with Shishu Sarothi.

A message from Sri Keshab Mahanta, Hon'ble Minister of Health and Family Welfare, Govt of Assam, who had been invited to inaugurate the symposium, but was unable to attend due to other engagements, was read out to the participants. (Attached in Annexure)

The invited panellists present were subsequently felicitated with *gamochas* and a token gift of handmade products of the students of Shishu Sarothi

Shishu Sarothi's Early Intervention services

A presentation on the Early Intervention services of Shishu Sarothi was made by senior physiotherapists Ms Archana Gogoi and Mr Dhanjit Kalita. Ms Archana Gogoi began by speaking about the importance of Early Intervention and cited the theory of neuroplasticity of the brain and its potential to facilitate the development of a child. Explaining how Early Intervention works,she went on to describe the nature of the work done by Shishu Sarothi in this area and listed the various programs taken up by the team including outreach programs across Assam, parent empowerment programs, tele rehab support, health check-ups and free play stimulation programs.



Thereafter, Mr Dhanjit Kalita spoke of the geographical reach of the Early Intervention services in different locations in Assam and shared statistics of the number of children enrolled and the number of children followed up in each of these programs over the last 5 years.

Ms Archana Gogoi also shared about the challenges in implementing the early intervention program including the effect it had during the pandemic. She wrapped up with a few impact stories of the changes that their EI efforts had affected in the lives of some children.

Early Intervention Services at Shishu Sar

Keynote Address by Dr Vibha Krishnamurthy

Expressing her happiness at being in the vibrant and positive environment of the campus at Shishu Sarothi, Dr Vibha Krishnamurthy began by saying that even though her presentation was on Early Identification and Early Intervention, she would like it to be "*a call to act*" and wanted to focus on the "why" and "how" of Early Intervention. She said that for some of those present in the audience the whole concept may be new since the science of Early Intervention has not been around for long. For those of who are familiar with the concept of EI, she was hoping that the presentation would provide the language that they will need to talk to their colleagues about why it is important to identify and intervene at the earliest.

Speaking about the prevalence of childhood disability she shared that earlier on, when she would talk about autism and other developmental disabilities, people would say that these disabilities are not prevalent in India. A study was done in 2018 with 5000 children from all over the country and even though the study found the prevalence of 1:8 ratio of children with developmental disabilities it did not capture all types of disabilities. She shared that there is a 15% prevalence of childhood disability in low- and middle-income countries according to WHO Disability Report 2011 and Lancet series on ECD. For a country like India, this implied that there were an estimated 52 million children with disabilities. This figure is way more than the prevalence of childhood cancer, juvenile diabetes and so many other obvious conditions. She raised the question that 'how could there be so many children with developmental disabilities?' and it almost seems impossible that such a huge figure could even exist.



She went on to cite live scenarios of 2 children, both aged 2.5-years who had speech and language delays. The first child was from an urban slum in Pune, who was moderately malnourished, and the mother was overwhelmed as she had 3 young children. This child had poverty related risk factors for developmental delays with an overwhelmed mother having prospects of malnutrition and anaemia. This case of developmental delay affects many children across India and predisposed them to acquiring a disabling condition. The second2.5-year-old child who hadautism spectrum disorder (ASD), was non-verbal and no one picked up on the fact that he had ASD till very late. Thus, she said that as it was a spectrum with no magical point where a child might have a disability. One could have a disability because of being poor, result from any one of the other Ds identified in RBSK; the Defects, Disease and Deficiencies and the child could end up having a form of disability. She said we need to keep in mind that when we talk about childhood disability, we must remember that other than visible disabilities, there are also many other children who are at risk. Some children are born with disabilities while for others there are many factors like delayed identification, and mothers and primary caregivers are not being given the proper mental health support. While citing the examples Dr Krishnamurthy said that for both the children, early identification and promoting child

development led to good outcomes. This statement has been repeated many times because there's science to prove it.
She then spoke about synaptic connections in the first 4 months of a baby's life and how it affects a child's development. She referred to the 2018 WHO Nurturing Care Framework, having been a part of the team that formulated that had 5 components and was based on the science of developmental paediatrics and the child's brain development, particularly in the first 3 years of life. The 5 components are **good health, adequate nutrition, opportunities for early learning, security and safety, and responsive caregiving.**

She went on to explain the science behind responsive caregiving. The child's brain is not passive, and it requires interactions to grow and develop. The to and fro activities of parents and caregivers with their child help the synapses to connect. Each back-and-forth interaction builds connections in the brain and repeated synaptic connections in the neurological circuits then form strong and connected fibres of the brain.

She showed a short video clip by Dr T Berry Brazelton, an American Paediatrician,author, and developer of the Neonatal Behavioral Assessment Scale (NBAS) to demonstrate what these connections of synapses looks like. She showed another video in the context of an Indian family. She explained how a simple game of peek-a-boo leads to development in all areas like fine motor, gross motor, cognition etc.



She shared a study, Anguish of the Abandoned Child by Dr Charles A. Nelson III and Dr Charles H.Zeanah, Jr, which was done in Romania during the reign of Nicolae Ceausescu to highlight the plight of orphaned Romanian children, that revealed the psychic and physical scars from first years spent without a loving, responsive caregiver. She explained how along with early identification; early intervention can change the outcome, to a large extent due to neuro-plasticity of the brain which is maximum in the early years of life, and decreases with age. In this study itself which was done over a period of time, it was found that when the institutionalized children were placed in foster care, where they got family intervention and care, before the age of 2 years, there was increased brain activity vis-a-vis the children who were placed in foster care after the of 2 years.

She then shared the Jamaican study on Early Childhood Development which demonstrates the continued beneficial impacts of home visiting programs, nutritional support, parent-child interactions and cognitive and social stimulation for infants and toddlers in closing the achievement gap and producing long term economic gains. The study found that a high-quality early childhood intervention boosted the earnings of severely disadvantaged children in Jamaica by 25% when they grew up into adulthood. This study shows how investing in early identification and early intervention via community development programs leads to lasting benefits.

When we talk to communities in community development programs about Early Intervention, they understand that it may not yield results immediately, but maybe 6 years down the line or 16

years, there will be a generation of high potential individuals or youths. She spoke about the importance of introspecting on certain questions before making recommendations to families, like how early intervention works, in terms of children with disability and its long-term effects.

Dr Krishnamurthy also spoke about the unique role of Health Care providers who are the first point of contact for parents with young children, how they provide continuity - where they monitor a child's development, how they are a trusted resource for families, and they are powerful advocates for children. She talked of their role in informing families about the importance of ECD, and of educating themon how to play and communicate with young children and teach families, use opportunities like immunization and minor sick visits, use tools to identify and monitor children with delays, map early intervention services in the community that provide evidence-based services, refer children with developmental delay as early as possible without waiting for a diagnosis. She spoke about how physicians present in the audience had the power to influence policymakers with their knowledge on Early Identification and Early Intervention



She shared some key messages for families that could help them to practice responsible care giving. Dr Krishnamurthy ended by sending out the key message that the brain's ability to change in response to experiences decreases over time and the amount of effort it requires increases over time. Thus, it is never too late to take that step towards Early Identification and Early Intervention as far as children with disabilities are concerned.

https://docs.google.com/presentation/d/1VZB5nIe6lETNSJfESVScJXCJV1h0q7Uk/edit?usp=sharing&ouid=116322403431351971071&rtpof=true&sd=true

PANEL DISCUSSION:

A panel discussion was conducted after a short tea break, with online and present panelists

- Dr Gayatri Bezboruah, HOD, Department of Paediatrics, GMCH
- Dr Vibha Krishnamurthy, Founder Director, UMMEED Child Development Centre
- Mr Joydeep Roy, Consultant RBSK
- Dr Aditi Barua, Professor, Department of Paediatrics, AMCH
- Dr M B Chhetri, Joint Commissioner for Persons with Disabilities-Technical, Govt of Sikkim
- Mrs Ketaki Bardalai, Executive Director, Shishu Sarothi

The panel discussion was moderated by Dr Vibha Krishnamurthy, who began by welcoming the diverse group of panellists and commented on their interconnected work on Early Intervention and expressed hope that all the panellists would optimize the work of Early Childhood Development especially for children and for children with disabilities.

Her first question was to Dr Gayatri Bezboruah, asking why she feels that it is important for physicians, particularly paediatricians, to know about Early Childhood Development and early intervention for children with disabilities. What are the challenges she faced as a paediatrician and what she has done to address them.

Dr Gayatri Bezboruahstated the paediatricians are a very small group in this framework and that there are many other contributors in Early Childhood Development and Early Intervention who need to join hands to make everybody understand about working together. It is important for paediatricians to understand that the management of this work is like an "octopus" which has 8 limbs and where the paediatricians are one of the limbs and that they cannot do anything alone. She expressed her view that considering the kind of health systems that have been developed in the country, there is a need for other health workers like ASHA, Anganwadi workers and ANMs who are in constant touch with children and families in the periphery to be trained in Early Identification and Early Intervention.



Dr Bezboruah spoke about Shishu Sarothi's EI services started in CRC during the tenure of the previous Executive Director, Mr Arman Ali. She also said families bring their children at a very late stage, sometimes between the ages of 10-12 years where there are slim chances of effective intervention and this was mostly due to denial and lack of understanding of the importance of Early Detection and Intervention.



Dr Krishnamurthy then asked Dr Aditi Barua about what made her decide to start an Early Intervention service at the premises of the Paediatrics department at AMCH and the circumstances prior to that.

Dr Aditi Baruashared that in Dibrugarh, before the implementation of RBSK very few cases of children with disabilities were registered, however, now that RBSK is in

place, cases began to rise where initially the paediatricians did the initial screening and later sent the children to the physiotherapy department for exercises. She admitted that although Early Intervention was suggested, no follow ups were done thereafter. She spoke about the limitations of the Department of Paediatrics in AMCH where they were short staffed and catered mostly to emergency cases. She gave the background of initiating Early Intervention services by Shishu Sarothi in the year 2021, and how it has complemented the work of the paediatrics department in providing services to children with disabilities, that they were unfortunately unable to do earlier. She shared that her colleagues too were very positive about the Early Intervention services that they had been unable to provide due to shortage of time and not having enough practical experience.

Dr Krishnamurthy then asked Mr Joydeep Roy about specific challenges faced in blending of the 4 Ds in RBSK, particularly disability, and what solutions that they have come up with.

Mr Joydeep Roygave a brief overview of RBSK Assam's work in 53 blocks with 300 Mobile Health Teams composed of medical officers, a staff nurse and ANM, who visits Anganwadi Centres and Government and Government aided schools. He then spoke about the department's struggle in dealing with parents who are often unaware about the importance of responsive caregiving due to stigmas attached to disability. He went on to say that physicians and organizations working in this area can contribute by creating awareness for parents around the issue of early intervention..

He then spoke of the award-winning initiative of the present Mission Director of NHM, Assam, Dr. M S Lakshmi Priya,who, in her previous role as Deputy Commissioner, Bongaigaon District, created *Buddy Mothers*, where the mother of a healthy child of an Anganwadi Centre was paired with the target mother. They were given diet charts indicating the daily food intake of their children and would have discussions on Tuesdays at the AWC. He also admitted that so far there has not been any collaboration with other organizations working in this area.

After a few technical glitches Dr M B Chetri was able to rejoin the discussion where Dr Vibha asked him to share his experiences working in Early Intervention in both Non government and Government sector.

Dr M B Chetri shared that his experience of working in non-governmental organizations earlier has made him realize that a lot of good work has been going in the field of Early Intervention in the country, but it has been confined and restricted to a certain group of professionals which caters to a small group of population. He stressed on the need to disseminate information and services and reach out to the unreached population by demystifying the techniques which otherwise sounds very scary for the common people, without compromising on the quality of services.

He stressed on the need to look at untapped resources and networking. He however stated that there was a lack of convergence of services with public health programs. The government is doing a lot of good work through RBSK which has been in existence since 2005. According to him in the areas of 4 Ds, **D1 -** Deficit at birth, **D2 -** Diseases at birth&**D3 -**Deficiencies mentioned in RBSK, the professionals in the services have been good. However**D4 -** delayed development and disability is the grey area and it does not seem to blend itself to the doctor's model. He said that part of the issue is the tendency of treating disability like a deficit that needs to be fixed, which does not work, because it requires multiple people to be involved so that the person can participate and is functional in society.

Discussion

The meeting was then opened up for discussion and comments, by Ms. Ketaki Bardalai.**Ms Sony Gill** from Bethany Society was the first person to share her views. She said that Bethany Society has been working in Early Intervention for the past 7-8 years. In the past year they have partnered with Ummeed and have learnt a lot from this collaboration, where community workers from the 5 districts of Meghalaya that they were working in had been trained on conducting surveys and following the strength-based approach to know about the development of the child. She shared that in this project they have reached out 250 children At their robust Early Intervention centre in Shillong which is also a diagnostic centre they have children from very remote areas of Meghalaya. She spoke about difficulties in mainstreaming children in school, however, there are certain schools that have started enrolling children with disabilities in their schools. She admitted a lot of things are happening in the sphere of Early Intervention albeit at a slow pace.



Ms Rumi Kalita from Mrinaljyoti, Duliajan, spoke about their Early Intervention services. She shared that since children and families come from very far off places in Upper Assam and Arunachal Pradesh to their centre, there are a lot of drop out cases. She spoke about increased incidence of CP and Autism cases and sought training and inputs to work with the children there.

Mr Pausuanlal Guite from Centre for Community Initiatives, Churachandpur spoke about their services and the challenges they face in terms of the children coming to them at a very late stage. He felt that awareness, early identification, and early intervention in that order is very important in Churachandpur district. He also indicated that the public health systems are not very friendly and there is little scope for convergence with their efforts.

Mr Pranab Kalpa Hazarika, a practicing neurodevelopmental therapist from Guwahati, and former Physiotherapist at ShishuSarothi shared his experience and bemoaned the lack of resources and poor remuneration of therapists. He said that while the state already has a lot of colleges offering physiotherapy courses, there was a great need for occupational therapists and that courses on OT should be started urgently. He spoke about coming up with a universal protocol on ASD as there were a lot of practitioners in Guwahati who were not following the correct approach.

Dr Sunil Kaul from 'the ant' spoke about their mental health programs and their struggle in terms of referrals to doctors and other organizations. He spoke about his organization's experience in training health workers and the challenges they faced in making them understand about the importance of the period just before a child is born. He feels that one should also focus on that period to reduce the incidence of risk factors in infants.

Dr Abhijit Dutta of Assam down town University spoke about the scope of including Early Intervention in their curriculum and exposure of the students by visiting or interning with organizations like Shishu Sarothi that had a robust Early Intervention Unit.

Dr Pallavi Goswami of College of Physiotherapy & Medical Sciences(CPMS) spoke about her intention of possible collaborations with Shishu Sarothi soon so that informed and educated students can take the work forward in the community for Early Identification and Early Intervention.

Dr Pubali Deka, Development Paediatrician at Apollo Hospitals, spoke about her struggle in working with families from rural set up and low economic background, since she works in a private hospital. She felt that after hearing the discussions at the symposium she can work on home based therapies and suggest these to families who are unable to travel all the way from their native place. She also spoke about the dearth of Occupational Therapists in the region and the mushrooming of private clinics who work in an unstructured way. She said it was importantfor a diagnosis to work in a structured way with a child even though it might seem that they are labelling a child.

Dr Ananta Baruah spoke about children and families in the tea gardens of upper Assam who, due to lack of financial support, are unable to go to the hospitals for intervention and the need to extend services into those geographical areas.

aMr. Francis Angampu of Caritas India spoke about how their Community Based Rehabilitation (CBR) work across the rural areas in NE region, has led them to realize that the reach of Early Intervention services was significantly low due to lack of trained human resources. He spoke about the possibility of collaboration with Shishu Sarothi in Rampur block in Kamrup district for outreach programs to train their CBR workers on the importance of Early Intervention.

Ms Nethrasikha Dutta from Caritas India also said that even though there are government mechanisms like RBSK, a lot of CBR workers do not know of the procedure to refer families to DEICs across Assam. Mr Joydeep Roy responded and gave her the information about the presence of DEICs in 10 districts where the families can be referred and also how to apply for RBSK referral cards. In response Dr Krishnamurthy also reiterated about the WHO Care Giver Training course which is imparted by Ummeed. Dr Gayatri Bezbaruah announced that the Indian Academy of Paediatrics Assam State Branch, would take up the onus to provide the contact numbers of professionals in the DEICs of the 10 districts in Assam for easy accessibility of Early Intervention services.

Mr Touhid Hussain from PRERONA Jorhat spoke about the importance and need of awareness on Early Intervention in the community where parents due to ignorance and stigma associated with disability bring children to their centre when they are past 6 years of age.

Ms Ketaki Bardalai brought the discussion to a close by thanking everyone for participating in the session that had brought out some interesting insights and solutions to take the Early Intervention work forward.

The symposium ended on a positive note with a commitment of all participants to work together to address the different needs and gaps in the sector, and with a vote of thanks by Ms Saswati

Barman, Coordinator, EI Services, Shishu Sarothi, where she acknowledged the Azim Premji Philanthropic Initiative (APPI) for supporting the symposium.