

autism

N E T W O R K

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Autism Network is a forum for expressing diverse opinions. Action For Autism does not hold itself responsible for opinions expressed by individual writers. Publication of any information does not mean support of Action For Autism.

INFORMATION

For information on receiving the Autism Network write to: Action For Autism, T 370 F Chiragh Dilli Gaon, 3rd Floor, New Delhi - 110 017, Tel: 29256469, 29256470.

Autism Network does not accept advertisements. Expenses are met through memberships, donations and sponsorships, from our readers, friends and well wishers.

YOUR CONTRIBUTIONS

Do you have any comments, suggestions to offer? Information and experience to share? We look forward to our readers' participation. Send letters, articles, illustrations to:

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Cover Illustration

'Draw a car/ Draw a house'
by
Vishu Singh, student at Open Door

WISHLIST !

FOR THE STUDENTS

- o The use of a room for one year to store AFA's printed materials
 - o School bus
 - o A Digital Camera
 - o Still Camera
 - o Rolls of film
- o Audio Cassettes of soothing music
 - o Blank audio cassettes
- o Children's tricycles/ slides/ swings/ seesaws
- o Paper to recycle for children's worksheets
- o Mattresses
- o Bean bags of all sizes
- o REAMS of A4 paper

FOR THE OFFICE

- o A Scanner
- o Two fast printers for computers in working condition

FOR THE NATIONAL CENTRE

- o Support for components of the NC Building

If you want to help, write to AFA or call:

- Priyanka Mazumdar: Tel. 2925 6469/70
- Indu Chaswal: Tel. 2609 4410
- Reeta: Tel. 2925 6469/70

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PAGE ONE

The very 'normal' looks of children with autism often leads to the greatest complications with regards to schooling. Parents are still misleadingly advised that their child has: "...more good genes than bad genes. He'll get all right." The children get admission into 'normal' nursery schools without much to-do, much ahead of, say, a child with Downs Syndrome. But eventually, the school finds it hard to deal with the specific needs of a child with autism, notwithstanding their so-called 'normal' looks. On the other hand, the child with Down Syndrome with more sophisticated social abilities manage to carry on. Advanced cognitive skills also sometimes give a misleading picture, till their difficulties in generalizing their learning invariably lead to problems at school. Despite this, mainstream schools are increasingly giving inclusion the nod. Others have started special needs sections where they are not averse to including children with pervasive developmental disorders.

This is coupled with a distinct increase in levels of awareness of autistic spectrum disorders among every level of society. The makers of a popular film flip-flopped on whether the protagonist was a person with autism or not(!) but in the process 'autism' featured repeatedly in the mainstream media. A popular TV serial features a lead character with an autistic brother: prompting the occasional young student to draw positive comparisons with their personal situations during classroom discussions on siblings. Regardless of the flawed representation of the autistic condition, the serial has become a great vehicle of awareness.

IMPORTANT

Please refer to the Action For Autism website: <http://www.autism-india.org> for upcoming conferences, workshops, events and other happenings.

Many of you do not receive AUTISM NETWORK on time to participate in some events or do not receive some issues at all.

We apologise for the vagaries of our postal system but suggest you check out our website periodically where we try and post all information well in advance.

The number of activities being undertaken on training and education by different organisations around the country has increased as well and Autism Network is happy to carry information on these. This was also the year of the World Autism Congress at Herning in Denmark, where AFA represented the South Asian autism community in a great experience of sharing and learning.

The year celebrates other events as well. This issue concludes ten years of unbroken publication of Autism Network. And as Autism Month kicks off the first batch of students trained under the Diploma in Special Education (Autism Spectrum Disorders) join the workforce.

In the meantime, sometimes upto a hundred children and adults continue to spend a crammed day at our Centre, and it's a tribute to the spirit of each one of these individuals that they flourish and carry on with zing and drive. We all look forward to moving in to our new centre by mid 2005. Inshallah, the next issue of Autism Network will celebrate that move! Till then we wish our readers a Joyous Christmas and a Splendid New Year ahead!

Activities planned in the 2005 NEW YEAR

- *December 04 and January 05*
Partner in research project on Sexuality and Autism with School of Psychology Deakin University Australia Researcher Archana Kaur
- *7 January*
Conduct Workshop in Kolkata on Communication
- *16 January*
Sponsored Walk for Autism
- *23 January*
Participate in and present Paper at Challenge for Autism in India Conference Bangalore
- *26 & 27 January*
Workshop in Dubai
- *5 February*
Workshop on Behaviour Modification

So is this school right for my child?

“Which school is best for my child: a ‘normal’ school or a special school?” This is one of the most repeated queries from parents once they have overcome the trauma of diagnosis of autism for their child. The world talks of inclusion and mainstreaming. And yet our children are in segregated schools. Should not all our children with autistic spectrum disorders be mainstreamed too.

AS parents agonise over what would be best for their child, they access the internet, and talk to various professionals. However, while most professionals nowadays talk of inclusion as one voice, what it means to each of them is often quite varied. “And finally,” as one parent commented “I think I am more confused now than when I started.”

INCLUSION is undoubtedly what each right thinking person wants. True inclusion is where all students of every ability, every social, every economic, every religious, and every other background, attend and participate fully in the educational provision nearest to them. No difference is made between one child and another: the only determining factor being their ‘student’-ness. Inclusive education aims at fostering every student’s participation in all aspects of the life of the learning community.

HOWEVER when different people speak of inclusion they have different and specific perspectives in mind. Some look at the economic aspect, some at the religious, others at caste, class, creed, and still others at ability. For us the focus is of course on varying ability: be it intellectual, physical, social, emotional, medical, or any other.

AT present college education for persons with autism in India is not even thought of. Except of course for those at the very able end of the spectrum who remain undiagnosed until into their adulthood when they recognize the characteristics of autism in themselves and thereby find an answer to their often perplexing difficulties through life.

FOR persons with autism with their different learning styles the situation can be somewhat more

complex than for those with other disabilities. For instance one is often asked: is it not detrimental to have schools for children with autism alone? After all autism is a social disability and how would they learn social skills if they are with other children with autism. Good point. But merely putting them in a mixed set up cannot teach social skills. In which case all children with autism who have typical siblings at home should have terrific social skills! After all, they spend the entire day with their siblings. Unfortunately that is not always the case. Much depends on the adults in the environment. The reality is that unless there is teaching of social skills and good facilitation of interaction most children with autism will not learn good social interaction skills. Whereas when that does happen, they learn to interact socially with other children with autism as well. But more of that later.

INCLUSION assumes that services and service providers adapt to the needs of the individual and not the other way round. Reality is that the individual is expected to adapt to the services available. Nowhere is it more pronounced as it is with the ‘invisible’ disabilities. Service providers are often more agreeable to make provisions for say ramps and audible announcements and adapted signage, than to allow a child with autism the facility of sitting up front and to a side, or the use of a computer in the classroom. Service providers are quite willing to say “Why should he use a computer when no one else does?” though it would be unthinkable for them to say “Why should we build a ramp for his use when others don’t use one”. The point being made is that people understand the need of a ramp, for instance, easier than the need of a child to use a computer for writing, when that child seems to have perfectly good use of his hands for eating and dressing.

WHAT we additionally need to keep in mind is that children with autism are not one huge homogenous body. They are individuals. And they all have individual educational requirements. These could range all the way from:

- total inclusion in regular mainstream school with or without an aide
- placement in special needs classroom in a mainstream school

A counselor recently got an interesting reminder to watch her language when talking to children with Aspergers Syndrome.

Counselor asks kid with aspie:
“How’s school going?”

Kid replies, “On and on.”

with some periods in the mainstream classrooms, with or without an aide

- special needs classroom in a mainstream school with only periods like break or music with the other children
- mixed disability school along with children with mental retardation, cerebral palsy, down syndrome, and so on
- autism specific school
- home school.

THIS list is neither exhaustive, nor is it laid out in order of 'better-ness' of a placement! However the common understanding is that the listing is one of 'best to worst' with terminology like 'least restrictive' being used for the top of the list and 'most restrictive' being used for the bottom of the list. Alas, as far as autistic spectrum disorders is concerned its not so simple and cut and dried as that. Fact is that each of these placements is the perfect one for some children and not so for others. Truth also is that one kind of placement may be just

right for a child now but not two years down the line. People change, children progress, their needs change, their requirements change.

OFTEN when we talk inclusion, the assumption is that the ability and special needs of the child alone are what determines the kind of placement required by a child. While that would be true in an ideal situation, we do not live in an ideal world. The appropriateness of a placement depends on a variety of factors that is extrinsic to the child in question. Is the school one where there is adequate awareness of autism and the needs of a person with autism? Is the school one where the teachers, the student body, and their parents are open to the simple understanding that children are different, that they may learn in different ways, and that it is okay to be different? While children can be quite outstanding bullies, often their levels of intolerance or acceptance, and their behaviour towards those who are different, are determined by the attitudes at home. *[To be continued]*

Making a Difference

Forum for Autism, Mumbai

The Forum for Autism, Mumbai has now become established as a full-fledged NGO. Its member volunteers have been giving valuable information and guidance to parents of newly diagnosed children with autism and to newly relocated parents. The Forum now has a computer, telephone, library with 350 books on autism and a full-time librarian at its Colaba office. Plans are afoot to set up two more branches to serve the needs of the central and northern parts of Mumbai. The Forum has been very active in organizing workshops at regular intervals to bring knowledge of the latest developments in autism to Mumbai.

IT organized a two-day workshop "Teaching Language and Appropriate Behaviour to Children and Adults with Developmental Disabilities: an introduction to Verbal Behaviour" by Dr Patrick McGreevy Ph.D, Board Certified Behaviour Analyst, Florida, USA. The workshop, which was organized with the help of Mrs Kamini Lakhani, Director, Support for Autistic Individuals (SAI) was held on the 5th and 6th of June at Nehru Science Centre, Worli. It was inaugurated by Ms. Merry Barua, Director, Action for Autism, Delhi and was well appreciated by the participants who came from different parts of the country.

FOLLOWING that, an all-encompassing training workshop for parents of autistic children and professionals dealing with autism was held by Ms Merry Barua and Ms Indu Chaswal, Action for Autism, Delhi. This workshop, organized by the Forum from 5th-8th August, 2004 was full of practical advice for the over 100 parents and professionals who attended it.

THE Annual General Meeting of the Forum for Autism was held on 11th September, 2004 at which the old committee was dissolved and a new one was appointed.

FORTHCOMING activities of the Forum include a one-day workshop on Sensory Integration by Dr Anjali Joshi and Dr Ashwini Vaishampayan. This workshop is planned to be held on 27th November, 2004 at KEM Hospital, from 9AM to 5PM.

MEANWHILE, the Forum has started brainstorming ideas for a group housing scheme.

IF autism parent support groups elsewhere in the country are also thinking on these lines, the Forum would love to hear from them.

World Autism Congress, 17 - 19 September 2004

Indu Chaswal

Hernning, a small yet modern town in Denmark was the host for the World Autism Congress 2004. Action for Autism had the privilege to be invited by the Autism Society of Denmark to attend the Congress.

WE arrived in Hernning after a four -hour drive along the beautiful landscape and over the sea. The following morning we were the guests of Lars Krurup, the Mayor of Hernning for a very warm welcome to his town. That evening the Congress was inaugurated at Scandinavia's biggest congress and conference centre.

THE three-day program included a general assembly, lectures, exhibitions, and cultural programmes. The conference was a well planned combination of interesting and diverse sessions on various issues related to Autism. The participants were well-known professionals, parents, teachers, and self advocates from all over the world.

THE evenings were a great opportunity for delegates from different cultures to share information, experiences, and enjoy the festive events and splendid dinner.

AFA's founder director Merry Barua gave a very well received presentation on 'Empowering Families'. She

also won an award of distinction for the work done by her in collaboration with the Autism Society of Denmark!

BACK in Copenhagen on 19 September we visited two schools and a sheltered workshop. Froyer Skolen, a school for children with Asperger Syndrome, has 45 students in the special wing of a regular school. Using TEACCH methodology the students learn school subjects along with other functional skills. Sofie Skolen is the oldest school for children with autism in Denmark with a residential unit in the same building. What impressed us most was the well-structured environment within which the school was run.

THE sheltered workshop Sovi, is of particular interest to us at the *Adhaar Work Skills Training Centre* at AFA. Sovi is an independent Company for adults with mild to moderate autism, that uses Visual Communication Support Systems, Social Histories, Comic Strips and CAT- box (Cognitive Affective Training). The adults working here travel on their own. Most live in group homes and a few stay with their families.

THE visits to the schools and the Sovi Workshop was for us an enriching experience to be shared with families and colleagues in this part of the world.

The Challenge of Autism in India Today

TOWN HALL BANGALORE • 23 - 25 JANUARY 2005

• **Pre-Conference Workshop:** 22 January 2005

1) An Integrative Biomedical & Psychological Approach To Treat Autistic Spectrum Disorders

Dr. Anthony Underwood & Dr. Lakshmi Prasanna

2) Challenges of autism through the years

Mrs. Jalaja Narayanan

Registration: Rs. 250/ - inclusive of lunch & tea

• **National Conference:** Organized by Karnataka Parents Association For Mentally Retarded Citizens and National Institute For Mentally Handicapped, Secunderabad.

- Day 1 – Sunday, 23 January 2005: Medical issues
- DAY 2 – Monday, 24 January 2005: Educational objectives
- DAY 3 – Tuesday, 25 January 2005: Social and community involvement

Registration: Rs. 600/ inclusive of lunch & tea

For application form, accommodation details contact: Karnataka Parents Association for Mentally Retarded Citizens, AMC Compound, Off Hosur Road, Near Kidwai Hospital Bangalore 560 029 Tel/Fax: 080-26564608/26563267 or Email: jpkpamrc@vsnl.net or vmathias@vsnl.com or info@ashafortautism.com



LETTERS

I am an Indian living abroad. I have a five year old girl G who is attending a regular school. She has been diagnosed in the autistic spectrum. She has been in special needs programme recommended by her paediatrician from the Starship Hospital. From the age of three she had a speech therapist, early developmental teacher and a psychologist. All have helped her in her progress.

She had delayed language development which was taken into focus at the age of three. She has developed language and is able to answer questions appropriately. She has understood various concepts and she is able to make sentences up to five to six words. Her language is improving though the clarity has to develop. She is following instructions in school and is now getting used to the school routine. She does not have the typical autistic behaviours, her main problem is not being able to make friends and develop bonding with kids of her age. She has no problems in interacting with older kids. I sit with her every day for two hours after her school helping her with math and reading which is developing. She is able to take part in all the activities which a normal five year old is able to do.

I was really moved with all the efforts you people are doing in India. I pray that you get all the necessary funds and are able to help people in India to face the problems associated with having a member of the family with autism. It is the biggest emotional problem and trauma any parent can face. If you want any help from my side I am willing to contribute.

S SANKAR
New Zealand

This is in relation to Question 1 of your 'Helpline Autism Network' issue of August 2004, regarding the advice from NIMHANS that a neurologist, psychiatrist, clinical psychologist, speech therapist, are required in a setting for children with autism. It is very misleading for the parents. I agree with you that this is an utopian situation. But then does Autism need this gamut of specialists.

Management of Autism totally depends on the perception of Autism to the person in contact with the child. It is a neuro-behavioural problem and it is a developmental problem.

It is noteworthy to mention that many Developmental Pediatricians are working on this subject and I was quite surprised not to see Pediatricians in the list. Pediatricians are the first line doctors of a child and are the first to notice the variations, thereby leading to early intervention.

I am a developmental pediatrician running a centre dedicated to Autism – the Assam Autism Foundation, and for any help required one may contact us at the address below:

DR SHABINA AHMED
Assam Autism Foundation
Amarawati Path,
Christian Basti
Near Dispur Post Office
Guwahati - 781005
Tel: 0361-2547536, 2548191, 98640-14608

We have been reading Autism Network for the last four years. We find it informative and it helps many parents get information and knowledge about autism and in bringing up their wards.

A & N SAHA
Mumbai

I am the father of a child with autism and I subscribe to Autism Network. I would like to thank you for the magazine which provides invaluable information which is helpful in dealing with my son.

I would appreciate it if you continue to give us more information on Autism and inform us about seminars or workshops held in the future.

N GROVER
Delhi

Reasons to Smile

Poonam Nanda

I have reasons to smile because the vision of seeing Vinnie as a productive member of this society does not seem a distant dream anymore. That is because of a set of dedicated teachers who have been instrumental in ensuring that Vinnie, who is a child with Autism Spectrum Disorder, is successfully mainstreamed and enjoys being part of a regular classroom. They have given us, Vinnie, me and my family reasons to smile.

Early Years

At two years and nine months Vinnie joined Stepping Stone Montessori House, Calcutta. When we learnt that Vinnie was a different child we were shattered, coupled with the fear that Vinnie may have to be withdrawn from school because of being 'different.' How misplaced my fears were! Under Principal Poonam Mitra, the teachers took special interest in Vinnie. I was asked to bring Vinnie a little earlier to school so that they could give her more individualized attention. Amongst other things, Vinnie learnt numbers, the alphabet and spellings of three letter words from them. She participated in all the school activities along with regular kids. On sport's day Vinnie participated in the 'Dhobi Race'. A slightly older boy was made Vinnie's partner to ensure Vinnie didn't mess up. Her days here were filled with fun and learning and she enjoyed every bit of it.

School Searching

Vinnie turned four and now there was need to look for another mainstream school for older children. Realizing that Vinnie could have severe difficulties in coping with a regular school and also because she needed Sensory Integration Therapy, I decided to move to Delhi. Here, my search for a school which also had learning center brought me face to face with the reality that schools catering to children with special needs weren't enough and there was also a definite paucity of special educators. The Heritage School, Gurgaon was then just starting its Learning Center and I decided to get Vinnie admitted there.

Vinnie's Difficulties

Vinnie has sensory dysfunction and light touch is painful and Vinnie tends to lose control if a stranger touches her lightly. Yet the feel of a breeze on her cheeks may be exhilarating and she may get absolutely absorbed by it.

She dreads loud and shrill sounds like that of a mixer, floor grinder, drill machine and even the school bell may cause physical and emotional distress. On the other hand distant sounds that are low can distract her such that she is deaf to what is being said to her. Certain smells are overpowering too. All this comes in the way of her paying attention in the classroom. Also, because of delay in fine motor coordination she is extremely slow in writing and copying from the board. Vinnie needs to be prepared for changes in routine in advance; else she can get upset and uncooperative. She has an excellent vocabulary but usage of language could be better. Not many teachers would welcome a child with these difficulties in their class.

New School

Vinnie attended the Learning Center for her academic work, and joined a mainstream classroom for activities like dance, clay modeling, and music. Honey, her class teacher played a crucial role in ensuring that Vinnie gradually became comfortable with other children in her class. For one complete academic session, Vinnie participated with this class in all the activities including stage functions. Training Vinnie to participate in these stage functions must have been tough but Honey never excluded Vinnie from any program. Gradually but surely Vinnie was becoming a part of her peer group.

Inclusion in Mainstream

Next year Vinnie turned six and went to Class 1. I was informed by the Learning Center that they wanted Vinnie to be mainstreamed for academics as well. I was gripped with fear. What if Vinnie, unable to tolerate too much touching by other kids, hit them? Will she be able to adjust to the noise level? Will the teacher have patience with her slow writing? Will she be able to focus in a classroom of 25 children? Will the other children accept her without ridiculing her? She is so comfortably settled in the Learning Center, why should we take chances by disrupting it?

I am grateful to the staff at the Learning Center who convinced me to mainstream Vinnie. Keeping my fingers crossed I prepared Vinnie and told her that she would now be going to Class 1 and not to the Learning Center. I was surprised at how thrilled she was! Her happiness

gave me courage but added a new worry. What if Vinnie is unable to cope and asked to go back to the Learning Center? This would rock her confidence and self esteem.

Teachers can be Angels

Angels at times come in human form and so did Anjali the class teacher. She sensitized the other children to Vinnie's tactile difficulties and gave Vinnie a loving and affectionate peer group. Vinnie would come back home with stories about her friends and insisted on changing her surname to Sheperd because her new friend's surname was also Sheperd. She told me that Raunak was her boy friend and when I asked her what boy friend meant she answered 'elder brother'. This was a new Vinnie- bubbling with excitement and full of conversation and stories about her many friends. One month has passed since Vinnie's inclusion into the mainstream classroom. Her teachers have ensured that this transition is smooth. The staff at the Learning Center remain in constant touch with her class teacher as well as her other teachers. Vinnie's writing is poor but Anjali encourages her for her efforts. When Vinnie is unable to finish copying from the board, her teacher allows her to take another child's notebook home to finish her work. Anjali's compassion and understanding coupled with firmness and motivation is working wonders with Vinnie. Sensory Dysfunction may pose difficulties in concentrating in a regular classroom but during this

month Vinnie learnt ascending and descending order, and spellings of new Hindi and English words in the mainstream class.

Peer Group

Now Vinnie does not want to sit a little away from other kids. She loves playing and dancing with all others in the rain dance with no apparent discomfort. She has learnt swimming and can now swim one breadth. She joins the other children on all school excursions. She is a part of the mainstream not cosmetically but in every sense of the term. On the way back from school I hear her friends calling out "Vinnie bye, Vinnie bye". "Hi Vinnie, Hi Vinnie", receives her all around. Right from the main gate of the school, through the reception area and the corridors of the school Vinnie is loved and taken care of. How can I forget to thank the parents of other children for inculcating the values of love, caring and compassion in their children. You must be proud parents and so am I for becoming part of a revolution where we do not run ahead but slow down a bit to hold the hands of someone who is slipping behind.

The management and the Principal of The Heritage School opened their doors to Vinnie and I can now relax because her school had joined hands with me. If all schools open their doors it will give all our children a reason to smile.

December: Autism Month

Activities planned by Autism Society West Bengal

• 11 December

'When there is a Disabled Person in the Family': A Workshop on family issues

Speakers: Dr JR Ram and Dr M Bannerjee

• 1 December to 23 December

Open House: ASWB will open its doors to other organisations to visit their resource center and observe the running of the school program. For further information contact: Autism Society West Bengal, Tel: 033 2573 0706, 98130139173

Activities planned by Action For Autism

- | | |
|----------------------|---|
| • 3 December | Observe World Disability Day |
| • 3 – 5 December | Training Workshop in Bangladesh |
| • 4 December | Family Picnic sponsored by McKinsey |
| • 12 December | AFA General Body Meeting |
| • Date to be decided | Trip to the Metro |
| • 18 December | Workshop on Writing Individual Educational Programmes |
| • Date to be decided | Launch of Diagnostic Kit |
| • 25 December | Chistmas Party |

संरचना—घर एवं स्कूल में

इन्दु चसवाल

उत्तर कैरोलीना युनिवर्सिटी (अमरीका) का "टीच" विभाग लगभग पच्चीस वर्षों से कार्यशील है और यहाँ आटिजम और संचारण दोष से प्रभावित लोगों को पढ़ाने और प्रशिक्षण देने के सफल तरीके विकसित किये गये हैं। इनमें सेबसे अधिक लाभदायक और प्रसिद्ध है (structure) या संरचना विधि। ऑटिस्टिक व्यक्ति में स्वयं कोस और अपनी प्रतिदिन होने वाली गतिविधियों को व्यवस्थित करने में कठिनाई होती है। नतीजा होता है अव्यवस्था जो कि उनकी बातों और उनकी क्रियों में दिखती है। संरचना द्वारा हम इस कमी को काफी हदतक पूरा कर सकते हैं।

उदाहरण :

यदी हम पाँच-छः वर्ष की आयु वाले बच्चे को कहें "एक चित्र बनाकर दिखाओ", तो वह बच्चा हमारी बात समझकर चित्र बनाकर दिखायेगा। हमें इस का एहसास ही नहीं होता कि इस साधारण बात को पूरा करने के लिये बच्चा निम्नोलिखित क्रियाओं को सही रूप से संगठित करता है :

- अपनी ड्रॉइंग (drawing) कॉपी या कोई अन्य कागज लेना
- चित्र बनाने के लिये कलम, रंग इत्यादी लेना
- किसी निश्चित आरामदायक स्थान पर बैठ जाना
- चित्र बनाने के लिये कल्पना करना
- चित्र पूरा हो जाने पर कलम, रंग इत्यादी को वापिस रखना
- चित्र दूसरे व्यक्ति को दिखाना
- मन में कोई प्रश्न उठने पर सही तरह से पूछकर अपना संदेह दूर करना जैसे : "किस वस्तु का चित्र बनाना है?" "क्या कॉपी या पेपर की शीट पर?" " क्या रंग भरने हैं?" इत्यादी ।

अब यही स्थिती एक ऑटिस्टिक बच्चे के साथ कैसे होगी, इस बारे में हम सोचते हैं। मान लीजिये की यह ऑटिस्टिक बच्चा छः से आठ वर्ष की आयु का है :

- सबसे पहले जब हम उसे कहेंगे की वह चित्र बनाये तो वह समझ नहीं पायेगा कि हम किस चित्र की बात कर रहे हैं।
- अपने इस कार्य को पूरा करने के लिये जो छोटी छोटी क्रियाएँ निश्चित क्रम में करनी होती है (पेपर अथवा कॉपी में रखने, कलम और रंग साथ में रखना, कुर्सी पर बैठकर काल्पनिक शक्ति व वार्तालाप द्वारा निर्णय करना कि क्या बनना है), उनको व्यवस्थित करने में इस ऑटिस्टिक बालक में सीमित गुण होंगे।

- बहुत से ऑटिस्टिक बालक, चित्र बनाते समय ध्यान केन्द्रित नहीं कर पायेंगे या फिर यह नहीं निर्णय ले पायेंगे कि कब उनकी ड्रॉइंग पूरी हो गई है। वह उसी कागज पर कलम घिसते रहेंगे।
- कोइ भी गड़बड़ या उलझन को सुलझाने के लिये दूसरे से पूछ ताछ उचित तरीके से नहीं कर पायेंगे।

ऐसी स्थिती में माता-पिता परेशान हो जाते हैं। दिनचर्या में घटने वाली क्रियायें जैसे कपड़े पहनना, रखना, नहाना इत्यादि में बच्चा बहुत अटपटा या अव्यवस्थित रहता है। परन्तु इसका अर्थ यह नहीं है कि व्यवस्थित होने के गुण ऑटिस्टिक बच्चा सीख ही नहीं सकता। हम उसे यह गुण सिखा सकते हैं, और इसके लिये अति लाभदायक सिद्ध हुइ है शिक्षा की विधि जिसे कहते हैं "संरचना" या "structured teaching"।

संरचना का अर्थ क्या है?

"संरचना" का अभिप्राय है "दार्शिक स्पष्टता देना जिसके द्वारा ऑटिस्टिक व्यक्ति देखकर समझ जाये कि उस से क्या प्रत्याशा या उम्मीद है"।

संरचना घर में और स्कूल में कैसे प्रदान कर सकते हैं?

हम दार्शिक स्पष्टता जीवन में तीन क्षेत्रों में दे सकते हैं। यह है:

1. घर व स्कूल के भौतिक वातावरण में।
2. समय के उपयोग में।
3. क्रियाओं में।

इन तीन क्षेत्रों में दार्शिक रूप से स्पष्टता देकर हम आटिस्टिक व्यक्ति के जीवन में पूर्वअनुमान या होने वाली स्थिति कि जानकारी की क्षमता बढ़ा सकते हैं। इस से वह अपने जीवन में आत्मनिर्भर बन सकता है।

ऑटिजम नेटवर्क के इस अंक में हम बात करेंगे "घर व स्कूल के भौतिक वातावरण को दार्शिक रूप से स्पष्ट या संरचित करना"

संरचना – बच्चे के भौतिक वातावरण में:

इसका अर्थ है स्कूल में जगह निश्चित करना, जहाँ विशेष क्रियाएँ हो सकती है। हम सब चाहे जितने भी छोटे या बड़े घर में रहते हो, कुछ खास काम रवास जगह पर ही करते हैं। जैसे की कोई परिवार भोजन

मेज-कुर्सी पर रखते हैं और कुछ परिवार नीचे जमीन पर बैठकर। वैसे ही पढ़ने का, खाने पकाने का, नहाने का स्थान अलग-अलग होता है। यदी हम भोजन अनियमित ढंग से अलग-अलग स्थान पर खायें कभी टेबल पर, कभी खड़े अलग स्थान पर खाये-कभी टेबल पर, कभी खड़े-खड़े, कभी पलंग पर, कभी जमीन पर, तो यह एक ऑटिस्टिक बालक के लिये उचित नहीं होगा। उसे समझ में नहीं आयेगा कि "भोजन करने का स्थान कौन सा है"। ऐसी स्थिति में रहने वाला आम साधारण बच्चा भी गड़बड़ा जायेगा पर हो सकता है कि किसी रिश्तेदार के घर या किसी रेस्टूरेंट में जब वह जायेगा तो उचित जगह पर ही बैठेगा। परन्तु ऑटिस्टिक बच्चे में समाजिक रूप से पिछड़ापन रहता है, जिसकी वजह से ऐसे में वह खड़े-खड़े खाना शुरू कर दे या मेज होने पर भी पलंग या जमीन पर बैठ जायें। इसलिये यह आवश्यक है कि अपने परिवार के अनुसार हम स्थान सीमांकन या स्थान निरूपण कर दें।

ऐसी बहुत सी क्रियाएँ होती हैं जो अलग-अलग समय पर हम एक ही स्थान में करते हैं। उदाहरण के लिये बच्चा भोजन के लिये डाईनिंग मेज पे बैठता है और अन्य दूसरे समय खेलने के लिये, लिखने के लिये भी वही बैठता है। ठीक इसी तरह वह वॉश बेसिन के सामने हाथ धोता है और दूसरे समय पर वहीं दाँत मन्जन भी करता है। ऐसे में हम बच्चे को दार्शिक स्पष्टता देने के लिये दार्शिक संकेत (visual cues) का प्रयोग कर सकते हैं।

दार्शिक संकेत (visual cue) कोई भी ऐसी वस्तु या वस्तु का चित्र हो सकता है, जो कि किसी विशेष क्रिया को सम्बोधित करता है।

उदाहरण :

यदी बच्चा देखता है कि मेज पर एक विशेष मेज पोष (table mat) या छोटी चट्टाई रखी है तो बच्चे को देखते ही पता चलेगा की खाना है। यदी इस संकेत (टेबल मैट या मेज पोष) के स्थान पर पेन्सिल बॉक्स रखा हो, तो बच्चा समझ जायेगा कि मेज पर लिखने का कार्य होगा।

बहुत से परिवार हैं जिन्होंने ऐसे दार्शिक संकेत प्रयोग किये हैं। एक परिवार ने टेबल मैट का प्रयोग किया और इसके द्वारा बच्चे को बाहर होटल में खाने की ट्रेनिंग दी। वह उस दार्शिक संकेत (टेबल मैट) को होटल में साथ ले जाते और टेबल पर लगाते। देखते ही बच्चा खाने के लिये बैठ जाता। साथ ही वह "खाने की अच्छी आदतों" की ट्रेनिंग भी दे रहे थे।

भौतिक वातावरण को और भी विशेष चीजें होती हैं। जैसे कि :

- फर्नीचर
- रोशनी

- ध्वनी
- बच्चे के सामाजिक वातावरण में रहने वाले लोगों के वस्त्र-आभूषण इत्यादी।
- घर व स्कूल में अतिरिक्त सामान।

कुछ विशेष सुझाव :

- घर में ऐसे परदे, बिस्तर के वस्त्र और घर के अन्य सेज-सज्जा की वस्तुओं का चुनाव बच्चे के आराम के आधार पर होने चाहिये।

- बिजली के सोत्रा (बल्ब, ट्यूब लाईट, रंगीन बल्ब इत्यादी) का चयन भी बच्चे की आवश्यकताओं को ध्यान में रख के करें। बहुत से बच्चे तेज बिजली नापसन्द करते हैं।

- यदी घर में जगह की कमी हो तो फर्नीचर (मेज, अलमारी इत्यादी) को ऐसे लगाये जिस से कि एक ही कमरे में अलग-अलग स्थान सीमांकित हो सकें।

उदाहरण - पलंग (बेड़) से कुछ दूर एक दरी बिछा दें। अलमारी के किसी एक ओर छोटा मेज कुर्सी हो। ऐसी संरचना से बच्चे को दार्शिक स्पष्टता होगी :

सोना - पलंग पर
खेलना - दरी पर

लिखना/खाना- मेज कुर्सी पर (अलग-अलग दार्शिक संकेत रखें)
आरम्भ में ऐसी स्पष्टता के साथ बच्चे को सरल भाषा और शारीरिक सहायता से सिखाया जायेगा और जल्दी ही बच्चा संरचना को पहचानने लगेगा।

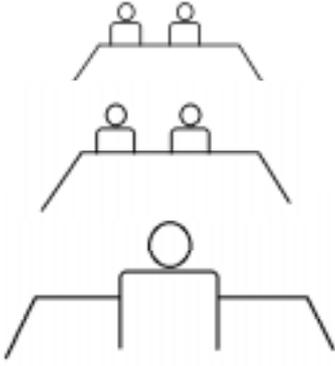
- स्कूल में भी ऐसी वस्तुओं का हटा दें जिस से बच्चे का ध्यान भटक सकता है। जैसे की दीवारों पर अधिक चित्रा इत्यादी।

- ऑटिस्टिक बच्चों के साथ काम करते समय अध्यापक अपनी वेष भूषा का ध्यान रखे। यदी बच्चा आभूषण, चमक, बिन्दी खुले बालों से ध्यान भटकता हो, तो इन्हें हटा दें।

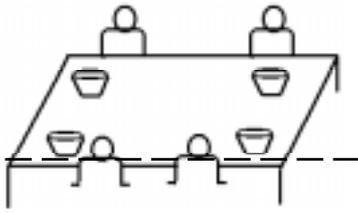
- ऑटिस्टिक बच्चे के साथ काम करते समय विशेष बातों का ध्यान रखें जैसे कि खिड़की के पास न बैठना, बच्चे से धीमे स्वर में बात करना, उसकी इच्छा अनुसार उचित स्पर्ष देना इत्यादी।

- स्कूल में खाने के समय मेज के विशेष कपड़े या प्लास्टिक से ढके ताकी वह देखने पर किसी दूसरी क्रिया के लिये से अलग लगे। मेजों और कुर्सियों की व्यवस्था भी बदली जा सकती है जिसे देख कर बच्चे को अहसास हो जाय कि क्या करना है।

उदाहरण :

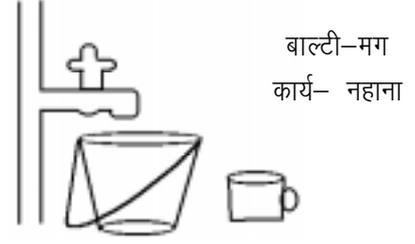


मेज-कुर्सी पंक्तियों में लगे हैं- पढ़ने का समय

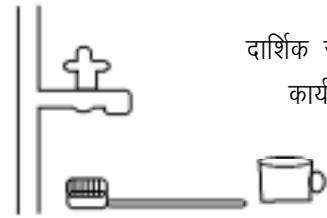


मेज जोड़कर कुर्सियों दोनों ओर लगी हैं।
भोजन का समय दार्शिक संकेत गिलास ।

दार्शिक संकेत (Visual Cues)



बाल्टी-मग
कार्य- नहाना



दार्शिक संकेत - ब्रश
कार्य- मँजन

एक ही स्थान-दो क्रियाओं के लिये

आपके बच्चे के साथ रोजाना की जिन्दगी

एस.सी. सक्सेना

जब आप के पास आटिस्म सहित कोई बच्चा है, तो प्रत्येक दिन एक चैलेन्ज का है। प्रत्येक दिन आपको ऐसे बच्चे से जूझना पड़ेगा जिसे आपसे संवाद या कोई बात कहने में कठिनाई है। प्रत्येक दिन आपको अपने आप तैयार करना है ऐसे बच्चे के पास पहुँचने को जो भावनात्मक रूप से पिछड़ा है।

नित्य की देखभाल में जब आप उसे सिखा रहे हो तब आपको देखना है कि आपका उद्देश्य बच्चे को परिवार का सदस्य बनाना है न कि उसका केन्द्र। दूसरे शब्दों में बच्चे की देखभाल और उसकी प्रशिक्षण में परिवार के सभी सदस्यों का उचित मात्रा में सहयोग जरूरी है और प्रत्येक सदस्य हिस्से में संतुलित उत्तरदायित्व ही रहना चाहिये।

हर बच्चे को अपनी जिन्दगी में एक (रूटीन) नियमितता की आवश्यकता होती है। यदि प्रत्येक दिन की घटनाएँ अलग-अलग या अनिश्चित हो, भविष्य के लिए इससे लगभग प्रत्येक बच्चा असुरक्षित और अंधकार मय

हो जायेगा। आटिस्म के बच्चे के लिये (रूटीन) नियमितता आवश्यक है। असल में बहुत से आटिस्म के बच्चों में समानता/एकरूपता के लिये हठ होता है। उनके रूटीन में थोड़े से बदलाव से या वातावरण के बदलाव से वे परेशान हो जाते हैं। इस प्रकार की कठोरता (inflexibility) /अपरिवर्तनता बच्चे के माँ-बाप को बहुत व्यग्र/दुखी कर सकती है। यह भविष्य की जानकारी आप अपने बच्चे को ऐसा वातावरण में (स्ट्रक्चर) दे सकती हैं जिसकी उसे आवश्यकता है।

(Structure) ढांचा और अनुकूलता

घरेलू रूटीन स्थापित करना बच्चे के लिय ढांचा (structure) तैयार करने का पहला कदम है। इस प्रकार का रूटीन विकसित करें कि परिवार में प्रत्येक उसमें आराम (comfort) महसूस करें और इसका लगातार पालन करे। अगर आप हतोत्साहित या दुखी होती हैं तो आटिस्म का बच्चा भी ऐसा ही महसूस कर सकता है दुर्भाग्य से इस

अनिश्चितता (confusion) बच्चा तरह-तरह के डिस्टर्बेंस/व्याकुलता के व्यवहार का प्रदर्शित करेगा जैसे अपने चोट, मारलेगा, शौच (toilet) करदेगा। इस लिए आपको पूरी तैयारी के साथ उतरना पड़ेगा कि परिवार का प्रत्येक दिन किस प्रकार से चले, तथा इस में प्रत्येक दिन की आवश्यकताएँ सम्मिलित हों। उदाहरण के लिए प्यार से समय सुनिश्चित करें कि कब आपका बच्चा नहायेगा, खेलेगा और खायेगा।

अगर आटिस्म वाले बच्चे की देखभाल के बारे में एक शब्द पर गौर देना है तो वह है दृढ़ता अनुकूलता (consistency)। बहुतसे आटिस्म के बच्चों को वातावरण से सीखने में बहुत कठिनाई आती है। वे तजुर्वे से अच्छी तरह नहीं सीखते। एक रास्ता है उनकी मदद करने का कि वातावरण को जहाँ तक सम्भव हो अनुकूल (consistent) बनायें। यह नियम लागू होता है बच्चे से आप के प्रत्येक व्यवहार पर। आरम्भ में अनुकूलता बहुत जरूरी है क्योंकि उनमें सीमित गुण होते हैं, जिनके कारण वह जो कुछ सीखते हैं उसे नई स्थिति में नहीं डाल पाते।

– उदाहरण के लिए बच्चा घर के मेज पर भोजन कर लेता है पर किसी रिश्तेदार के घर में या किसी रेस्टोरेन्ट में मेज पर फसाद रवड़ा कर देता है।

ऐसी स्थिति में यह सोचें कि अभी खाना खाने बाहर नहीं जायेंगे क्योंकि कम समझ आटिस्म का एक गुण है पर भविष्य में बच्चा सीख लेगा यदि सभी उसी प्रकार से व्यवहार करें। उदाहरण के लिये यह सुनिश्चित करें कि परिवार का प्रत्येक सदस्य उन्हीं शब्दों का प्रयोग करे जब आपके बच्चे को सिखा/ पढ़ा रहा हो साथ ही मौखिक व शारीरिक स्पर्श (पुचकारना आदि), पुरस्कार (reward) देने में भी/यदि प्रत्येक अनुकूल/एकसा है तब आपके बच्चे का व्यवहार अधिक विश्वसनीय होगा इसके बावजूद भी कि क्या वातावरण है व कैसा स्थान है। एकबार नई कुशलता स्थापित करदी जाती है तो आप धीरे-धीरे भिन्नता ला सकते हैं उससे कहने (request) या सामान स्थान में। इससे आपके बच्चे की अधिक अनुकूलन (flexible) में मदद मिलेगी।

आटिस्म के में चुनिंदा ध्यान “selected attention” या उत्तेजित अत्यधिक चुनाव “stimulus over selectivity” देरवी जाती है। इस का तात्पर्य है कि आपका बच्चा किसी स्थिति पर या स्थिति की एक सम्भावना पर अधिक ध्यान (over focus) देता है और ध्यान देने पर समर्थ नहीं है जब तक कि विशेष चरित्रा (characteristic) उपस्थित न हो। आटिस्म वाला बच्चा मुश्किल से पहचानता है (recognise) ध्यान देता है किसी विशिष्टता पर। उदाहरण के लिये आपका बच्चा चित्र में कार के रंग पर ध्यान दे सकता है पर स्वयं कार पर नहीं और

वह कार के चित्र को नहीं पहचानेगा यदि वह उसके सामने किस अन्य रंगों में रखी जाती है। और अगर वह समझता है कि सिखते समय उसकी माँ के बाल काले रंग के थे तो वह अपनी कुशलता का प्रदर्शन तब नहीं करेगा जब वह किसी भूरे बालों वाले के साथ हो। अर्थात् वह किसी भी भिन्नता के साथ एकसा व्यवहार नहीं करेगा। इससे माँ-बाप को आटिस्म के बच्चे की साधरीकरण की समस्या में फ्रस्टेशन (frustration) व कन्फ्यूजन (confusion) होगी। इस समस्या से लड़ने का एक ही तरीका है कि सुनिश्चित करें कि बच्चे को सिखाने की स्थिति (situation) एकसी रहे। केवल थोड़ा सा ही बदलाव करें।

उदाहरण के लिए बच्चे के शरीर के अंगों की पहचान के लिये जो भी उसके साथ काम करें प्रत्येक को प्रयुक्त करना चाहिए “अपना सर छुओ” स्थिरता से यानी सभी को एक शब्द कहना चाहिए किसी अंग के लिए। यद्यपि व्यक्ति जो उसे सिरवा रहा है व स्थान अलग प्रथक होना चाहिए। इस तरह से आपका बच्चा इस शब्द को समझने में अड़ि एक समर्थ होगा “अपना सर छुओ” यह सिखाने का प्रमुख तरीका है।

आप अन्य को जो आपके बच्चे के साथ संलग्न हैं या सम्पर्क में हैं उन्हें इस स्थिरता का तरीका समझा सकते हैं इस पाठ को पढ़ा कर तब साथ-साथ बैठें और तप करें कि आप अपने बच्चे से किस प्रकार व्यवहार (respond) करेंगे। आप एक कल्पित वातावरण बनाये व एक दूसरे से प्रेक्टिस करें। आप पिछली स्थितियों के बारे में विचार विनिमय करें वे किस प्रकार और अच्छी तरह हैंडिल की जा सकती थी। साथ-साथ काम करते हुए आप रूपरेखा (outline) बनाने में समर्थ होंगे कि आप किस प्रकार से व्यवहार (act) करना चाहते हैं अकेले और सामूहिक दोनों तरह से।

अनुशासन एवं व्यवहार का प्रबन्धन (Management)

आटिज्म के बच्चे के बहुत से माता-पिता अपने बच्चे को अनुशासन में रखना कठिन मानते हैं। वे साधारण तथा बच्चे के असामान्य व्यवहार पर ही ध्यान देते हैं। इस कठिनाई का एक कारण अधिकतर बच्चे के देखभाल की किताबें उनके अनुशासन की व्यूहरचन करती हैं वे आटिज्म के बच्चे से बिल्कुल अलग होती हैं। और स्थिति को खराब होने से बचाने के लिये अभिभावकों को अनावश्यक और तरह-तरह की सलाह का मुकाबला व अजनभीयों से कूटनीति पूर्वक करना चाहिए।

ऐसे कोई जादुई सूत्रा नहीं है कि आपका बच्चा हमेशा सही व्यवहार करेगा। किन्तु संयुक्त तजुर्वे अन्य पेरेन्ट्स के व वर्षों के प्रोफेशनल्स की खोज ने दर्शाया है कि लागू व्यवहारिक विश्लेषण (Applied Behaviour Analysis – ABA) अल्प अधिक मायने/उपयोगिता रखता है आटिज्म के बच्चे के व्यवहार के बदलने में। प्राथमिक

(basically) व्यूह रचना से समझा जाता है। मानाजाता है कि सभी व्यवहार समझा जाता है घटनाओं के द्वारा जो होती है और उसके बाद के व्यवहार पर। यदि कोई घटना होती है या बच्चा कोई व्यवहार करता है तो बच्चे द्वारा उसके प्रदर्शन की सम्भावना रही है।

उदाहरण के लिये माता-पिता या अध्यापक द्वारा काम करवाने पर बच्चा क्रोध इस लिए कर सकता है क्यों कि वह सम्भवतः काम करने की इच्छा नहीं रखता। यदि बच्चा इस क्रोध के परिणाम को जानता है अपने व्यवहार के कारण तो वह उसी व्यवहार को दुबारा प्रदर्शित करेगा। अगर वह उस के परिणाम को नहीं पसंद करता तो वह उस व्यवहार को दुबारा नहीं करेगा। इसलिये यदि माता-पिता बच्चे के क्रोध या रोने पर काम बंद करते हैं, तो भविष्य में बच्चा फिर यह व्यवहार दिखाएगा।

निम्न तकनीकी व उदाहरण सहायक होंगे इन शिक्षाओं सिद्धान्तों के स्पष्टीकरण में तथा आप के प्रभाव को बढ़ायेंगे आपके बच्चे के व्यवहार को व्यवस्थित करने में।

पकड़ें/ समझें कि आपका बच्चा अच्छा हो रहा है।

जब भी बच्चा ऐसा व्यवहार दिखाये जो आप चाहते हैं तो तुरन्त पुरस्कार दें। इस से भविष्य में इस व्यवहार के होने की संभावना बड़ेगी।

आटिज्म के बच्चों के अध्ययन ने यह भी सलाह दी है कि पेरेन्ट्स को जब अपने बच्चे की बड़ाई कर रहे हो तो विशिष्ट होना चाहिए। विशेष भाषा का प्रयोग करें। "अच्छा आप अपना कोट पहने" एक साधारण से वक्तव्य की तरह नहीं कि जैसे "अच्छा किया"। विशेषतौर की मदद से आपका बच्चा समझता है सही व्यवहार जो कि प्रोत्साहित किया जा रहा है। यह अक्सर देता है स्पर्शनीय इनाम जैसे खाना य खिलौने उसकी बड़ाई के साथ-साथ विशेषतौर से उसको सिखाने के पहले चरण में। क्यों कि आटिज्म के बच्चे नहीं पाते परस्पर समाजिक परितोसिक, छूने वाले उपहारों का अधिक उपयोग उनके उद्देश्य को बढ़ाता है।

शुरू में ही रोकें

जब आपका बच्चा दुरव्यवहार कर रहा है, आप के हाथ में तुरन्त एक समस्या है। कभी-कभी ये निर्णय करना मुश्किल हो जाता है कि एक बार होने वाले दुरव्यवहार के बारे में क्या करें। उदाहरण के लिये यह प्राकृतिक है कि घबड़ाहट महसूस करें व असहाय जब आपका बच्चा शुरू करदे जोर-जोर का चिल्लाना बाजार के बीच में। कभी-कभी यद्यपि आप रोक सकते हैं व्यवहार को वास्तव में इसके शुरू होने से पहले। अक्सर पेरेन्ट्स महसूस नहीं करते कि वे पहले से योजना बना सकते हैं और रोकने के उपाय कर सकते हैं मुसीबत (crisis) उत्पन्न होने पर उसपर चर्चा करने से यहां कुछ बचाव के उपाय/ तरीके हैं जिन्हें आप उपयोगी पासकते हैं।

• Left: *Danseuse Sharon Lowen performs at the Concert in aid of the AFA National Centre.*

Top Right: *AFA students sing.* Bottom Right: *Chief Guest Mrs Gursharan Kaur, Wife of our PM, at the event*

(The Brick Ad
Please take it from the CD)

HELPLINE



Q I work in The Concerned for Working Children. We are a private NGO working to eradicate child labour through their participation and realisation of their rights. I have been through your website – it is extremely informative, comprehensive and up-to-date. I am doing a research project on out-of-school children – reasons and factors deterring them from entering the formal school system. I am doing a section on children with disabilities. Can autistic children be successfully integrated into the formal school system? A similar question was posted in your ‘Autism Q&A’ section where you said a few schools have managed to integrate autistic children. I was wondering how this was done. What would be the required changes in policy to make this happen in terms of training of teachers, infrastructure, learning aids, methodology, etc. How would a government school integrate an autistic child?

A Your query would require a very long answer. Suffice to say that yes some children with autism can be mainstreamed. Some require no support and get by. Others do require support – often more social support rather than intellectual since they have difficulty in negotiating social rules. The best way to include children with autism is teacher sensitisation and training: some teachers find it very hard allowing for adaptations for a child with autism. Whereas with most other disabilities you can ‘see’ what the difficulties are, with autism it is not so obvious, and since the difficulties are social, teachers are often resistant to making adaptations. One of the concrete learning aids many children with autism would benefit from is computers; Other than some change in methodology, and sensitive teachers who are willing to make adaptations for the child. With adequate support government schools too can include children with autism. Of course it goes without saying that a student body that is by and large sensitized is essential for successful inclusion.

Q I am an Indian living in the UK. I heard that the vaccine called MMR which is for Mumps, Measles and Rubella causes Autism in children. We cannot decide if we should get my sister vaccinated with the same. She is about 16 months old. The doctor says we could get three different vaccines for the three diseases. Would that be a safer option? Kindly advice as we are greatly confused.

A It is a hard decision given all the confusion on the issue. Not giving the vaccination leaves the child susceptible to Measles, Mumps and Rubella. Despite research clearly indicating prenatal and genetic basis of autism there is a strong lobby that believes that the vaccine will cause autism. Interestingly, we know families who vaccinated their older child who now has Aspergers, and skipped the vaccine for the younger one who later received a diagnosis of Autism. It is a tough decision and finally one that the family alone can take. Perhaps your GP can help you take the decision.

Q My daughter is ten years old. She has Autistic Spectrum Disorder. She has been attending a special school since three years in Mumbai. We get lots of help from special educators, speech therapist, and occupational therapist. She is developing. If possible she will get vocational training from her special school in future. But we are now worried about her long term rehabilitation we do not know about residential centres in India. We know many centres where mentally ill persons are rehabilitated but they are not equipped to care for persons with autism after the death of the parents. We are looking for your suggestion.

A First of all we want to commend you on how well you have worked with your daughter and appreciate your positive approach towards her learning workskills. Your concern regarding her future when parents will not be around is the worry of almost every family having an autistic child. We presume that you are in touch with the parents support groups at Mumbai and are aware about the guardianship issues under the National Trust. We do not have information on any long stay rehabilitation centres that are run exclusively for persons with autism. However we do know of individuals with autism who are in Adhaar, a residential centre in Thane District. In the past Jai Vakeel School in Mumbai also did take in some youngsters with autism in their boarding and perhaps still do.

There are various models of long stay residences all over the world. One option is that wherein the persons with autism can live within the community in small group homes run by parents and if possible along with relatives and friends. To make this dream come true one needs to

identify parents of children and adults with autism who would like to work together to form trusts and set up such units. This of course needs sincere team efforts that can be made with guidance from organizations/ parents / professionals with experience, and the National Trust.

Q I have a son B, who has no speech. He is 14 years old and has a diagnosis of autism and I have been helped immensely in his upbringing by Autism Network since the last eight years. I have a few queries with reference to your issue of December 2003, Vol X, No 3. In the Helpline section of this issue you have referred to a set of four EASe CDs, which help children deal with sound sensitivities. Can you give us some information about these CDs and how to procure them? As my son is extra sensitive to some sounds, I hope they can help him.

B gets very upset when others talk normally among themselves, although he does not mind when we talk to him continuously. Can we do something about it? As we are staying in a small place in Orissa, we do not have adequate school or professional facilities here. So B remains at home and I am his parent, teacher and guide, all in one.

A It is good to learn of the progress B is making and we are glad that Autism Network has been of help in this. When you say that your son gets upset when others talk amongst themselves, perhaps you could try and see if it has anything to do with his feeling left out of the conversation that leads him to acting upset? Without having all the details it is a difficult to guess what it is about the situation that makes him upset. It is only when we understand what is behind the behaviour, and also what is maintaining the behaviour, can one suggest a way to deal with it. However, some of the things you could do is try and include him in your interactions with others. Ask other members of the family to do the same. In addition, give him different non-verbal modes of communication: using cards or signs for instance. Being able to communicate will take care of a lot of difficult behaviours since much of challenging behaviours are often a mode of communication.

Regarding the EASe CDs, the CDs are available from Vision Audio Inc, 611 Anchor Drive, Joppa, MD 21085, USA Tel: 001-888-213-7858. They can be ordered over the internet from their site <http://www.vision-audio.com>

Q I am an insulin-dependent mother to a boy just turned three this November. He has been diagnosed to

have Global Developmental Delay when he was a year old. Since then he has been on occupational therapy, and just three months ago we have incorporated speech therapy. What I noticed is that he frequently tiptoes and shakes (or wiggles) his arms and hands. Could these be signs of autism? I need some light on this please.

A The behaviours you mention may not mean anything. Or they may: only a direct observation of your son can help clarify this.

What would you say is your son's developmental age now? Supposing if he is at an 18 month level physically, does he do other things a child of 18 months would do?

Does he look when you try to draw his attention to anything? When there is an aeroplane in the sky and you say "*look at the plane*" does he look or does he not respond? If you point to the aeroplane with a pointed finger and say "Look at the plane" will he look up directly at the sky or will he first look at your finger before following the direction where you are pointing. A typically developing child will be more apt to do the latter. Does he turn to look at you when you take his name? When you come into the room after a period and take his name does he look at you and then follow you with his gaze as you move around the room? What does he do when there are other children around?

Perhaps the best way to clarify your doubts would be to contact the Philippines Autism Society.

Q I have a 20 year old student who was just recently diagnosed with autism. Until this time he was treated as someone having mental retardation. My question is: How does one teach someone with moderate to severe autism the concept that stealing is not a good thing to do?

A The concept of theft is a very abstract concept. It also requires an ability to read minds in order for me, for instance, to understand how a person would feel if I stole her favourite table linen since it was her mother who had embroidered and gifted it to her. For a person with moderate to severe autism, this level of understanding of minds might be difficult.

Therefore rather than trying to teach that 'stealing' is 'bad', what one would have to teach is the concept of 'mine' and 'not mine' and that I do not take something that is 'not mine' without asking or without being asked to. Such a concept would perhaps be easier to teach.

Q I was reading autism network issue for the month of August 2004. In this issue there is an article by Ashwini Chaswal about income tax concession (80 DD of Rs 40,000) to parents of children with disabilities. Does this apply to children with autism and those with PDD-NOS?

A In the recent finance budget of FY 2004-05 Autism has also been included as a disability for which income tax rebate U/S 80-DD and US 80 U shall now be available. 80 DD (with similar retrospect for 80 U) allows for income tax rebate to a person who has a disabled dependent. The amount of deduction allowed is divided into two categories viz. Rs 50,000 for disability between 40% to 80% and Rs 75,000 for severe disability above 80%. Norms have been set based on IQ levels to identify the percentage of disability in case of mentally retarded dependents.

We still need a criteria for issuance of a disability certificate stating 'autism,' but it is not yet clear how the 'percentage' of disability is to be determined. Apart from the fact that to determine IQ in persons with autism is difficult and requires a high level of expertise, IQ alone in autism does not always indicate level of functionality.

Therefore one can try and get a certificate from a government hospital, but the deduction in the tax will depend on the results of the assessment that must state the percentage disability (measured on basis of the IQ).

Q My three year old daughter is diagnosed 'Autistic Featured' by JSS Hospital Mysore and KMC Hospital, Manipal, in their differential diagnosis. She is taken for speech therapy to KMC regularly and I could notice a slight change in her activities but not in her speech. Kindly suggest for further steps that I can take to cure my daughter at the earliest before it is too late.

A The purpose of a differential diagnosis is to rule out all other developmental, neurological or genetic disorders which may show characteristics or 'features' that are similar to, or that may overlap with those seen on the Autistic spectrum. From your letter, it appears your three year old has been diagnosed as falling within the Autistic Spectrum.

Findings suggest that giving speech therapy alone may be helpful; however, progress can be limited due to the nature of the disorder. It is vital for you to understand

your child's difficulties. We suggest you speak additionally to a special educator or psychologist, who has a sound understanding of Autism and perhaps you yourself read up on autism to help you understand your child better.

To date, research indicates that giving early intervention in the form of specific and appropriate training methods that are tailored to your child's needs and learning style is the one way to help your child reach her maximum potential. Prior to this, it is important that a special educator take a detailed assessment of your child's strengths and difficulties to develop an individual education plan for your child. There are a number of intervention styles / methods, and you would want to choose one that would benefit your child most.

Autism is a complex lifelong developmental disorder, and has no cure, medical or therapeutic. However, through early intervention, many children have been able to lead productive and meaningful lives with support from their family, friends and professionals. A number of other organisations around India provide early intervention such as at Action For Autism.

BEHAVIOUR MODIFICATION

An Interactive Workshop by Action for Autism

INDIAN SOCIAL INSTITUTE, 10 INSTITUTIONAL AREA,
LODI ROAD, NEW DELHI

Saturday 5 February 2005 • 10 a.m. – 4 p.m.

The workshop will cover an understanding of the reasons behind the unusual behaviours of children on the spectrum, on their management, as well as how to teach new behaviours and strengthen and maintain existing appropriate behaviours.

Registration:

(including lunch, teas & workshop materials)

- Rs.300/- for Full Members and Life Members
 - Rs.400/- for Non members
 - Rs 500/- for spot registrations

For registration forms please send a self addressed stamped envelope to:

Action for Autism

T370F Chirag Dilli, New Delhi -110 017

Workshop on Developing Individualised Educational Plans

INDIAN SOCIAL INSTITUTE, 10 INSTITUTIONAL AREA, LODI ROAD, NEW DELHI

18 December 2004

Children with special needs require educational programmes that are specific to their individual and unique requirements. Planning is crucial in developing appropriate programmes because every child is an individual with specific needs. This workshop will help us to understand and review individual needs and determine and develop IEPs that include all areas of skills so that learning is not narrowly focused only on certain aspects, but has a broader and well balanced vision.

Our Resource Person:

Mithu Sen is an MS in Special Education from Madison University with extensive experience in teaching children with special needs, as well as training in Psycho-educational analysis, Brain Gym, and Direct Instruction.

Mithu has worked with children having a range of special needs including SLD, ADHD, ADD, PDD and Slow Learners.

Mithu is currently teaching at the Hamilton Learning Centre, Lawrence College, Ontario. Mithu has worked with a range of strategies including Remediation Plus, Reading Mastery, Reasoning and Writing, Encoding and Decoding and Word Attack programs, SRA expressive writing series, and Saxon Math.

Registration: (including lunch, teas & workshop materials)

Rs.350/- for Non members

Rs.300/- for all except Associate members.

INCOME TAX REBATE

A Good Beginning but the Struggle for Certificates Goes On

Ashwani Chaswal

In the recent finance budget of FY 2004-05 Autism has also been included as a disability for which the benefit of income tax rebate U/S 80-DD and US 80 U shall now be available. In this regard the following issues need to be pondered over:

80 DD (with similar retrospect for 80 U) allows for income tax rebate to a person who has a disabled dependent. The amount of deduction allowed is divided into two categories viz. Rs.50, 000 for disability between 40% - 80% and Rs. 75,000 for severe disability above 80%. Norms have been set based on IQ levels to identify the percentage disability in case of mentally retarded dependents. The 'medical authority' to certify such conditions is also defined reasonably well.

IN the case of Autism however, while tax exemption upto Rs. 50,000 income can be allowed based on a medical certificate simply certifying 'autism', the definition of severe disability still remains ambiguous. This is because autism certainly cannot be labeled a disability over, or less than, 80% based on the IQ levels of the person with autism.

ABOVE all, any such exemption is possible only after first obtaining a disability certificate that certifies 'autism' and /or the percentage thereof. As per the present status however, even the medical authority to certify the condition of autism is unclear as the same is to be clarified by another central government notification.

IT is of utmost importance therefore, that the issue of obtaining disability certificates is addressed as a priority so that the parents, who are otherwise faced with innumerable challenges in life as a result of their children's condition, are able to avail at least the bare minimum concessions allowed by the government.

It is worth a thought whether the tax exemption of Rs. 75,000/- U/S 80 U in case of Mental Retardation or Autism may ever be actually availed by any individual because in both the cases the person himself / herself in that category is unlikely to have that kind of personal income to pay income tax. Even if such a person has some kind of an inherited income, he will in all probabilities be under guardianship, with the finances being managed by the guardian

MEMBERSHIP TO AFA

To continue to receive 'Autism Network' please complete the application below, cut or photocopy, and return it to us as soon as possible.

MEMBERSHIP DETAILS

Parents: Associate Member – Annual: Rs 150/-, Full Member – Annual: Rs 500/-, Life Member: Rs 5000/-

Professionals: Associate Member – Annual: Rs 150/-, Full Member – Annual: Rs 1000/-, Institutional Member – Annual: Rs 2000/-, Overseas Membership – Parents \$ 30, Professionals \$ 50

Associate Members receive copies of Autism Network and information on all upcoming events and activities. In addition, Full Members, Life Members, Overseas Members and Institutional Members are entitled to concessionary rates for AFA events and workshops.

New Renewal Date _____

Name _____

Address _____

State _____ Pin/Zip _____

Phone _____ Email _____

I am a: (tick all that apply)

Parent Relative _____

Professional _____

Other _____

If you are a parent of a person with autism, please answer:

Child's name _____ Sex _____

Date of birth _____

Diagnosis (if known) _____

• I wish to become a member of AFA and enclose:

Rs 150/- Rs 500/- Rs 1000/- Rs 2000/-

Rs 5000/-

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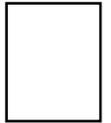
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Contributions are tax exempt under Section 80 G of Income Tax Act.

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AFA Mission Statement

To facilitate a barrier free environment;
to empower families of persons with autism;
and to act as a catalyst for change
that will enable persons with autism to live
as fully participating members of the community.



Email: autism@vsnl.com
AFA Homepage: <http://www.autism-india.org>