

DEVELOPMENTAL PAEDIATRICS

&

india

Implications for Developing Nations

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Disability or Neuro disability, especially in children, may or may not be visible. Visible disabilities like Cerebral Palsy occurs in proportion of not less than one in five hundred live births. Whereas, non visible disability like Autism may be as high as one in hundred living children. ADHD (Attention Deficit Hyperactivity Disorder) is quoted as 3 to 5% and Dyslexia(specific learning disability) is as high as one in ten for school going children. All together,EBD(Emotional/Educational, Behavioural, Developmental) problems in children are estimated to be in the order of 1 in 5.

To address the social, economic and health care of such morbidity, every borough in the U.K. has a specialist centre to address such problem specifically and scientifically. They are called Child Development Centers. It was thought for a long time that such centers are not feasible in Indian context. However, need has driven the demand. A large number of well-intended individuals have tried to address plight of such children(Special Needs Children) by opening centers through individual donation or N.G.O. Government Hospitals have tried it in bits and pieces. Solution, however, could not be reached satisfactorily.

It was not reached, not because of lack of good intention or efforts. The limiting factor was Technology and Expertise.

Child Development Center (CDC), Apollo Gleneagles Hospital (AGH) was envisioned to bring an essential quality and to test out the concept on the Indian soil. CDC ADH is incidentally, India's first CDC in a corporate health care setup. High quality input with multi-disciplinary work in the U.K's model in best practice has brought the proof that with adequate input , such affected children of our country also excels as good as their western counterparts.

It is our hope that the best practice model of CDC AGH is utilized to help the difficulties of our country (Special Needs Children) to such a level of technological standard, which was only available in the Developed Nations in the recent past.

With current level of available expertise there is no reason why this technical assistance cannot be brought to the poorest of poor of India (and consequently to the entire developing nations) at a very affordable cost. As this is not cost intensive requirement but a human resource intensive need,countries who claim of a tradition of culture of trying to do good for the masses, there should be no reason not to succeed in this pathway, if the claims are genuine.

China till 2009 did not seem to have a developmental Pediatrician in their country. However, they were seen to be making a concerted effort to start good quality CDC as they have realized the good gain in Social Capital through such preventative health care activity and are currently making concerted efforts to install the science to capture the human resource capital. But the challenges are steep.

Here, we have some innovation with our existing model for advancement in healthcare in mega proportion with its positive population effects.

For example, a common tragedy of our children is when some of them cannot perform trivial fine and gross motor tasks of daily living, they are branded as "clumsy", "lazy", "odd" or "silly"! These children are often victims of bullying and insults of all sorts. Even their parents, teachers and nears and dears can abuse them without realizing that these children are none of those. Instead, many of them are suffering from the malady of DCD [Developmental Coordination Disorder]. Similar discriminations are faced by children with Speech, Language and Communication Needs [SLCN] Children, children with Behavioural Disorders, visible disabilities (e.g. a child with a hearing aid) or any other EBD problem.

What is even more tragic is that when some of these children are even brought to the doctors, including child specialists, doctors may pronounce them as “no problem” [Item No. 20 of Pediatric Symptom Checklist (PSC); Nelson Textbook of Pediatrics, Page No. 59, 19th Edition (latest), Indian Edition – “*Been to the doctor, doctor finding nothing wrong*”]. This may erroneously reinforce the misconception that the child is not achieving common tasks like buttoning-unbuttoning or tying the shoelaces on purpose (not talking or not talking sense in SLCN group or not studying in Dyslexia group)!

This tragedy hits every corner of the world. That is why PSC is incorporated in the Nelson's Paediatric Textbook from the USA (which is widely used by the Paediatricians world over) so that if a child in the USA approaches a child specialist there and the doctor does not find anything wrong, instead of brushing it away, the doctor has an obligation to do something about it as the next step of management.

For example, (s)he can complete the Questionnaire with due diligence, refer the child to an expert centre where there are healthcare professionals who are more equipped to deal with such matters (the first 6 chapters in the Nelson's). CDC, AGH is just one of such centres. As a pioneering model for India's corporate healthcare sector, its inception and sustenance has dispelled the myth, that “it only happens in the UK, USA” (a common rhetoric, hitherto used to block such development in the past).

CDC AGH model's importance is steeped in the fact that a large majority (61 – 87%, as quoted in different sources) of Indian healthcare remains in private hands!

Good clinical practice in these topics is therefore, of such national importance that our fraternity has an obligation to learn about such topics maintaining our knowledgebase at par with the best of the world.

A proposed model of work up with such EBD children are as follows:

Primary Care: Pediatricians, doctors and healthcare professionals must identify red flag signs early. Please refer to Pediatric Symptom Checklist or PSC (Nelson's Text Book of Pediatrics, 19th Edition, P-59 of Indian Subcontinent Edition) and M-CHAT or **Modified Checklist for Autism in Toddlers** (www.firstsigns.org). Alternatively Trivandam Checklist for Autism in Toddlers may be used in India.

If the primary care healthcare professional suspects possible delay in milestones, they should refer the child early (Primary or Secondary Prevention) to a resourced centre equivalent to Early Start Center of the UK. Primary care professional ought to maintain joint care with the resourced centre of its catering geography. Early Start centres must have properly trained Developmental Professionals (not just qualifications, but the Clinical Governance ensured).

Secondary Care: Resourced centers should evaluate the child using their agreed protocol of expert clinical screening, confirmation of diagnosis and expert intervention (Disability Limitation through Early Intervention). Secondary care centers (Early Start / Sure Start Centers) should refer on to Child Development Centers for further expert management for EBD problems in 0-18 years age range.

Secondary care professional has a unique role in ensuring that the recommendations are carried out adequately at the primary care level.

Tertiary Care: Child Development Centers should be as fully resourced and developed as possible to deal with all of the above. Moreover, it is accepted that each CDC will have their own flavor of expertise e.g. one CDC may be renowned for assisted devices (e.g. orthoses and braces) while the other may be highly specialized in Neuro-Developmental Therapy (NDT or Bobath Methods), one may be famous for Vision Therapy (Orthotics) while another may be deemed best in Sensory Integration (SIPT) techniques.

In current Indian context, a private practitioner may see a child, where (s)he is worried about say, the child's motor development, where there is a history of neonatal jaundice [example]. (S)he may give parents some parent information sheets to go home with and come back after a stipulated time frame (follow up). If professional worry persists (s)he may reassure parents/carers that there are good centers to take care of such children and refer the child on with adequate counseling of the importance of Early Intervention (EI) at a resourced center. Parents/carers should be requested to return following their Initial Contact with the resourced center to empower the model of shared care.

The presentation will deal with the history, SWOT analysis, Care Pathways and vision ahead for advancing this innovation, already in practice in India, how Developmental Paediatrics can forge ahead in India's preservation in preserving and enhancing its Social Capital. Indian Academy of Pediatrics' Presidential Action Plan 2014 has proposed a "Psychological Vaccine", which proposes taking on a part of this dream already and Dr. Bhattacharya is one of its designer and executor at the national level. ICF-CY [International Classification of Functioning – Children and Youth] approaches it from another direction, where Dr. Bhattacharya is involved internationally at its pioneering Paediatric Model on Core Standard setting (Cerebral Palsy) through a WHO International research initiative.

Our Indian model in corporate healthcare sector is likely to reverberate successfully for rest of the developing world to learn and execute from.

As a start, we can all promote use of two internationally validated screening [Early Red Flag signs] tools, which can be copied on both sides of any A4 sheet by any healthcare professional throughout the developing world, which are attached alongwith.

Pediatric Symptom Checklist (PSC)

Emotional and physical health go together in children. Because parents are often the first to notice a problem with their child's behavior, emotions, or learning, you may help your child get the best care possible by answering these questions. Please indicate which statement best describes your child.

Please mark under the heading that best describes your child:

- | | Never | Sometimes | Often |
|---------------------------------------------------------|-------|-----------|-------|
| 1. Complains of aches and pains | 1 | | |
| 2. Spends more time alone | 2 | | |
| 3. Tires easily, has little energy | 3 | | |
| 4. Fidgety, unable to sit still | 4 | | |
| 5. Has trouble with teacher | 5 | | |
| 6. Less interested in school | 6 | | |
| 7. Acts as if driven by a motor | 7 | | |
| 8. Daydreams too much | 8 | | |
| 9. Distracted easily | 9 | | |
| 10. Is afraid of new situations | 10 | | |
| 11. Feels sad, unhappy | 11 | | |
| 12. Is irritable, angry | 12 | | |
| 13. Feels hopeless | 13 | | |
| 14. Has trouble concentrating | 14 | | |
| 15. Less interested in friends | 15 | | |
| 16. Fights with other children | 16 | | |
| 17. Absent from school | 17 | | |
| 18. School grades dropping | 18 | | |
| 19. Is down on him- or herself | 19 | | |
| 20. Visits the doctor with doctor finding nothing wrong | 20 | | |
| 21. Has trouble sleeping | 21 | | |
| 22. Worries a lot | 22 | | |
| 23. Wants to be with you more than before | 23 | | |
| 24. Feels he or she is bad | 24 | | |
| 25. Takes unnecessary risks | 25 | | |
| 26. Gets hurt frequently | 26 | | |
| 27. Seems to be having less fun | 27 | | |
| 28. Acts younger than children his or her age | 28 | | |
| 29. Dose not listen to rules | 29 | | |
| 30. Does not show feelings | 30 | | |
| 31. Does not understand other people's feelings | 31 | | |
| 32. Teases others | 32 | | |
| 33. Blames others for his or her troubles | 33 | | |
| 34. Takes things that do not belong to him or her | 34 | | |
| 35. Refuses to share | 35 | | |
| Total score _____ | | | |

Does your child have any emotional or behavioral problems for which she or he needs help? () N () Y

Are there any services that you would like your child to receive for these problems? () N () Y

If yes, what services? _____

Figure 18-1 Pediatric Symptom Checklist. (From Green M, Palfrey JS, editors: *Bright futures: guidelines of the health supervision of infants, children, and adolescents*, ed 2, revised, Arlington, VA, 2002, National Center for Education in Maternal and Child Health.)

M-CHAT

Please fill out the following about how your child usually is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

- | | | |
|--------------------------------------------------------------------------------------------------------------------------|-----|----|
| 1. Does your child enjoy being swung, bounced on your knee, etc.? | Yes | No |
| 2. Does your child take an interest in other children? | Yes | No |
| 3. Does your child like climbing on things, such as up stairs? | Yes | No |
| 4. Does your child enjoy playing peek-a-boo/hide-and-seek? | Yes | No |
| 5. Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things? | Yes | No |
| 6. Does your child ever use his/her index finger to point, to ask for something? | Yes | No |
| 7. Does your child ever use his/her index finger to point, to indicate interest in something? | Yes | No |
| 8. Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them? | Yes | No |
| 9. Does your child ever bring objects over to you (parent) to show you something? | Yes | No |
| 10. Does your child look you in the eye for more than a second or two? | Yes | No |
| 11. Does your child ever seem oversensitive to noise? (e.g., plugging ears) | Yes | No |
| 12. Does your child smile in response to your face or your smile? | Yes | No |
| 13. Does your child imitate you? (e.g., you make a face-will your child imitate it?) | Yes | No |
| 14. Does your child respond to his/her name when you call? | Yes | No |
| 15. If you point at a toy across the room, does your child look at it? | Yes | No |
| 16. Does your child walk? | Yes | No |
| 17. Does your child look at things you are looking at? | Yes | No |
| 18. Does your child make unusual finger movements near his/her face? | Yes | No |
| 19. Does your child try to attract your attention to his/her own activity? | Yes | No |
| 20. Have you ever wondered if your child is deaf? | Yes | No |
| 21. Does your child understand what people say? | Yes | No |
| 22. Does your child sometimes stare at nothing or wander with no purpose? | Yes | No |
| 23. Does your child look at your face to check your reaction when faced with something unfamiliar? | Yes | No |