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Research Paper

A Study of Current Interventions for Autism Spectrum Disorder in India

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ABSTRACT

Background: There are multiple practices and various interventions currently available in India claiming to help treat a child with Autism Spectrum Disorder (ASD). The social structure and support from school do not integrate and accommodate a child with ASD in the mainstream. They are often sent to special schools and treated like a child with an intellectual disability. The government of India has many schemes for children with autism and their families but to avail these facilities, they need to have a disability certificate. Currently there is no specific disability certificate for children with autism, still they can opt for a disability certificate in the category of Autism with Mental Retardation. **Method:** This study encompasses details of interventions currently being practiced in India and highlights the lack of a structured intervention program resulting in high disability in these children. For this purpose, a telephonic interview was conducted with 20 organizations in a different part of India. Out of which seven of those organizations submitted details of their diagnostic pathways, short term and long-term results and problems they faced. **Result:** The results showed that out of seven organizations only 2 of them used standard diagnostic tools like ADOS-2 and ADI-R, and rest of the 5 organizations were just using screening tools. Lack of uniform application of fully validated and translated autism diagnostic tools makes it difficult to estimate the exact prevalence of diagnosis in Autism in India. On the basis of data given by the 7 organizations, only one organization presented their long-term data of 5 years in which their results were 90% successful integration into mainstream or independent life. Out of the rest 6 organizations, only two of them presented their short-term results and one of the among them presented a case study of 3 children in which they were using sensory integration. Most of the organizations agreed that the main problem they face is that with the use of various interventions, they were only able to control the symptoms for a period of time, and another problem faced was that the parents of these kids keep moving from one therapy center to another due to which they were not able to see long term results of the interventions provided

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by them. **Conclusion:** based on the findings of the study it can be concluded that in India, there are many interventions available still 90% of the organizations are not able to publish their short- or long-term results. There is a little hope for these children and there is a need for a program with clear outcome-based intervention. The program needs to be near to their house as these are long term problems and like western countries, the school needs to invest in adapting to the needs of these children and provide early year support. Some of these children are naturally gifted and the government needs to adapt the curriculum so these talented individuals do not go wasted in society.

Keywords: *Survey, Autism Interventions, Autism Result In India, Current Status*

Autism Spectrum Disorder is diagnosed on the basis of DSM 5, criteria being persistent deficits in social communication and social interaction across multiple contexts restricted, repetitive patterns of behavior, interests, or activities, social interaction and repetitive, restricted & stereotype pattern of behaviour.[1] The symptoms must be present in the early developmental period although they may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life and symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

The pooled estimated prevalence of ASD was found to be 14.6 per 1000 (1 in 68) children aged 8 years, *in a* population-based prevalence estimate done in the United States.[2] *India is* a populous country of nearly 1.3 billion people with children ≤15 years constituting nearly one-third of the population.[3] It has been estimated that more than 2 million people might be affected by ASD in India.[4] Most of the reported studies on ASD are based upon hospital-based data and thus lack the exact information on the prevalence estimates of this disorder in India.[5]

Growing evidence on the effectiveness of early intervention programmes on outcomes highlights the need for early identification of individuals with ASD.[6] Therefore, for the purpose of diagnosis of ASD in the Indian population, National Institute for Mentally Handicapped developed an Indian tool for diagnosis of Autism in 2009 called the Indian Scale for the Assessment of Autism (ISAA, Test Manual). It consists of six domains, which are, social relationship & reciprocity, emotional responsiveness, speech-language & communication, behavior patterns, sensory aspect and cognitive component.[7] ISAA had a sensitivity 93.3, a specificity of 97.4, however, it's level of agreement with CARS measured by Kappa coefficient was low (0.14). Another Diagnostic Tool for Autism Spectrum Disorder developed by AIIMS (INDT-ASD) is also used for diagnosing which is based on DSM-5 criteria, it has a sensitivity of 98.4% and specificity of 91.7% to diagnose ASD.[8] Many of the organizations reported using different developmental screening tools CARS, Ages and Stages Questionnaires (ASQ), Modified Checklist for Autism in Toddlers (MCHAT).

A 2012 study, led by a government epidemiologist, found that 4 percent of children lost their diagnosis by age 8 suggesting earlier identification of ASD symptoms may be associated with response to intervention efforts.[9] In spite of the evidence of the effectiveness of early diagnosis, the interventions available in India are focusing on symptoms and behavior modification. In Autism the behavior changes with age and environment causing new challenges if the focus is mainly on symptoms. Parents & caregivers of children with autism tend to become frustrated and distressed by the lack of evidence-based treatment and

medication available for autism. This makes them desperate for any intervention that will improve their child's condition. Families of autistic children commonly turn to unproven alternative therapies that claim to be effective. As a result, parents and caregivers spend valuable time and money on unproven therapies rather than focusing their resources on therapies backed by extensive research. Some of the most common interventions practiced by the organizations surveyed in India are ABA, Sensory Integration, occupational therapy, conventional speech therapy, supplements, diets, Ayurvedic interventions like gut therapy, stem cell, hyperbaric Oxygen therapy, Chelation Therapy etc, which have been discussed below:

1. Programs based on ABA is a method of teaching appropriate behaviors by breaking down the tasks into small discrete steps and training in a systematic and precise way. The theory behind using ABA is that children with autism have difficulty in learning through imitation and listening as their normal peers do. The highly structured format seems to meet the needs of those who have autism and who typically respond to directness and routine. There is a different type of ABA techniques like Discrete trial training (DTT), the Early intensive behavioral intervention (EIBI), Verbal behavioral intervention (VBI) and Pivotal response training (PRT). This is the most widely used intervention in Autism but in a research paper in 2012 reviewed one randomized controlled trial (RCT) and four controlled clinical trials (CCTs) and concluded that there is some evidence that EIBI is an effective therapy.[10] But the same authors updated their paper in 2018 with recent RCTs and CCTs, which show that there is only weak evidence supporting EIBI.[11]
2. Sensory Integration was one of the most widely used interventions but none of the organizations presented any long-term data to support its evidence in children with autism. The results of a systematic review done by Leon H. et. al. (2015) also concluded that the overall studies do not provide convincing evidence for the efficacy of sensory integration therapy.[12]
3. Another popular intervention that is used for autism treatment in India is occupational therapy. Occupational Therapy places emphasis on assessing and providing interventions in the area of sensory-motor, emotional regulation, social relationship and self-advocacy skills.
4. Conventional Speech Therapy- Speech therapy is an intervention which aims at enhancing a child's speech skills and abilities to understand and express language, including nonverbal language.
5. Supplements- Williamson, E., et.al (2017) in a review found that Omega-3 fatty acid supplementation was not associated with improvements in challenging behaviors.
6. Medical Interventions- there is a lot of research done on the effectiveness of medicine intervention in treatment of children with autism. Williamson, E., et.al (2017) in a review of current medical interventions concluded that Risperidone and aripiprazole ameliorated challenging behaviors in the short term (<6 months), but had clinically significant side effects, other medicine like Methylphenidate and atomoxetine were also associated with improvements in hyperactivity in small, short-term RCTs (with uncontrolled open label extensions).[13] Atomoxetine plus parent training was not more effective for hyperactivity than atomoxetine alone. Some positive effects were reported with other agents studied (risperidone adjuncts, melatonin), but few studies addressed the same agent or outcomes. They also quoted that data on longer term (≥6 months) results and harms of interventions are lacking.
7. Ayurvedic interventions like gut therapy- Ayurveda, being one of the oldest medical practise in India, also provides interventions for Autism under Gut Therapy Protocol. Singh et al, (2018) in a study to know the effect of Ayurveda Gut Therapy Protocol

(AGTP) in the behavioral symptoms of children with ASD found significant improvement in behavior symptoms and gut symptoms of children with autism, however it was a short-term study and there is no evidence for long term impact of gut therapy.[14]

8. Stem Cell- Stem cells are the fundamental elements forming all the tissues of the human body. They are unique cells with an ability to rapidly multiply and convert into any type of tissue in the body. The main purpose of these cells is to regenerate, repair and replace damaged tissue. They are naturally capable of traveling towards the damaged areas and start the repair process. In a study done by Sharma et. al. (2013) in a non- randomized study with a small sample found significant improvement along with few adverse events, and suggest studies with larger sample and control group.[15]
9. Hyperbaric Oxygen therapy- (HBOT) is the medical use of oxygen at a level that is higher than atmospheric pressure. “Hyper " means more and “Baric” means pressure, i.e., this therapy uses pressure to distribute more oxygen into body tissues such as the brain along with blood, cerebrospinal fluid, etc. Since there have been hypotheses regarding brain and gut inflammation, brain hypoperfusion, and aberrant oxidative stress in ASD, there is increasing interest in using it. Rossignol et. al., (2007) in a clinical trial studied the effect of HBOT, they found that pre-and post-parental observations indicated statistically significant improvements in both groups, including motivation, speech, and cognitive awareness, however they did not quote any long-term efficacy of HBOT.[16]
10. Chelation Therapy- This therapy is based on the possibility that Autism occurs as a result of certain heavy metals, such as lead, mercury, aluminum and arsenic, etc. in the bloodstream of the child. It is thus, a means to ‘cleanse’ the blood of these heavy metals. There was one organization which mentioned the use of Chelation Therapy. Although in a study done by Bren J., (2013) he reported that approximately half a million patients with autism spectrum disorders are subjected to chelation therapy in the US annually and his findings indicated that unnecessary chelation therapy is expensive, can cause significant acute adverse effects, and may be associated with long-term consequences.[17] James S, Stevenson SW, Silove N, Williams K.(2015) in a systematic review reported no clinical trial evidence was found to suggest that pharmaceutical chelation is an effective intervention for ASD. Given prior reports of serious adverse events, such as hypocalcaemia, renal impairment and reported death, the risks of using chelation for ASD currently outweigh proven benefits.[18]

If we look at the research evidence and clinical studies done in the context of various interventions available. It can be stated that although there is not much research done on effective intervention options available for Autism in India, still the purpose of this study is to discover the evidence-based interventions available in India and to understand how they are helping an individual with ASD and their families in managing their difficulties.

METHODOLOGY

Participants

For the purpose of this review, organizations were contacted (through email and telephone) to present their work in a conference, organized on World Autism Awareness Day. They were asked to include following information related to the interventions they provide for the management or early intervention of autism. The main criteria to be included in the presentation were following-

1. What are the diagnostic tools being used for diagnosis of autism?

2. What parent support programs or interventions do they provide to parents of children with ASD?
3. What type of intervention is being used, and who is leading the organization?
4. Any outcome measurement data, or audits being done?

RESULT

For the purpose of review 20 organizations contacted and 7 agreed to submit and present their work including the details of diagnostic pathway, report of autism intervention therapies and short term and long-term results in autism.

The first step in autism early intervention is always diagnosis, for this purpose the information provided by the organizations was analyzed and we found that only 42.9 % organizations are using diagnostic tools and 57.1% of organizations are using screening tools for identification. Out of all participating organizations only 14.3% organizations using ISAA and ADI-R, 28.6% are using ADOS 2 and 42.9% are using no standard diagnostic instruments. Out of these seven organizations 28.6% organizations reported using CARS, 57.1%. Name of diagnostic and screening tools used by the organizations can be seen in the Table 1 below:

Table 1: What are the diagnostic tools being used for diagnosis of autism?

Diagnostic Tool	Percent	Screening Tool	Percent
ISAA	14.3 (1/7)	CARS	28.6 (2/7)
ADI-R	14.3 (1/7)		
ADOS 2	28.6 (2/7)		
NOTA	42.9 (3/7)	NOTA	71.4

Abbreviations: ISAA: Indian Scale for the Assessment of Autism, ADI-R: Autism Diagnostic Interview Revised, ADOS-2: Autism Diagnostic Observation Schedule: 2, NOTA: None of the Above, Childhood Autism Rating Scale-2 (CARS)

Once a diagnosis is confirmed, along with early intervention of the child with ASD, supporting families through psycheducation, or family support group is most important to make an early intervention successful. To answer this, we analyzed out of the seven organizations how many were providing some or other kind of parenting intervention. The findings can be seen in Table 2.

Table 2: What parent support programs or interventions do they provide to parents of children with ASD?

Parenting Training included	Percent
Yes	71.4
No	28.5
Total	100.0

It can be seen from the above table, that out of seven organizations 71.2% organizations are providing parental training and 28.5% are not providing any parental interventions or support programs along with early intervention for autism.

To answer our third question which was, what kind of interventions are being used and who is leading the organization, we analyzed the presented data an found that out of seven organizations most of them were lead by either a therapist or a psychologist, and found that

there was only one center which was lead by a multidisciplinary team, and headed by a pediatric neurologist, one other organization was run by an ayurvedic pediatrician. Out of the seven organizations, only two organizations presented their results in terms of improvement in child and parent related outcomes. Details of the finding can be seen in the table 3 below:

Table 3: A list of organizations, their founder and results are listed below:

Name	City	Lead	Improvement in Child Outcome
Tata Comm Deal Trust	All Over India	Occupational Therapist	76%
Anonymous	Chennai	ABA Therapist	N/A
Anonymous	Lucknow	Rehabilitation Psychologist	N/A
Anonymous	Lucknow	Psychologist	N/A
Geniuslane	Lucknow	Pediatric Neurologist	90%
Anonymous	Lucknow	Ayurvedic Pediatrician	N/A
Anonymous	New Delhi	Social Communication Therapist/Child Psychologist	N/A

Note: The table contains names of organizations who presented their results, for the purpose of confidentiality, names of five organizations have been anonymised.

DISCUSSION

There are currently multi-disciplinary practices like occupation therapy, speech and communication therapy, applied behavior analysis, sensory training, picture exchange communication system, sensory integration therapy, action commitment therapy, Ayurveda, medicine and more being used in India in autism intervention. This article presents the integration and evaluation of the best practice currently available for autism in India. Table 2 showed that less than half 42.9% organizations are using gold standard diagnostic tools such as ADOS 2 and ADIR etc. and 57.1% organizations are using screening tools like CARS, or are doing no screening or diagnostic assessment at all. These findings show a lack of diagnostic procedure, and pathway.

Many organizations, nonprofit and profit have been providing treatment and services for autism care in different parts of the country. To begin with, Comm Deal Trust has developed a program using different methods, mainly occupational therapy and Speech and communication therapy to assist and enhance each child's individual lags and skills. They informed that monitoring of progress or lack of it, within strict time frames, is also a core component and strength of their program since it maximizes inclusion in mainstream schools and society.

Moreover, sensory integration training, behavioral training, PECS (picture exchange communication system) and speech and communication programs is another common treatment program provided in many organizations such as Creative Minds, Lucknow, and Rising Sun Development Center. Early intensive occupational therapy is another intervention approach that has shown good progress in Autism in 3 years old and younger children. Potential Therapy Center, New Delhi uses play-based intervention in which research based social communication therapy, occupational therapy, social play language therapy coordinates with speech therapy and special education for treatment and result shows that these interventions effectively improve one of the primary deficits in autism ie.

Social communication. Integrated intervention also shows improvement in skills such as sensory, oro-motor and play domain.

In addition, organizations like WeCan, Chennai are with the beliefs in treatment of autism through Applied Behavior Analysis. ABA is a scientific discipline in which techniques can lead to a change in the behavior of social significance. Tools like PEAK, the latest ABA tool for programming (New York), PECS (picture exchange communication system), social skills program along with ACT (action commitment therapy) are used for treatment at WeCan the Focus of WeCan is Two-fold-early intervention for autism and providing life skills to individuals with autism.

Furthermore, a multi-disciplinary practice called I-BAC (Intervention Based on Assessment Cycle) which is guided by the principle of applied behavior analysis and developmental intervention provided in child developmental centers like Geniuslane, Lucknow. This system was developed for improving parent's understanding of autism, and improving home environment using assessment, based on an algorithm which provides intervention according to the development level of the child. New software assessments were developed based on Early Years Foundation skills and using latest government guidelines and UK Curriculum of Excellence. These I-BAC digitally delivered early intervention were able to reduce autism related behavior in children, and improve the early years foundation skills of the child. The organization's interventions have shown positive results in 90 % of individuals with autism with marked improvement in the quality of life of children and their families.

Gut management of children through ayurveda therapies and lifestyle guidelines programs of ayurveda given to the parents of children with autism also have promising influence in the positive outcome of behavior of children with autism spectrum disorders. The science of ayurveda considers ASD as an errant lifestyle generated status of human being rather than a disease. A paradigm shift in the synchrony between man and nature, especially after the industrial revolution by the human effort to fortify the national welfare and by the human effort to fortify the national welfare and health indices led to many diseases.

After Gut Therapy Protocol (AGTP), their gut symptoms and behavioral symptoms were significantly ($p<0.05$) reduced; the correlation coefficient of their changes was +0.83. on evaluation of the course of lifestyle guidelines given to parents a highly significant change ($p<0.001$) in the WHO-QOL -BREF (Quality of life parameter for Parents) was noted in the physical and psychological domain a highly significant change was noted ($p<0.001$) three components of family impact questionnaire among parents similarly in Childhood Autism Rating Scale (CARS) and Indian Scale for Assessment of Autism (ISAA) after the parental course among their children.

CONCLUSION

Along with evidence-based interventions, few non-evidence-based interventions are also being used in India, like hyperbaric Oxygen therapy, Chelation Therapy etc. which is not recommended to be used for treatment in ASD. The evidence- based interventions like sensory-integration therapy, applied behavior analysis, occupational therapy and picture exchange communication systems are majorly used for autism in India. In terms of their efficacy in the Indian population, not many research studies or clinical audits are available to assess the intervention outcome. However, the practice of clinical audit can be seen in one organization from this review, i.e., Geniuslane, and Tata Comm Deal Trust. Moreover, there is active participation of organizations, like Autism Connect and Action for Autism, in

spreading awareness of autism through various platforms like conferences, events for parents and children and also through best practice awards. Since major improvement can be seen through IBAC (90%), which is a new model for interventions in autism. Although more research and transparency are needed from the organization in terms of auditing, and presenting their work, only then the best practice can be generalized to support children and families on the spectrum.

REFERENCES

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington, VA: American Psychiatric Association; 2013.
2. Elsabbagh M, Divan G, Koh JY, Kim YS, Kauchali S, Marcin C, *et al*. Global prevalence of autism and other pervasive developmental disorders. Autism Res 2012;5: 160e79.
3. Krishnamurthy V. A clinical experience of autism in India. J Dev Behav Pediatr 2008; 29:331-3.
4. Jain R, Juneja M, Sairam S. Children with developmental disabilities in India: Age of initial concern and referral for rehabilitation services, and reasons for the delay in referral. J Child Neurol 2013; 28:455-60.
5. Kommu JV, Gayathri KR, Srinath S, Girimaji SC, Seshadri S, Gopalakrishna G, et al. Profile of two hundred children with autism spectrum disorder from a tertiary child and adolescent psychiatry center. Asian J Psychiatr 2017; 28:51-6.008;29:331-3.
6. Mukherjee, et al., Diagnostic Accuracy of Indian Scale for Assessment of Autism (ISAA) in Children Aged 2-9 Years. *Indian Pediatrics* Volume 52, March 15, 2015
7. Gulati S, Kaushik JS, Saini L, Sondhi V, Madaan P, Arora NK, et al. (2019) Development and validation of DSM-5 based diagnostic tool for children with Autism Spectrum Disorder. PLoS ONE 14(3): e0213242. https://doi.org/10.1371/journal.pone.0213242
8. Wiggins, L. D., Baio, J., Schieve, L., Lee, L. C., Nicholas, J., & Rice, C. E. (2012). Retention of autism spectrum diagnoses by community professionals: Findings from the autism and developmental disabilities monitoring network, 2000 and 2006. Journal of Developmental and Behavioral Pediatrics, 33(5), 387-395. doi:10.1097/DBP.0b013e3182560b2f
9. Reichow B, Barton EE, Boyd BA, Hume K (2012). Early intensive intervention (EIBI) for young children with autism spectrum disorders (ASD). Cochrane Database Syst Rev. 2012; 17:0.
10. Reichow B, Hume K, Barton EE, Boyd BA. (2012). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). Cochrane Database Syst Rev. 2018; 5:0.
11. Leong H., Carter M., Stephenson J. (2015). A systematic review of sensory integration therapy for individuals with disabilities: Single case design studies. *J. Dev. Phys. Disabil.* 27 183–206. 10.1016/j.ridd.2015.09.022
12. Kadar M, McDonald R, Lentin P. (2012) Evidence-based practice in occupational therapy services for children with autism spectrum disorders in Victoria, Australia. Aust Occup Ther J. 2012 Aug; 59(4):284-93. Epub 2012 Jul 1.
13. Williamson E, Sathe NA, Andrews JC, et al. Medical Therapies for Children with Autism Spectrum Disorder—An Update [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2017 May. (Comparative Effectiveness Reviews, No. 189.) Preface.

14. Singh et. al. (2018). A non-linear dynamic Ayurveda approach for the management of children with autism spectrum disorder. Conference Proceedings, World Autism Awareness Day Conference, Association of Child Brain Research.
15. Sharma et. al. (2013). Autologous Bone Marrow Mononuclear Cell Therapy for Autism: An Open-Label Proof of Concept Study. Hindawi Publishing Corporation. Stem Cells International Volume 2013, Article ID 623875, http://dx.doi.org/10.1155/2013/623875
16. Rossignol, D. A., Rossignol, L. W., James, S. J., Melnyk, S., & Mumper, E. (2007). The effects of hyperbaric oxygen therapy on oxidative stress, inflammation, and symptoms in children with autism: an open-label pilot study. BMC pediatrics, 7,36. Doi :10.1186/1471-2431-7-36
17. Bren J., (2013). Commentary on the Abuse of Metal Chelation Therapy in Patients with Autism Spectrum Disorders. J. Med. Toxicol. (2013) 9:370–372 DOI 10.1007/s13181-013-0345-4
18. James S, Stevenson SW, Silove N, Williams K., (2015). Chelation for autism spectrum disorder (ASD). Cochrane Database Syst Rev. 2015 May 11; 5:CD010766. Epub 2015 May 11.

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Conflict of Interest
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