Relevance of the Universal Practice Model for Early Detection and Early Intervention in Children with Special Needs - The Kolkata Development Model

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Abstract

Children with Special Needs pose one of the greatest threats of non-communicable diseases or global burden of disabilities on earth. Although we know that these conditions need Early Detection and expert Early Intervention, effective models of practices are sorely lacking. Great advances have been made in sub-domains of neuro-disabilities. But the need for a Universal Care Pathway still eludes us. This is especially true for the developing world, where the bulk of the global burden exists.

Kolkata Development Model proposes a unique and unifying practice model, which efficiently combines and simplifies management of all neurodevelopmental disorders and Special Needs in children. The model has been in existence for more than a decade with plenty of anecdotal evidences of its magical efficiency that puts such children in near normal Functionality [vide International Classification of Functioning (ICF)].

This concept article attempts to put the model in written format so that real research on its efficacy can truly begin. Kolkata Development Model not only seem to work for the developing world, it shows potential to be equally effective in large parts of the developed world too, with local modifications.

Keywords: Kolkata Development Model; Neuro-developmental Disorders, Special Needs

Introduction

Special Needs in children like, Neuro-developmental problems such as Autism, ADHD (Attention Deficit Hyperactivity Disorder), DCD (Developmental Coordination Disorders), Dyslexia, Learning Delay (LD), Intellectual Disability (ID) and Emotional and Psychosocial Disorders like Low Mood, Low Self Esteem, Frozen Watchfulness, Inappropriate Affect etc. produces the largest burden of non-communicable diseases in children and need to be spotted and reported early (Early Detection) and addressed expertly and promptly (Early Intervention). We know that, otherwise, delay leads to downward spiral with lasting morbidity through adolescence and adulthood [1].

Global burden of these problems is said to be in the order of 1 in 5 to 1 in 6 children (prevalence rate)1! Considering the mental health disorders along with these Special Needs, poses even a greater threat with at least 1 in 4 children suffering [2,3].

Biopsychosocial Model of multifactorial causation of diseases are increasingly understood by the care providers for children (see the diagram adopted from Nelsons Textbook of Pediatrics [2,3] below).

Figure 1
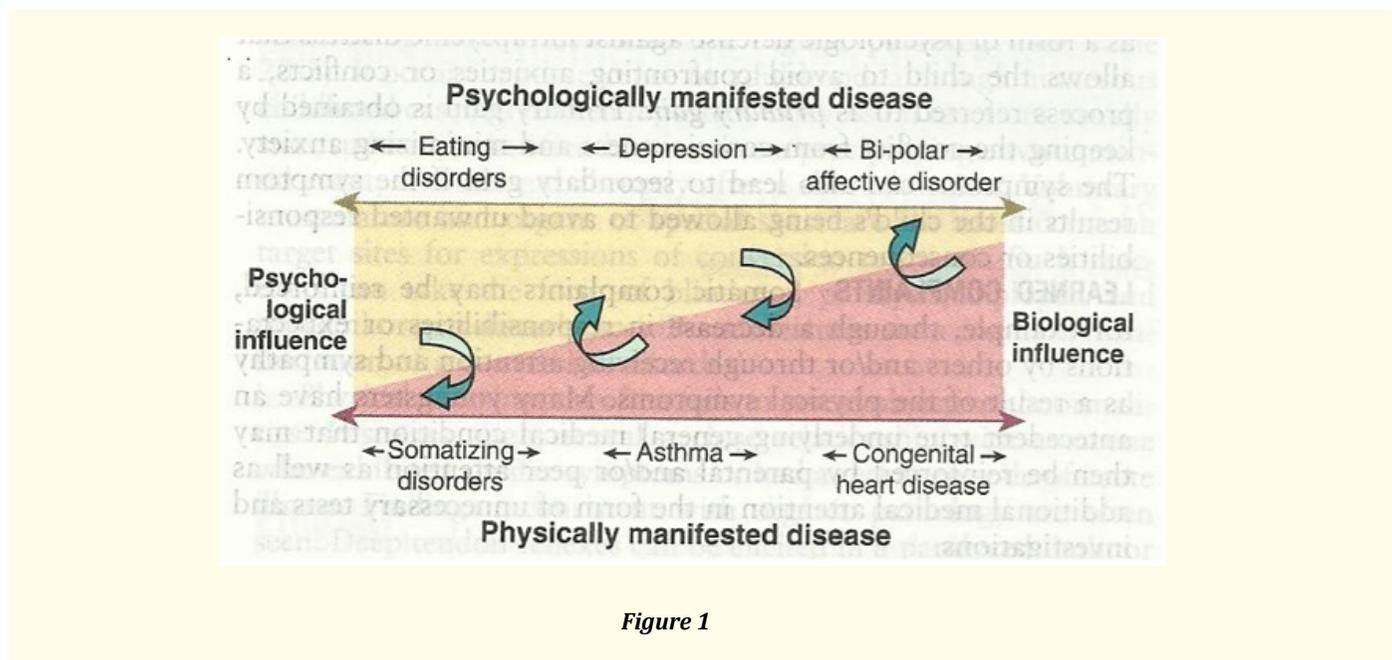
Many children born very preterm have cognitive and minor motor problems later, even if they are attending mainstream schools [4]. Since 1 in 4 of school goers suffer, the suffering can remain hidden in front of our eyes. Societies are known to "normalize" many such preventable maladies, allowing apathy and non-intervention' in the bud'!

Difficulties in Cognitive and emotional regulation affect functioning of moderately preterm children, as school problems, a slightly lower IQ, attention and behavioral problems are seen compared to term-born children. Identification and monitoring of precursors of these problems at younger age is need of the hour to prevent their march towards downward spiraling effects later [5].

Moderately Preterm children had higher scores on all syndrome scales, internalising, externalising and total problems than term-born controls. The mean difference on total problems was 4.04 (95% CI 2.08 to 6.00). Prevalence rates of elevated externalising problem scores were highest in boys (10.5%) and internalising problems were highest in girls (9.9%). MP children were at greater risk for somatic complaints (OR 1.92, 95% CI 1.09 to 3.38), internalising (OR 2.40, 95% CI 1.48 to 3.87), externalising (OR 1.69, 95% CI 1.07 to 2.67) and total problems (OR 1.84, 95% CI 1.12 to 3.00) [6].

Primary Care Physicians were found to be only less than 20% efficient in identifying EBD [Emotional, Behavioural and Developmental problems [1] in children.

Subsyndromal and sub-threshold (sub-clinical) cases of Neuro-developmental Disorders like, Autism, ADHD (Attention Deficit and Hyperactivity Disorder), Learning Disorders (LD) and Difficulties and Neuro-disabilities like CP (Cerebral Palsy), Spina bifida occulta etc. are mostly detected after their neural-plasticity are compromised, more commonly in the developing world [7].

Therefore, there is a crucial need to develop a practice model for Early Detection and effective expert Early Intervention in the population level for sub-syndromal and sub-threshold level Special Needs, which can work even in a developing nation's setting. Such model needed to be user friendly and affordable. Moreover, ideally the Model should cater to the children with already developed Special Needs too.

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Objectives of the Study

To refine a model of combination of (1) effective Early Detection and Early Interventional Tools for children with Special Needs and (2) a Universal Practice Mode for them, which works efficiently for all Paediatric age groups. We are calling it the Kolkata Developmental Model after the city where the synthesis took place.

Methods

Combining (1) (a) Prechtle's [8] Methods for General Movements Assessments (GMA) for accurate (98%) Early Detection (ED) for Cerebral Palsy (CP) in At-Risk Population, (b) LEAP-CP Study [9] looking at parent delivered Early Intervention (EI) delivered to infants screened positive for CP using GMA (c) use of Measurable Eye Tracking [10] in Infancy, (d) Infant Start [11], a Parent-Implemented Intervention for Symptomatic Infants for Autism Spectrum Disorder (ASD) and (e) PACT Study, UK archiving evidence of success for ASD treatment [12] through parent training, we can identify risks of most neuro-developmental disorders in early infancy, thereby instituting a novel method of interventions based on available science. When these scientific practices are amalgamated in practice, efficiently together in a Practice Model, it emerged as a clinically highly effective intervention. This enabled us to propose a Universal Care Pathway for such children, as Kolkata Development Model. This model has already been presented at the Glasgow Annual Conference of RCPCH [Royal College of Paediatrics and Child Health], UK on 13th March, 2018; the EACD [European Academy of Childhood Disability] Annual Conference, Tbilisi, Georgia on 26th May in a Symposium, 2018 and Keynote Address at Paris International Pediatric Conference (Allied Health) on 16th August, 2018. At the London Conference, 2019 this Keynote address is presented with members from Child Development Centre, Apollo Gleneagles Hospital, Kolkata presenting some of its key scientific components. This model proves to be capable of being adoptable equally, with local adjustments, both in resource-crunched as well as resourced countries, equally. That model has since then been proposed as a poster at the 2019 Annual EACD Conference in Paris with Dr. Leisbeth Siderius, Consultant Paediatrician from Netherlands and Shyamani Hettiaracchi, Consultant Paediatric Speech and Language Therapist from Kelaniya University in Colombo in Sri Lanka, jointly.

Novak., *et al*. has published GMA (General Movement Assessment) or Prechtl's Assessment as International Practice Standard for Newborn Follow-up of at risk babies [13]. In another publication, the group has shown that Parent Training, Parent Engagement and Parent Participation (including home based interventions, which is at the heart of LEAP-CP Study) prove to be having much superior evidence base of success in treatment of Cerebral Palsy [14]. If we couple that with similar findings from Autism Treatment Recent Evidences [11,12].

Therefore, in a nutshell, we call Kolkata Development Model a Universal Practice model, that combines Prechtl's GM Assessment and other accepted Early Detection tools for Early Detection at any age or stage of entry to our services. This is followed by a comprehensive Parent Training Module, called Program of Care or PoC by us, which is supported by various evidences like the PACT Study, UK [12]. Early Intervention is a combination of centre-based as well as home based (e.g. LEAP-CP) multidisciplinary remediation program. This combined approach seem to result in almost universal inclusive education to those children with special needs, that access our Kolkata Development Model.

Results

At the Child Development Centre, Apollo Gleneagles Hospital, Kolkata, India, formally from 2009 September and informally from 2007 September, structured modular Parent Training remained at the heart of its practices, whenever parents and care givers presented with a child (0 - 18 years) with any problem that (1) they or their healthcare professionals considered as a neuro-developmental problem, (2) any problem that could not be solved by their Primary Care Physicians [1,15] or (3) incidentally suspected when presented for common ailments.

Over next 10 - 12 years, what became obvious is that high level of success can be sustained in most cases presented at the centre. Please refer at the end of the Results section for examples.

The observational findings can be summarized as follows:

1. Most children presented and undergone input using The Kolkata Development Model, either normalized or became functional enough to enroll in normal schools.

2. Children of
   a. Any age (0 - 18 yrs)
   b. Any neurodevelopmental disorder
   c. Any severity

3. Could expect such positive outcome, at varying length of full engagements

4. Low drop-off rate (high engagement rate)

5. Relatively low cost, given the rate of 'success' of the treatment.

For example, we conducted a small pilot study recently, to review retrospectively, as how the performance of the Kolkata Development Model have been, in terms of including children with special needs to "normal" schools. The results are tabulated below.

Pilot Study of Kolkata Development Model									
Study Duration: 4 sample months (4 random samples with 1 month in each quarter)									
Study Period: 5 years back (retrospective)									
Inclusion Criteria					**Exclusion Criteria**				
1. Any child (0-18 yrs) enrolling at CDC, AGH 2. With any neurodisability and 3. With any other Paediatric Complaints					1. None				
Aim					**Objective**				
To find out how many children with Special Needs were included in mainstream schools following access to Kolkata Development Model					1. To find out the number of children presented to CDC, AGH with Special Needs and 2. To find out how many of these children with Special Needs were included in mainstream schools				
Total number of New Cases at CDC, AGH					**Total number of children with Special Needs out of them**				
Month 1	Month 2	Month 3	Month 4	Total	Month 1	Month 2	Month 3	Month 4	Total
114	202	183	111	610	92	134	152	68	446
73.11% of total new cases were Children with Special Needs (CwSN) at CDC, AGH									
Case distribution of the CwSN (n = 446) according to Neurodisability									
Month 1		Month 2		Month 3		Month 4		**Total**	
ASD	14	ASD	28	ASD	30	ASD	11	ASD	83
ADHD	12	ADHD	20	ADHD	34	ADHD	11	ADHD	77
LD/ID	22	LD/ID	15	LD/ID	23	LD/ID	10	LD/ID	70
GDD	13	GDD	18	GDD	22	GDD	13	GDD	66
Mixed	28	Mixed	42	Mixed	39	Mixed	19	Mixed	128
Other	03	Other	11	Other	04	Other	04	Other	22
Total	92		134		152		68		446

Table 1

Months	Schooling status at presentation ASD				ADHD				LD/ID				GDD				Mixed				Other				Total			
	N	O	S	M	N	O	S	M	N	O	S	M	N	O	S	M	N	O	S	M	N	O	S	M	N	O	S	M
1	8	4	2	0	4	4	2	2	10	6	5	1	4	3	5	1	11	10	4	3	0	1	1	1	37	28	19	8
2	8	7	10	3	4	7	6	3	5	3	6	1	5	3	8	2	19	3	17	3	4	2	4	1	45	25	51	13
3	13	11	5	1	10	11	7	6	9	6	7	1	5	5	9	3	15	2	18	4	0	2	0	2	52	37	46	17
4	6	3	1	1	5	3	3	0	3	4	3	0	3	2	4	4	8	3	7	1	1	1	2	0	26	16	20	6
Total	35	25	18	5	23	25	18	11	27	19	21	3	17	13	26	10	53	18	46	11	5	6	7	4	160	106	136	44

N = Normal (Mainstream); O = Out of school; S = Special School; M = Miscellaneous (e.g. home)

Table 2

Following intervention using The Kolkata Development Model, these figures were as follows.

Months	Schooling status at discharge ASD				ADHD				LD/ID				GDD				Mixed				Other				Total			
	N	O	S	M	N	O	S	M	N	O	S	M	N	O	S	M	N	O	S	M	N	O	S	M	N	O	S	M
1	12	0	2	0	12	0	0	0	20	0	2	0	8	1	4	0	24	0	3	1	2	0	1	0	78	1	12	1
2	22	2	4	0	20	0	0	0	13	0	2	0	13	1	4	0	38	1	1	2	9	0	2	0	115	4	13	2
3	27	0	2	1	30	1	2	1	20	0	2	1	14	1	6	1	33	2	4	0	3	0	1	0	127	4	17	4
4	10	0	1	0	10	0	1	0	9	0	1	0	10	1	1	1	17	0	2	0	4	0	0	0	60	1	6	1
Total	71	2	9	1	72	1	3	1	62	0	7	1	45	4	15	2	112	3	10	3	18	0	4	0	380	10	48	8

N = Normal (Mainstream); O = Out of school; S = Special School; M = Miscellaneous (e.g. home)

Table 3

Discussion

160 Children with Special Needs were able to access mainstream school at presentation (35.87%). But after going through The Kolkata Development Model intervention, 380 children with Special Needs out of those 446 were successfully included in the mainstream schools (85%).

15% (66/446) children, who failed to cope with the mainstream curriculum, are largely children who have severe affliction or familial social issues of extreme nature. Sub analysis of this cohort is currently underway.

Moreover, the successfully included 85% have done it in the average time period of engagement of eight (8) months only. Sub analysis of this is also being undertaken at present.

This 85% were not just children with mild or moderate affliction only. More than half were severely affected at diagnosis using internationally validated, standardized assessment tools like ADI-R, ADOS, Griffiths, Bayleys, Connors etc.

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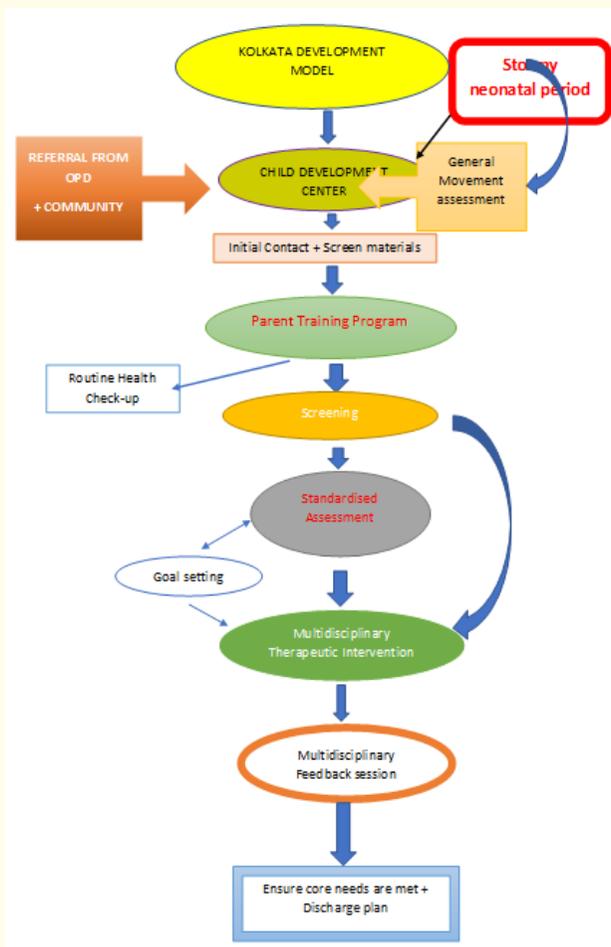## What is the Kolkata development model?

Figure 2

What are the salient features of the Kolkata development model?

1. Multidisciplinary
2. One-stop shop
3. Modular practice model
4. Goal directed
5. Standardisable
6. Universally applicable (see below)
7. Theoretically reproducible

What are the merits of the Kolkata development model?

1. Allows Choice and Partnership Approach (CAPA)
2. Low cost (relatively)

3. Universally applicable to

4. Any age (point of entry)

5. Any neuro-developmental conditions

6. Any degree of severity

7. High rate of success

What are the demerits of the Kolkata development model?

1. Standardizable but yet to be standardized

2. Some unanswered questions:

   a. What is the rate of success?

   b. What is meant by success?

   c. What is the rate of engagement?

   d. What is meant exactly by engagement?

   e. How low in cost?

   f. What is meant by low cost? Etc.

3. Claims need to be examined in different settings by different observers

However, anecdotes (Evidence E; delphi consensus) needs to be added to our small pilot. Qualitative Research around the experiences by care givers and professionals involved must be incorporated to get the real feel of this achievement. Sub analyses of this pilot study will also add value to the current evidence.

Recommendation

Research Kolkata Development Model in (a) other settings, (b) prospectively as well as (c) retrospectively with (d) bigger numbers and (e) by different observers.

Conclusion

Kolkata Development Model proposes a simple, effective, universal care pathway for all children with Special Needs, including all sorts of neuro-developmental conditions, which is relatively simple, cheap and usable in both resourced and resource-crunched situations. This model needs to be researched widely now.

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