

## Awareness-rehabilitation facilities: Children with autism spectrum disorder-Telangana

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### Abstract

ASD (Autism Spectrum disorders) is a common condition and estimated to affect 1 in 65 persons in India. The awareness gradually grew and consequently the number of reported cases of autism increased dramatically in the 2000s and early 2010s. The objective was to conduct a survey on awareness and rehabilitation facilities available for the children with autism spectrum disorders in Telangana. Participants were 30 parents of children with autism spectrum disorders. Results indicate out 30 children, 24(80%) children were attending Behavioural /Psychological intervention, 30(100%) children were attending speech and language intervention, 23(76%) children were attending special education, 09(30%) children were attending occupational therapy, 14(46%) children were attending sensory integration therapy, 30(100%) children were on pharmacotherapy and therapies. Professionals consulted by parents were mostly paediatricians; this showed a lack of awareness about Psychologists, Speech language pathologists and other professionals. Awareness among the parents about the autism was very less in parents, when the problem persists most of the parents are first visiting paediatrician or neurologist or ENT doctors but none of them visited psychologist or psychiatrist or the speech language pathologists. After identifying the problem with the references majority of the parents are utilizing services of Psychologists, Speech therapists, Occupational Therapists and Pharmacotherapy to improve their children. This indicates there is awareness about Psychologists and Speech language pathologist and other therapists after detecting the problem of their child.

**Keywords:** Rehabilitation, Facilities, Autism Spectrum Disorders (ASD), Speech and Language Pathologists, Psychologists, Telangana

### 1. Introduction

Autism is the paradigmatic condition among a class of disorders marked by social and communication deficits and behavioral rigidities called the pervasive developmental disorders (American Psychiatric Association, 2000) [1], also variably called the autism spectrum disorders and it is classified as a life-long disability (Dawson & Osterling, 1997) [4]. Researchers are not sure whether or not this communication delay is a result of a low desire to interact and communicate with others, or if this avoidance is fueled by the inherent difficulties with speech and language (Russo & Bailey, 2000) and it is no longer considered as an unusual condition, and the number of children being referred for developmental disabilities assessments with a differential diagnosis of autism continues to increase every year.

ASD (Autism Spectrum disorders) is estimated to affect 1 in 150 persons; thus, it is no longer considered a rare disorder (Kuehn, 2007) [9]. The earliest reference of "autism" in Indian literature was reported in 1959, but the knowledge about autism was limited. The awareness gradually grew and consequently the number of reported cases of autism increased dramatically in the 1990s and early 2000s. This can be attributed to either increase in the actual prevalence or improved diagnostic tools. A recent meta-analysis of 37 prevalence studies of autism reported from USA, UK, European countries and Japan has estimated that the prevalence of autism is 7.1 per 10,000 in individuals under 18 years of age (Williams and Higgins, 2006) Overall; boys are affected more often than girls and the average male: female ratio is 3.8:1 . In recent times in the USA and UK, population studies had

suggested that the prevalence of autism has increased two to three times over the last three decades (Yeargin-Allsopp, Rice, Murphy , 2003 [18]; Gurney *et al.*, 2003 ; Barbaresi *et al.*, 2005) .There is no data available from India of prevalence rates of autism in the general population. However, authors of recent case series reports of 16 and 62 autistic children from tertiary hospitals in Chandigarh and New Delhi, respectively, have stated that autism is not uncommon in India (Singhi *et al.*, 2002; Kalra *et al.*, 2005). Its diagnosis is frequently missed as there is tremendous lack of awareness and knowledge about the disorder among health professionals (Singhi *et al.*, 2002; Kalra *et al.*, 2005) However it was reported that one in 10,000 children ten years ago in India, the prevalence is 3-4 per 1,000 live births now. The incidence rate is approximately 1 in 90,666 or 11,914 people in India. According to estimates, over 2 million people are living with autism in India. Rapid advances in the fields of cognitive and affective developmental neuroscience, developmental psychopathology neurobiology, genetics, and applied behavior analysis have contributed to a more optimistic outcome for individuals with ASD. These advances have led to new methods for early detection and more effective treatments but still there exists a controversy about this diagnosis, including whether it is "almost autism" or "atypical autism" (Towbin, 1997) [15]. However there is no one single unified theory that explains the etiology of autism. Structural MRI brain studies have detected, though not consistently, increased volume of the total brain and abnormalities in the cerebellum, frontal lobe and limbic system (amygdala and hippocampus) in young children with autism (Cody *et al.*, 2002; Acosta *et al.* 2004) [2]. Although no one

specific cause of autism is known, current research links it to biological or neurological differences in the brain. Moreover there are no efficacious treatments to treat this core deficit; thus, behavioral and social skills interventions remain at the forefront (Wink, Erickson, & McDougle, 2010) <sup>[17]</sup>. Hence an accurate diagnosis is based on observations of the child's communication, behaviour and developmental levels which will have a great impact on intervention. In the field of autism, a driving force behind research on how symptoms are recognized and diagnosed has been the understanding that earlier treatment can lead to a more positive outcome. While much about the course of autism is still unclear, the importance of early intervention for such children is almost universally acknowledged (National Research Council, 2001; Klinger & Dawson, 1996; Powers, 1992) <sup>[11]</sup>. Early intervention programs also have an impact on child functioning, often leading to full inclusion programs in elementary school (Dawson & Osterling, 1997) <sup>[4]</sup>. Further evidence for the critical importance of early intervention is provided by studies contrasting the effects of later intervention significant differences in improvement for children who begin a program before the age of 5 as compared to those who begin after the age of 5. Clearly, the operative philosophy behind intervention for autism is to intervene as quickly as possible.

During the past three decades, conceptualizations of ASD have changed dramatically. Autism was previously considered a disorder with an extremely poor prognosis with only 50% of individuals developing spoken language (Dawson, 1989). It has now been demonstrated that 75–95% of children who receive early intensive behavioral intervention develop useful speech by age 5 (Lovaas, 1987; McGee, Morrier, & Daly, 1999; Rogers, 1998) <sup>[10]</sup>.

Children with autism need help to develop early skills in establishing joint attention, imitation of others, communicating interest and meaning as well as immediate wants, understanding the language of others, getting on with and enjoying the company of other people, tolerating change, and so on. This broad agenda has spawned a broad range of approaches to early intervention, with controversial claims for their efficacy. Some intensive programmes, involving up to 40 hours of structured input to the child every week, have claimed to restore 'normal functioning'.

Over the years, there have been many treatments developed for children with autism, evolving from different philosophies. These include behavioral interventions, developmental interventions, and cognitive-behavioral interventions. While each program is based on a different philosophy and uses unique intervention strategies, there is also considerable overlap in components of the programs. Finally, there are intervention approaches involving parents in behaviour management and promotion of communication skills which are non-intensive, utilizing teaching within everyday situations. Three separate groups of studies have now reported that a significant proportion of children receiving intensive intervention early in life make outstanding progress, with autism symptoms diminishing and developmental outcomes improving such that these children no longer have evidence of disability. As every autistic child is unique the interventions are highly individualized to target his/her specific deficits in imitation, attention, motivation, compliance and initiation of interaction. Skills are taught in small steps, mastered and then generalized. Individualized one-to-one therapy is provided in a

distraction-free structured environment by behavioural therapists under supervision of a developmental pediatrician. Only positive reinforcement is used to teach the child (Simonoff, 1993) <sup>[12]</sup>. Parents are trained to generalize the skills learnt by their child in the home environment. Early intervention therapy not only reduces disruptive behaviors such as, aggression, hyperactivity and temper tantrums which impair learning but also prevents their development (Simonoff, 1993) <sup>[12]</sup>. The outcomes for children with autism are variable, reflecting the influence of comorbidities, such as intellectual handicap and mental health, as well as family functioning. Non-retarded autistic children who continue to experience difficulties in regular schools may need to attend special schools to continue their education (Keen *et al.*, 2004) <sup>[7]</sup>.

Because of multiple areas of development, including not only social and communication disabilities but also atypical patterns in play and delays in cognitive development among many others. There is a need, therefore, to adopt a comprehensive developmental approach (Sparrow, Carter, et al., 1995) <sup>[14]</sup>, which emphasizes the assessment of multiple areas of functioning and the reciprocal impact of abilities and disabilities. By explicitly framing the assessment in terms of the normative course of development, it is possible to appreciate delays in the acquisition of skills that emerge systematically in typical children. Hence, reflecting the need for a cohesive clinical team benefiting from expertise in different disciplines (Klin et al., 1997) <sup>[8]</sup>, working together in a highly integrated manner. Moreover most referrals to clinics are still within the age range of preschool and school age, and problems related to ASD have gained acceptance in the recent times. Parents and teachers understand that these children struggle to cope with the demands of their homes, school, and society. Therefore, educational interests of children with ASD cannot be overlooked through which it would be possible to educate these children and turn them into productive citizens.

## 2. Need for the study

There has been a paucity of studies on diagnostic beliefs and practices of diagnosis of autism conducted in developing countries. India comprises 25% of the world's population, yet practically nothing is known of diagnostic practices of autism in these countries. India is a country of over 1 billion people and is poised to become the world's most populous country within the next few decades (Cohen, 2001); currently, India alone accounts for 21% of the world's population growth. Under the assumption that autism is a population-based disorder, even the conservative estimates of 4 to 5 persons in 10,000 affected by autism indicate that there are a staggering half-million people in India with the disorder. Other prevalence estimates (e.g., Gillberg, Grufman, Persson, & Themner, 1986), indicate there may be as many as 2 million people in India with autism. In fact, the number of schools providing education to children with autism is severely limited as compared to the need. However, the range of services is extremely varied and diverse ranging from autism specific services to mainstream schools. The majority of children with autism who attend school do so at the nearest special needs facility accessible.

The efforts to increase early diagnosis coupled with the rise in number of qualified special teachers, professionals and setting up of more special / appropriately equipped regular schools is paving the way for early educational and behavioural

interventions, enabling the child to make significant gains – steps which are particularly required in India. Hence whether an appropriate treatment program is being established in schools would be one which incorporates both the general needs of children with autism along with the specific needs of the child. Moreover the high costs of treatment and interventions along with the growing numbers of individuals affected are placing enormous challenges and burdens on parents and the majority of focus has been on early intervention, with the belief that early and intensive intervention can lead to better outcomes. Ultimately, the hope is that individuals will require less support as adults if early intervention is effectively done.

Moreover it has been reported that individuals with autism respond well to a highly structured, specialized education and behavior modification. In the west there are several special centers for children with autism/P.D.D that offer these services there has hardly been any sustained effort at offering therapy for children with P.D.D in India. During the last few years parents and other concerned individuals, in the larger urban cities have initiated some efforts at establishing these services. Given the increase in the number of children being diagnosed / identified as autistic/PDD and the lack of services it is necessary that we have an understanding of the existing facilities prior to undertaking serious efforts to setting up of comprehensive and cohesive training measures. Hence the present study is undertaken to review the existing facilities available for children and to provide a summary of overall approaches to clinical evaluation of children with ASDs, around schools in Hyderabad which reflects the need for a cohesive clinical team benefiting from expertise in different disciplines (Klin *et al.*, 1997) <sup>[8]</sup>, working together in a highly integrated manner. (Sparrow, Carter, Racusin, & Morris, 1995) <sup>[14]</sup>.

### 3. Aim of the study

The aim of the study is to identify the rehabilitation facilities available for the children with autism spectrum disorders in Telangana.

Objectives of the study:

1. To examine the extent to which parents sort help for professional support concerned with autism rehabilitation.
2. To identify the rehabilitation facilities that are being utilized by the parents of children with autism spectrum disorders.

### 4. Methodology

The current study was aimed to conduct survey on rehabilitation facilities available for the children with autistic features in Telangana. The following objectives were formulated for the study.

To examine the extent to which parents sought help for professional support concerned with rehabilitation for children with autism spectrum disorders.

To identify the rehabilitation facilities that are being utilized by the parents of children with autism spectrum disorders.

### Subjects

The subjects of the study consisted of thirty mothers of children with autistic spectrum disorders from three different schools for autism in Telangana. The age ranges of all the subjects were between 25-32 years with a mean age of 28

years. Subjects participated in the current study were chosen randomly from three different schools for autism.

### Selection criteria

Thirty parents of children with autism spectrum disorders were selected based on the following criteria.

Parents should have a minimum qualification of SSC.

Participants from both nuclear and joint family were included.

All the subjects were natives of Hyderabad and 17 speak Telugu, 3 speak Hindi and English and 10 speak Telugu and English.

### Procedure

The study was carried out in two phases. Phase I includes developing a questionnaire, securing feedback on the survey from an expert panel and creating a final draft. Phase II includes administration of the questionnaire.

### Phase 1: Developing a questionnaire

Questionnaire was developed to identify the rehabilitation facilities available for the children with autism spectrum disorders which consist of simple yes or no questions, forced choice questions and multiple choice questions. The questionnaire was validated by distributing it to 10 speech language pathologists with a minimum 5 years of clinical experience in the field. Speech language pathologist corrected questions as per the purpose of study and suggested list of questions and returned them back. All 10 Speech Language pathologists agreed that the theme of the questionnaire is appropriate. The questions which were too lengthy and more formal were removed from the questionnaire based on their opinion. The questions were made simpler to understand as per their suggestions. These changes were made and incorporated before administering on the individuals.

Before administering on the parents of children with autism spectrum disorders the questionnaire was administered on 5 parents know whether the questionnaire is serving the purpose of the study as a pilot study. Questionnaire consists of demographic data, Symptomatology of the children with autism spectrum disorders, first professional consulted by the parents, utilization of rehabilitation services and suggestions given by the parents of children with autism spectrum disorders to improve rehabilitation facilities. Informed written consent was obtained from the parents of all children prior to administration of the questionnaire which was given in appendix I. Parents were informed about the purpose of the study the interview questions and information regarding confidentiality

### Phase 2: Administration of the Questionnaire

Questionnaire was distributed among the parents of the children with autism spectrum disorders who are willing to participate in the study. They were also explained that this information will be strictly used only for scientific study and will be kept confidential. The participants signed the informed consent form for research. Parents filled the questionnaire related to rehabilitation services available for the children with autism spectrum disorders in Telangana. Once the responses were obtained the questionnaires were collected back. Then the data was tabulated and analysed according to the objectives given in the study.

**5. Results and discussion**

The study was aimed to explore the availability of rehabilitation facilities for the children with autism spectrum disorders in schools around Telangana. Data was collected by administering a questionnaire to 30 parents of the children with

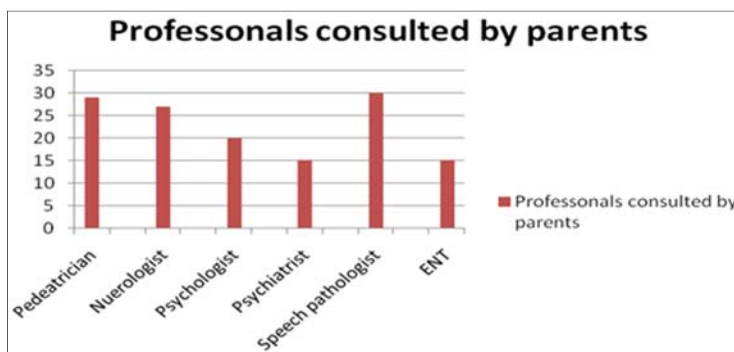
autism spectrum disorders. Results were studied in the following subsections:

- Professional consultation by parents:
  - Utilization of facilities by parents:
- The children were from the age range of 4yrs-12½yrs.

**Professionals consulted**

**Table 1:** Representing the professionals consulted by the parents

Paediatrician	Neurologist	Psychologist	Psychiatrist	Speech pathologist	ENT
29	27	20	15	30	15



**Fig 1:** professionals consulted by parents

As mentioned in review of literature parents of children with autism spectrum disorders consult many professionals to rule out the problem of their children.

Out of all the subjects, 29(96.6%) subjects consulted paediatrician, 27(90%) subjects consulted neurologist,

20(66.6%) subjects consulted psychologist, 15(50%) subjects consulted psychiatrists, 29(96%) subjects consulted speech language pathologist, and 15(50%) subjects consulted ENT doctor to rule out the condition of their children.

**Table 2:** parents concern for the first consultation:

Professionals	Consultation	No. of clients
Paediatrician	I	18
Neurologist	II	5
Psychologist	III	0
Psychiatrist	IV	0
Speech pathologist	V	0
ENT	VI	7



**Fig 2:** Parental concern for initial professional consultation

Out of 30 subjects 18(60%) parents consulted paediatrician, 5(16.6%) parents consulted neurologist, 7(23.3%) parents consulted ENT doctor. None of the parent consulted psychologist, psychiatrist and speech pathologist as first consultation. Dawson indicating that, although there is no

pharmacological cures for autism spectrum disorders and only a few medications that appear to be effective in relieving symptoms. Still most of the parents choose paediatrician as their first consultation.

Utilization of facilities

Table 3: Rehabilitation/Interventions undergoing

Psychological	Speech and language	Special education	Occupational therapy	Sensory Integration therapy	Drug therapy	Alternative therapy
24	30	23	09	14	30	0

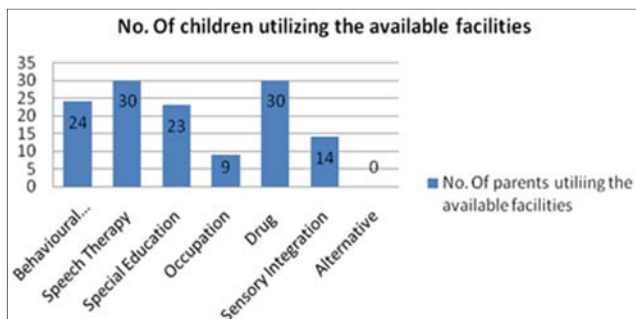


Fig 3: No. of children utilizing the available facilities

The above table and the graph represent the number of parents who are utilizing the facilities available across Telangana.

Out of 30 children, 24(80%) children were attending behavioral/psychological intervention, 30(100%) children were attending speech and language intervention. 23(76%) children were attending special education. 09(30%) children were attending occupational therapy. 14(46%) children were attending sensory integration therapy. 30(100%) children were using drug therapy. And no child was taking alternative therapy. So, the highest percentage of children were going to speech and drug therapy with 100% utilization followed by behavioral therapy, special education, sensory integration, occupational therapy and alternative facilities with percentage of 80, 76, 46, 30 and 0 respectively.

The results were in congruence with the finding of the study by Green et al. (2006) indicating that children with ASD are receiving a wide number of treatments. Further, individual child characteristics may be a factor in determining the intervention programs chosen by the clinician. Occupational therapy and sensory integration therapy were utilized less compared to other interventions considered contributing to characteristics exhibited by those individual children.

Table 4: Medical management undergone

S. No.	Allopathy	Ayurvedi	Homeopathy
16		-	-
09			
3			

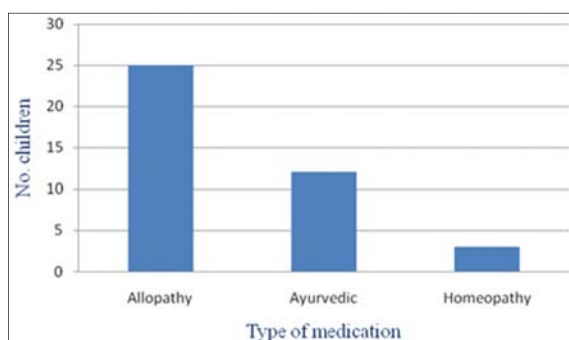


Fig 4: shows the type of medication used

Out of 30 children 16(53.3%) children using only allopathic drugs, 9(30%) children using homeopathy and ayurvedic medicines, and 3(10%) children using ayurvedic and homeopathy medicines. Majority of the parents are going for allopathic treatment than homeopathy and ayurvedic to control the behaviour manifestations of children.

6. Discussion

Most parents in the study had never heard of autism prior to their child’s diagnosis. In some cases, although the parents noticed an abnormality, they denied it at first. Some parents sought hospital referral, but their suspicions were sometimes dismissed by doctors who were not familiar with ASD. In such cases, the pathway to care was delayed until the child was diagnosed by a well-known pediatrician or psychiatrist, at which point the diagnosis was accepted. Most parents sought intervention once they accepted the diagnosis. Doctors often recommended special intervention centers to parents directly after diagnosis. Their options were clear, but given the lack of unified standards for such centers, many parents wanted their children to enter the most well-known centers. This led to long waiting times and intervention delays. The costs of attending such centers are a burden even to middle class families in Telangana.

The significance of this survey was that this was the first of its kind to be conducted in Telangana. There were two critical findings in this survey. First, is to examine the extent to which parents sought help for professional support concerned with autism rehabilitation and the second was that to identify the rehabilitation facilities that are being utilized by the parents.

All the respondents were well satisfied with the facilities that are available for the children with autism spectrum disorders however they reported that their children need the quality of each therapy has to be improved. 60% of the respondents reported that their children need individual attention during therapy sessions. They also reported that the number of special schools for autism has to be increased as many are far to reach and are facing difficulty to travel with the child. Most of the parents (90%) reported that the expenditure on each therapy that they were spending was too high for them. Apart from these findings, the parents of children with autism spectrum disorders suggested that awareness of rehabilitation services should be improved among medical professionals particularly paediatricians as most parents consult paediatrician first and pre-school teachers for early identification and intervention. They also suggested that the child needs an individual attention from the professional and they need extensive intervention for improving the expressive language skills. In brief the results of the survey on rehabilitation facilities available for the children with autism spectrum disorders in Telangana indicate that most parents consulted paediatrician regarding their child’s problem initially. All the professionals are reported to diagnose children based on interviewing the parents and observing the child

7. Conclusion

Awareness among the parents about the autism was very less in

parents, when the problem persists most of the parents are first visiting paediatrician or neurologist or ENT doctors but none of them visited psychologist or psychiatrist or the speech language pathologists. After identifying the problem with the references majority of the parents are utilizing services of speech therapy and drug therapy to improve their children. This indicates there is awareness about speech language pathologist after detecting the problem of their child. Similar study was conducted in Karnataka 10 years back that time, parents not even known about autism, but now parents are aware of autism and the treatment approaches. With present technology parents are exploring themselves to get the better results in their children.

### Implication of the study

The findings of the current study showed

1. That parents were using a wide range of rehabilitative services.
2. The most commonly used treatments have varying degrees of empirical support.
3. In addition, the number and types of treatments currently being used by parents varied with the age and type/severity of the child's disability.
4. One implication of these findings is that parents had ready access to their objective and data-based consumer-friendly information on a range of specific treatments; depending on the age and type/severity of the child's disability.

The study was inexpensive, examiner was able to target a specific group and obtain a large number of respondents in Telangana. This study has demonstrated a way to include the voices of parents about their child's ASD through survey.

### Limitations

Lack of variability in gender

Severity of autism was not taken up for consideration.

Children of all age groups was considered

### Future Directions

The survey can be conducted on a larger number with comparison of variables like gender and education.

The survey can be carried out in other geographical region.

The effect of taking certain client specific treatments can be highlighted through proper controlled studies.

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