

Educating Children with Mental Retardation having Autism Spectrum Disorders (ASD)

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FOREWORD

The two investigators of this project on 'Educating children with mental retardation having autism spectrum disorders' have sincerely worked through the project on the aspects of education models and service strategies and came out with a wonderful project report. Especially in the Indian scenario, education models and teaching/service strategies for the persons with mental retardation having autism spectrum disorders are scarce. I am sure that many teachers and professionals working with this kind of population would be very happy to have different models and strategies developed through research mode that are tested and tried.

Added to this they have come out with few FAQs that were asked by parents, teachers and professionals during their research work, and answers to them from reliable sources, that would be of immense help to those who are interested in understanding autism spectrum disorders. Apart from these, they provided information on profile of organizations working with children with autism that is of help to parents and teachers.

I am sure that this work and the report will be of tremendous help to those who are interested to work and concerned with the persons with mental retardation having autism spectrum disorders.

I wish them all the best.

A handwritten signature in black ink, appearing to read 'L. Govinda Rao', written over a horizontal line.

(Dr. L. GOVINDA RAO)
DIRECTOR, NIMH

PREFACE

This publication is an outcome of a project carried out at our Institute. Research and development being one of the major objectives of our Institute, a number of projects have been carried out in the past. In the area of special education, the research projects have resulted in assessment tools, skill training packages, curriculum guidelines, prototypes of teaching learning materials, computer software for students with mental retardation and research articles publications in journals. This helped in bridging the gaps in the continuum of education of children with mental retardation. It also resulted in identifying gaps that needed to be filled. One major area that needed focus was packages for education of children having mental retardation and additional disabilities. One such condition includes those with mental retardation and autism spectrum disorders (ASD). The project was undertaken to study the status of such children and the educational practices existing for them in our country.

This document is divided into chapters with each chapter providing information on the specific objectives of the project as delineated in the introductory chapter. In addition, compilation of frequently asked questions (FAQs) and answers for them is also provided with sources of the information.

Chapter I gives information on the project objectives. Chapter II contains details on the profile of persons with mental retardation having ASD registered at NIMH during the specific period. Chapter III has information on the analysis of the needs of families having children with ASD. Chapter IV provides information on organisations working for persons having ASD in the country. Detailed information on each organisation as provided by the informants is included in the appendix. Chapter V has details on models and strategies for teaching children with ASD that are found successful.

As mentioned earlier, FAQs and answers are also provided which can be a ready reference for users. Needless to say, references used for the study is provided at the end.

This publication is an outcome of efforts by many professionals as seen in the earlier pages. This is required, considering the complex condition that ASD is, all the more so when the individual also has mental retardation.

This effort is a small step and we realize that a lot more needs to be done to help persons with ASD and mental retardation to lead independent lives. It is hoped that all the professionals, student trainees, parents and others who are interested in ASD find this compilation useful.

N.C.Srinivas

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ACKNOWLEDGEMENT

We place on record our gratitude to our Director, Dr.L.Govinda Rao for his guidance and support in conduct of the research. As it is seen the project team consisted of a number of professionals at different stages of the project and their expertise has been of immense significance in carrying out the project. We thank all the members of the project. A number of organizations working for the children with autism kindly responded to our request and sent information which is compiled and projected in this report. We thank all the organizations for their kind cooperation in this regard. Children with ASD and their families were very cooperative during the data collection. Without their cooperation, the project could not have been completed. We place on record our appreciation to the children and their families for their cooperation. In addition to the project team, all the staff members in the Department of Special Education and Special Education Centre at NIMH have involved themselves in providing critical comments during development of service model for students with ASD, which has helped in developing the functional model at the Institute. We thank all of them. We acknowledge the support of Mr.Hari Babu and Mr.Sivashankaran for their secretarial assistance. We thank Shri T.Pitchiah, Accounts Officer and Shri Rama Mohana Rao, Asst.Administrative Officer for the administrative support in printing of the project report.

Jayanthi Narayan

N.C.Srinivas

CONTENTS

S.No	Name of the topic	Page No.
1	Introduction	13
2	Profile of children with Autism Spectrum Disorders	17
3	Analysis of Needs of families having children with Autism Spectrum Disorders	24
4	Current status of educational facilities for children with ASD	30
5	Service Models and teaching strategies for education of children with ASD	37
6	References	50
7	Frequently asked questions on Autism	55
8	Profile of organisations working with children with Autism	89

INTRODUCTION

Education of children with disabilities has progressed remarkably in the last two decades in India. The shift from 'charity to right' has brought many children with disabilities to educational settings. 86th amendment of Constitution of India has ensured Right to Education (Government of India, 2002). Biwako Millennium framework (2003) to which India is a signatory, aims at inclusive, barrier free and right-based society. Increase in the number of special schools for children with mental retardation from 70 schools in 1970s to about 1000 schools in 2002 (Reddy 2002) is a proof for the progress. Yet the appropriateness of education to each child is questionable. A considerable number of children with mental retardation have additional disabilities such cerebral palsy, sensory impairments and Autism Spectrum Disorders (ASD). Are we doing justice to these children in terms of appropriate education? Until recently, the special teacher training programmes in mental retardation in the country did not focus on preparation of teachers with adequate competencies to educate children with additional disabilities.

The revised teacher-training programme is still underway and the efficacy is to be studied. Yet, these children with ASD get enrolled in special schools. Either they are mistaken for having mental retardation or they are denied admission in other schools. Therefore, it is essential that the teachers are well equipped in terms of knowledge and skills to educate children with additional disabilities. There is an urgent demand for appropriate educational facility for education of children with mental retardation and Autism Spectrum Disorders (ASD).

Autism Spectrum Disorders :

According to the widely accepted classification systems of mental disorders viz.: Diagnostic and Statistical Manual of Mental Disorders-IV edition (DSM-IV), American Psychiatric Association 1994 and International Classification of Diseases - 10th Edition (ICD 10), World Health Organisation, 1992, disorders such as ASD are grouped under the category of Pervasive Development Disorders (PDD).

Autism was identified way back in the year 1943. Commonly, Autism is defined as a clinical condition in which a person is withdrawn into a private world, unable to communicate with others or respond to the environment. People with classical Autism show three types of symptoms. Impaired social interaction, difficulty with verbal and nonverbal communication and imagination, unusual or severely limited activities and interests. Autism is often referred to as "Autism spectrum disorder" [ASD], meaning the symptoms and characteristics of autism can present themselves in a wide variety of combinations.

Autism Spectrum Disorder (ASD), as the name suggests is a combination of symptoms overlapping with other disabilities. This makes the task of assessment and diagnosis difficult. In addition, intervention requires efforts of a team of professionals including a Pediatrician, a Psychiatrist, a Speech Pathologist, a Psychologist, an Occupational Therapist and a Special Educator.

Fombonne(1999) as reported by Smith (2004) reveals that the incidence rate of autism has increased from 2 to 5 children out of every 10,000 in 1970s to 7.5 children out of 10,000 in 1987. When Aspergers and other ASD diagnoses are included, the incidence rate will be further increased. ASD is currently observed to have a prevalence of 2 per thousand population (Ramesh 2003).

ASD is believed to be present at birth, but often a child with ASD is not identified until he is about 2 to 3 years of age. This is because usually deficiency in language and communication development is evident only around this age drawing the attention of parents. During this period, the child would also exhibit atypical social behaviour causing concern. Because of the variations found in the symptoms exhibited by children with Autism, an accurate number to indicate prevalence of the condition is difficult. Further, multiple definitions of the condition adds to the complexity.

'Auto' is a Greek word meaning self. Children with autism have impairments in their social and communicative behaviours. They frequently exhibit intense preoccupation with a single subject, activity or a gesture (Rodier, 2000). Such behaviours suggest that the person lives with 'self' without interacting with others, leading to the name autism. All children with autism may not have all symptoms. If two children with ASD are compared, they may be found to have impairment in language and communication, but may not be having similarities in other behaviours. There may be differences in their communication behaviour also. Because of such wide heterogeneity in characteristics, this condition is being referred to as Autism Spectrum Disorders(ASD).

Autism Spectrum Disorders (ASD) groups together five specific disorders namely autism, Childhood Disintegrative Disorder(CDD), Aspergers syndrome, Rett syndrome and Pervasive Developmental Disorder not otherwise specified (PDD NOS) (Smith 2004). Though these disorders share similar behavioural traits, there is considerable variance in the skills exhibited.

A combination of some of the following symptoms will lead to suspecting ASD in a person, demanding detailed assessment.

- Failure to interact with other people
- Delay or abnormal language development
- Inappropriate emotional expression or reaction
- Stereotypical, repetitive self-stimulatory behaviour
- Poor eye contact, exhibiting behaviour as if not seeing or hearing events happening around them
- Mute or having echolalia – repeating exactly what is heard without understanding
- Atypical play behaviour
- Impaired flexibility – resistance to change in the environment

Children with mental retardation having ASD

Because of the overlapping symptoms, children with ASD are often mistaken for having other conditions such as mental retardation, hearing impairment, childhood schizophrenia or other emotional disturbance. It is also possible that a child with mental retardation has autism spectrum disorders. It is estimated that about 75% of children with ASD have mental retardation (Smith 2004). This wide range of cognitive ability has resulted in the usage of terms such as low functioning and high functioning autism, where low functioning refers to those with mental retardation (Smith 2004).

Current Scenario

Children with ASD, ideally should have appropriate educational facilities. In western countries, legislation on the education of children with special needs includes ASD. In India, currently autism is covered by National Trust Act for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities (1999). This Act aims at providing guardianship.

Educational facilities

General and special educational systems currently do not have specific focus on autism. A few voluntary organisations provide education to children with ASD. Many low functioning children with ASD are admitted to special schools for children with mental retardation. The schools do not have trained teachers to meet their educational needs. Rehabilitation Council of India has approved Diploma in Special Education for children with Autism for training teachers and is carried out in a few centres in the country. In short, the existing facilities are far too few to meet the needs demanding specific focus at macro level for education of children with autism.

The need for the study

NIMH has, as one of its objectives to develop service models for children with mental retardation and associated disabilities. In the areas of special education, curriculum development,

assessment, educational programming and evaluation systems were developed through project mode to meet the educational needs in the continuum of educational services for persons with mental retardation in the age range of 3 years to 18 years. In the process of working with students with mental retardation, it was found that a large number of children have low incidence conditions associated with mental retardation which includes sensory impairment, autism and profound mental retardation. For each of these conditions, a systematic educational model is required in order to meet the educational needs of all children with mental retardation, irrespective of age, severity level and associated conditions. About 75% of children with ASD have mental retardation. It is imperative that they receive appropriate education. With this end in view, a project was undertaken to develop educational service models for children with ASD.

Specific objectives

1. To compile and analyse information on children with mental retardation having ASD who are referred to special education services at NIMH.
2. To analyse the perceived needs of parents of children with mental retardation having ASD
3. To compile and review information on the educational facilities available for persons with (ASD) in India.
4. To evolve suitable models and strategies that provide maximum opportunities for education of children having mental retardation with ASD.

Objective-1 Information on children with ASD who were referred to special educational services at NIMH was collected and analysed. The details are discussed in the section on Profile of Children with Autism Spectrum Disorders.

Objective-2 A questionnaire was given to parents to find out their perceived needs with regard to their child with ASD. The details are provided in the section on Analysis of needs of families having children with Autism Spectrum Disorders.

Objective-3 Information from organisations in India working for persons with ASD was collected on a prescribed form and the details are compiled. The details are seen in section on Current status of educational facilities for children with ASD

Objective-4 The details on models and strategies that were found suitable in the course of working with children with ASD are given in the section on Service models and teaching strategies for education of children with ASD.

PROFILE OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

At NIMH, all the clients registered are assessed and suitable programming is made by a multidisciplinary team consisting of a special educator, a rehabilitation psychologist and a medical professional (Psychiatrist/Pediatrician). Referrals as required are made to audiology, speech pathology, early intervention, physiotherapy, occupational therapy, special education, including Special Education Centre, psychological intervention, vocational training or further detailed investigation outside the institute such as genetic investigations or chromosomal analysis. Follow up of the clients are made predominantly through home based instructions, referral to special, Integrated or inclusive schools with periodic follow up, mobile services and vocational training and placement. The subjects for the study were drawn from those registered at NIMH and referred to special education services.

Procedure

All children diagnosed as having ASD and referred by the assessment team for educational intervention during a period of five years (1995 - 2000) formed the subjects for the study. In a structured schedule, information was collected through a semi-structured interview for each of the subjects. Parents, jointly or individually were the informants for the study. Wherever required, the questions were translated into the language the informant would find easy to communicate. The questionnaire included queries on demographic details, parental perception of the condition before diagnosis, typical behaviours observed by the parents and treatment and training being provided. Teacher observations on characteristics were also collected on a questionnaire. The data thus gathered was analysed.

Results

A total of 90 children with ASD formed the subjects. Table 1 shows the age and gender distribution of the subjects which reveals that children aged six years and below constitute 58.9% of the sample and 70 of the total 90 clients are male. Early identification and seeking services by the parents is an indicator of increase in the awareness. The male-female ratio concurs with the earlier findings where the ratio is reported to be 3 or 4:1 (NICHD 2001). However, we have to keep in mind that the number of subjects here are referred/voluntary registrations and not the outcome of any survey or epidemiological study. The number of cases referred has shown decrease with the increase in age, which poses the question, 'where are the older individuals with ASD?' It is to be investigated as to whether they are in the appropriate educational/training environment.

Table 1 : Age and gender distribution of the clients with ASD

N=90

Year	1995		1996		1997		1998		1999		2000		Total		Grand Total
	M	F	M	F	M	F	M	F	M	F	M	F	M	F	
Age in yrs 0-6	0	0	1	2	4	3	11	2	9	5	15	1	40	13	53 (58.9%)
7-13	2	2	4	1	6	3	6	0	7	1	3	0	28	7	35 (38.9%)
14-20	0	0	1	0	1	0	0	0	0	0	0	0	2	0	2 (2.2%)
Total	2	2	6	3	11	6	17	2	16	6	18	1	70 (77.7%)	20 (22.2%)	90 (100%)

Prevalence estimates as documented by U.S. National Institute of Child Health and Human Development (2001) shows one in 500 persons to be autistic or having some form of this kind of disorder. Prevalence studies on ASD in India is the need of the hour to plan on service provisions.

Diagnosis

Table 2 shows details on the diagnosis of autism with other associated conditions. It reveals that among the clients diagnosed as having autism/autistic disorders, more than one third (35%) of them are diagnosed as having mental retardation. This could be because NIMH caters to those with mental retardation. General prevalence of individuals with autism having mental retardation is reported to be about 75% (DSM IV, 1995; p.67).

Table 2 Diagnosis of children with ASD

N=90

Diagnosis	Male	Female	Total (*)
Autism/autistic disorder	15	3	18 (20%)
Asperger's syndrome	2	0	2(2.2%)
Autistic features	11	2	13(14.4%)
Autism with mental retardation	23	9	32(35.5%)
Autism/ADHD	2	1	3(3.3%)
Rett's syndrome	0	2	2(2.2%)
Borderline/mild devt.delay	5	3	8(8.8%)
Childhood psychosis	1	0	1(1.1%)
PDD	7	0	7(7.7%)
Tuberous sclerosis with autism	2	0	2(2.2%)
Fragile X synd. With autism	2	0	2(2.2%)
Total	70	20	90(100%)

Conditions suspected for autism reveals overlapping symptoms, which needs to be looked into carefully. An incorrect move in terms of diagnosis and placement will have adverse effect on the child's future. As noted by National Alliance for Autism Research (NAAR, 2003) in the United States of America, Autism and autistic like behaviour may co-occur with many other neurological conditions. This makes the diagnostic process more difficult.

Age of Diagnosis

A total of 30 children (33.3%) were reported to have been diagnosed before three years of age while 39 (43.3%) children were diagnosed between 4 to 6 years. The remaining 21 (23.3%) were diagnosed between 7 and 15 years. It is a good sign that majority of parents are sensitive to the condition and seek help early in the lives of the children.

Professional involvement in Diagnosis

A total of 31% of parents reported that the diagnosis was made by a medical doctor (paediatrician/psychiatrist), while 20% reported special educator, 18% reported psychologist and 16% reported speech pathologist as professionals who informed them of the diagnosis. It is important to mention here that many parents came to NIMH after having known the diagnosis while some were diagnosed at the Institute by the assessment team. Due to the very nature of ASD, which has overlapping characteristics with other conditions, it is important to have a team of professionals to arrive at an accurate diagnosis.

Birth Order

An analysis of the birth order revealed that 43% of the children were first born of whom 21% were only child to their parents. A total of 36% were second born or later in the birth order to their parents. In depth study on the relationship if any, between birth order and autism is essential to be carried out.

Education and Socioeconomic status of the families :

The data showed that above 50% of the families had a monthly income of Rs.10,000 or more with both parents having educational qualification ranging from higher secondary to post graduation or specific professional qualification. It was interesting to find that the registration of cases from poorer families having an income of less than Rs.2000 per month with lower educational qualification ranging from illiteracy to having attended high school were minimum with 17% and the education . The reason may be lack of awareness about the condition among the latter group. This observation points to the necessity for steps towards creation of awareness among the poorer and less educated people about ASD.

Teachers' observations

Table. 3 Teachers' observations on children with ASD

N=90*

S. No.	Characteristics	Number of children **
1	Aloof/prefers to be alone	67 (74)
2	Language delay	53(59)
3	Echolalia	44(49)
4	Playing with hands/flapping hands	43(47)
5	poor eye contact/avoids gaze/looks from the corner of the eye	41(45)
6	Ritualistic/repetitive/rigid play	38(42)
7	Does not respond to name/when called	37(41)
8	Keeps wandering	37(41)
9	Deviant response to sensory stimuli	30(35)
10	Over attachment to mother/caretaker	25(27)
11	Insistence on sameness	22(25)
12	Likes music, sings tunes exactly	23(25)
13	Specially fascinated by TV ads/programs	22(24)
14	Loss of previously acquired language	14(15)
15	Lacks abstract reasoning ability	13(14)
16	Refusal/difficulty to write	11(12)
17	Failure in/incorrect usage of pronouns	8(9)
18	Extraordinary performance in one or more areas	4(4.4)
19	Loss of previously acquired motor skills	2(2.2)

* Multiple responses recorded

** Percentages in parenthesis

Table 3 reveals some of the characteristics observed by the teachers in children with ASD. As can be seen, 'staying aloof (74%)', followed by 'language delay' (59%) were found to be the most striking behaviours observed. Echolalia (49%), playing with hands (47%), lack of eye contact (45%), ritualistic play (41%) and wandering behaviour (41%) have also been noted by a considerable number of teachers. If teachers are sensitive to the typical behaviours of children with ASD, early diagnosis and intervention will be a possibility. A simple check list which is easy to use for screening can be used by the teachers to educate the parents and public on identifying children suspected to be having ASD.

Parental Perceptions

Table 4: Parental perception of the condition before diagnosis

N=90*

Parental perceptions	No of children		
	Male	Female	Total
Language delayed/cannot hear properly	58	14	72 (80%)
Aloof/prefers to be alone	35	9	44 (49%)
Too good a child	5	1	6 (7%)
Does not recognize parents/family members	5	1	6 (7%)
Does not respond when called	11	2	13 (14%)
Plays with hands	29	6	35 (38%)
Keeps wandering	33	3	36 (40%)

*multiple responses recorded

A comparison of Table 3 with Table 4 shows that certain characteristics are visible and are easily noted by many of the parents and teachers. Language delay and being aloof is strikingly visible. 'Being aloof' was noted by maximum number of teachers (74%) while language delay (80%) was noted by majority parents. This may be because teachers are in a position to compare the child with ASD with other children. For parents, 'inability' to speak might be a major concern to seek help. The term Autism, which originates from the Greek word 'auto' meaning 'self' seems to be justified when the obvious characteristics are taken into consideration. The triad of characteristics required for a diagnosis of autism, namely, impairment in social behaviour, impairment in communication behaviour and restricted interests or impairment in flexibility are noted by a considerable number of parents. The perception of "too good a child" may be due to the fact that children with ASD do not have demands on the parents as they are generally aloof.

Intervention practices

Table 5. Intervention Practices

N = 90

Practices	No of children
Special Education only	21(23%)
Medical intervention + Spl.Education	20(22%)
Home training in Spl.Ed + speech & language	15(16%)
Special school Education + Speech language	8 (9%)
Regular Education + Spl.Education	7(8%)
Regular Education	7(8%)
Regular Education + Drugs	6(7%)
Special Education + Speech language + Drugs	5(6%)
Regular Education + Speech language + Drugs	1(1%)

As seen in Table 5, a combination of regular education and special education is being received by the children with ASD. Medical, speech and language intervention and special education in combination are opted by majority of the parents for their child with ASD. As noted by NAAR (2003), the optimal treatment for autism involves an educational programme that is suited to the child's developmental level. The programme should also be ecologically viable to be more meaningful to the child.

Findings :

The findings of the analysis reveal that :

1. Families having male children with ASD is more than those with female children who have sought services.
2. A large number of children were diagnosed before the age of 6 years.
3. A considerable number of children with ASD were firstborn.
4. Any qualified professional may suspect diagnosis of ASD but a team of experts is desirable considering the varied overlapping symptoms present in children with ASD.
5. Language delay, staying aloof, echolalia, lack of eye contact and ritualistic play behaviour were observed in children with ASD by majority of parents and teachers.
6. Families with lower economic and educational status have reported fewer number of cases, which may be due to lack of awareness about the condition.
7. Speech and Language therapy, medical intervention and special and regular educational interventions are in practice for helping children with ASD.

Implications :

- In-depth study on status of children with ASD in their late childhood and adolescence needs to be carried out.
- Relationship between birth order and incidence of ASD may be focused as an area to be studied.
- Combination of various treatment, training and educational programmes needs to be studied for providing comprehensive management programme for those with ASD.
- Sensitisation programmes should be carried out for regular school teachers on ASD.

- Systematic teacher preparation to educate children with ASD is a priority need in the country. In service training of certified teachers of single disability may also be considered for this purpose.
- Periodic group parent training programmes should be conducted to give an opportunity to the parents to exchange views and form parent groups.
- Awareness programmes for the public especially focusing on the poorer families is essential to provide assistance to children with ASD early in their lives.

ANALYSIS OF NEEDS OF FAMILIES HAVING CHILDREN WITH AUTISM SPECTRUM DISORDERS

Needs based planning and interventions lead to systematic service provision to children with disabilities. As the needs are unique to each child within the given range of disabilities, an assessment of the needs of the child, his family and the environment in which he lives is imperative in developing intervention plans. As noted by Slutsky and Paris (2000) obtaining sensory and activity histories by talking to the child's parents, primary caregivers and teachers will help in the analysis of child's behaviours. Knowledge on the child's likes and dislikes is essential to gain insight into the effectiveness of child's sensory systems. Similarly collecting information on family constitution, religious and cultural practices of the family and specific concerns of the caregiver with regard to the child will help in developing a tailor made programme to meet specific needs of the child and family. Therefore, for the present study, as a primary goal, needs of families were compiled and analysed.

Methodology

TOOL

A semi-structured questionnaire was developed with partly close ended and partly open-ended questions. The questionnaire was validated by administering on 15 parents and based on responses the questionnaire was modified, by removing ambiguity without distorting the contents.

Subjects

A total of 99 parents of children with ASD who were registered at NIMH and were receiving special educational services formed the subjects. Details on age and gender of children attending the educational services are seen in Figure. I and Figure. II respectively.

Procedure

The questionnaire was translated to Hindi, Telugu or other regional language as needed. The parents were informed about the purpose of the study, parents' role and the expected outcome of the study. The parents who consented to participate in the study were given the questionnaire and were requested to provide responses. For illiterate parents, the questions were read out and the responses were recorded by the researcher verbatim. After collecting the responses the needs were analysed on eleven sub-categories.

Results

As seen in Figure I and II, Children below five years are the largest in number. As the age advances, number of children referred reduced, perhaps because they are already attending suitable educational facility elsewhere or are not aware or are dissatisfied with the existing facilities and dropped out. It can be seen that male children are more, which is in line with the incidence of the conditions. It can also be probably due to more number of parents of male children than female children seeking services.

Figure.I Gender Distribution of Children with ASD whose parents Participated

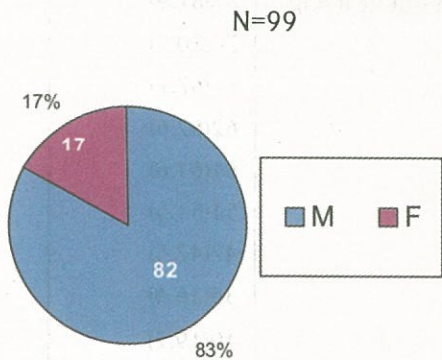


Figure.II – Age wise distribution of children with ASD whose parents participated

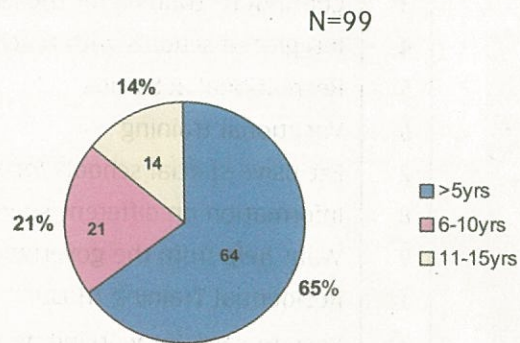


Figure. III: Distribution of number of children with varied diagnosis of ASD whose parents participated

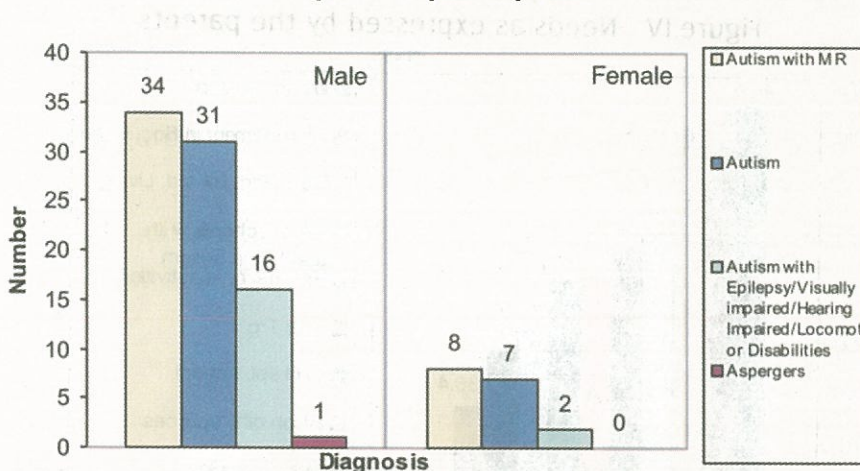


Figure III shows the distribution of children with autism spectrum disorders. Autism with mental retardation is the highest which is natural as the institute caters primarily to persons with mental retardation. It may also be because about 75% of persons with ASD have mental retardation (DSM IV)

Needs of parents

The open-ended responses were categorized into eleven areas as per expressed needs and analyzed. (Table I, Fig.IV)

Table I – Needs as expressed by parents

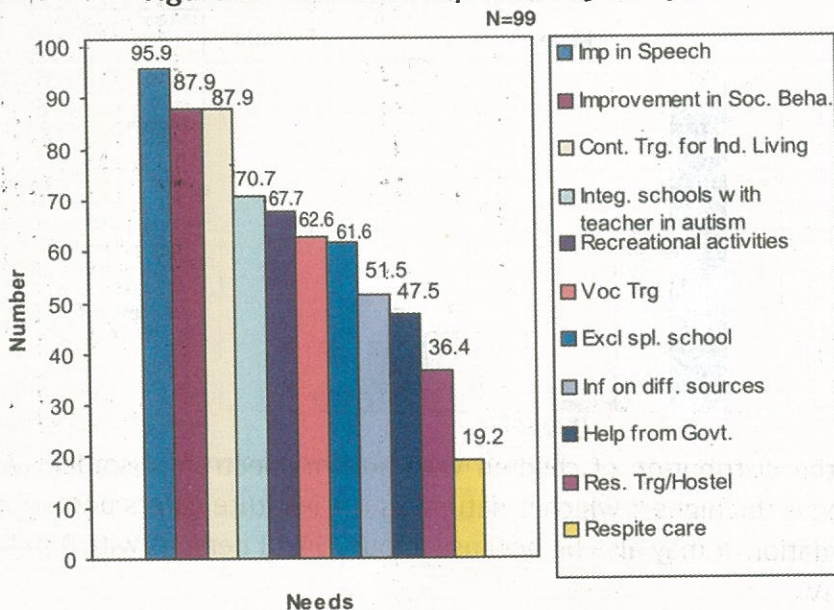
N=99

Sl. No.	Needs	Number Responded (*)
1	Improvement in speech so that child can express needs	95 (95.9)
2	Improvement in Social Behaviour	87(87.9)
3	Continuous training for the child for independent living	87(87.9)
4	Integrated schools with teacher in autism	70(70.7)
5	Recreational activities	67(67.7)
6	Vocational training	62(62.6)
7	Exclusive special schools for autism	61(61.6)
8	Information on different sources	51(51.5)
9	Want help from the government	47(47.5)
10	Residential Training /Hostel	36(36.4)
11	Respite care(for working mothers)	19(19.2)

percentage in parenthesis

(*) Multiple response

Figure.IV Needs as expressed by the parents



It is natural that improvement in speech was the priority of maximum number of parents (95%), as it is one of the easily observable milestones of normal growth of development. Improvement in social behaviour is a need by a large number of parents (87%) as the parents rightly perceive social skills as a major competency required for independent living. As per ICD 10 and DSM IV both social skill deficit and communications deficits are identified as two major characteristics for diagnosis of autism.

Among the other needs, 87% of parents have felt the need for continuous training for their child, which reflects inadequacy of training facilities in our country. Recreation and vocational activities are also conspicuous by their absence and 70% and 67% of parents respectively have indicated the need.

The expressed needs are further grouped into Facility needs and training/support needs as seen in Table II and Table. III (Figure V &VI respectively).

Information and facilities related need analysis

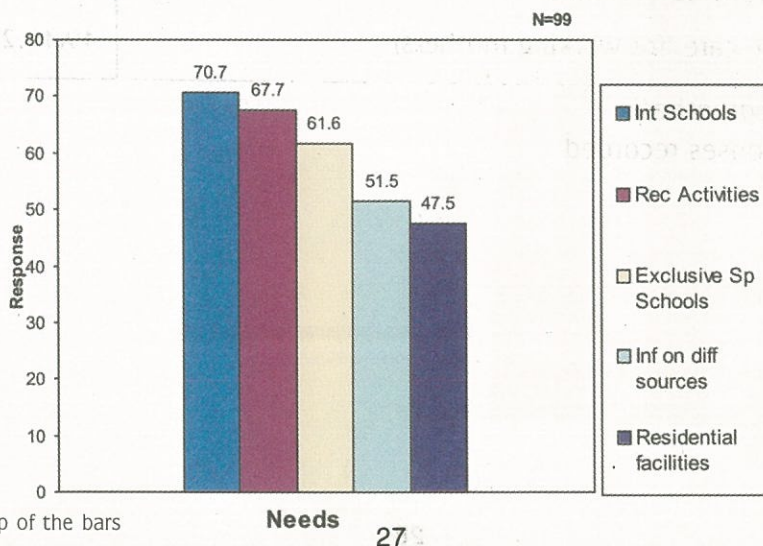
Table II – Need analysis on facilities

N=99

S.No	Needs	No. of Response (*)
1	Integrated schools with teachers trained in autism	70 (70.7%)
2	Recreational activities	67 (67.7%)
3	Exclusive special schools for autism	61 (61.6%)
4	Details on different sources of information	51 (51.5%)
5	Residential facilities	36 (36.6%)

(*) Multiple response percentage in parenthesis

Figure.V - Information and Facilities Related Needs



* percentages on top of the bars

Among educational facilities majority (70%) have felt the need for integrated school, only 61.6% have asked for special schools and about one third have expressed the need (36%) for residential facilities. This is a strong indication for the planners to strengthen the educational systems to include children with ASD. Hopefully, the Sarva Shiksha Abhiyan (SSA) will fulfill this need of the parents. A considerable number of parents (51.5%) seek information on services, which indicates an urgent need to develop and/or compile awareness materials on ASD.

Training related need analysis

Majority of the parents (95%) expressed the need for the training of speech, language and communication in their children. Need for training to improve the social behaviour and continuous training for independent living was expressed by a large number of parents (87%). About 47% parents felt the need for help from Government. About 19% have asked for respite care facilities for working mothers which indicates that they require a change from taking care of the child either as a respite and/or to do their other chores and duties effectively,

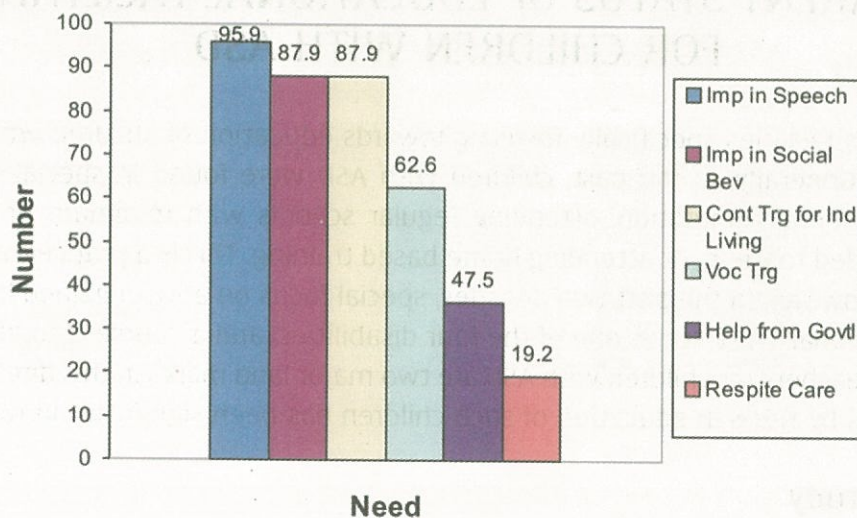
Table. III - Need Analysis on training/support

S.No	Needs	No. of Response*
1	Improvement in speech so that child can express needs	95(95.9%)
2	Improvement in Social Behaviour	87(87.9%)
3	Continous training for the child for independent living	87(87.9%)
4	vocational training	62(62.6%)
5	Help from Government	47(47.5%)
6	Respite care (for working mothers)	19(19.2%)

percentage in parenthesis

** Multiple responses recorded*

Figure.VI - Training Related Need Analysis



Findings and Implications

It is consistently seen that parents perceived needs are towards improvement in speech, social behaviour and independent living. They also aspire for appropriate educational facilities and vocational training. The signals are very clear. There is an urgent need in the following areas.

1. Inclusion of persons with ASD in Disabilities Act (1995) so that they have equal opportunities, protection of rights and Full participation like any other citizen.
2. Clear cut directions and provisions in National Trust Act (1999) for guardianship.
3. Teacher training programmes approved by Rehabilitation Council of India, (RCI) for regular educators, special educators and continuing rehabilitation education programmes for updating professionals in the area of autism spectrum disorders.
4. Voluntary efforts need to be supported by the Government by technical and financial assistance.
5. Parent groups and parent training programmes need strengthening so that every child with ASD has continuous support.
6. Inclusive education programme through Sarva Siksha Abhiyan (SSA) should have a special focus on ASD.
7. Parental needs are to be studied periodically so that their concerns can be addressed with specific focus.

CURRENT STATUS OF EDUCATIONAL FACILITIES FOR CHILDREN WITH ASD

As noted earlier, facilities specifically focusing towards education of children with ASD is of recent origin. Generally, in the past, children with ASD were found in special schools for children with mental retardation, attending regular schools with minimum or no special attention provided to them, or attending home based training. This is a practice even today in many places. However, in the past two decades, special focus on autism gained importance. Inclusion in National Trust Act as one of the four disabilities, and a course recognized by RCI for training of teachers for children with ASD are two major landmarks in this direction in our country. Efforts by NGOs in education of such children has been significant in recent years.

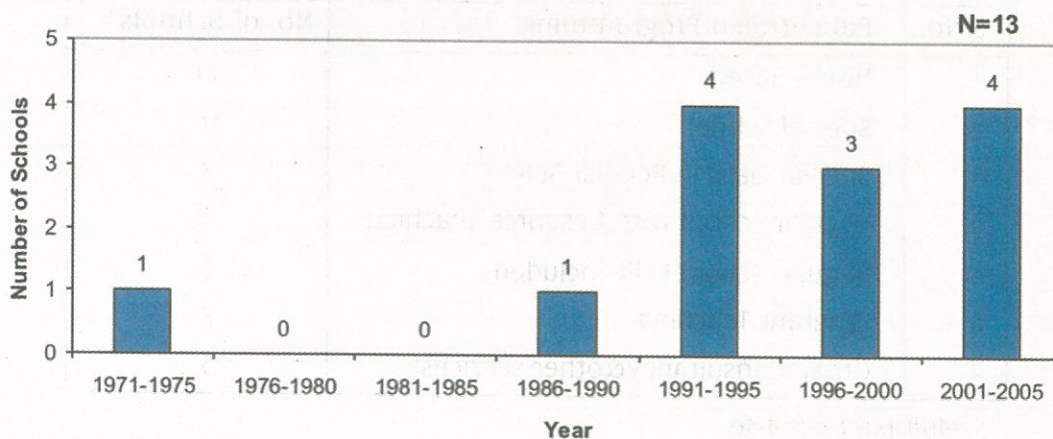
Aim of the study

Though there are such facilities for children with ASD, families and professionals are not aware, as the information is not available at one place in the form of a document. Therefore, we made an effort to put together, the information by compiling the same from various organizations working for persons with ASD. The aim of the study was to collect information from the organizations regarding their profile, types of services offered and such other relevant information, analyse and document the information collected.

Procedure

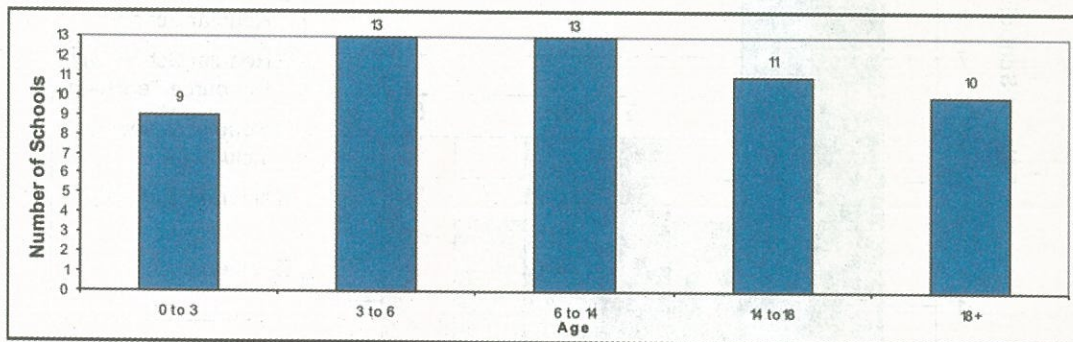
During the present project period, we carried out a survey of the existing educational facilities for children with ASD in the country. We identified the organisations from the mailing list of the INDO-US seminar on Autism held in March, 2004 at NIMH for which all the organisations were sent information and 16 organisations responded. For the present survey, we sent questionnaires to these 16 organisations. We sent reminders thrice with the duration of one month between reminders to those who had not responded. A total of 13 organisations responded. The details provided by the organisations are analysed and presented here. Profiles of each organisation is given in the appendix. Details on the year of establishment are given in Figure 1.

Fig. I Year of establishment of organisations working with children having ASD



Between 1970 and early 2005, emergence of organisations has been on the increase. It is seen that from 1990s the increase has been relatively rapid. (Fig.1) Voluntary efforts and autism parent groups played a significant role in creating awareness about the condition in the past two decades which may be responsible for the increase in the number of organisations.

Fig. II. Age range of children admitted in the organization working for ASD



About 9 organisations admit children in the age range of 0-3 years while all the 13 organisations admitted children in the age range of 3 to 14 years. Out of them 10 admitted students of 18 years and above. As the facilities are too few in number, it is a good sign that majority admit children of all ages with ASD (fig. II).

Table –I Educational programming followed in different organizations*

S.No.	Educational Programming	No. of Schools*
1	Home Based	11
2	Special School	10
3	Special Class in Regular School	3
4	Regular School with Resource Teaching	5
5	Regular School Fully included	5
6	Itinerant Teaching	3
7	Other (consultancy&other services)	5

* Multiple response

Figure III : Educational programming followed in different organisations

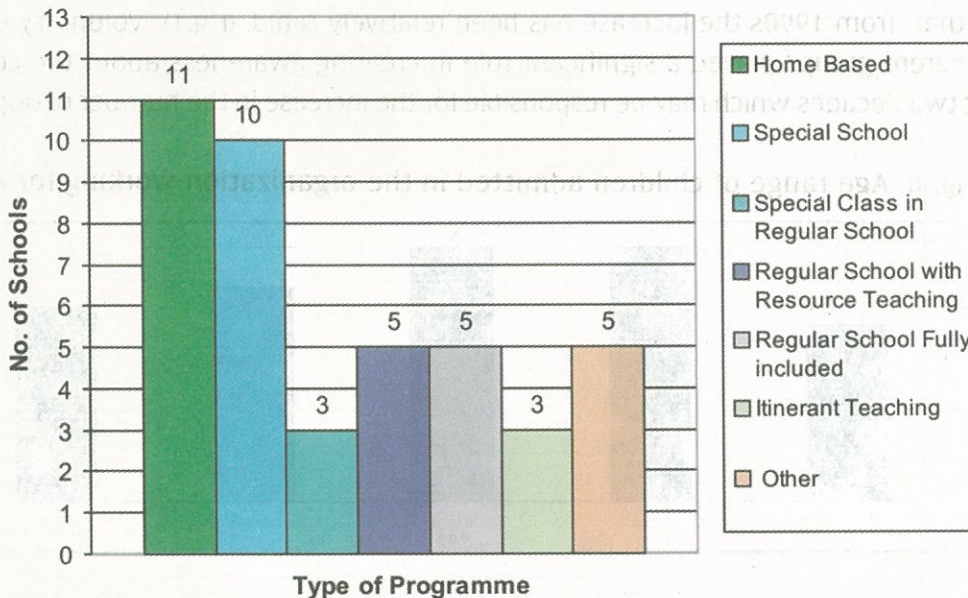


Table 1 and Figure 3 show the educational models singly or in combination being followed by the organisation. For specific details of models followed in each of the organisations please see appendix. The Table I and figure III here show the combinations of models. As it can be seen, home based training is the highest (11) in number closely followed by special schools (10). Education in regular schools with resource room and full inclusion is emerging and five organisations follow the system. Itinerant teaching and special classes in regular schools are also in practice in three organisations. Consultancy services and other specific models are seen in five organisations.

Home-based training is a positive trend as it ensures early education to children as well as it meets the educational needs through parent training when the child has no access to school. By this, the precious years are utilized effectively in educating the child.

Education in special schools is predominantly in the schools for children with mental retardation. It is estimated that 75% of children with ASD have mental retardation and therefore special schools for children with mental retardation should be equipped to train these children. However, in reality, many schools admit children with ASD but do not have trained teachers in ASD to meet the children's educational needs.

Profile of professionals working in the organisations

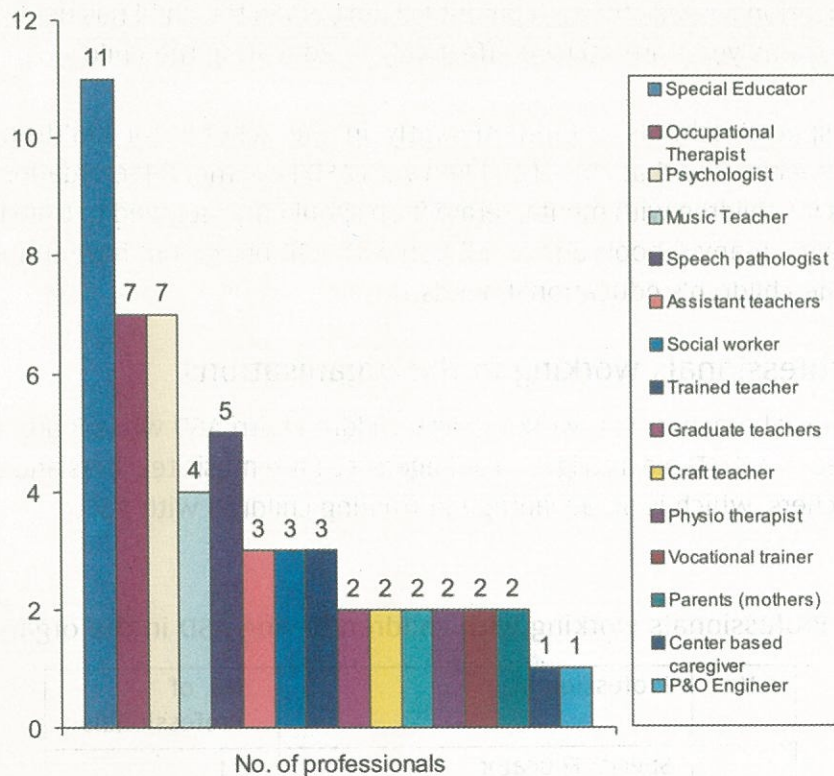
Majority are special teachers (11) working with children with ASD while 3 are reported to be specially trained in ASD (Table II & Fig III). Four agencies have music teachers and three agencies have craft teachers, which is an advantage in training children with ASD.

Professionals

Table. II Professionals working with children having ASD in the organisations

S.No	Professionals	No. of Professionals
1	Special Educator	11
2	Occupational Therapist	7
3	Psychologist	7
4	Music Teacher	4
5	Speech pathologist	5
6	Assistant teachers	3
7	Social worker	3
8	Trained teacher (ASD)	3
9	Graduate teachers	2
10	Craft teacher	2
11	Psychiatrist	2
12	Physio therapist	2
13	Vocational trainer	2
14	Parents (mothers)	2
15	Center based caregiver	1
16	P&O Engineer	1

Figure. IV Professionals working with children having ASD



Two other major professionals in training children with ASD are Occupational Therapists and Psychologists. Seven agencies are reported to have engaged both these professionals. Training involving Sensory Integration Therapy is carried out by Occupational Therapist and behaviour modification is carried out by Psychologists, which form integral part of the overall comprehensive training of children with ASD. Deficit in language and communication is a major characteristic of autism, which calls for the support of a Speech Therapist. Five organisations have engaged Speech Therapists. Other professionals including Social Workers (3 org), Medical Doctors (3 org), Physiotherapists (2 org) and Vocational Instructors (3 org) are also found to be the team members providing intervention to persons with ASD. Other professionals include parents, P&O engineers, and caregivers in a few organizations.

Teaching strategies

Speech and language intervention (10) and visually cued instructions (10) are followed in majority of the organizations (Table.III, Fig.V).

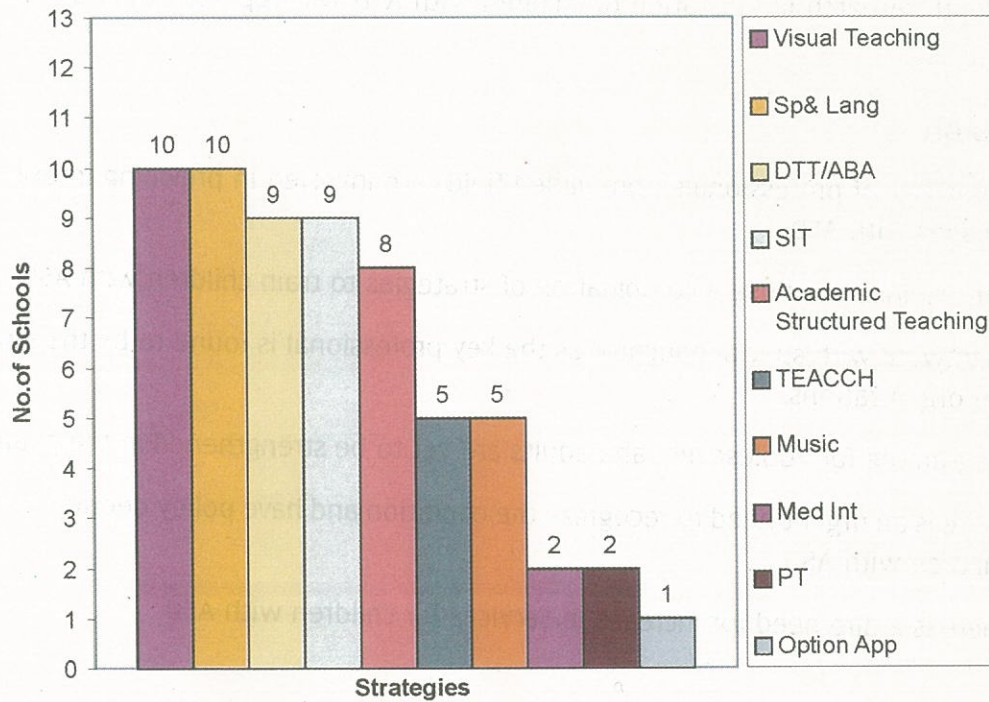
Table III: Teaching strategies adopted in the organisations

N=13*

S.No	Teaching strategies	No of schools
1	Visually cued instructions	10
2	Speech & Language	10
3	Discrete Trial Training, Applied Behaviour Analysis, Lovaas	9
4	Sensory Integration Therapy	9
5	Structured Academic Teaching	8
6	TEACCH	5
7	Music	5
8	Medical Intervention	2
9	Physiotherapy	2
10	Option Approach	1

* multiple responses

Figure. V- Teaching Strategies followed in different



Sensory Integration Therapy (SIT), Applied Behaviour Analysis (ABA), Discrete Trial Training (DTT) and Lovaas technique are followed by 9 organisations. Structured teaching and academic instructions are followed in 8 organisations. Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) which is reported to be very effective in teaching children with ASD is followed in 5 organisations while music as an intervention method is used in 5 organisations. All organisations use combinations of more than one method to get best results. Physiotherapy and medical interventions are also provided in some organisations. As it can be seen, a combination of visual instructions DTT, SIT, ABA and TEACCH along with language intervention are the most popularly used methods in teaching children with ASD. Depending upon the student's profile, combinations of the methods are adapted by the teachers to get the best results.

Recommendations by the organizations

Most of the organizations observed that awareness among the families and public about autism and ASD is very low which hinders effective training of children with ASD in early years. The respondents highlighted the urgent need for creation of awareness through sensitization and orientation programmes which should be followed by systematic training of parents. Teacher training programmes exclusively for teaching children with autism and in-service training for professionals who work with persons with ASD to update them with recent development emerged as an important recommendation. Increase in service facilities and in depth research in education of children with ASD was reported as the need of the hour.

Conclusion :

- A number of professionals from varied fields are involved in providing intervention to persons with ASD.
- The organizations use a combination of strategies to train children with ASD.
- Teamwork with special educator as the key professional is found to be the strength of the organizations.
- Programme for adolescents and adults are yet to be strengthened in the country.
- There is an urgent need to recognize the condition and have policy decision to educate children with ASD.
- There is a dire need for increase in services for children with ASD.

Service Models and Teaching Strategies for Education of children with ASD

As children with ASD have unique profiles of symptoms, developing educational programme for them is a challenge. In addition to the profile of the student with ASD, the available resources, environmental variables and viability of the proposed programme need to be carefully considered. Structured environment, functional communication, functional skill selection, focus on social skill and positive approach are essential for teaching children with Autism or ASD. About 75% of children with ASD are observed to have mental retardation, which makes the educational programme a real challenge for them.

Due to over selectivity, children with ASD may have difficulties in bonding or recognizing people and are inhibited to form close relationships (Madrona 2003). This further makes it difficult for the teacher to plan and organize teaching programme. Certain intervention techniques are reported to be useful in educating children with ASD which include behavioural teaching, environmental structuring, picture activity scheduling and visually cued instructions (Perry and Condillac, 2003).

While strategies of teaching and classroom arrangements are on the one hand, the educational provision with the objective to provide least restrictive and most inclusive environment is on the other, on which would depend the effectiveness of the strategy used for teaching.

India is a country where inclusive education is an emerging trend and special schools are the largest among the educational facilities. As such, education of children with ASD is largely offered in special schools or by voluntary organisations. Awareness about autism and ASD is emerging in recent years, leading to focus on early intervention and inclusive education. However, there is no clear-cut direction in this regard. A number of voluntary organisations established for educating children with ASD provide the necessary support to families and children with ASD. If children with ASD are to get appropriate education, focus on educational models considering the varied socio, economic conditions of the country is essential. One of the objectives of the present study is to explore the feasible models and educational strategies used to meet the educational needs of children with ASD.

Feasibility of emerging educational models

The clients registered at NIMH as described in Chapter 2 (N=99) were assessed and diagnosed by a team of experts consisting of medical doctor (Paediatrician/Psychiatrist), psychologist and special educator followed by planning of training programme. For specific Screening and

assessment for autism CHAT and CARS are used respectively. During educational planning, the profile of the child, parental status and expectation, available resources and educational programmes and support services were considered. A detailed functional assessment of current level of functioning was conducted by using NIMH Functional Assessment Checklist for Programming (NIMH FACP) and IEP was planned.

All children initially receive center-based instruction and home based training. Generally mothers were given training. Parents were eager to get the appropriate placement for their children. After finding out the ability level, readiness and parental choice, the children were placed in one of the four models namely

- Special schools for children with mental retardation
- Regular schools
- Home-based training
- Unit established by parent group (parent initiative)

Children in all the groups continued to receive extra support in education through home-based instructions irrespective of the model in which they are admitted. Parent would visit NIMH with the child periodically to receive educational, medical, psychological and language intervention. The frequency of the visit would depend on the need of the child, and the distance to travel by the parents ranging from weekly visit to quarterly visit.

Table-I : Placement of Number of Children with ASD in each of the Model

N=99

Age in years	Special school		Regular school		Home training		Parent initiative		Total
	M	F	M	F	M	F	M	F	
Below 5 years	05 (5%)	04 (4%)	05 (5%)	01 (1%)	37 (37%)	07 (7%)	05 (5%)	00	64 (64.6%)
6-10	02 (2%)	01 (1%)	03 (3%)	00	14 (14%)	01 (1%)	00	00	21 (21.2%)
11 and above	03 (3%)	01 (1%)	03 (3%)	00	05 (5%)	02 (2%)	00	00	14 (14%)
Total	10 (10%)	06 (6%)	11 (11%)	01 (1%)	56 (56%)	10 (10%)	05 (5%)	00	99 (100%)
	16		1		66		5		

The Special Education Center (SEC) at NIMH is established to serve as a laboratory special school for student trainees of human resource development programmes conducted at NIMH. As per the decision of the multi disciplinary team, and parental consent, children are referred for admission.

The regular schools were identified in twin cities of Hyderabad and Secunderabad by contacting Principals, creating awareness and after gaining their confidence and willingness children were sent there for admission. The special educator team member of the Project would visit the school and provide support once a week. During the course of the project, a few parents requested support for organizing a unit for autism. The fourth model emerged through this effort. Table I shows placement of children in each model.

MODEL I

Special School for Children with Mental Retardation:

As seen in Table I, the highest enrolment after home-based training is found to be in special school (16%). Out of a total 103 children enrolled in SEC, 16 children were with ASD. They were placed in different classes based on their ability levels ranging from pre-primary levels to pre-vocational levels. The students were trained by their class teachers based on the IEPs developed. As the children had ASD in addition to the mental retardation, they required one-to-one instructions to meet their unique needs. This was provided by structuring their individualized training in a separate resource room. The teaching strategies included visually cued instruction, DTT, ABA and structured environment. In addition, the class teachers were supported for planning classroom activities suitable for improving social communication, daily living and academic skills for the children. Thus, each child with ASD would have one-to-one session with resource teacher and occupational therapist once in a day for a duration of 40 minutes. Per day in addition, resource teacher visited the class and provided support and clarified concerns of the class teachers so that the child is comfortable in group setting. Parents were also provided support for home training of the enrolled children in SEC.

As per the system followed in SEC, quarterly evaluation is carried out by the class teacher. After the children started to attend the services, it was noted that there was considerable improvement in general in all the children. During parents' meeting the parents informed that such support should be continuously provided to their children as they are seeing marked progress particularly in social skills of their children. Pairing a student without ASD to the one with ASD in class for training purposes was found helpful.

Records were maintained both by the class teacher of their respective class and also by the resource teacher of the research team. Having seen that this model of providing additional

one-to-one attention along with the routine classroom activities for children with mental retardation and ASD is beneficial to the children, it is planned to regularly provide such support in the Special Education Center (SEC). In addition, all the regular class teachers in the special education center will be provided with intensive training in the strategies successfully used for education of children with ASD.

MODEL II

Regular / Inclusive schools:

As mentioned earlier, the 86th amendment of Constitution of India (2002), ensures Right to Education and that no child must be deprived of education. It is natural that every parent would look for the best educational environment for their child irrespective of their child's condition. They would want to admit their child in the best school in the city in order to provide such education to enable him to have a bright future. A parent of a child with a disability is not an exception to this. Unfortunately the number of regular schools that admit children with disabilities, especially ASD are conspicuous by their absence.

About 27 schools were approached with the request to include child with ASD, and five schools accepted to admit them and only three schools sustained the programme. This shows that there is a need for preparation of the regular education system for inclusion of children with special needs particularly ASD. While the teachers expressed lack of competency, the administrators expressed reluctance to admit children with ASD. In 7 schools after one month of admission, they discharged the children from school expressing inability to teach the child, or that he is 'unable' to learn. Such children too attended services at NIMH with regular intervals. The research staff of NIMH consisting of a special educator and an occupational therapist visited such schools once a week to assist the class teacher in the education of children with ASD. The teacher concerned was given the educational programme which had to be followed during the teaching hour. Many a time, the class teachers in particular visited NIMH to get the programme to be followed and were very pleased with the progress. The focus was on development of social skills, communication skills and reduction of stereotypical behaviour in children with ASD.

Teachers in inclusive schools informed that they would need constant support from special educators and observed that the children with ASD exhibited splinter skills such as extra ordinarily good ability in drawing, puzzles or memory recall but over all academic performance was average or below average. Some teachers informed that a few children with ASD were above average in specific subjects such as Mathematics or English. About 7 children discontinued school due to inability to cope with academics. As noted by Sattler (2003)

many of the learning and behavioural difficulties seen in persons with autism are also found in children with developmental disabilities. Therefore, current level of functioning needs assessment. Children with ASD show certain strength with significantly higher performance in some areas such as visual motor and memory skills. Social skills and communication skills remain a challenge and need focus. The non-disabled children in the class gradually accepted the child with ASD but it took 6 months to 9 months for them to accept.

Most of the parents were willing to get an admission for their child with ASD in regular schools, but the schools were reluctant to admit. A few of them who admitted, were restricting the strength of admission of children with ASD to 4-5 only. Though the children with ASD show splinter skills as mentioned earlier is thought to be (according to the school management) not sufficient to fulfill the pass criteria of that particular school which in turn would lower their school's achievement records.

With the inclusive education gaining support through Sarva Shiksha Abhiyan (SSA) perhaps arrangements in regular schools for education of such children will improve in future. This study such has also revealed that those with ASD in regular schools improved in social and communication area considerably, while academic area required prolonged support and additional efforts. Pairing with peers in rotation improved the social skills and communication skills in children with ASD and resulted in better acceptance by non-disabled children.

MODEL III

Home –based training

It is seen from Table I that a large number of children continue to be receiving home-based instructions alone (66.5%).

As the clients with ASD were referred to autism unit after diagnosis, a detailed assessment for education was made and priority goals identified. Parents were demonstrated the training including educational programme and Sensory Integration Therapy (SIT) to be followed at home.

After the 45 minutes training session in the unit, the parents were also given home programme schedule to be followed at home to have continuity. Mostly the mothers were responsible for the home based training because most of the mothers were housewives and some working mothers chose to resign their jobs because of their children with ASD. There were some families who even shifted from other cities, Secunderabad to avail the services. This model was also beneficial for those who lived far away as family cottage facility of NIMH helped parents to stay for a week to 15 days and avail the services.

The programmes given to parents to be followed at home varied from weekly to quarterly depending upon parental convenience. Thus, flexibility of this programme was a strength. Out of 66 parents in this model of service, 41 visited once a week, 13 once a month, 10 once in a quarter and 2 (from abroad) once a year to avail the services.

Children showed improvement in home based training but parents expressed stress. It is natural that about 73% of the parents were eager to find a suitable school for their child but were not satisfied with the existing school facilities.

MODEL 1V

Unit Established by Parent Group

After having tried admitting their children in regular schools and special schools and not satisfied, some of the parents decided to establish their own unit and sought help. After registering their organization, they hired a place and equipped the place with material as suggested. NIMH team visited and helped them periodically. Parents took turn to run the center and also engaged a special teacher.

Apart from the special education services and SIT services as suggested by the NIMH team, these parents were also following "Diet therapy" and "Music Therapy" on their own by taking suitable advise elsewhere. The center works from 10 A.M to 3:30 P.M. understandably the Parent group was concerned about a stable educational arrangement as they expressed that they cannot be the 'teachers' for their children all the time. They requested help of trained teachers.

Observations

- Majority of children with ASD receive home training.
- A considerable number of children with ASD are enrolled in special schools for children with mental retardation.
- Children below 6 years of age receiving services were more in number.
- Male children were more than female children enrolled for educational services.
- Educational options for children with mental retardation having ASD can be (a) centre based instructions and home based training (b) special schools (c) inclusive schools (d) parent initiatives.
- The choice of the educational model depends on the child's level of functioning and parental aspiration.
- All children need home based training initially. Team support of medical, psychological and language intervention along with education is imperative for progress of the child.

- To get the acceptance of regular schools to include children with ASD, there is a need for intensive, structured sensitization programme and sharing of success stories.
- Teachers in special schools for children with mental retardation need training through continuing educational programmes or refresher courses to become competent in training children with ASD and mental retardation.
- Parent organisation need strengthening through parent professional partnership.
- Recognizing autism as a disability through P.W.D.Act(1995) will strengthen and promote education of children with ASD by receiving Government support.

Teaching strategies

Appropriate service models and teaching strategies are two major components essential for successful training of children with mental retardation having ASD to bring out their potentials optimally. During the course of working with children with MR having ASD, various strategies were applied and found that the following strategies were found effective singly or in combination depending upon the need of the child and the skill area to be trained. Four different strategies were predominantly applied for best results in educating children with ASD. The details are given below.

1. Discrete Trial Training (DTT)
2. Structured Environment (Study Carrel)
3. Visual Communication (VC) (Visually cued instruction)
4. Sensory Integration Therapy (SIT)

1. Discrete Trail Training (DTT)

DTT developed by Lovaas is one of the methods of providing intervention for teaching children with Autism/ ASD. DTT has four distinct parts (Anderson, Taras and Cannon 1996).

- a. the trainers presentation,
- b. the child's response,
- c. the consequence,
- d. a short pause between the consequence and the next instruction.

It provides structured, individualized training to the child based on the principle of applied behavior analysis. In this method, the teacher prompts the child to respond to a stimulus in a specific manner through a series of repetitions over a period of time. The correct response is immediately rewarded. By this, the child learns the expected behaviour. The intensity and duration of training is the distinguishing feature. DTT programmes generally involve several hours of direct one to one instruction per day over many months or years.

Typically, in DTT, the teacher provides instructions, and waits for 3-5 seconds for response and if needed provides prompts. The prompts are usually sequenced as verbal, gestural and physical based on the needs. When the child responds, he/ she is rewarded with the predetermined reinforcers. Within a session, about five times a procedure is repeated for each objective selected for learning. Rewards have to be immediate for success of DTT. Therefore, the teacher means a reward belt in which she keeps the rewards ready.

Newsom and Rincover (1989) explains that DTT can be used to teach basic skills such as attending, as well as very complex verbal and social behaviours necessary to function independently.

Treatment begins with two primary goals: teaching "learning readiness" skills such as sitting on a chair and attending and decreasing behaviours that interfere with learning, such as tantrums and aggressions. In addition, the basic rules of social interactions are established. Children are taught how to learn from the environment through the introduction of clear stimulus-response-reward cycles.

Once the child has learnt to sit quietly and attend, more complex skills such as social behaviour and communication can be taught. Children with Autism typically do not learn from their environment spontaneously, and therefore need to be taught virtually everything they are expected to learn (Green, 1995). Therefore, as part of a broader applied behaviour analysis intervention, discrete trials target numerous goals and objectives.



'Reward Belt' for DTT worn by the teacher

DTT was found to be very effective for all children with ASD who participated in the project. The techniques used in this strategy was clearly explained to all the parents and/or caregivers who were responsible for training the child at home. When the research staff of NIMH, who included a special educator and a occupational therapist visited schools for programming, the concerned teachers were trained in DTT.

2. Structured Environment:

Structured teaching environment is an intervention philosophy developed by the University of North Carolina, Division of TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children). Structured teaching is an approach in instructing children with autism. It allows for implementation of a variety of instructional methods. Structured teaching describes the 'conditions' under which a person should be taught rather than 'where' or 'what' to be taught. Therefore it is a system for organizing their environments by developing appropriate activities and helping people with autism understand what is expected of them.

Primary components of structured teaching include structural modification and visual schedules along with systematic teaching:

Physical structure

Physical structure is a procedure of environmental organization wherein visual boundaries are clearly indicated. Physical structure minimises visual and auditory distraction.

Children with ASD need predictability in their routine with distractions minimized in the learning environment as far as possible. This can be achieved by

- establishing routine
- ensuring predictability
- structuring the environment with study carrels and relevant material
- moving slowly from highly structured to natural setting without disturbing or upsetting the student with ASD
- Teaching one to one task and gradually extending to group activities

Unstructured environment and time can be a challenge on a child with ASD. Therefore time, place and activities should be carefully structured. A chart with pictorial (if the child cannot read) or written indication will help in structuring all the three aspects- time, place and activity. It can also indicate the person(s) with whom activity needs to be carried out. Visual cues are the best supports to children with ASD to understand and utilize the environment optimally.



Structured environment

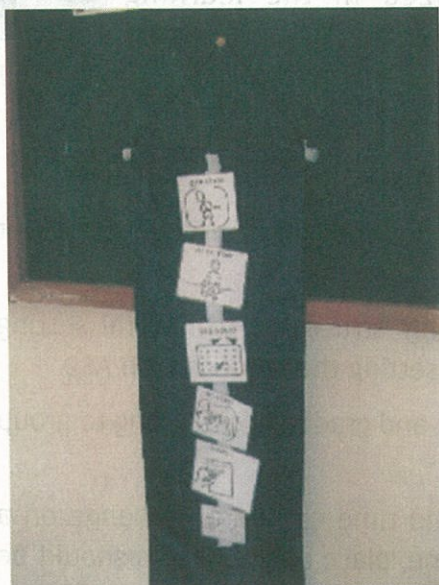


Structured environment

3. Visual communication

Actual photographs and picture symbols are effective in communicating with children with ASD. Children with mental retardation and ASD understand communication through pictures that are ordered sequentially to refer to activities. Children with ASD are known to have over selectivity – that is, responding to smaller aspect of a complex stimulus. For instance, recognizing a person by his/her mannerism or bangle or chain she wears and fails to recognize the person when that particular stimulus is not present. This characteristic prevents them from developing recognition of people or bonding with them. To encourage children with ASD to respond to multiple cues, specific techniques are used. Within stimulus prompting is a method where a relevant cue is exaggerated and presented to the child. Another method is use of appropriate reinforcement for correct response to presented cues. On mastering the presented skills, the technique can be applied to learning of new tasks.

Picture exchange communication system and picture activity schedules are most commonly used by teachers to communicate and train children with ASD. Children who read may prefer written schedules. Initially the teacher prompts to follow the picture cues. Once the child learns to follow, gradually the cues are faded and the child works independently. Predictability of what in ahead makes a child with ASD feel secure. Visual communication of the time table /days activity is very helpful in letting the child understand the requence of activities.



Visual Communication of activites

This is an excellent support in classroom setting. In addition, parents have reported success in use of picture activity schedules at home.

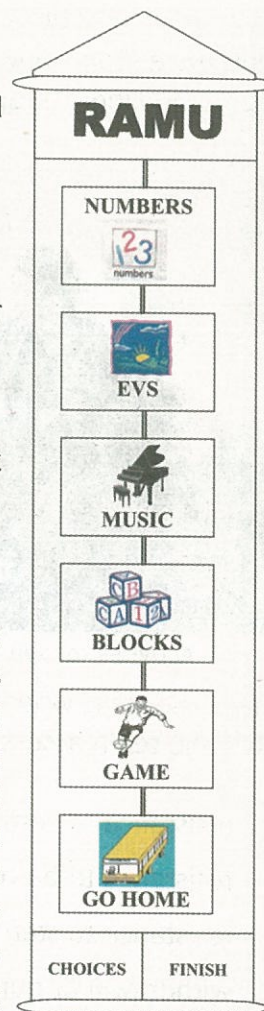
It is easy to prepare and use the picture/timetable. Select photographs or pictures or words (as the case may be), to refer to the communication requirements of the student. Have a cloth 4 feet x 9 inches with stiff edges fixed like calendars on the narrow ends and facility to hang it. In the centre, fix a long strip of velcro. Make the schedule in sequence using pictures from top to bottom. Put the choices/extra pictures in the lower left pocket. Train the student to look at the schedule from top to bottom and carry out the activities as per the symbol presented. As and when he completes each activity, he can take out the picture card and put in the right lower pocket. By this, he can make out how many are done and what are still left to complete. This also allows him to change activities if he wishes, by exchanging the scheduled one with one from the left pocket that holds alternate ones (choices with the consent of the teacher). Having teacher's name and place of activity can be a variation in the chart. If the pictures are laminated they will have a longer life. Mayer Johnson picture symbols are found to be very effective with children with ASD.

Advantages of Visual Communication :

- Visual communication schedule helps the student to understand the days activity.
- It is clear, intentional and initiated by the child.
- Helps in organizing sequential memory.
- Helps when there is a verbal language comprehension in order to understand what is expected.
- Lessens the anxiety level as he knows what is expected.
- Transition from one activity to next is easier and present frustration in the child.

4. Sensory Integration Therapy (SIT)

Sensory integration therapy formed part of the training programme along with education. The team members were involved with parents and teachers to provide the comprehensive programme. In children without disabilities, sensory integration develops automatically, spontaneously and continuously, without any difficulty. Children would receive multisensory experiences, combine and use the information received for more complex skills. Dysfunction of sensory integration happens when brain is not able to organize the received sensory information for use due to various reasons. When a child has sensory integration dysfunction characterized by inefficiencies in organizing



the sensory information within the nervous system, we often see inconsistencies in performance (Murray-Slutsky, Paris, 2000). Teachers and parents see the tremendous potentials of the child, but get puzzled and frustrated at the unexplained inconsistencies in performance.

Sensory integration therapy involves providing the child with holistic learning experiences, which would enable him to perceive a complete picture of a task or situation leading to performance of the task meaningfully. This should also be so planned to gradually lead him in learning complex tasks progressively.

The training unit of the project included an occupational therapist as a team member, who carried out sensory integration therapy to all the children registered in a systematic and structured manner. Children enrolled in all the models described earlier, were exposed to SIT where the respective parents and the teachers were demonstrated how to carry out the therapy. Play situations and classroom situations were also used suitably for the therapy. Parents were shown how to use the home environment for SIT. In addition, structured activities using trampoline, therapy balls, ball pools and such other materials were also carried out



Activites for sensory integration



Activites for sensory integration

Some of the areas where SIT was found effective as reported by the parents, class teachers as well as the team assessment included,

- resistance to combing, washing or cutting hair (because of tactile defensiveness)
- resistance to bathing
- resistance to standing in the queue for prayer/assembly
- withdrawal or punching others who touch the child lightly

- dislike to wearing socks
- avoiding new clothing
- undressing inappropriately
- 'picky eater'
- use of only fingertips while using toys, crayons, pencils
- resistance to getting the hands dirty or avoiding messy material. Hurries to wash off even a speck of dirt.
- toe walking to avoid contact with the ground
- fear of heights
- fear of walking on uneven surfaces
- preference to sleep on the floor than on a bed
- covering of ears to noises and demonstrating increased anxiety
- masturbation
- rocking
- self biting and biting others
- under-responsive to touch

Making use of the various environmental stimuli in a systematic manner with the understanding of the profile of each child with ASD holds the key to effective sensory integration therapy.

Each strategy has its own merits and limitations. It is important that the trainer who imparts the skills has a thorough understanding of the individual with ASD, his family, the environment in which he lives, available resources and the objectives laid down for training. This would help in selection of appropriate strategy or combination of strategies to teach the child. It is important that the trainer is competent in imparting the skill using a particular strategy. Keeping pace with recent developments and trends in the field is very essential for the trainer as the development is rapid. Technological advances are to be taken advantage of in training individuals with ASD.

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San Diego: Author.

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Handbook of autism and pervasive developmental disorders New York: Wiley

Smith. D.D.(2004) Introduction to Special Education, Boston:Pearson Pub.Co PP 431

Suggested Web Sites.

www.gov.nip/vacsafe/concerns/autism/default.htm#prevalance

www.nichd.nih.gov/publications/pubs/autism/htm

<http://www.iidc.indiana.edu/irca/behavior/discreterl.html>.

http://www.asatonline.org/about_autism/autism_info06.html.

<http://www.our-kids.org/Books/autism.htm>

<http://www.cesa7.k12wi.us/sped/autism/structure/str10.htm>

<http://www.autism.society.org/site/pageserver?pagename=behavioral and communication approaches>

**FREQUENTLY
ASKED QUESTIONS
ON ASD**

FREQUENTLY ASKED QUESTIONS ON ASD

There are many concerns and questions in the minds of parents as well as professionals regarding autism. Here, an attempt is made to answer some of the frequently asked questions (FAQs). Many of these questions were asked by the parents having children with autism who were attending services at NIMH. Some of the questions were asked by the professionals attending training programs at NIMH. The questions cover understanding autism spectrum disorders, Diagnosis of autism, Medical aspects, Educational aspects, Behavioral aspects and Therapeutic aspects. The answers were sought from varied sources including text books, journals, internet search and personal contacts with professionals. It is to be noted that this effort is an attempt to compile the information at one place and make it available to the readers. Hence, for more information and its authenticity, the reader may refer to the source. Dates of accession of website is not given as one may want to see the update on the website.

UNDERSTANDING AUTISM SPECTRUM DISORDERS

1. What is the origin and the meaning of the word autism ?

'Auto' is a Greek word which means 'self'. Typical autistic behaviour includes lack of responsiveness to other people, gross impairment in communication, inappropriate emotional expressions, poor eye contact and stereotypical responses to environment. Such behaviours would suggest to the onlooker that the person lives with 'self' without involving himself with the environment. Therefore such children are called 'autistic' and the condition is called 'autism'. In 1943, Leo Kanner a child psychiatrist at Johns Hopkins University Medical School first described children with this condition as having 'early infantile autism'.

Reference :

- Baron-Cohen, Bolton P (1994) Autism – The Facts, New York: Oxford University Press

2. Is Autism caused by faulty parenting ?

Autism was once thought to be caused by faulty parenting. However, this has been proven to be absolutely false. Initially it was believed that the parents were at fault, particularly the mother who was held responsible for not providing sufficient warmth and affection for her child. Autism is not caused by faulty parenting, abuse, neglect, or other childhood trauma.

Reference :

- Baron-Cohen, Bolton P (1994) Autism – The Facts, New York: Oxford University Press Inc.

3. What is ASD?

Autism Spectrum Disorder (ASD), as the term suggests, is no one diagnosis or label. Rather there are several labels that place people at different points on the spectrum. At one end of the spectrum, diagnostic labels such as : Asperger Syndrome”, ‘High Functioning Autism” and ‘PDD-NOS” are used. At the other end of spectrum you will find labels such as “Autism,” “Classic Autism” and “Kanner Autism”.

The term ASD is used because there is great variation from person to person depending on the severity and combination of each area of impairment. ASD may also coexist with other conditions or disorders, including intellectual disability, speech and language disorders, anxiety and depression, epilepsy, attention disorders, and down syndrome.

Reference :

- Baron-Cohen, Bolton P (1994) Autism – The Facts, New York: Oxford University Press Inc.

4. What is autism?

Autism is defined as severely incapacitating life long developmental disability that typically appears during the first three years of life.

In autism, the impairments in the social and communication areas are severe and sustained, and clearly present before the age of three years. The child is often anxious, has poor attention and motivation, responds unusually to many different stimuli and is observed as being ‘different’ from other children. Speech is delayed, or largely absent.

Reference :

- Slutsky, C.M and Betty A.Paris, B.A., (2000) Exploring the Spectrum of Autism and Pervasive Developmental Disorders, Therapy Skill Builders, USA.

5. Whom to contact for help in India?

Whether you or your child's pediatrician is the first to suspect autism, your child will need to be referred to someone who specializes in diagnosing autism spectrum disorders. This may be a developmental pediatrician, a psychiatrist or psychologist. Other professionals may be included who are better able to observe and test your child in specific areas.

This multidisciplinary assessment team may include some or all of the following professionals. They may also be involved in treatment programs.

- Developmental pediatrician: Treats health problems of children with developmental delays or handicaps.

- Child psychiatrist: A medical doctor, who may be involved in the initial diagnosis, can prescribe medication for emotional adjustment and social relationships.
- Clinical Psychologist: Specializes in understanding the nature and impact of developmental disabilities including autism spectrum disorders
- Occupational therapist: Focuses on practical self-help skills that will aid in daily living such as dressing, co-ordination of movement, and fine motor skills.
- Physical therapist: helps to improve the use of bones, muscles, joints and nerves to develop muscle strength, co-ordination and motor skills.
- Speech/Language therapist: Involved in the improvement of communication skills including speech and language.
- Social worker: May provide counseling services or act as case manager helping to arrange service.
- Special educator : Specially qualified to teach children with disabilities

It is important that parents and professionals work together for the child's benefit. the professionals will use their experience and training to make recommendations about unique knowledge about his/her needs and abilities.

Once a treatment program is in place, communication between parents and professionals is essential to monitor the child's progress.

6. Name some websites on Autism?

- www.polyxio.com
- www.autism-society.org
- www.autism.org/contents.html
- www.autism.com/ari
- www.autismindia.com
- www.signaleader.com
- www.withyoueverystepoftheway.com
- www.amazon.com
- www.aspergersnet.org
- www.aspergerinfo.org
- www.autismchronical.com

- www.specialneeds.com
- www.autismweb.com/resources.htm
- www.aacap.org/publications/factsam/83.htm
- www.laureatelearning.com

7. What causes autism?

Autism has no single cause. Researchers believe several genes, as well as environmental factors such as viruses or chemicals, contribute to the disorder. Studies of people with autism have found abnormalities in several regions of brain, including the cerebellum, amygdala, hippocampus septum and mamillary bodies. Neurons in these regions appear smaller than normal and have stunted nerve fibers, which may interfere with nerve signaling. These abnormalities suggest that autism results from disruption of normal brain development.

Other studies suggest that people with autism have abnormalities of serotonin or other signaling molecules in the brain. While these findings are intriguing, they are preliminary and require further study. The early belief that parental practices are responsible for autism has now been disproved. In a minority of cases, disorders such as Fragile-X syndrome, tuberculosis, untreated phenylketonuria (pku), and congenital rubella causes autistic behaviour. While people with schizophrenia may show some autistic-like behaviour, their symptoms usually do not appear until late teens or early adulthood.

Reference :

- <http://www.autismsociety.org/site/pageserver/?pagename=autismcases>

8. What is the job scope for persons with ASD?

The provision of vocational training and work opportunities is fraught with many difficulties (Ellis. K. 1990). There is a choice between supplying some form of work-based therapeutic activity in a sheltered environment, or of providing useful work opportunities in a disciplined setting. Work is meaningful and based on each person's strengths and abilities. For example, people with autism with good eye-hand co-ordination who do complex, repetitive actions are often especially good at assembling and manufacturing tasks. A worker with a low IQ and limited language skills might be trained to work in a restaurant sorting silverware and folding napkins. Adults with higher-level skills might be trained to assemble electronic equipment or do office work.

Based on their skills and interests, participants in such programs fill positions in printing, retail, clerical, manufacturing, and other companies. Once they are carefully trained in a task,

they are put to work alongside the regular staff. Like other employees, they are paid for their labour, receive employee benefits, and are included in staff events like company picnics and retirement parties. Employers find that the autistic behaviours, limited social skills, and even occasional tantrums or aggression, do not greatly affect the worker's ability to work efficiently.

Reference :

- Cohen, S.B., Bolton. P. (1993) Autism, The Facts: Oxford university Press, New York. Pp 82. Website: www.autism_resources.com/autism.faq.html
- Ellis.K., Autism, Professional Perspectives and Practice (1990), St. Edunsbury Press: Great Britain. Pp 142.

9. What are the unusual abilities of children with ASD?

Some people with autism show unusual abilities. Some of the extraordinary abilities of some autistic children may be as follows:

- Ability to draw detailed, realistic pictures in three-dimensional perspective.
- Toddlers with autism are so visually skilled that they can put complex jigsaw puzzles together.
- Begin to read exceptionally early sometimes even before they begin to speak.
- Extraordinary ability to play musical instruments that they have never been taught, play a song accurately after hearing it once, or name any note they hear.
- Ability to memorize entire television shows, pages of the phone book, or the scores of every major league baseball game for 20 years.

Such skills are known as islets of intelligence or savant skills.

Reference :

- www.autism_resources.com/autism.faq.html

10. Can autism be out grown?

At present, there is no cure for autism. Nor do children outgrow it. But the capacity to learn and develop new skills is within every child.

With time, children with autism mature and new strengths emerge. Many children with autism seem to go through developmental spurts between ages 5 and 13. Some children in treatment programs lose enough of their most disabling symptoms to function reasonably well in a regular classroom. Some children with autism make truly dramatic strides. Of course, those with normal or near-normal intelligence and those who develop language tend to have outcomes. But even children who start off poorly may make impressive progress.

While it is natural for parents to hope that their child will “become normal” they should take pride in whatever strides their child does make. Many parents, looking back over the years and find their child has progressed far beyond their initial expectations.

Reference :

- www.autism_resources.com/autism.faq.html

11. What is the meaning of 'islets of abilities' in persons with ASD ?

Persons with ASD are found to be good in certain areas – in fact better than those without autistic tendencies. This can be noted in their visual spatial abilities, such as exquisite drawings with finer details, jigsaw puzzles and calendar calculation. The best documented examples are their musical abilities, rote memory, finding shapes within patterns, precocious reading, intricate drawings and memory for finer details. This is also known as splinter skills or savant abilities. Bernard Kimland used the term ‘autistic savant’ to describe this character. What could be the cause of such abilities and talents is still unknown.

Reference :

- Cohen S.B., Bolton P (1994). Autism, The facts. Oxford ; Oxford University Press Pp. 53-54.

12. Can Children with ASD study like other children ?

Siegel as quoted by Cowley (2003) estimates that 25 per cent of classically autistic children respond to intensive interventions and that 7 percent do well enough to attend mainstream schools and lead normal lives. The response rates are much higher among mildly affected children and experts agree that early intervention is the key to success.

Reference :

- Cowley, G.(2003) Girls, Boys and Autism, New York: Newsweek. September 8 2003. pp 49.

13. Name some well-known researchers and practitioners in the field of autism?

Leo Kanner : Credited with identifying early infantile autism in 30s and 40s and who gave it the label “early infantile autism” in 1943.

Hans Aspergers : Working in Austria, published ‘Autistic psychopathology in childhood’ one year after Kanner’s paper (though it was submitted before Kanner was published). Because of the war probably completely unaware of Kanner’s work. It appears that Asperger’s patients were somewhat less impaired in communication than Kanner’s. Unlike Kanner, he believed in a biological, rather than a psychological, cause. His paper appears in Frith’s Autism and Asperger syndrome.

Bernard Rimland : A researcher and parent who reportedly undertook to study the causes of autism, expecting to find a psychological cause, but came to the conclusion that the cause is biological. He wrote a book in 1964 on the subject, over the long run, has been very influential.

Bruno Bettelheim : Freudian psychiatrist who wrote on a number of topics including autism. Works from the point of view that it is a psychiatric condition.

Eric Schopler : Founder of TEACCH program in North Carolina. One of the first professionals to involve parents in treatment and education of children with autism.

Ole Iver Lovaas : Developer of Discrete Trial Training (DTT), a form of operant conditioning (behaviour modification) designed to treat autism.

Michael Rutter : British researcher, worked extensively on autism in the 1970's, still involved.

Rosemary Crossley : In Australia, first to try the use of facilitated communication with autistic children.

Douglas Biklen : Introduced facilitated communication in USA based upon the work of Rosemary Crossley.

Guy Berard : Physician in Annecy, France who developed the Audiokinetron, one of the possible devices used in Auditory Integration Training.

Martha Welch : Primary promoter of Holding Therapy in USA.

Uta Frith : Wrote books on subject. <http://www.edu.ulc.ac.uk/uta/home.htm>

Stanley Greenspan : Wrote books on child with developmental disabilities, though not specifically autism spectrum.

Reference :

- http://www.autism_resources.com/autismfaq_well.html

14. Can persons with autism get married?

This is a query that requires a response from functional viewpoint rather than legal or medical viewpoints. Individuals with autism are known to have impairment in social behaviours. As they grow-up, emerging sexuality and lack of skills to understand and behave appropriately makes life more complex for them. While marriage is a right of every person, the ability to manage self, spouse and family needs to be considered.

Documentary evidence shows that very few marry, although some do learn to enjoy heterosexual companionship. Symptoms become a bit less severe in adulthood but the basic difficulty in relatedness remains the single most significant impairment in establishing a fully independent style of living for even the most able autistic people.

References :

- Perry A and Condillac R (2003) Evidence based practices for children and Adolescents with Autism Spectrum Disorders. Ontario : Children's Mental Health, Pp 78.
- Reynolds CR & Mann L (2987) Encyclopaedia of Special Education, New York: John Wiley and Pp 163.
- Smith D.D. (2004) Introduction to Special Education Boston : Pearson Pp. 427.

DIAGNOSIS OF ASD

15. How is autism /ASD diagnosed?

One of the most difficult tasks in dealing autism/ASD is diagnosing it. Children with autism may meet normal developmental milestones, then seems to stop. These milestones vary in each individual. Some of the following frequently used criteria developed by researchers and therapists can be used as diagnostic criteria for autism.

- Absence or impairment of imaginative and social play.
- Impaired ability to make friends with peers.
- Impaired ability to initiate or sustain a conversation with others.
- Stereotyped, repetitive, or unusual use of language.
- Restricted patterns of interests that are abnormal in intensity or focus.
- Apparently inflexible adherence to specific routines or rituals.
- Preoccupation with parts of objects.

Reference :

- Seigel. B., The World of Autistic Child (1996): Oxford University Press, New York, pp9-13.

Website : <http://www.autismsociety.org/site/pageserver?/pagename =autismdiagnosis>

16. What are the symptoms of ASD?

The symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe although autism is defined by a certain set of behaviors. Children and adults can exhibit any combinations of the behaviours in any degree of severity. Two children, both with the same diagnosis, can act very differently from one another and have varying skills.

Every person with autism, has a unique personality and combination of characteristics. Mildly affected may exhibit only slight delays in language and greater challenges with social interactions. They may have difficulty in initiating /maintaining a conversation. Communication is often described as talking to others. People with autism process and respond to information in unique ways. In some, aggressive and /or self-injurious behaviour may be present. Persons with autism may also exhibit some of the following traits.

- Insistence of sameness: resistance to change.
- Difficulty in expressing needs
- use of gestures or pointing instead of words.
- Repeating words or phrases in place of normal, responsive language.
- Laughing, crying, showing distress for reasons not apparent to others.
- Prefers to be alone/alooof
- Tantrums.
- Difficulty in mixing with others.
- May not want to cuddle or be cuddled.
- Little or no eye contact.
- Unresponsive to normal teaching methods.
- Sustained odd play.
- Spinning objects.
- Inappropriate attachments to objects.
- Apparent over-sensitivity or under sensitivity to pain.
- No real fears of dangers.
- Noticeable physical over-activity or extreme under activity.
- Uneven gross/fine motor skills.
- No response to verbal cues.

Reference :

- Stanford A., Aspergers syndrome and Long-term Relationships (2003) Jessica Kingsley Publishers, England, pp 26-27.
- <http://www.autism-society.org/site/pageserver/?pagename=autismcharacteristics>

17. What are the tests used to diagnose ASD?

Some of the screening tools used for diagnosing ASD are :-

1. Checklist for Autism in Toddlers (CHAT: Baron – Cohen, Allen, & Gillberg, 1992; Baron – Cohen et al., 1996)
2. The Autism Screening Questionnaire (ASQ : Berument, Rutter, Lord, Pikles, & Bailey 1999)
3. The Autism Spectrum Screening Questionnaire (ASSQ: Ehlers, Gillberg, & Wing, 1999)

4. Pervasive Developmental Disorder Screening Test (PDDST: Siegel, 1996)
5. Screening Tool for Autism in Two Year Olds (STAT : Stone et al., 2000)

Other Assessment Tools are:-

1. The Childhood Autism Rating Scale (CARS: Schopler et al. 1971, 1980, 1988).
2. The Autism Diagnostic Observation Schedule (ADOS: Lord, Rutter, DiLavore, & Risi, 2001).
3. Autism Diagnostic Interview – Revised (ADI- R; Lord et al, 1997)
4. Diagnostic and Statistical Manual of Mental Disorders (DSM IV) Criteria.
5. Autism Behaviour Checklist. (ABC :Krug et al, 1978, 1980)
6. Gilliam Autism Rating Scale (Gilliam, 1995)
7. Behaviour Rating Instrument for Autistic and Atypical Children (BRIAAC; Rutter berg et al, 1966, 1977).
8. Autism Descriptors Checklist (ADC; Fisch, Cohen, Wolf & Friedman, 1985)

Reference :

- Schopler, E., and McSibov, G.B. (1988) Diagnosis and Assessment in Autism. New York: Plenum Press.

18. How to differentiate the behaviours in the infants with autism and without autism?

The following are some of the differentiating features of infants with autism and without autism:

S.No.	Infants with autism	Infants without autism
1.	Avoid eye contact	Read mother's face
2.	Seem deaf	Attracted by sounds
3.	Regression in speech	Keep adding to vocabulary and expanding grammatical usage
4.	Act as if unaware of the coming and going of others	Anxious with strangers
5.	Inaccessible, as if in a shell	Recognize familiar faces and smile.
6.	Get fixed on single item or activity	Move from one item or activity to another
7.	Practice strange actions like rocking or hand- flapping	Use body purposefully to reach or acquire objects
8.	Sniff or lick toys	Explore and play with toys
9.	Show no sensitivity to burns or bruises	Seek pleasure and avoid pain

Reference : www.autism_resources.com/autism.faq.html

19. What are the social symptoms of autism?

Some of the social symptoms of children with autism are:

- In the first few months of life, many do not interact and they avoid eye contact.
- Prefer being alone.
- They may resist attention and affection or passively accept hugs and cuddling.
- They rarely become upset when the parent leaves or show pleasure when the parent returns.
- They take longer to learn to interpret what others are thinking and feeling.
- Subtle social cues-whether a smile, a wink, or a grimace-may have little meaning. Without the ability to interpret gestures and facial expressions, the social world may seem bewildering.
- People with autism have problems seeing things from another person's perspective. This inability leads to inability to predict or understand other people's actions.
- Some people get physically aggressive particularly when they are in strange or overwhelming environment, or when angry and frustrated, they are capable of breaking things, attacking others, or harming themselves.

Reference :

- Ellis.K., Autism, Professional Perspectives and Practice (1990), St. Edunsbury Press: Great Britain. Pp 4-5
- Seigel. B., The World of Autistic Child (1996): Oxford University Press, New York, pp25-42.

Website : www.autism_resources.com/autism.faq.html

20. What are the sensory symptoms of autism?

Some of the sensory symptoms of persons with autism are:

Adaptations to input from the senses :

Usually in children with autism, sensory information is faulty or the input from the various senses fail to merge into coherent picture Hence the child's experiences of the world can be confusing.

As a result of a brain malfunction, many children with autism are highly attuned or even painfully sensitive to certain sounds, textures, tastes, and smells.

In autism, the brain also seems unable to balance the senses appropriately; hence some children with autism seem oblivious to extreme cold or pain.

In some people, the senses are even scrambled, one child gags when she feels a certain texture, some hear sound when someone touches a point on his chin, another experiences certain sounds as colours.

Some children find the feel of clothes touching their skin so disturbing that they can't focus on anything else.

Auditory hyposensitivity and hypersensitivity :

Some children cover their ears and scream at the sound of a vacuum cleaner, a distant airplane, a telephone ring, or even the wind.

Reference :

- Seigel. B., The World of Autistic Child (1996): New York, Oxford University Press, pp77-81.

Website : www.autism_resources.com/autism.faq.html

21. How early we can identify autism?

With the advent of standardized diagnostic tools, notably the Autism Diagnostic Interview-Revised (ADI-R) and the Autistic Diagnostic Observation Schedule-Generic (ADOS-G), expert clinicians are now able to diagnose autism reliably by age 3, and even by age 2 years. However, evidence indicates that most children are not diagnosed prior to age 4 years, typically at least 2 years after parents first seek professional advice because they are concerned about their child's development.

Diagnosis of autism is based on the identification of symptoms before the age 3. However, the diagnosis can be made even after 3 years of age. Recent studies show that the problem can be identified as early as infancy in certain cases.

Reference :

- www.autism_resources.com/autism.faq.html

22. Do the symptoms of autism change over time?

Reports from researchers indicate that some symptoms in many children with autism improve with intervention or as the children mature. Some people with autism lead normal or near normal lives. However, reports from parents of children with autism indicate that some

children's language skills regress early in life, usually before age three. This regression often seems linked to epilepsy or seizure-like brain activity. On the other hand adolescence also worsen behaviour problems and the individuals with ASD become depressed or increasingly unmanageable. Parents should be ready to adjust treatment for their child's changing needs.

Reference:

- http://www.childdevelopmentinfo.com/disorder/autism-fact_sheetshtm#symptoms

23. What is pharmacotherapy for autism?

Pharmacotherapy is use of medicine. But remember, there is no curative treatment for autism, and psychotropic drugs have only a minimal role to play in its mangement. As a rule, drugs should be used sparingly and only when other strategies to reduce maladptive behaviours have been properly tried and have failed to bring about the desired changes. Use of drugs should remain infrequent before age 5 years.

Reference :

- www.autism_resources.com/autism.faq.html

24. What is neurobiofeedback treatment for ASD?

Neuro bio feedback is a non-invasive, user-friendly procedure by which brainwave activity is detected. It is a technique designed to teach people how to control their brainwaves, using the latest computer technology. It is also known as EEG Biofeedback. In case of ASD, it organizes the brain to function better in different contexts like assisting individuals in learning self-regulation skills that improve their functioning. Those requiring academic and remedial training may engage in activities like reading, writing, math's, listening, concentrarion and memory skills while linked to the training program.

Biofeedback gives information about a body function, eg.,the level of sweat, muscle tension, heart rate and breathing.

Neuro and biofeedback training can be combined, because relaxed concentration is an optimal state for learning.

Reference :

- www.autism_resources.com/autism.faq.html

25. Are there drugs that decrease ASD?

Drugs don't cure autism, but many autistic children suffer from multiple problems such as depression or seizures, and the drugs can help with those secondary problems.

Reference :

- www.autism_resources.com/autism.faq.html

26. What is 'G' therapy?

G-therapy involves intake of a special combination of herbal extracts in potentised form and salts of the body and has been reported to be beneficial for treatment of a variety of neurodevelopmental disabilities including autism.

Reference :

- <http://www.g-therapy.org/wonders.htm>, www.G-therapy.Org

EDUCATIONAL ASPECTS IN AUTISM

27. What are the various educational facilities for children with Autism/ASD?

Children with ASD ideally should attend regular education with support facilities provided to them. Many who advocate inclusion do so primarily on the basis of value judgment because empirical data examining the outcome of full inclusions are rare. However it is to be kept in mind that enthusiasm of inclusion should not take precedence over the more important goal of appropriate education. Studies show that intensive early intervention services have positive results, thus indicating the need for involvement in the early years.

Key elements of successful programmes for children with ASD include a) supportive teaching environments, b) plans for generalization, c) predictable and routine schedules, d) functional approaches to address problem behaviours, e) supports for programme transitions, f) family involvement.

Whatever is the service facility chosen, students with ASD will learn better if the environment is carefully created so that events are predictable with proper scheduling of routine activities. While communicating, direct statements are to be used with concrete examples, avoiding metaphors and opportunity should be provided for observing peer models.

Whether in inclusive schools, special schools or in home based training, the curriculum should focus on child's strengths and needs, highly structured, with inbuilt social and communication skills with functional approaches to reduction of problem behaviours.

In India currently, the service facilities are established by voluntary organizations and Non-Government organizations (a list appended). The service provisions vary, ranging from special schools, inclusive schools and home based teaching programmes.

References :

- Smith D.D.(2004) Introduction to Special Education, Boston : Pearson Pp.432-433
- Jansen J.E. (2002) Understanding the Nature of Autism – A guide to ASD, San Antonio : Therapy skill builders
- Kellegrew DH (1996) Integrated school placement for children with disabilities Koegel R.L. & Koegel L.K (Eds) Teaching Children with Autism Baltimore : Paul H. Brookes Pp. 134-136

28. What is structured teaching approach in educating children with autism?

Structured teaching is an intervention to educate children with ASD. It allows for implementation of variety of instructional methods including visual support strategies, picture exchange communication system (PECS), sensory integration strategies, discrete trial training, music/rhythm intervention, and Greenspans floor time. Structured teaching is a system for organizing the environments, developing appropriate activities and helping people with autism understand what is expected of them.

Primary components of structured teaching includes physical structure, visual schedules and specific teaching methods. Eric Schopler, founder of Division of TEACCH in early 1970s established the foundation for structured teaching by demonstrating that people with autism process visual information more easily than verbal information.

Reference :

- Stokes. S, (2003) Structured teaching strategies for supporting students with Autism. Published under contract with CESA 7 funded by discretionary grant from the WIS Dept. of public instruction. <http://www.cesa7.k12.wi.us/sped/autism/structure>.

29. How to include children with autism for education?

Full inclusion refers to instructional practices that seek to accommodate students with disabilities in regular education class, such that the student's primary placement is considered as regular education environment. In essence, 'integrated' environment consists of bringing the child to the services, while full inclusion practices bring services to the child.

For successful inclusion of children with ASD learning characteristics of children with ASD should be considered. Their learning characteristics include organizational difficulties, sequencing difficulties, inability to generalize, impaired social and communication skills and rigid interests and behaviours. They show difference to social rules and conventions (Mesibov 1991). Their stereo typical behaviours and perseveration add to the difficulty in relating to the environment. Inclusion demands acceptance of the child by the environment as well as the child accepting the environment.

Therefore for successful inclusion, preparation of peers, teachers and the families with regard to ASD is very important.

National Research Council report (2001) (USA) has listed the following steps which are proven to be effective for education of children with ASD.

- begin as early as possible
- use curriculum focusing on communication, social, play, cognitive, behavioural, motor, self help goals
- include planning for generalization and transition to next setting
- involve families actively
- teach specific goals in settings with typical peer whenever possible
- Use data based decision making process

Depending upon the level of functioning, severity, age and rate of progress, many children with ASD do quite well in school.

Reference :

- National Research Council (2001) Educating children with autism Committee on Education and interventions for children with autism Washington DC ; National Academy Press
- Mesibov G.B.(1991) Learning styles of students with autism. The advocate, winter 12-14

30. How to create learning environment for optimum learning in children with ASD ?

Minimize visual-auditory distraction by,

- painting the environment in absorbing colors rather than reflecting colors
- limiting the amount of visual clutter by not crowding the walls, and by covering shelves by door/ curtains

- controlling the amount of light through use of curtains
- creating visual boundaries by clearly indicating beginning and ending of each area
- organizing the environment
- reducing auditory distraction by carpeting the floor
- creating study carrels to minimize distractions
- developing suitable instructional area for one to one, play, leisure, sensory integration and so on
- developing visual schedules for activities so that predictability is increased and anxiety in the child is reduced
- by organizing material and space
- ensuring clarity in instruction

Reference :

- Division TEACCH (1998) 'Structured teaching' Training manual North Carolina : Chapee Hill., Kranowitz. C.S. (2003) The out of sine Child has fun, Atlanta : Pedigree Book.

31. What is Functional Analysis?

Functional analysis is analysing the behaviour of the person in relation to the environment. It is identifying environmental events (causes), which are directly observable and potentially manipulatable (which can be changed) and deals with behaviour in currently occurring situations.

There are a number of models available for analysing behaviour. One of the simple models is ABC model. It involves understanding the behaviour in terms of what happens immediately before the behaviour (Antecedents), what happens during the behaviour (Behaviour) and what happens immediately after the behaviour (Consequence).

Reference :

- Peshwaria et al, (1994) Behavioural Approach in Teaching Mentally Retarded Children - A Manual for Teachers. Secunderabad: NIMH Publication.
- Yule, W. & Carr, J (1987), Behaviour Modification for people with mental handicaps, 2nd edition. London: Chapman & Hall.

33. Can Children with ASD study like other children ?

Siegel as quoted by Cowley (2003) estimates that 25 per cent of classically autistic children respond to intensive interventions and that 7 percent do well enough to attend mainstream

schools and lead normal lives. The response rates are much higher among mildly affected children and experts agree that early intervention is the key to success.

Reference :

- Cowley, G.(2003) Girls, Boys and Autism, New York: Newsweek. September 8 2003. pp 49.

34. What are the classroom strategies for working with children with autism?

Teach specific life skills in the social, behavioural, communication, academic, functional, and problem solving realms.

- Present information visually and verbally. Use cards and pictures to present a concept.
- Give clear and short directions.
- Structure the environment so that the child has minimal distractions.
- Develop schedules using visual cues or pictures along with verbal clues.
- Be consistent and structure in creating and presenting activities.
- Reinforcement during and after each accomplished task.
- Verbally praise the child for every effort made.
- Teach behavioural expectations. Each expectation should be presented so that the student knows exactly what is expected of him or her.
- One to one teacher-pupil ratio is ideal, if resources allow.

Reference :

- Cohen .SB., Bolton. P. (1993) Autism, The Facts: Oxford university Press, New York. Pp 60-62.

Website : www.autism_resources.com/autism.faq.html

34. What is floor time?

An educational model developed by child psychiatrist Stanley Greenspan. Floor Time is much like play therapy in that it builds an increasing larger circle of interaction between a child and an adult in a developmentally based sequence. Greenspan has described six stages of emotional development that children meet to develop a foundation for more advanced learning- a developmental ladder that must be climbed one rung at a time. Children with autism may have trouble with this developmental ladder for a number of reasons, such as over and under reacting to senses, difficulty in processing information, or difficulty in getting their body to do what they want.

Through the use of Floor Time, parents and educators can help the child move up the developmental ladder by following the child's lead and building on what the child does to encourage more interactions. Floor Time does not treat the child with autism in separate pieces for speech development or motor development but rather addresses the emotional development, in contrast to other approaches, which tend to focus on cognitive development. It is frequently used for child's daily play time in conjunction with other methods such as ABA (Applied Behaviour Analysis).

Website : <http://www.floortime.org/fags>.

35. What is TEACCH?

TEACCH (Treatment and Education of Autistic and related Communication Handicapped*Children) was developed at the school of medicine at the University of North Carolina in the 1970 & It is a structured teaching approach based on the idea that the environment should be adapted to the child with autism, not the child to environment. It uses no one specific technique, but rather is a program based around the child's functioning level. It is highly individualized, uses the child's visual and spatial strengths to compensate for social and communication deficits through the physical arrangement of the classroom, visual system for schedules and transition, individualized work system, task and material.

Rather than teach a specific skill or behaviour, the TEACCH approach aims to provide the child with the skills to understand his or her world and other people's behaviour. For example, some children with autism scream when they are in pain. The TEACCH approach would search for the cause of the screaming and teach the child how to signal pain through communication skills.

The treatment includes both language and behaviour focused intervention programmes. Some of the main TEACCH strategies can be grouped under four headings:

1. Physical structure
2. Daily schedules or time tables
3. Work systems
4. Visual instruction

Reference:

- Schopler Eric, Bourgordien M.E., Van, B.Marie M. (1993), *Preschool Issues in Autism*, Plenum Publishing Corporation, New York.
- Cohen S.B., Bolton P., (1993), *Autism, The Facts*, Oxford, New York.

36. Where can we buy TEACCH?

One can buy TEACCH at the following address:

Division TEACCH,
School of Medicine,
310, Medical School,
Wing E, 222h,
Chapel Hill, N.C. 27514. USA
(or) at www.uncedn/depts/teacch

BEHAVIORAL ASPECTS IN ASD

37. Do they participate in play and other social activities like other children ?

In a typically developing child, stages of play development includes the following stages:-

1. Solo play – the child plays alone
2. Parallel play – more than one child play parallelly in the same environment without regarding others
3. On looker – the child watches others playing without participating.
4. Associative play - more than one child carry on with ones own respective play activity in the same environment and interacts with others only if needed.
5. Cooperative play – children play together taking roles to pretend like others (also known as pretend play) such as teacher-students, thief-police, daddy-mummy, doctor-patient and so on. Following these, children learn organized, rule governed games.

Many a time, an autistic child due to the specific characteristic of impairment in social behaviour and rigid interests and behaviours do not reach the **on looker stage** and therefore other stages do not follow. Therefore, it is critical that the intervention should be planned to enhance social understanding, social relationship and play skills.

Reference :

- Wolfberg PJ(1995) Enhancing Children's play in K.A.Quill (Ed) Teaching Children with Autism: Strategies to Enhance communication and Socialization, New York: Delmar Publisher
- Rutherford, K.(2001)(reviewer) The Power of Play, www.kidshealth.org.
- Narayan, J.Riggion (2005) creating play environment for children with visual inpairment and multiple disabilites & Boston: Hilton/Perkins

38. What is meant by 'restrictive interest' of autistic children'?

'Restrictive interest' refers to the limited repetitive stereotyped patterns of behaviour, interests and activities in children with ASD. It is exhibited by

- a. pre-occupation with one or more of stereotyped restricted pattern of interest that is abnormal either in intensity or focus – such as playing with fingers, winding toys, threads or puzzles.
- b. following non-functional rituals or routines such as lining up the toys in a particular manner every day.
- c. stereotyped and repetitive motor mannerism such as hand or finger flapping.
- d. persistent preoccupation with parts of objects such as wheel of the toy car rather than the car itself.

Not a lot is understood about the function of this type of behaviour. It is not known whether children with autism learn this type of behaviour in response to their experiences in the world or whether this aspect just does not develop until they are older.

Reference :

- American Psychiatric Association (1994) Diagnostic and statistical Manual of Mental disorders, Washington DC : American Psychiatric Association.
- Smith D.D. (2004) Introduction to Special Education Boston : Pearson.

39. What is impairment in flexibility ?

Persons having autistic disorders are found to have an unwillingness to have familiar routines changed or delayed. They have reluctance to participate in new activities or to process unexpected events. Any change or interruption in the routine will produce extreme anxiety in them. One may find them insisting on using the same utensils for food, same route to reach a place and the timetable strictly adhered to. This behaviour in children with ASD is considered as impairment in flexibility.

Reference :

- Reynolds C.R. and Mann L (1989) Encyclopaedia of Special Education, New York : John Wiley and Sons Pp. 166.

40. What is theory of mind?

Mind has three components. Namely, Cognitive, Conative and Affective. Theory of mind is being able to infer the full range of mental states (such as desires, interactions, imagination, emotions, etc.) that cause action. An individual is said to have developed a Theory of mind, if he is able to reflect on the contents of one's own mind and the mind of others.

Reference:

- Baron-Cohen, Simon, and John Swettenham (1997). " Theory of Mind in Autism'. Its relationship to Executive Function & Central Coherence." In.
- Donald J. Cohen & Fred R. Volkmar, eds., Handbook of Autism & Pervasive Developmental Disorders. 2nd Ed. (PP. 880-893). New York: John Wiley & Sons, Inc
- Simon, Baron- Cohen (1998), " Autism and "Theory of Mind"; An Introduction and Review, International Symposium on Autism; Conference Proceedings, Geneva: Future Horizons, Inc.

41. What is Behaviour Modification?

Behaviour Modification, based on B.F.Skinner's operant conditioning is an active intervention approach whereby caregivers (1) observe, measure and evaluate current observable behavioural patterns; (2) identify environmental antecedents and consequences; (3) establish new behavioural objectives and (4) advance the learning of new behaviour or modify current behaviour via the manipulation of identified antecedents and consequences. Behaviour Modification involves application of principles of conditioning and learning.

Reference:

- Colman, A.M. (2001) Oxford Dictionary of Psychology.
- Zirpoli, T.J., Melloy, K.J. (1993) Behaviour Management: Applications for Teachers and Parents, Maxwell MacMillan Canada, Inc.

42. Why do they have behaviour such as hand gaze, spinning object?

Behaviours such as hand gaze and spinning object are stereotypic in nature. Researchers have suggested various reasons for this one set of theories suggest that these behaviours provide the person with sensory stimulation (i.e., the person's is hyposensitive). Due to some dysfunctional system in the brain or periphery, the body craves stimulation; and thus, the person engages in these behaviours to excite or arouse the nervous system.

One specific theory states that these behaviours release beta-endorphins in the body (endogeneous opiate-like substances) and provides the person with some form of internal pleasure.

Another set of theories states that these behaviours are exhibited to calm a person (i.e., the person's is hypersensitive). That is, the environment is too stimulating and the person is in a state of sensory-overload. As a result, the individual engages in these behaviours to block-out the over-stimulating environment, and his/her attention becomes focused inwardly.

Reference :

- <http://www.autisticsociety.org/article238.html>

43. Why do some children with autism have self injurious behavior?

Some children with autism may have self-injurious behavior like biting themselves, head banging, etc. The exact reason for this behavior is not understood. However, the children with autism may show increased levels of opioid substances in the brain, which is considered as probable reason for the insensitiveness to pain in these children.

Reference :

- <http://www.autisticsociety.org/article238.html>

44. What is Lovaas?

Ole Ivar Lovaas is known for developing and testing the methods of behavioural psychology to help children with autism, eventually to be known as behavioural analysis. This program involves quickly repeated trials and a very vigorous style of interaction with the child that definitely works and reinforcing positively for his successes, counter balancing any initial aversion or resistance to the task.

Reference:

- Bryna Siegel, B.(1996), The World of the Autistic Child, Oxford, New York.
- Jones.G., Educational Provision for Children with Autism and Asperger Syndrome (2002), David Fulton Publishers., London. Pp 53.
<http://www.autism-pdd-net/treaforme.htm/#lovaas>
- Lovaas, O.I., & Smith T (1998) Intensive behavioural treatment for young autistic children in B.B. Lahey and A.E. Kasden (Eds.) Advances in clinical psychology. Newyork : plenum

THRPEUTIC ASPECTS IN ASD

45. What is hippo therapy?

Hippo is the Greek term for horse (therapeutic riding). The animals become the apparatus, appliance, device or instrument, represented in treatment and utilized for assistance.

The hippo therapy is believed to

- Normalize muscle tone
- Mobilize joints
- Improve postural control
- Improve fitness
- Improve balance and equilibrium reactions
- Improve functional activity
- Improve self – esteem and independence
- Motivate
- Develops, mobility, balance and co-ordination

Reference:

- <http://www.enablelink.org/animal/alliance/index.html>

46. What is dolphin therapy?

Dolphin therapy was first tried in the 1970s by David Nathanson, a psychologist who believed that interactions with dolphins would increase a child's attention, enhancing cognitive processes. Through a number of studies, he reported that children with disabilities learned faster and retained information longer, when they were with dolphins compared to children who learned in a classroom setting.

Reference :

- Aarons, Maureen and Gittens, Tess (1992) The Hand Book of Autism, A guide for Parents and Professionals, Routledge Publishers, London.

47. What is holding therapy?

Holding therapy is a technique wherein the parents would hold their autistic children very tightly. By doing so, Bruno Bettelheim, a New York Psychiatrist believes that the children would emerge from their autistic world. Holding therapy gained widespread attention when Dr. Martha Welch, a child psychiatrist from Newyork, began using it as a means of working with children with autism. During holding therapy, the parent attempts to make contact with

the child in various ways. This may mean simply comforting a distressed child, but often the parent may hold the child for a period of time, even if the child is fighting against the embrace. The child sits or lies face to face with the parents, who try to establish eye contact, as well as to share feelings verbally throughout the holding sessions. The parent remains calm and in control and offers comfort when the child stops resisting, which is believed to help the child to adjust and overcome sensory overload.

Reference:

- Siegel B, The World of Autistic Child, (1996), Oxford University Press, USA.
- Aarons, M. and Gittens, T. (1992) The Hand Book of Autism, A guide for Parents and Professionals, Routledge Publishers, London.

Website: <http://www.autism-pdd.net/treaforme.html#holding>

48. What are PECS and FC?

PECS: Picture Exchange Communication system (PECS) is an augmented communication program helpful to get language started as well as to provide a way of communicating for those children who do not talk. It teaches very young children-as young as 2 years of age and promotes a mode of communication.

PECS is a program to help children and adults with autism to acquire functional communication skills. This teaches children to exchange a picture for something they want – an item or activity. The advantage of PECS is that it is clear, intentional and initiated by the child. The child hands you a picture, and his or her request is immediately understood. It also makes it easy for the child with autism to communicate with anyone- all they have to do is to accept the picture, and suitably respond

FC: Facilitated Communication was developed in the 1970's in Australia by an aide who was trying to help a patient to communicate. FC involves a facilitator who, by supporting an individual's hand or arm, helps the person communicate through the use of a computer or typewriter.

Reference:

- Schopler, E., Mesibov, B.G. (1995) Learning and Cognition in Autism, New York : Plenum
- Jones, G., Educational Provision for Children with Autism and Asperger Syndrome (2002), London, David Fulton Publishers.

49. Autistic children have echolalic speech. What does it mean?

Echolalia is defined as the most common form of unconventional verbal behaviour. Echolalia means repetition by the child, of verbal information stated by others. (E.g. People's conversational exchanges, songs etc.)

- Echolalia can include repetition of part of the utterance as well as an identical repetition of the entire spoken utterance, some times including an exact replication of the inflectional pattern used by the speaker.
- Echolalia can be immediate or delayed.
- Echolalia occurs in normal language development yet decreases as the typically developing child gains more spontaneous generative language. In children with autism, echolalia occurs with greater frequency and lasts for a longer period of time as the child with autism typically experiences significant difficulty developing spontaneous generative language skills.
- Echolalia is reflective of how the child processes information. The child with autism processes information as a whole "chunk" without processing the individual words that comprise the utterance. In processing the unanalyzed "chunks" of verbal information, many children with autism also process part of the context in which these words were stated, including sensory and emotional details.

The presence of echolalia in children with autism can be a positive indicator for future meaningful language development. It indicates that the child is at least processing language, although at a "surface" level.

Reference :

- Hegde, M.N. (1996), "On language disorders in children", California : Singular publishing group. www.autism_resources.com/autism.faq.html

50. What is Highasi?

Daily Life Therapy, pioneered by Dr.Kiyo Kitahara at the Higashi School in Japan that emphasizes vigorous physical exercises and sports. The school is open to students of 3-22, years of age. It includes who have Autistic /Autistic like behaviours or Pervasive Developmental Disorder.It does not serve Multi-handicapped (physically disabled), Severe/Profound Mental Retardation, Emotionally Disturbed, Character Disorder, or Uncontrolled Seizure Disorder. This method was developed in Japan and imported into the USA. It includes elements normally found in the education of autistic children, but places unusual attention to physical exercise.

Upon entering high school, all students participate in community work and ultimately employment. Areas of employment opportunities include clerical, custodial, stocking, food service and landscaping. All vocational students are paid employees. We do not know what percentage of autistic children may be helped by daily Life Therapy.

Website: www.musashino-higashi.org/english.html.

51. Can music help them?

Yes, music can definitely help a person with ASD, because

Music is considered a “universal language” which provides bridges in a non-threatening setting between people and/or between individuals and their environment, facilitating relationships, learning, self-expression, and communication.

Music captures and helps maintain attention. It is highly motivating and may be used as a natural “reinforcer” for desired responses and can stimulate clients to reduce negative and/or self-stimulatory response and increase participation in more appropriate and socially acceptable ways.

Music therapy enables those without language to communicate, participate and express themselves non-verbally. Very often music therapy also assists in the development of verbal communication, speech, and language skills. The interpersonal timing and reciprocity in shared play, turn-taking, listening and responding to another person are augmented in music therapy with children and adults with autism to accommodate and address their styles of communication.

Music therapy allows individuals with autism, an opportunity to develop identification and appropriate expression of their emotions. Pre academic skills such as colours, letters, numbers, body parts, etc can be taught in a playful manner through music.

Reference:

- Knoblock.P.(1982), Teaching and Mainstreaming Autistic Children, Love Publishing Company,USA.
- Jones.G., Educational Provision for Children with Autism and Asperger Syndrome (2002), David Fulton Publishers., London. Pp 57-58.

52. What is Sensory Integration?

Sensory integration is a theory and technique developed by A. Jean Ayres, an occupational therapist. We are constantly bombarded by external and internal sensory input. By the process of sensory integration the inputs from one or more of our sensory systems, registering the stimuli, and constantly analyzing which stimuli are important on a conscious or unconscious level, we make decisions about which stimuli to attend or react and how much of our attention to direct to it. This is how we are able to make appropriate responses to stimuli.

Reference : Slutsky, C.M., Paris, B.A., (2000) Exploring the Spectrum of Autism and Pervasive Developmental Disorders, N.Y : Therapy Skill Builders.

53. How is SIT helpful for autistic children?

Development is a spiraling process. Skills are acquired in many different domains at the same time. Eg. Babies learning to eat with a spoon are receiving and integrating sensory information from:

- Touch receptors from the spoon and the textures in the mouth and on the face.
- Proprioceptive receptors from the jaw as they chew, from the weight of the spoon, and as they guide their arm movement.
- Visual receptors as they look at food and guide their arms from the plate to their mouths.
- Olfactory receptors from the aroma of the food.
- Gustatory receptors as they taste the food.

The following functions are mastered:

- Gross motor skills of posture staying upright, stabilizing the head, opening and closing the jaw balance, and hand-to mouth pattern.
- Fine motor skills of hand control, tool usage (spoon) and eye-hand coordination.
- Oral motor control of the tongue, lips and jaw.
- Executive functions of planning and squeezing.

Reference :

- Slutsky, C.M. Paris, B.A.,(2000) Exploring the Spectrum of Autism and Pervasive Developmental Disorders, N.Y. Therapy Skill Builders.

54. What is OHTA method?

OHTA method is cognitive developmental therapy (CDT) by Ohta staging. This was developed by Dr. Masataka Ohta in 1989. It is believed that autistic children reject tasks because of cognitive disorders. Based on the piagetian theory an assessment tool was developed, and based on the assessment results the children are classified as functioning at a particular stage (Ohta staging). The therapy believes that first, if children are given appropriate tasks, they would learn these tasks spontaneously; second, if the tasks are arranged appropriately in the order of cognitive development, as a result of learning, specific cognitive disorder of autistic children is corrected or at least cognitive development is corrected. The primary aims of CDT are to help overcome or compensate for the primary cognitive disabilities, to facilitate development of adaptive skills, and to reduce or prevent maladaptive behaviors.

Reference :

- Ohta, M. & Nagai, Y. (1992). *Jiheishouchiryoku no Totatuten (New approach for Autism: Cognitive developmental therapy according to Ohta's staging)*. Nihonbunkakagakusha, Tokyo, Japan.

55. What is AIT?

AIT is Auditory Integration Training developed by Dr. Guy Berard to help people with auditory processing problems. AIT is accomplished by a device which randomly selects sounds of high and low frequencies from music source and sends via headphones to the trainee. In addition, if the trainee has auditory peaks (obtained at frequencies where the person is hypersensitive) in his/her hearing (as evident from an audiogram), those frequencies are filtered out completely or partially from the music. According to Dr. Berard, after the completion of the training, all frequencies should be perceived equally well; and the person should no longer have peaks in his/her hearing. As of now, we do not know exactly how AIT may affect a person's behavior. Hypothetical explanations are available regarding the effects of AIT. Individuals with autism are reported to have auditory processing problems. So some individuals with autism, especially those who have auditory peaks in their hearing, may benefit from AIT.

Reference:

- www.autismindia.com

56. Can children with autism speak?

Many children with autism do develop speech, but at a later age when compared to non autistic children. Unlike other children their initial speech development is in the form of phrases and word combinations that are quite intelligible. Their speech is characterized by echolalia, literalness, metamorphosis and use of concrete words. Pronoun reversals, subject-

object reversals, omission of articles and inappropriate grammar are quite common in their speech.

Some children with autism may remain mute throughout their life. But they do communicate through alternate forms of communication like writing / gestures. Chances of developing speech /communication in children with autism increase if diagnosed and provided speech therapy in early ages.

Reference :

- Bernstein D.K and Tiegerman E.M (1993), "Language and Communication Disorders in Children", London : Mac Millan Publishing Company.

57. Can children with autism communicate? What are the ways in which they communicate?

Many children with autism communicate through one or the other means. Some develop speech communication and conversational skills. Few children's speech may consist of abnormalities like high pitched and monotonous voice, echolalia, irrelevant expressions but the functional speech communication is present. Others who fail to develop speech also communicate, using alternate modes like gestures, writing and pictures.

Reference:

- Deena K. Bernstein D.K. and Tiegerman E.M(1993), "Language and Communication Disorders in Children", London : Mac Millan Publishing Company.

58. What is delayed echolalia?

Delayed echolalia is late parrot like meaningless repetition of what others say or what is heard. The delay may be from few minutes to few days. These repetitions may not have any relation to the context or situation on hand.

Reference :

- Hegde M.N. (1996), "On language disorders in children", Singular publishing group, California.

59. Why children with autism do not imitate others speech?

Children with autism do not imitate other's speech due to inadequate or lack of response to speech and slower acquisition of speech sounds production and language. They show disinterest in communication and meaningful exchange.

Reference :

- Deich R.F. and Hodges P.M(1978), " Language and Speech", New york : Brunner/Mazel publishers.

60. Why children with autism do not point to people and things?

Children with autism generally have a lower level of responsiveness in comparison with other groups. Hence these children are less responsive to people and things. This lower level of responsiveness leads to the problems in pointing to people and things.

Reference :

- Deich R.F. and Hodges P.M(1978), " Language and Speech", New york : Brunner/Mazel publishers.

61. Is it true that children with ASD do not maintain eye contact, why?

Yes, it is true that majority of children with ASD do not maintain eye contact. In fact this is one of the salient characteristics of autism. These children do not look or orient their gaze towards the people. They avert their eyes when someone talks to them.

This is because children with autism have a lower level of responsiveness to surrounding things and people. Due to this they do not maintain eye contact and not because of aversion to people or any kind of visual impairment .

Reference:

- Bernstein & D.K Tiegerman E.M.,(1993), "Language and Communication Disorders in Children", London : Mac Millan Publishing Company,
- Deich R.F. & Hodges P.M (1978), " Language and Speech", New york : Brunner/Mazel publishers.

Appendix

Profile of Organisations Offering Services for Children with Autism

About this compilation.....

Our Institute conducted an international workshop on Autism (INDO US Workshop on Autism) from 10th March 2004 to 13th March 2004. During that time a large number of organizations were invited. A total of 16 organizations responded. During the current project,(2004) a questionnaire was sent to these 16 organizations requesting for specific details. Reminders were sent twice with one-month duration between reminders to those organizations who had not responded. As a result, information on 13 organizations was collected which is compiled and presented here in the following pages. For ease of use, the names of the organizations are sequenced alphabetically. We wish to mention here that the information provided by each of the organization is compiled as it is and the respective organization & is responsible for the accuracy of the content. We take this opportunity to thank the concerned persons of all the organizations who took time and efforts to provide information. We hope this compilation is useful to parents, professionals and all concerned.

Action for Autism

Name and designation of informant : Ms. Merry Barua
Address : T 370 f Chirag Dilli,
Third floor, New Delhi-110017
Phone : (011) 29256469 / 29256470
Fax : (011) 29256470
E-mail : autism@vsnl .com
Year of establishment : Feb 1991

Type of children with disabilities admitted :

ASD, Autism, Aspergers syndrome, PDD (NOS), Autism with Retts disorder, Cerebral palsy, Hearing impairment, MR,LD

Age range of children admitted : 0-14 Years

Educational programmes offered :

Home based, special school, special class in regular school, regular school with resource teaching, regular school fully included, itinerant teaching.

Approaches used

Eclectic approach, structured teaching, TEACCH, applied behaviour analysis/DTT, verbal behaviour analysis, The options

Materials used for teaching:

Visual strategies(picture / object /written schedules), Work system, Cards and folders for picture exchange communication systems, (PECS), Assessment tools developed by the organization, Other TLMs developed

Support services offered:

Sensory Integration Therapy(SIT), Speech and language therapy, Music therapy, Medical interventions through psychiatrists, Respite care by providing care givers, Information to parents about recent developments and practices.

Extent of parental involvement :

Parents observe classes whenever possible, sometimes encouraged to volunteer or work with own child under a therapists observation, parent teacher meeting (PTM) once a week, IEPs prepared in consultation with the family, Feed back on our work. We also have a mother child programme to train mothers.

Highlights / strengths of the programme :

understanding autism and its needs, exclusive training of teachers in ASD, understanding and application of the effective methods in Indian perspective

ASHA

(Academy of Severe Handicaps and Autism)

Name and Designation of the informant	: Mrs. Jayashree Ramesh
Address	: S-123, Kirlosker Colony, 3 rd stage, 4 th Block, Basaveswaranagar, Bangalore-560079.
Phone	: 080-23225279 / 23230357
Fax	: 080-22258103
E-mail	: info@ashaforautism.com
Year of establishment	: August 1995
Type of children with disabilities admitted	: Autism, Autism with MR, SL
Age range of children admitted	: 0-14 years
Educational programmes offered	: Home based, Special school

Educational strategies / approaches used :

Structured teaching with visual base, Augmentative communication, Objects, pictures and words are used according to the child's ability, Eclectic approach comprising of behaviour modification, Aspects of TEACCH, Sensory integration, Facilitated communication and structured teaching into our programme.

Materials used for teaching :

Specific teaching aids are developed by the teachers according to the child's needs.

Support services offered :

Child Psychiatrist, Child Psychologist, Occupational therapists, trained parents.

Extent of parental involvement :

Six trained mothers working on regular basis helping in all possible ways.

Highlights / strengths of the programme :

Trained special educators, and teacher assistants working on ratio of 1:2 or 3. Seminars / workshops by bringing in experts from different places to enhance our own understanding of Autism and keeping in touch with latest developments.

District Disability Rehabilitation Center

MADURAI

Name and designation of the informant	: Mr. G. Senthil Kumar Occupational Therapist
Address	: C/o Govt. Special School for Orthopaedically Handicapped Children Villapuram Housing Board Subramaniapuram Post, Madurai -62501
Phone	: 0452-2674726
Fax	: 0452-2674726
E-mail	: dcdmdu@yahoo.com
Year of establishment	: June 2000
Type of children with disabilities admitted	: ASD
Age range of children admitted	: 0-18 years
Educational programmes offered	: Home Based

Educational strategies / approaches used :

Structured Learning, Behavioral Analysis, Sensory Integration, Communication training.

Materials used for teaching:

Eco-friendly Park, Low cost sensory stimulation aid, Seesaw, swing, tunnel, ladder etc prepared by locally available resources.

Support services offered:

Early Intervention, Special Education Services, Therapeutic Services, Family Counseling.

Extent of parental involvement :

support for children with disabilities in their natural home setting.

Highlights / strengths of the programme :

Educational aid using locally, available resources, Parental awareness before planning of education to autistic children, Good communication between parents of autistic children and staff, Community awareness, training programmes for community workers and special teachers.

Institute for Remedial Intervention Services (IRIS)

Name and designation of the informant	: Ms. Mythily Chari Founder and Director
Address	: 120 Defence Colony, Chennai 32.
Phone	: (044) 22310968
Fax	: nil
E-mail	: mythily@autismindia.com
Year of establishment	: Not Mentioned
Type of children with disabilities admitted	: ASD
Age range of children admitted	: 0-18+

***Educational programmes offered :**

Home based, Special school, Special class in regular school, Regular school with resource teaching, Regular school fully included.

Educational strategies / approaches used:

Holistic Approach, TEACCH, PECS, Visual Strategies, Behaviour Management, (Positive behaviour support)

Materials used for teaching :

Resource materials have been developed, (currently under process for publication)

Support services offered :

As mentioned in educational Programmes

Extent of parental involvement :

3-day training programme is given to parents who come for consultation. Parents are involved as partners in the child's training.

Highlights / strengths of the programme:

Child centered. Activities are community supported rather than 'center' based. Early intervention programme. HRD-workshops/Training.

Manohar Education Trust

Manohar Vidyasadan

Name and designation of the informant	: Mrs. Anitha Sharma, Organizer Ratna Dass, Special Educator
Address	: 21, 12 th Cross 5 th main, Indiranagar 1 st Stage, Bangalore
Phone	: 080-20103591 (A.Sharma) 9880789747 (R.Das)
Fax	: Not given
E-mail	: Not given
Year of establishment	: 1991
Type of children with disabilities admitted	: ASD, LD/SL, Mild MR, Speech Delay
Age range of children admitted	: 3-14 years

Educational programmes offered :

Regular school with resource teaching with part time pullout programe. Nursery to 6th standard.

Educational strategies / approaches used :

Applied Behaviour Analysis, Language Pathology Special Language Training, Training in play skill, Art and Craft, Imagination skills etc.

Materials used for teaching :

Flash cards, Montessori materials, Puzzles, Work sheets. Other various ready made and teacher made aids.

Support services offered :

Sensory integration therapy, Speech and language therapy, OT, PT, ST professionals.

Extent of parental involvement :

Parents are consulted, counselled guided periodically regarding their children's needs and development. Parents are utilized as extended resource workers.

Highlights / strengths of the programme :

Children with ASD/Autism get to interact, exposed to normal children and children with other disabilities, Language stimulation and Behaviour Modification process are given better scope. Academic potentials are fully explored

Navajyothi Child Psychiatry Centre

Name and designation of the informant	: Ms. Fanny, MSW, Psychiatric Social Worker Sr, Serena, Special Educator, DMR
Address	: Dr. SitaLakshmi George, Navajyothi Child Psychiatry Centre, Kusumagiri PO, Kakkanad, Kochi-682030.
Phone	: 0484-2422215, 2422160
Fax	: Not given
E-mail	: Not given
Year of establishment	: 1995
Type of children with disabilities admitted	: Hospital Setting (Navajyothi Autism Project)
Age range of children admitted	: 0-14 years

Educational programmes offered:

Home Based, Special School, Special Regular school with resource teaching, Regular school fully included, Itinerant teaching, In-house training, Training for socialization.

Educational strategies/approaches used :

Home based skills

Materials used for teaching:

Picture cards, Number cards.

Support services offered:

No specific therapy.

Extent of parental involvement:

Parent child training.

Highlights / strengths of the programme :

Strengthening of the family, Tailor made training programme for the child after understanding the needs, 1:1:1 i.e. child to therapist to mother method of training.

Parents Association for Autistic Children (PAAC)

Name and designation of the informant	: 1. K. Lakshmi, Secretary. 2. K.S. Lakshmi, Treasurer.
Address	: 4-180/136, Sai Baba Officers Colony, Sainikpuri, Secunderabad-94
Phone	: 31053955
Fax	: Not given
E-mail	: autismpaac@yahoo.co.in
Year of establishment	: February , 2004
Type of children with disabilities admitted	: Autism, Hyperactive disorder, Mild MR, Moderate MR.
Age range of children admitted	: 3-14 years
Educational programmes offered	: Mother and child program

Educational strategies / approaches used :

Basically mother and child program and very often children are exchanged for training with the other mothers to develop interaction

Materials used for teaching :

Different materials to develop gross and fine motor skills, cognitive skills, PECS.

Support services offered :

Periodically we consult professionals for help.

Extent of parental involvement :

Full fledged parental involvement.

Highlights / strengths of the programme :

Basically positive, Spotting the inherent talent in children and developing such talent with innovative ideas

*This organization emerged during the project period of the Autism project at NIMH and is being provided with technical support.

Center for Autism Management

PARADIP

- Name and designation of the informant** : Dr. Mrs. Mallika Benergee
Hony. Director
- Address** : 1. (Project) 864, Lake Town,
Block-A, Kol-700089.
2. (Off) 203/B, Lake Town, Block-B,
Kol-700089.
3. (Res) 129/1, Bangur Avenue, Block-B,
Kol-700055.
- Phone** : 1. (Project) 033-2534-0891,
2. (Off) 033-2534-1832,
3. (Res) 033-2574-8503
4. (Mobile) 9331047831.
- Fax** : Not given
- E-mail** : mallib@hotmail.com
- Year of establishment** : 2004
- Type of children with disabilities admitted** : Autistic
- Age range of children admitted** : 3-14 years
- Educational programmes offered** : Home Based, Special School.

Educational strategies / approaches used :

Classical Learning theories, LOVAAS technique, TEACCH, Speech therapy, Music therapy, Dance therapy, SIT.

Materials used for teaching :

Flash cards, Montessori Material, Trampoline, Stepper, Static cycle, Music System, Pre-vocation training material.

Support services offered :

Speech therapy, Music therapy, Dance or Movement therapy, SIT, Physiotherapy.

Extent of parental involvement :

Parent teacher meeting, Parental counseling by counsellor, Parental training, parent body named 'Padakshep' arrange sports, picnic, saraswathi puja and summer camp every year.

Highlights / strengths of the programme :

Teachers, Parents, Materials, Books

S.P.J. Sadhana School for Developmentally Handicapped

- Name and designation of the informant** : Sr. E. Garwande, Principal
- Address** : Dr. Rocendo Ribeiro
Children's Complex,
Sophia College Campus,
Bhulabhai Desai Road,
Mumbai-400026.
- Phone** : 23517913, 23510853
- Fax** : 022-23511954
- E-mail** : ssadhana@hathway.com
- Year of establishment** : 1973
- Type of children with disabilities admitted** : Mentally challenged and Autism
- Age range of children admitted** : 3-18+ years
- Educational programmes offered** : Home based, Special School,
2 sheltered workshops.
- Educational strategies / approaches used :**
FACE Program Facing autism
- Materials used for teaching :**
Teaching plan as per the child's needs.
- Support services offered :**
Brain Gym, PECS program, Art therapy, Music therapy.
- Extent of parental involvement :**
On a regular basis a daily follow up written in the diary, Parent- teacher interaction as and when required and 6 weekly open day.
- Highlights / strengths of the programme :**
Teaching plans based on each child's unique behaviors and experience and expertise of the staff.

Sairam Autism Center

(The research society for the care, treatment and training for the children in need of special care)

Name and designation of the informant : Ms. Rashmi Desai,
Occupational Therapist

Address : Jai Vakeel Special School
Opp. Milan Industrial Estate
Abhyudaya Nagar,
Sewri hill, Sewri, Mumbai-400028

Phone : 022- 2470 1231,
022- 2470 2285

Fax : 091-022-02470 2285

E-mail : res@bom3.vsnl.net.in

Year of establishment : Sairam AutismCenter.(1998)

Type of children with disabilities admitted : ASD, Fragile X Mental deficiency Syndrome with Autism, Downs syndrome with Autism, Aspergers Syndrome, Autism due to any other chromosomal abnormalities

Age range of children admitted : 3-14 years

Educational programmes offered : Home based, Special school.

Educational strategies / approaches used :

Applied Behaviour Analysis by Lovaas

Materials used for teaching :

Conventional teaching materials, Functional based and child specific, audiovisual mode (computers) for teaching.

Support services offered :

Occupational therapy, Speech therapy, Psychiatric opinion if needed.

Extent of parental involvement :

Parents are trained to carry on home-based training. Other family members are called and counselled about the child's condition for a better home program.

Highlights / strengths of the programme : Thorough assessment by a team of professionals. Latest mode of education by using Applied Behaviour Analysis method. Parent training programmes for a better home training program.

Samarpan Center for Autism Spectrum Disorder

Name and designation of the informant	: Ms. Shiante Lobo Principal
Address	: M.G. Road, Near Kesarkar Garden, Vile Park (E), Mumbai 400057.
Phone	: (022) 56043998
Fax	: Not given
E-mail	: samarpan_asd@rediff.com
Year of establishment	: 2002
Type of children with disabilities admitted	: Autism, Aspergers syndrome, PDD-NOS, Fragile-X.
Age range of children admitted	: 6-18+ years
Educational programmes offered	: Home based, Special school.
Educational strategies / approaches used	: Lovaas method using DTT, TEACCH, ABA, Incidental teaching, ACC, VBA
Materials used for teaching	: TLMs prepared as per the child's needs.

Support services offered :

Speech and language therapy, Occupational therapy, Special education, Home based program, Pre-vocational, Vocational training.

Extent of parental involvement:

They are being trained to train their children at home. Involved in IEP planning.

Highlights / strengths of the programme:

Highly structured individualized program. Qualified and well-equipped team of professionals, coordinated multi disciplinary approach, continual staff development program

Special Education Center run by NIMH

Name and designation of the informant	:	Mr. Ganesh Shreregar Principal
Address	:	National Institute for the Mentally Handicapped, Manovikas Nagar, Secunderabad - 500 009.
Phone	:	040-27751741 Ext. 214
Fax	:	040-27750198
E-mail	:	ganeshua@yahoo.com
Year of establishment	:	1987
Type of children with disabilities admitted	:	Mild and Moderate MR, Severe, Profound Multiple Handicapped, Autistic Children
Age range of children admitted	:	3-18 years
Educational programmes offered	:	Home based training, Special School, Regular School fully integrated.

Educational strategies / approaches used :

Sensory integration and calming activities, Strategies to decrease tension and increase attention, Communication skills, Social skills, DTT, structured environment.

Materials used for teaching :

Visual interactive Schedule (TLM) Teaching learning Material depending on the individual need. Charts, Flip Boards, Flash Cards, Computers.

Support services offered :

Sensory stimulation, Play therapy, Occupational therapy, Sand therapy, Water therapy, Speech and Language therapy, Behaviour modification, medical attention when needed.

Extent of parental involvement :

Parental involvement for follow-up program at home. Parent-teacher meetings, Cultural programme, Summer camps

Highlights / strengths of the programme :

Programmes based on the child's interests. Use of appropriate material for sensory stimulation

Ummeed Child Development Center

Name and designation of the informant : Mr. Vineet Iyengar
Chief Operating Officer

Address : 7A Chinoy Mansion,
Warden Road,
Mumbai - 400 036

Phone : 91-22-23632932 / 23632258

Fax : Not given

E-mail : ummeed@vsnl.net

Year of establishment : 2001

Type of children with disabilities admitted :

ASD, Downs Syndrome, ADD/ADHD, Motor Co-ordination Delays, Mental Retardation, Cerebral Palsy, Seizure Disorder, Global Developmental Delays, Tourett's Syndrome, Selective Mutism, Sensori neural Hearing Loss, Academic Difficulties, Learning Disabilities, Attention Issues, Behavioural Issues, Developmental Issues

Age range of children admitted : 0-18+ years

Educational programmes offered : Depends on the individual need of the child

Educational strategies / approaches used :

Behavior therapy, Principles of ABA, PECS, Signs and cues, Speech therapy, TEACCH.

Materials used for teaching :

PECS, Visual schedule boards, Flash cards

Support services offered :

ABA, Speech and Language therapy, Occupational therapy, Physical therapy.

Extent of parental involvement :

Parents carry out home program with the professional's help.

Highlights / strengths of the programme:

Integrated approach, ABA , ST , OT

Language and Child Development Center

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