

Effect of Multidisciplinary Intervention on Clinical Outcomes of Children with Autism Spectrum Disorder in Mumbai, India

Samir H Dalwai¹, Deepti Kanade Modak¹, Ameya P Bondre^{1*}, Sajeda Ansari¹,
Dania Siddiqui¹, Diksha Gajria¹

1. New Horizons Child Development Centre, Mumbai, India

ABSTRACT

Purpose: To analyse clinical outcomes in terms of functional changes in children with Autism Spectrum Disorder (ASD), before and after receiving a multidisciplinary developmental intervention programme.

Methods: Structured goal-oriented multidisciplinary intervention, individualised to each child, was implemented through 5 child development centres in Mumbai, India, in 2014-2015. Secondary data analysis of 38 children diagnosed with ASD, in the age group of 2.1 - 6.1 years, was conducted. All children received occupational therapy and speech therapy, and parental counselling was also done. The average number of intervention sessions were 48-72 for occupational therapy (twice or thrice a week), 24-48 for speech therapy (once or twice a week) and 5-6 for parental counselling (once a month). Childhood Autism Rating Scale (CARS) and Vineland Social Maturity Scale (VSMS) were used for assessment, before and after intervention.

Results: Mean positive difference in CARS total scores through paired t-test was 4.18 ($p < 0.0001$). Significant positive changes in functional ability were observed in most of the sub-scales (relating to people; object use; visual response; verbal and non-verbal communication; taste, smell and touch response and use; level and consistency of intellectual response and general impression). Paired t-test also showed significant positive changes on all VSMS sub-scales, except Socialisation.

Conclusions: The model used in this multidisciplinary intervention, and adherence to its protocols, has the potential to improve functional ability (or the child's adaptation to his/her condition) in children with ASD, in a region with limited awareness of developmental disabilities.

* **Corresponding Author:** Ameya P Bondre, Project Coordinator, New Horizons Health and Research Foundation, Mumbai, India. Email: ameyabondre@newhorizonsindia.org

Limitations: *Separate effects of factors outside the intervention could not be tested due to inadequate sample sizes for sub-analyses. Results also need to be validated by tests that do not depend on parental reporting (e.g., CARS and VSMS) but assess the performance of the child instead.*

Key words: *Child development centre, autism, Mumbai, Individualised Therapy-Education Programme.*

INTRODUCTION

According to Census 2011, there are about 463 million people in India in the age group of 0-19 years (Ministry of Home Affairs, 2011). The degree of development in emerging economies - like India - depends on how best communities and systems tap the potential of the younger population, often referred to as the 'demographic dividend'. However, neurodevelopmental delays and disorders in children can weaken the demographic potential. About 65 million of the 200 million under-5 children globally that are estimated to have developmental delays are in India (Grantham-McGregor, 2007). The onset of these developmental delays often occurs in early childhood with key consequences for later life, such as poor schooling and low adult incomes.

Yet, data on disability and specific neurodevelopmental disorders (e.g., Autism Spectrum Disorder, Attention Deficit Hyperactivity Disorder, Intellectual Disability and Learning Disability) has been scarce. Census 2011 revealed that 26.8 million of the total 1210 million population (or 2.2%) in India had one or more disabilities (Ministry of Home Affairs, 2011). An independent survey conducted by the International Clinical Epidemiology Network (INCLIN) across 4000 households in six states of the country revealed that among children between 2-9 years of age, 18% had one or more neurodevelopmental disorders in rural areas and 13% in cities (India Today, 2013; Silberberg, 2014). If these prevalence figures are applied to the 0-9 year age group, then it can be inferred that about 30 million children in rural areas and 8 million children in cities may have one or more neurodevelopmental disorders.

Autism Spectrum Disorder (ASD) is characterised by persistent deficits in social communication and social interaction, as well as repetitive and restrictive patterns of behaviour, interests and activities (American Psychiatric Association, 2013). ASD is an emerging developmental condition that today affects 1 in every 68 children in the United States (CDC, 2014). However, prevalence estimates in

India are unclear. The INCLLEN survey reported a prevalence of 1 in 66 children. However, other surveys conducted by non-profit organisations and hospital-based studies reported prevalence rates between 1 in 500 and 1 in 1000 children (Sopan, 2014-15; Raina, 2015). The variation in prevalence estimates can be attributed to the difference in measurement methods and indigenous (self-made) assessment tools used in some of these studies. Lack of standardised and reliable estimates of children with ASD, in spite of the recognised large number of individuals with disabilities, reflects the underemphasised burden of Autism.

The public health burden of Autism is compounded by low awareness and acceptance of the condition among caregivers, leading to delayed care-seeking. Moreover, effective interventions with a multidisciplinary approach are limited. The prevalent understanding among caregivers and the community-at-large is that ASD 'cannot be cured'. It is known to clinicians and researchers that 'lack of cure' does not imply 'lack of improved functional ability on receiving intervention'. However most parents in India do not know this, thereby contributing to their generally less positive attitudes towards ASD and its treatment, and perpetuating stigma.

Most studies on ASD in India have been local and have focussed on clinical profiles of children (Kalra, 2005; Juneja, 2010; Kishore, 2011). Few researchers have studied the effect of interventions on functional abilities of children, and evidence on multidisciplinary interventions is scarce. Impact of multidisciplinary intervention needs to be adequately studied and consistently communicated, not only to the academic and medical community but also to caregivers of children with ASD and other stakeholders. This is necessary to combat widespread perceptions like 'no treatment', 'no effective treatment' and 'no cure' for ASD, given the socio-cultural environment in developing countries like India.

Objective

This study aims to assess pre- and post-intervention changes in clinical outcomes (i.e., functional abilities) of children with Autism Spectrum Disorder who receive a multidisciplinary intervention programme.

METHOD

Setting

The study setting is the city of Mumbai, which is the capital of Maharashtra state. The state of Maharashtra has a population of 112.3 million people (Census 2011), of which 12.4 million people (Census 2011) live in Mumbai. The state population approximates to the population of Mexico which is 123 million (World Population Review, 2015). Assuming a conservative prevalence of 1 in 500 individuals with ASD, it is possible that about 224,748 individuals (children and adults) in Maharashtra and 24,884 individuals in Mumbai may have ASD. Notably, Maharashtra is one of the more developed states in India, with 45.2% urban population. This suggests the need to tap existing secondary and tertiary care systems in cities and incorporate multidisciplinary approaches within these systems, to effectively address developmental disorders such as ASD.

Intervention

Data for this study was obtained from 5 child development centres in Mumbai, which provide a multidisciplinary intervention for children with neurodevelopmental disorders. Founded in 2003, the intervention is multidisciplinary, comprehensive, goal-oriented, coordinated and measurable. The team headed by a Developmental Paediatrician (DP), includes an audiologist, clinical and counselling psychologists, occupational therapists, physical therapists, remedial educators and speech therapists, in addition to visiting specialists (i.e., ophthalmologist, neurologist, paediatric orthopaedic surgeon, psychiatrist and nutritionists). At the child development centres, each child receives individual assessment and therapy under specific disciplines. Analysis of the child's strengths and challenges leads to formulation of an intervention programme that is executed for a defined period of time (e.g. 6 months). Each child is re-evaluated after completion of the intervention, to assess whether therapeutic goals have been attained and a revised intervention programme is then developed. All intervention programmes are referred to as 'Individualised Therapy-Education Programmes' (IT-EP). Under IT-EP, parents, family members and school officials are also counselled every month to maximise impact. Thus, each child receives a complete, end-to-end and outcome-oriented intervention for his/her developmental concerns. On average, IT-EP is currently serving 250-300 children with special needs on a daily basis

and conducting 38,000 individualised intervention sessions annually; the implication is that 1500 new children receive the intervention during a year.

In the present study, all children received three components of IT-EP: occupational therapy, speech therapy and monthly counselling for parents. Intervention sessions were standardised in IT-EP, i.e., 45 minutes in duration with a therapist-child ratio of 1:1. The number of intervention sessions received by children during their IT-EP period (of at least 6 months) were 48-72 for occupational therapy (twice or thrice a week) and 24-48 for speech therapy (once or twice a week), with 5-6 parental counselling sessions (once a month). Importance of parental counselling to the overall effectiveness of IT-EP has been discussed subsequently, after the section on Results.

This study measured intervention outcomes in children with Autism using specific screening and assessment scales (discussed in the section on analysis) and focussed on improvement in functioning as measured by these scales. Hence, the focus was not on roles of other IT-EP therapists, i.e., the current analysis studied the roles of the occupational therapist, speech therapist and counselling psychologist, supervised by the Developmental Paediatrician. However, children were referred for other services as well; for instance, those with Autism and academic concerns were referred for remedial education. In addition, all children were seen by consulting professionals such as the Nutritionist.

Ethical Clearance

Written informed consent was obtained from all caregivers as part of regular clinical protocols. This included consent to use de-identified clinical data pertaining to children for research purposes.

Study Sample

Due to resource and time constraints, a convenience sample was selected comprising children who had completed their evaluations and first re-evaluations (i.e., after receiving the first cycle of individualised IT-EP for at least 6 months) across the 5 centres.

Inclusion criteria:

- a) Children diagnosed with Autism after evaluation using Childhood Autism Rating Scale (CARS), Vineland Social Maturity Scale (VSMS) and fifth edition

of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V).

Details of these assessments have been provided subsequently.

- 2) Children with total score of 28 or above (on CARS) and social quotient of 30 or above (on VSMS). These cut-off points reflected Autism of certain severity hypothesised to respond to at least 6 months of an IT-EP.
- 3) Children who opted for IT-EP and completed IT-EP for at least 6 months.
- 4) Children whose re-evaluation had been conducted in 2015.

Children who did not meet any of these criteria were not included in the study.

Quantitative Analysis

Secondary analysis of data pertaining to 38 children identified with ASD was conducted, using MS-Excel 2007 and Stata-12; these children were diagnosed using the fifth edition of Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). The sample included 34 boys and 4 girls. Age range of children was 2.1 - 6.1 years (mean age 3.3 years) at evaluation and 2.8 - 7.7 years at re-evaluation (mean age 4.3 years). It is to be noted that children received IT-EP for a period of at least 6 months (range 6-9 months) but there was a time lapse between scheduling of re-evaluations, documenting results and availability of reports; thus explaining the difference in mean age between evaluation and re-evaluation. Monthly family income of caregivers ranged from INR 16,000 - INR 33,000 (or £160 - £331 approximately), classified as 'middle income' group (Venkataramakrishnan, 2015).

Childhood Autism Rating Scale (CARS) and Vineland Social Maturity Scale (VSMS) were used for assessment of functional outcomes, before and after IT-EP (Doll, 1953; Schopler, 1980). Statistical tests of significance (paired t-tests for calculating difference in means) were used. To perform these statistical tests, normality of distribution of CARS total scores as well as social quotients assessed by VSMS, at evaluation and re-evaluation, were checked in advance (refer Figures 2-5). However, it is to be noted that in the case of VSMS, social ages were used for analysis to evaluate pre- and post-intervention effects, as social quotient is influenced by increasing chronological age (Social Quotient = [Social Age/Chronological Age] multiplied by 100). Information was obtained on parents' education and the changes made in the home environment. These background variables were hypothesised to influence the effect of IT-EP on clinical outcomes.

A change in the home environment during the IT-EP period was defined as the presence of any one of the following: increasing parental availability for the child; relocating house/ city; hiring a house helper/ caretaker for the whole day; hiring a house helper/ caretaker for half a day; changing the child's school; enrolling the child in a day-care centre; changing the family structure (e.g., from joint family to nuclear family or vice versa); changing the number of family member(s) (e.g., birth of a baby/ death of a family member) and addition of a pet animal.

RESULTS

In terms of parental education, the proportion of mothers who had completed undergraduate, graduate and post-graduate education was 18%, 43% and 37% respectively; while 20%, 40% and 30% of fathers had completed undergraduate, graduate and post-graduate education, respectively. Out of 27 children, changes in home environment were experienced by 88.8%. Table 1 summarises the background data, as reported by parents.

Table 1: Background data reported by Parents

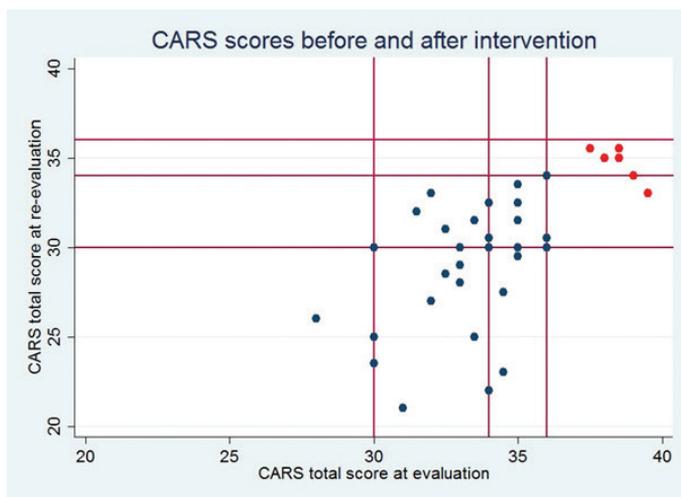
Co-variable	Distribution
Maternal education status (n = 32) ¹	Undergraduate: 18%, Graduate: 43%, Post-graduate: 37%
Paternal education status (n = 30) ²	Undergraduate: 20%, Graduate: 40%, Post-graduate: 30%
Change in home environment (n = 27) ³	No change: 11.1%, Change: 88.8%

¹6 missing values, ²8 missing values, ³11 missing values due to parental refusals to provide information

In terms of assessment on CARS, difference in mean total CARS score at evaluation and re-evaluation was significant (4.2, $p = 0.0000$, 95% confidence interval: 3.21 – 5.15). Mean total CARS scores at evaluation and re-evaluation were 34.1 and 29.9 respectively. Significant differences were noted in 8 out of 14 sub-scales: relating to people; object use; visual response; taste/smell and touch response and use; verbal communication; non-verbal communication; level and consistency of intellectual response and general impression. Of the 38 children, 35 showed improvement in total CARS scores at re-evaluation. Graphical representation of CARS scores is presented in Figure 1.

Figure 1: Childhood Autism Rating Scale (CARS) scores - before and after Intervention

Note: Each dot represents a child. Blue dots indicate mild-moderate Autism according to CARS (score of 30-36) and red dots indicate severe Autism (score of more than 36). Higher scores indicate greater difficulties experienced by children to adapt to their developmental condition or lower functional ability. For most children, the graph shows a decrease in range of scores from evaluation (before intervention) to re-evaluation (after intervention).



In terms of assessment on VSMS, difference in mean social age at evaluation and re-evaluation was significant (0.85 years, $p = 0.0000$, 95% confidence interval: 0.58 – 1.1 years). Mean social ages at evaluation and re-evaluation were 2.21 years and 3.06 years respectively. Significant differences between evaluation and re-evaluation in averages of percentages of items completed ('passed') by children relative to their chronological age, were noted in all sub-scales of VSMS except socialisation. These sub-scales included: self-help general, self-help eating, self-help dressing, occupation, communication and locomotion. Of the 38 children, 31 showed increase in mean social age at re-evaluation. Tables 2 and 3 provide results of sub-scale assessments for VSMS and CARS.

Differences in mean total CARS scores and social ages were calculated for different background variables, i.e., parental education status and changes in home environment. These results were compared with overall differences in mean scores and social ages, and have been summarised in Tables 4 and 5.

Table 2: Paired t-test Results to detect differences in means of total scores at evaluation and re-evaluations (evaluation minus re-evaluation) on Childhood Autism Rating Scale (CARS)

Note: Positive differences indicate improvements in functional ability or adaptation, i.e., a decrease in scores from evaluation (before intervention) to re-evaluation (after intervention).

n = 38 children	Difference between mean total CARS scores at Evaluation and Re-evaluation (evaluation minus re-evaluation)	P value at significance level of 0.05	95% Confidence interval for difference in mean total CARS scores
CARS total score*	4.18	0.0000	3.21 – 5.15
Sub-scales			
Relating to people*	0.28	0.0068	0.085 – 0.493
Emotional response	0.17	0.1458	-0.06 – 0.40
Body use	0.22	0.1009	-0.04 – 0.49
Object use*	0.25	0.0181	0.04 – 0.45
Adaptation to change	0.15	0.2253	-0.10 – 0.41
Visual response*	0.30	0.0009	0.13 – 0.47
Listening response	0.22	0.0578	-0.007 – 0.45
Taste, Smell and Touch response and use*	0.36	0.0033	0.13 – 0.60
Fear or Nervousness	0.68	0.2735	-0.56 – 1.93
Verbal Communication*	0.34	0.0036	0.11 – 0.56
Non-verbal Communication*	0.28	0.0226	0.04 – 0.53
Activity Level	0.17	0.0793	-0.02 – 0.36
Level and Consistency of Intellectual Response*	0.31	0.0002	0.16 – 0.47

Table 3: Paired t-test results to detect differences in averages of percentages achieved by children of completing items in Vineland Social Maturity Scale (VSMS) sub-scales relative to their age, at evaluation and at re-evaluation (re-evaluation minus evaluation)

Note (a): Percentage of items completed by a child = (total items completed/items supposed to be completed as per age) multiplied by 100; these percentages were averaged across 38 children at evaluation and at re-evaluation; thereafter paired t- tests were conducted to calculate the differences in these averages.

Note (b): *indicates statistical significance at 0.05 (p values less than 0.05); Sub-scale on self-direction was not applicable for the study age-group as it measures the child's ability to independently move about and take responsibility for self and others.

n = 38 children	Differences between averages of percentages of completing items in VSMS sub-scales at evaluation and at re-evaluation (re-evaluation minus evaluation)	P value at significance level of 0.05	95% Confidence interval for differences
Self-Help General*	6.2	0.0053	1.9 – 10.5
Self-Help Eating*	19.4	0.0000	12.5 – 26.3
Self-Help Dressing*	20.11	0.0001	11.1 – 29.1
Socialisation	1.09	0.7638	-6.2 – 8.4
Occupation*	9.5	0.0008	4.2 – 14.8
Communication*	19.5	0.0000	12.1 - 27
Locomotion*	6.4	0.0148	1.34 – 11.5

Table 4: Mean difference in total CARS score (evaluation minus re-evaluation), as per background variables

Note: Positive differences indicate lower scores at re-evaluation (after intervention) than at evaluation (before intervention) reflecting increased functional ability (higher score on CARS reflects lower functional ability).

Mean difference in total CARS score (evaluation – re-evaluation)	
Mother's education graduate level /higher (n = 26)	4.6 P value = 0.0000 95% CI: 3.6 – 5.6
Father's education graduate level / higher (n = 24)	4.2 P value = 0.0000 95% CI: 3.2 – 5.3
Children experiencing change(s) in home environment during intervention period (n = 24)	4.5 P value = 0.0000 95% CI: 3.4 – 5.5
All children (n = 38)	4.1 P value = 0.0000 95% CI: 3.2 – 5.1

Table 5: Mean difference in social age (re-evaluation minus evaluation) as per background variables

Note: Positive differences indicate higher social age at re-evaluation (after intervention) than at evaluation (before intervention), reflecting increased functional ability.

Mean difference in social age (re-evaluation – evaluation)	
Mother's education graduate level /higher (n = 26)	0.97 P value = 0.0000 95% CI: 0.64 – 1.29
Father's education graduate level / higher (n = 24)	0.96 P value = 0.0000 95% CI: 0.63 – 1.30
Children experiencing change(s) in home environment during intervention period (n = 24)	0.80 P value = 0.0000 95% CI: 0.47 – 1.11
All children (n = 38)	0.84 P value = 0.0000 95% CI: 0.58 – 1.1

DISCUSSION

This is one of the few cross-sectional studies demonstrating the impact of a multidisciplinary and individualised developmental intervention on functional abilities of children with ASD. Majority of children in the study sample showed positive changes in functional ability as indicated by results of CARS and VSMS assessments. This could be partly due to the integrated, individualised and multidisciplinary nature of the intervention.

Interpretation of results of CARS assessments (refer Table 2)

Positive differences in mean scores (total and sub-scale scores) between evaluation and re-evaluation (i.e., score at evaluation minus score at re-evaluation) were noted. Since higher scores indicated greater degrees of developmental difficulty, these differences implied an increase in functional ability of the child or the child's increased adaptation to his/her developmental difficulties, after receiving IT-EP. Most of the mean differences at sub-scale level were statistically significant. At re-evaluation, children showed greater adaptation to sensory difficulties and increased ability for non-verbal and verbal communication. In contrast, children seemed to have persistent difficulties in adapting to change and did not show any significant changes in their emotional responses. These results reflected the potential of a multidisciplinary intervention to differentially impact various developmental domains. For example, sensory integration was impacted, but more complex developmental objectives like adapting to changes in environment were not achieved during the first intervention cycle of IT-EP (i.e., before the first re-evaluation).

Figure 2: Distribution of CARS total score at Evaluation

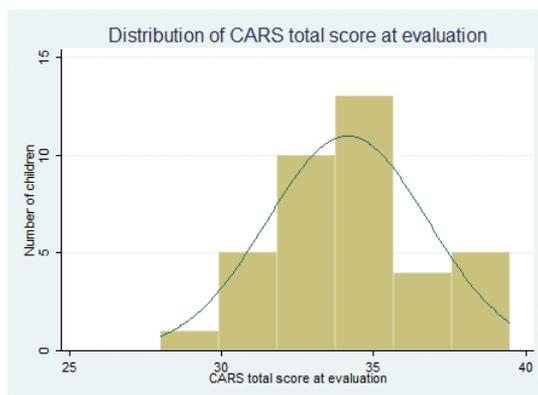
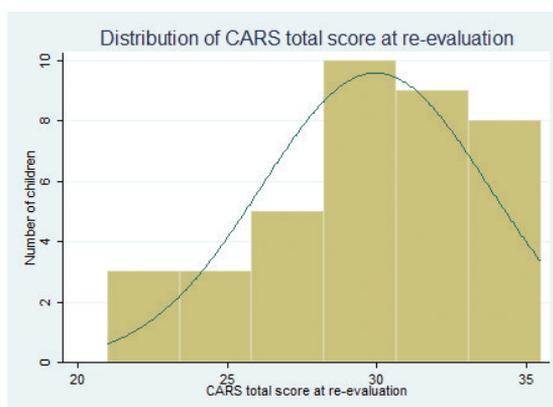


Figure 3: Distribution of CARS total score at Re-evaluation



Interpretation of results of VSMS assessments (refer Table 3)

Significant increase in mean social age at re-evaluation indicated therapeutic effect of IT-EP. Consistent with results of CARS analysis, most sub-scales showed positive differences (re-evaluation minus evaluation) in percentages of items completed or 'passed' in VSMS sub-scales, averaged across all children. Thus, children 'passed' more items in sub-scales relative to their age, at re-evaluation than at evaluation. However, this was not noted in the case of socialisation, possibly due to the IT-EP period being too limited to potentially impact complex developmental abilities like social skills.

Figure 4: Distribution of VSMS social quotient at Evaluation

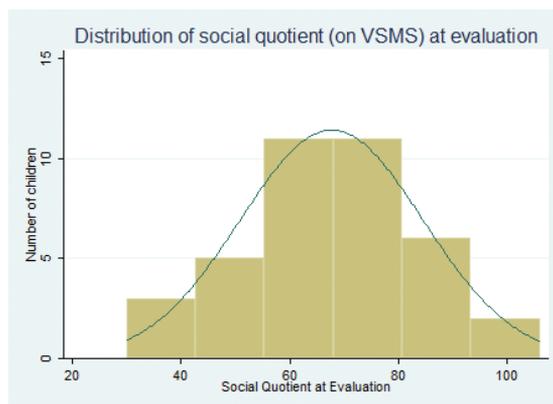
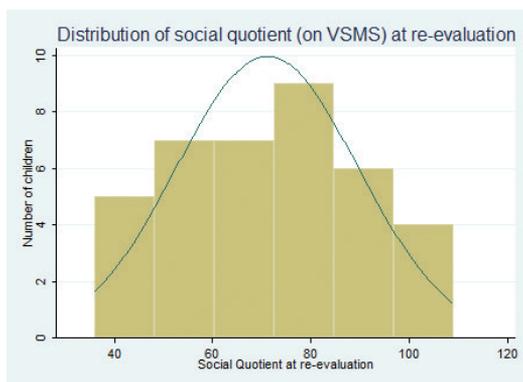


Figure 5: Distribution of VSMS social quotient at Re-evaluation

Adapted Parental Counselling

Monthly parental counselling is a critical component of IT-EP that contributes to its effectiveness. Although analysis of the effect of separate IT-EP components (such as parental counselling) was not the focus of this study, a discussion on the counselling approach followed under IT-EP has been included.

IT-EP includes adaptations in standard counselling methods such as cognitive-behaviour therapy and behaviour modification. Contextual factors justify the need for these adaptations. In India, there is low awareness and acceptance of childhood disabilities by parents, resulting in delayed care-seeking (Wilcox, 2007; Desai, 2012; Divan, 2012). Majority of children who have developmental disorders do not receive timely and effective intervention. The interventions that exist mostly involve single disciplines (e.g., a paediatrician or occupational therapist) that do not comprehensively address a child's multi-faceted developmental condition. In view of these constraints, parenting is a challenge. Parents are not only expected to take care of the child routinely, but also periodically engage with multiple health and education professionals to avail of effective intervention. Problems faced by parents have been studied and categorized as social, psychological and financial problems (Nimbalkar, 2014). These problems shape attitudes of parents toward the child's condition as well as the intervention received by the child. Thus, to meet parental needs, counsellors need to adapt their methods within the IT-EP framework. Since counselling here is a component of a larger developmental programme, adaptations in counselling are put in place to ensure that specific IT-EP goals are met within a defined time-frame. These adaptations have been discussed as follows:

1. Parental acceptance of the child's condition

The first few counselling sessions tend to focus on parental acceptance of the child's condition. The process aims to reach a consensus between the parent(s) and the counsellor on activities that are 'acceptable' and 'unacceptable' in the child's routine, based on clinical implications of the child's diagnostic condition. Consequences of acceptable and unacceptable activities are discussed. Accordingly, parents are counselled to encourage certain activities and discourage others.

2. Adherence to intervention

IT-EP enables regular communication between various developmental therapists. Thus, a therapist/counsellor can adequately explain the child's progress to the parent and suggest ways to meet pre-determined goals. The IT-EP goals, per se, are also communicated to the parent during the counselling sessions to ensure that they understand the reasons behind these goals and see a purpose in their child's therapy, which will have a positive effect on compliance.

3. Best practices in the child's routine

IT-EP team has formulated 'best practices' for parents in order to positively impact developmental concerns (e.g., hyperactivity). Parents are counselled to adhere to these practices and made to understand that the effectiveness of IT-EP would depend on adherence. These practices focus on reducing exposure to electronic gadgets and television, especially animation; avoiding food which has preservatives and additives; increasing outdoor play in the evening; and increasing hours of sleep at night. When routine concerns in adhering to these practices are expressed, alternative strategies are suggested by the IT-EP team. These practices have been formulated on the basis of evidence on unhealthy daily habits predisposing children to developmental concerns, particularly inattention and hyperactivity (Quach, 2011; Arnold, 2012; Gentile, 2012; Pontiflex, 2013; Smith, 2013). Parents are also encouraged to maintain a daily diary to note the child's routine difficulties (e.g., not sitting in one place, throwing objects, etc.), and this is reviewed during each monthly parental counselling session. This actively involves parents in the therapeutic process.

4. Goal-driven approaches

Counsellors under IT-EP have found that parents need to be 'directed', depending on their preparedness and the child's condition, in order to meet therapeutic

goals. While therapeutic goals need to be collaboratively set between the IT-EP team and the parents, there are circumstances when parents need further instruction. For example, it has been observed that parents of a child with ASD often tend to give in to the child's demands when he/she is not able to verbalise. However, this reinforces the child's tendency to fulfil demands in a developmentally inappropriate manner. This kind of parental behaviour is discussed during the counselling sessions. The parents are motivated to communicate with the child extensively, in order to gradually enable the child to verbalise his/her needs. Such goal-driven approaches ensure that parents have clear expectations from IT-EP, and the IT-EP team (including counsellors) expect compliance by parents.

5. Home programme under IT-EP

Parents are encouraged to continue developmental activities at home. However, given the typically resource-limited environments, therapists counsel parents to make best use of any available opportunities and resources. For example, parents are encouraged to engage the child in domestic chores that improve concentration, such as stringing beads, punching holes in card-paper and putting shoe-laces through the holes, or sorting beans or pulses of different kinds (the latter also strengthens fine motor skills). Counselling also attempts to tap the contextual advantages; for example, domestic chores are more often assigned to Indian children, as compared to their Western counterparts. These tasks play an important role in fostering a sense of responsibility and self-esteem in children. Counsellors encourage parents to assign these household chores; this increases motivation in children and translates into undertaking academic responsibilities such as initiating and completing home assignments given by teachers.

6. Relevance of relationships to the child's development

Parents are encouraged to engage children who have difficulties in socialisation, in telephonic conversations with their relatives. This helps in modeling appropriate social behaviour. Children who have writing difficulties should be encouraged to draft short letters to relatives. This builds self-confidence. A range of relationships - with siblings, grandparents, other elders within joint families, neighbours or relatives - are utilised. Thus caregivers, apart from parents, help in 'mentoring' the child. In this sense, Indian children have more options than their Western counterparts, which is another contextual advantage.

7. Advice emphasised in the Indian context

Certain aspects of counselling are relevant to both developed and developing country settings, such as not forcing the child to perform a task that she dislikes; providing several breaks during a task; consistently and positively encouraging the child to complete a task, and to set a daily time-table for better planning and greater self-regulation. These aspects, although not specific to Indian parents, are worth noting. It has been observed by developmental therapists that children with disabilities in the Indian context are under pressure from parents to complete tasks - either a home assignment given by the teacher or a self-help task. In addition, parents have informed counsellors that children's concentration and interest in activities that were previously disliked, improve after intervals or 'breaks'. These intervals have helped parents to determine the child's 'saturation point', and thereby enabled counsellors to modify therapeutic goals in order to improve concentration.

CONCLUSION

The study demonstrates that the model used in the aforesaid multidisciplinary intervention programme and adherence to its protocols have the potential to improve functioning in children with ASD. This is relevant in a country like India where there is limited awareness of developmental disabilities and interventions capable of improving functional ability.

Implications

This is one of the few quantitative analyses focussed on improvement of functional ability in children with Autism who receive multidisciplinary intervention in the Indian context. It is not only relevant for the academic community, but also for the community of parents, teachers and other key stakeholders of the child. This evidence on therapeutic experiences of children with Autism can dispel incorrect notions, including the prevalent perception in India that children with Autism 'cannot improve' (also perceived as 'no cure' in the eyes of caregivers). The study also highlights the need to consistently engage parents within the format of a multidisciplinary intervention.

Limitations

In terms of background variables, higher maternal education combined with IT-EP seemed to contribute to greater functional adaptation. However, this inference

cannot be validated in the absence of further rigorous statistical tests. The education level of the fathers did not seem to have a comparable effect, probably because mothers were the primary caregivers. Most of the children experienced changes in the home environment but due to the low total sample size and variance it was difficult to ascertain whether those changes influenced the impact of IT-EP. Thus, due to smaller sub-samples, separate effects of factors outside the intervention could not be adequately assessed (e.g., through regression analyses). Further studies should include a statistically determined sample size representing the population of interest, namely all children identified with features of ASD and reporting to the 5 child development centres.

Out of the (approximately) 1500 children reporting annually to the five child development centres, about 600 are identified with Autism. However, all of them do not opt for therapy due to financial and logistical difficulties in continuing for the minimum period of 6 months. Children also drop out when families are not able to complete the full course of IT-EP for the same reasons. Moreover, the sample size was reduced to 38 by the inclusion criteria: they were required to have a defined clinical profile of Autism on CARS and VSMS, should have received at least 6 months of IT-EP, and re-evaluation should have been completed by 2015. It should also be noted that due to the establishment of new centres, 1500 children with special needs reported to the centres annually only from 2012-2015. The first three centres were established between 2003 and 2005, and the other two centres between 2012 and 2014.

The results also need to be validated by tests that do not depend only on clinician's observations and parental reporting (like CARS and VSMS) but assess the performance of the child instead; for example, tests such as the Indian adaptation of the Bayley Scales of Infant Development or the Developmental Assessment Scale for Indian Infants (DASII). However, since the current study was conducted within the existing clinical system of the multidisciplinary centre, DASII was not administered due to time constraints as 35-45 minutes is required to complete assessment for every child, and younger children take longer time. In addition, the average age of children at evaluation was below 4 years, and hyperactivity in such young ones add to the difficulty in administering DASII.

The Autism Diagnostic Observation Schedule (ADOS) could not be used due to its high cost. Since IT-EP has standardised clinical protocols across the 5 child development centres, it was not feasible to administer ADOS in all the centres in the absence of external funding. This reflects the situation on the ground in

most developing countries, where clinical observation and parental reporting seem to be the best methods available for assessing the large numbers of children reporting with developmental concerns. Further research should validate the results of this study using methods that focus on the child's developmental performance during an assessment.

Bias due to clinicians' effectiveness was factored into the study. Non-pharmacological interventions like IT-EP could be influenced by variations in the effectiveness of individual therapists. Since children from all 5 centres were included, their responses could have differed across therapists. However, the IT-EP model includes 2 weeks (80 hours) of pre-intervention training for all recruited professionals. Training is conducted by the same trainers and standardised across all 5 centres. Guidelines for training are formulated by a core team of experienced developmental therapists, under the supervision of a developmental paediatrician. Therapists are trained to adhere to these guidelines. An example of a standardised methodology is the weekly clinical meeting conducted at all centres, during which all therapists at a given centre discuss developmental conditions of individual children and arrive at a collaborative IT-EP for every child. Thus, IT-EP includes checks and balances to minimise bias due to clinicians' effect.

The study did not have a control group of children receiving non-multidisciplinary or 'stand-alone' therapies (e.g., intervention by only an occupational therapist or a speech therapist). In the absence of a control group, the analysis attempted to explain the effect of some confounding factors, namely parental education and changes in home environment during the IT-EP period. Correlation between child's age at evaluation and magnitude of difference in CARS total scores between evaluation and re-evaluation (or degree of improvement in functioning, as assessed on CARS) was non-significant and small (0.04; p value = 0.8). Correlation between child's age at evaluation and magnitude of difference in social ages between evaluation and re-evaluation (or degree of improvement in functioning, as assessed on VSMS), was non-significant and small (-0.16; p value = 0.33). However, other confounding factors were not accounted for. For instance, in an urban setting like Mumbai, children with special needs tend to receive developmental therapy at multiple locations. Children enrolled in this study could have received therapy outside IT-EP; however data pertaining to the same could not be obtained. Follow-up studies should consider these aspects. Moreover, urban caregivers tend to develop greater insights after receiving

developmental treatment. This enables them to introduce modified interventions at home, which the study could not account for.

A planned prospective study could have helped to provide better insights into effectiveness of IT-EP. However, the team was constrained in this respect, since most available scales cannot adequately track monthly progress of children with Autism who are under therapy, with optimum objectivity. This is partly due to substantial differences in age and severity levels among children, and difficulties in observing every child on a periodic basis. The current system includes qualitative observations by therapists through monthly progress reports (besides parental reporting), but these were not included in the study due to their subjective nature.

Finally, in terms of other analyses conducted with the huge database of IT-EP, the study team conducted a retrospective analysis of data pertaining to evaluation of 1300 children reporting with special needs from 2009-2012, which was published in 2014 (Duggal, 2014). Currently, the team is conducting a retrospective outcome analysis to evaluate the effectiveness of IT-EP (to measure pre- and post-intervention changes in functioning), including children who received intervention from 2013 - 2015.

ACKNOWLEDGEMENT

The authors thank all the developmental therapists and counsellors of the child development centres for their cooperation during the data collection phase of the study. This study was self-funded.

REFERENCES

American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (DSM-5®). 5th ed. Arlington, VA: American Psychiatric Publishing.

Arnold LE, Lofthouse N, Hurt E (2012). Artificial food colours and attention-deficit/hyperactivity symptoms: conclusions to dye for. *Neurotherapeutics*; 9(3): 599-609.

doi: 10.1007/s13311-012-0133-x.

Datta D (2013). Autism is rising alarmingly in India. How far is the new science from finding a cure? New research busts old myths and brings new hope. *India Today*. [Accessed on 1 December 2015]. Available from: <http://indiatoday.intoday.in/story/autism-autistic-mind-western-syndrome-myths-about-autism-autistic-children/1/322242.html>

Desai M, Divan G, Wertz F, Patel V (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcult Psychiatry*; 49(3-4): 613-637. doi: 10.1177/1363461512447139

Divan G, Vajaratkar V, Desai M, Strik-Lievers L, Patel V (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Res*; 5(3): 190-200. doi: 10.1002/aur.1225.

Doll EA (1953). *The measurement of social competence: A manual for the Vineland Social Maturity Scale*. US: Educational Test Bureau Educational Publishers.

Duggal C, Dalwai S, Bopanna K, Datta V, Chatterjee S (2014). Childhood developmental and psychological disorders: Trends in presentation and interventions in a multidisciplinary child development centre. *Indian J Soc Work*; 75: 495-522.

Center for Disease Control and Prevention – CDC (2014). Facts about Autism. *Autism Speaks*. Online resource. [Accessed on 23 November 2015]. Available from: <https://www.autismspeaks.org/what-autism/facts-about-autism>

Gentile DA, Swing EL, Lim CG, Khoo A (2012). Video game playing, attention problems, and impulsiveness: Evidence of bidirectional causality. *Psychol Pop Media Cult*; 1(1): 62-70.

Ministry of Home Affairs (2011). *Census 2011 report*. New Delhi: Ministry of Home Affairs, Government of India.

Grantham-McGregor S, Cheung YB, Cueto S, Glewwe P, Richter L, Strupp B (2007). Developmental potential in the first 5 years for children in developing countries. *Lancet*; 369(9555): 60-70. doi: [http://dx.doi.org/10.1016/S0140-6736\(07\)60032-4](http://dx.doi.org/10.1016/S0140-6736(07)60032-4).

Juneja M, Sharma S, Mukherjee SB (2010). Sensitivity of the autism behaviour checklist in Indian autistic children. *J Dev Behav Pediatr*; 31(1): 48–49. doi:10.1097/DBP.0b013e3181c7241a.

Kalra V, Seth R, Sapra S (2005). Autism – experiences in a tertiary care hospital. *Indian J Pediatr*; 72(3): 227 – 230. doi: 10.1007/BF02859263

Kishore MT, Basu A (2011). Early concerns of mothers of children later diagnosed with autism: Implications for early identification. *Res Autism SpectrDisord*; 5(1): 157–163.

Nimbalkar S, Raithatha S, Shah R, Panchal DA (2014). A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in western India. *ISRN Family Medicine*; 2014(2014): 1-6. doi:<http://dx.doi.org/10.1155/2014/769619>

Pontifex MB, Saliba BJ, Raine LB, Pichiatti DL, Hillman CH (2013). Exercise improves behavioural, neurocognitive, and scholastic performance in children with attention-deficit/hyperactivity disorder. *J Pediatr*; 162(3): 543-551. doi: 10.1016/j.jpeds.2012.08.036.

Quach J, Hiscock H, Ukoumunne OC, Wake M (2011). A brief sleep intervention improves outcomes in the school entry year: A randomised controlled trial. *Paediatrics*; 128(4): 692-701. doi:10.1542/peds.2011-0409

Raina SK, Kashyap V, Bhardwaj AK, Kumar D, Chander V (2015). Prevalence of autism spectrum disorders among children (1-10 years of age) – Findings of a mid-term report from Northwest India. *J Postgrad Med*; 61(4): 243-246. doi:10.4103/0022-3859.166512.

Schopler E, Reichler RJ, DeVellis RF, Daly K (1980). Towards objective classification of childhood autism: Childhood Autism Rating Scale (CARS). *J Autism Dev Disord*; 10(1): 91–103. doi:10.1007/BF02408436

Silberberg D (2014). Neurodevelopmental disorders in India: From epidemiology to public policy. *World Neurology*. [Accessed on 1 December 2015]. Available from: <http://www.worldneurologyonline.com/article/neurodevelopmental-disorders-india-epidemiology-public-policy/>

Smith AL, Hoza B, Linnea K, McQuade JD, Tomb M, Vaughn AJ, Shoulberg EK, Hook H (2013). Pilot physical activity intervention reduces severity of ADHD symptoms in young children. *J AttenDisord*; 17(1): 70-82. doi: 10.1177/1087054711417395

Society of Parents of Children with Autistic Disorders – SOPAN (2015). What is the prevalence of autism in India? Online Resource. [Accessed on 23 November 2015]. Available from: <http://sopan.org/blog/#>

Venkataramakrishnan R (2015). Everyone in India thinks they are ‘middle class’ and almost no one actually is. [Accessed on 1 December 2015]. Available from: <http://scroll.in/article/740011/everyone-in-india-thinks-they-are-middle-class-and-almost-no-one-actually-is>

Wilcox C, Washburn R, Patel V (2007). Seeking help for attention deficit hyperactivity disorder in developing countries: A study of parental explanatory models in Goa, India. *Soc Sci Med*; 64(8): 1600-1610.

World Population Review (2015). Mexico population 2015. Online Resource. [Accessed on 23 November 2015]. Available from: <http://worldpopulationreview.com/countries/mexico-population/>