

REHABILITATION FACILITIES AVAILABLE FOR CHILDREN WITH AUTISM/PDD IN BANGALORE CITY - A SURVEY

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ABSTRACT

The aim of the study was to collate the information on rehabilitation services available for children with Autism/PDD in Bangalore City. A personal interview with open-ended questions was formulated. Parents of 30 children with Autism/PDD were chosen for the interview. Answers were transcribed in a response form. The results of the survey on management of children with autism, in Bangalore City indicated that most parents initially consulted their pediatrician regarding their child's problem. All the professionals consulted are reported to have diagnosed the children on the basis of interviewing the parents and observing the child. Centres providing rehabilitation services for children with Autism/PDD are few in number. Behavioural, Communication and Special education programmes are the management services that are availed of maximally, followed by medical management, but these services are not available at any one centre. We conclude that rehabilitation services through team approach under a single roof is most urgently needed for children with Autism / PDD in Bangalore city.

INTRODUCTION

Autism and the related pervasive developmental disorders are characterised by patterns of delay and deviance in the development of social, communicative, and cognitive skills, which manifest in the first years of life. There is no known specific cause of autism. The current research links it to biological / neurological causes. An accurate diagnosis is based on observations of the child's communication, behaviour and social development. There is no single approach, which is effective in alleviating symptoms of autism in all cases, because of the spectrum nature of autism and the many combinations, which can occur. It has been reported that individuals with autism respond well to highly structured, specialised education and behaviour modification. In the West, there are several special centres for children with Autism/PDD that offer these services. There has hardly been any sustained effort at offering therapy for children with Autism and /or PDD in India. During the last few years, parents and other concerned individuals, in the larger metropolitan cities have initiated some efforts at establishing these services. Given the increase in the number of children being diagnosed /identified as Autism/PDD and the abysmal lack of services, it is necessary that we have an understanding of the existing facilities prior to initiating new training measures in order to meet the rehabilitative/educational needs of these children, more comprehensively.

METHOD

Data for the study was collected from the following centres:

ASHA (Academy of Severe Handicaps and Autism)

DEC (Developmental centre for Exceptional Children)

SRCISH (Dr. S.R Chandrashekar Institute of Speech and Hearing)

These three centres were chosen for the study as they provide the rehabilitation services for maximum number of children with Autism/PDD in Bangalore City. The centres were very positive about the survey and were helpful in arranging the interviews. Parents at these centres responded with full co-operation.

SUBJECTS

Parents of 30 children with Autism/PDD were interviewed.

TOOLS

A personal interview with open-ended questions was formulated. The list of questions addressed the following areas:

(a) demographic data

- (b) medical history
- (c) symptomatology
- (d) professionals consulted
- (e) diagnostic and assessment procedures used
- (f) intervention/management strategies used and their outcome and
- (g) Suggestions to improve rehabilitation services

A N A L Y S I S

The parent's answers were transcribed in a response form and analysed.

R E S U L T S

The results of the study are presented in Tables 1 to 3d followed by a description of the major trends seen.

1			✓	✓	✓	✓	✓	✓		✓
2	✓	✓	✓	✓	✓	✓	✓	✓	✓	
3	✓			✓	✓	✓	✓			✓
4			✓	✓	✓	✓	✓	✓	✓	✓
5	✓		✓	✓	✓	✓		✓		
6	✓	✓		✓	✓	✓		✓		
7		✓			✓	✓			✓	
8	✓		✓	✓	✓	✓	✓	✓	✓	✓
9				✓	✓	✓	✓			
10	✓	✓		✓	✓	✓	✓	✓		
11	✓	✓		✓	✓	✓	✓	✓		
12		✓		✓	✓	✓		✓		
13	✓			✓	✓	✓		✓	✓	
14			✓	✓	✓	✓		✓	✓	✓
15	✓		✓	✓	✓	✓	✓	✓	✓	✓
16	✓	✓	✓	✓	✓	✓	✓			
17				✓	✓	✓	✓			
18		✓	✓	✓	✓	✓		✓		
19				✓	✓	✓	✓	✓		
20	✓			✓	✓	✓				
21	✓	✓		✓	✓	✓	✓	✓		
22	✓			✓	✓	✓	✓	✓		✓
23		✓		✓	✓	✓				✓
24	✓	✓		✓	✓	✓		✓		
25			✓	✓	✓	✓				
26	✓	✓	✓	✓	✓	✓		✓		
27				✓	✓	✓				
28	✓		✓	✓	✓	✓		✓		
29	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
30			✓	✓	✓	✓				
Total	17	13	13	29	30	30	15	22	8	9

Table1: gives the information on symptomatology characteristic of children with Autism/PDD.

Lack of eye contact, lack of attention and absence of social play are the three symptoms reported to have been present in all 30 children. Immediate echolalia, self-stimulation and gestures to communicate have been reported in more than 15 children. The rest of the symptoms which are reported to have been present in less than 15 children are pre- occupation with objects, insistence on routine, delayed echolalia and hyperactivity.

**T a b l e 2 : P r o f e s s i o n a l s
c o n s u l t e d**

Professional Consulted	I	II	III	IV	V
Neurologist	1				
Paediatrician	12	6			
Psychiatrist	8	5	1		
Psychologist	4	6	3		
Speech Pathologist	4	4	9		
Special Educator	1	9	12	3	1

**T a b l e 2 : P r o f e s s i o n a l s
C o n s u l t e d**

The number of professionals consulted range from 1 to 5. Of these, most parents consulted the Paediatrician regarding their child's problem, followed by consultations with a Psychiatrist. Rehabilitators such as Psychologists, Speech language pathologists, and Special educators were often consulted later, that is as the second, third or fourth consultation.

All the professionals consulted are reported to have diagnosed children based on interviewing the parents and observing the child.

As reported by parents, appropriate referrals to the rehabilitation professionals by medical professionals were lacking. This indicates the necessity to provide a Directory of Centres providing rehabilitation services for children with Autism/PDD to the concerned medical professionals. This will facilitate early and appropriate intervention to these children.

Table 3: Intervention/management

1		✓	✓		
2	✓	✓	✓		
3			✓		
4			✓		
5	✓	✓			
6		✓	✓		✓
7				✓	
8		✓			
9		✓			
10		✓	✓		
11	✓			✓	
12		✓			
13			✓		
14			✓		
15	✓			✓	
16		✓			
17			✓	✓	
18	✓	✓			

19			✓	✓	
20				✓	
21			✓		
22				✓	
23	✓	✓		✓	
24	✓			✓	
25	✓			✓	
26	✓			✓	
27				✓	
28			✓		✓
29		✓			
30		✓		✓	
Total	9	13	13	13	2

T a b l e 3 : I n t e r v e n t i o n / m a n a g e m e n t :

Behavioural, communication and special education programmes are the three management services, that are availed of maximally (13 each), followed by medical management (9). 17 of the 30 children were receiving two or more interventions (medical and/or rehabilitation), of these 9 received any two rehabilitative procedures.

These rehabilitative services are provided at different centres and they work independently indicating the lack of team approach towards the intervention for children with Autism/PDD. Lack of availability of all the required rehabilitative services at any one centre results in hardships in terms of time, money and transport.

2	• Immubromine			
	• Megavitamins			
	• Paradoxin			
	• Bethadoxin			
	• Zevitt			
3	-	✓		✓
5	• Fludac syrup	-		-
11	- ✓			✓
15	• Respiridon			
	• Floxidin syrup	-		-
18	• Immubromine			
	• Alkaline	-		-
23	• Etnol			
	• Seranase			
	• Dimethylglycine (DMG)			
	• Megavitamins	-		-
24	✓	-		-
25	✓	-		✓

- Seranase tablets
(Side-effects-Lethargic, drowsy and vomiting)

T a b l e 3 a : M e d i c a l M a n a g e m e n t :

No significant changes have been reported by parents consequent to the intake of allopathic medicines. As reported in the literature, efforts to find effective medications have been largely unsuccessful so far, as they have little or no effect on the behaviour of these children. Hence, most researchers believe that therapists should try behavioural interventions first, especially when working with young children.

Good appetite and sleep has been reported in children under Ayurvedic and Homeopathic treatment.

Table 3b: Psychological /Behavioural Management

1	4 yrs/m	1yrs - 2mths	2/week - 1hr	✓		✓	✓
2	4 yrs/m	2mths	2/week - 1hrs	x	x	x	x
5	5 yrs/m	2 ½ yrs	2/week- 3hrs	✓	✓		
6	5 ½ yrs/m	2yrs	3/ week 3hrs	✓		✓	✓
8	6 yrs/m	2yrs	3/ week - 3hrs	✓	✓		✓
9	6 yrs/m	3mths	2/week - 1hr	x	x	x	x
10	7yrs/m	1yrs	2/ week - 3hrs	✓			✓
12	7 ½ yrs/m	3mths	2/ week 1 hr	x	x	x	x
16	8 yrs/m	4 ½ yrs	3/week - 3hrs	✓	✓		
18	8 ½ yrs/m	2mths	1/week 2hrs	x	x	x	x
23	10 yrs/m	1yr*	2/week - 1hr	✓			✓
29	14 ½ yrs /m	6 yrs*	3/week 1 hr	✓	✓	✓	
30	16 yrs /f	2 yrs*	5/week - 2 hrs				✓

* - indicates discontinuation from behaviour therapy. ✓ - indicates improvement in the given aspects due to behavioural therapy.

✗ - indicates no improvement.

T a b l e 3 b :
P s y c h o l o g i c a l / B e h a v i o u r a l
M a n a g e m e n t :

13 children in the age range of 4 years to 16 years are reported to have undergone psychological/behavioural management with the duration of therapy ranging from 2 months to 6 years, with the frequency of sessions being 2/week to 5/week of 1 ½ hours duration. This indicates the lack of intensiveness in the therapy programme, which is crucial.

Improvement is reported in children attending behaviour therapy from a minimum of 1 year to 6 years, with a frequency of 2 to 9 hours per week.

T a b l e 3 c : C o m m u n i c a t i o n :
s p e e c h a n d l a n g u a g e t h e r a p y

1	4yrs/m	8mths	2/week - 1hr	✓		✓
2	4yrs/m	4mths	3/week 45mins	✓		
3	4yrs/m	1½ yrs	2/week 45mins	✓		✓
4	5yrs/m	2yrs	3/week- 1hr	✓		✓
6	5½ yrs/m	1hr	2/week 1yr	✓	✓	
10	7 yrs/m	1yr	2/week - 1hr	✓	✓	
13	7yrs 9mth/m	1yr*	2/week	✓		✓
14	8yrs/m	3mths	2/week - 1hr	✗	✗	✗

17	8yrs/m	3mths*	2/week - 1hr	✗		✗	✗
19	9yrs/m	3mths*	2/week- 1hr	✓			
21	10yrs/m	1yr*	2/week	✓			✓
22	10yrs/m	3yrs	2/week	✓			✓
28	12yrs/m	7yrs	3/week - 1hr	✓	✓	✓	✓

* - indicates discontinuity of speech therapy. ✓ - indicates improvement in the given aspects due to speech therapy. ✗ - indicates no improvement.

**T a b l e 3 c : C o m m u n i c a t i o n :
s p e e c h a n d l a n g u a g e t h e r a p y**

13 children in the age range of 4 years to 12 years are reported to have undergone speech and language therapy with the duration of therapy ranging from 3 months to 7 years with the frequency of sessions being 2/week to 3/week of 45 minutes to 1 hour duration. This indicates the lack of intensiveness in the therapy programme, which is important for the child's overall language development.

Improvement in terms of comprehension has been reported in children attending speech therapy for a minimum of 4 months to 7 years with a frequency of 2 hours to 3 hours per week.

7	6yrs/m	3mths	5days/wk	✓		✓	
11	7yrs/m	11/2yrs	5days/wk 6hrs	✓			✓
15	8yrs/m	2mths	5days/wk 6hrs	✓	✓		
17	8yrs/m	11/2mths	5days/wk 6hrs				✓
19	9yrs/m	11/2mths	5days/wk 6hrs	X	X	X	X
20	9 1/2 yrs/m	2mths	5days/wk 6hrs	X	X	X	X
22	10 yrs/m	4yrs	8hrswk 6hrs	✓			✓
23	10 yrs/m	2mths	5days/wk 6hrs	X	X	X	X
24	10 yrs/m	2yrs	5days/wk 6hrs		✓		
25	11yrs/m	2yrs	5days/wk 6hrs		✓		✓
26	11 yrs/m	2mths	5days/wk 6hrs	X	X	X	X

✓ Indicates improvement in the given aspects. X – ndicates no improvement at all.

T a b l e 3 d : S p e c i a l e d u c a t i o n

11 children in the age range of 6 years to 11 yrs are reported to have received special education ranging from 1 ½ months to 4 years with the frequency of sessions being 8hours/week to 30 hours/week.

Improvement is reported in children attending special education classes from a minimum of 3 months to 4 years with a frequency of 8 hours to 30 hours per week.

S U M M A R Y A N D C O N C L U S I O N

As reported in the literature, approximately 15 out of every 10,000 individuals have autism and its associated behaviours. There is no medical test for diagnosing autism. Social interaction, communication and behaviour are the major aspects affected in autism.

Behavioural, medical, communication, psychodynamic, sensory integration and others are the therapeutic approaches put forth for the rehabilitation of the individuals with autism. Autism is a complex disorder and there is no single approach, which is effective in alleviating all symptoms of autism in all cases.

In India, the rehabilitation of children with autism is relatively new and consists of scattered and isolated efforts. The present study has been conducted to collate the information on availability of rehabilitation facilities for children with autism in Bangalore City.

Most parents reported that they initially consulted Paediatricians regarding their child's problem. Rehabilitators such as Psychologists, Speech Language Pathologists and Special educators were often consulted later. Parents reported that early referrals to the rehabilitators for appropriate intervention would have helped and stressed the need for this information being made available to medical practitioners.

The three management services that are availed of maximally are Behavioural, Communication and Special Education Programmes. These services are provided independently, indicating the lack of team approach in the intervention of these children which further results in hardships for parents in terms of time, money and transport.

The results of the study indicate that the centres providing rehabilitation services for children with Autism/PDD are few in number and that these are scattered all over Bangalore. The survey emphasised the lack of services through team approach under one single roof for these children in Bangalore city.

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A C K N O W L E D G E M E N T S

This study was carried out as a part of Master's Dissertation by the first author under the guidance of the second author. We are grateful to all the parents who participated in this study. This study has been carried out at Dr.S.R. Chandrasekhar Institute of Speech & Hearing, Bangalore, India.