autism

NETWORK

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Cover Illustration

'Sachin Tendulkar batting to a Brett Lee ball
by
Rishab Raj Bhatia, 6 year old student, St Xaviers, Mumbai

WISHLIST !

FOR THE STUDENTS

- o The use of a room for one year to store AFA's printed materials
- o A minibus or van
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- o Still Camera o Rolls of film
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- 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:

- Aran Corrigan: Tel. 2925 6469/70
- Indu Chaswal: Tel. 2609 4410
- Rita: Tel. 2925 6469/70

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2004 begins on a truly upbeat note. Suddenly things seem to be falling in place. Our efforts at raising awareness show very gratifying results. More people have heard of autism than ever before. When people learn that I work with Action For Autism the response is more on the lines of "Honestly, till a year ago I did not know that autism existed," as opposed to the earlier, more common refrain of, "What's that?!" More interestingly, in the week before writing this piece, I had no less than four persons come up to me and ask if I had read Mark Haddon's *The Curious Incident of the Dog in the Nighttime*! Which is a wonderfully moving book that Professor Shirshendu Chakrabarti has reviewed for this issue.

Construction of The National Centre for Autism

Can You Help ?

WE NEED....

- 110 tons of steel
- 9000 bags of cement
- 8 lac bricks
- 500 sq metres of glass
- 1325 sq metres of Kota stone slab
- 160 sq metres of white commercial tiles
- 510 sq metres of glazed tiles
- 15 wall-mounted WC's
- 10 oval wash basins
- 5 stainless steel sinks.

Call Reeta Sabharwal 98111 03702

IN February NIMH Secunderabad hosted a four-day Indo-US workshop on autism in collaboration with the National Institute of Disability and Rehabilitation Research USA. The workshop saw a large number of presentations that had been selected after a 'stringent screening process.' However, a number of the presentations ranged from being self-congratulatory (to use a mild term), using debatable research methods, to seeming downright pointless. The pity was that some of the really good presentations had to be abbreviated to accommodate these, while others simply could not be accommodated due to lack of time. Unfortunate, since many participants took four days out of tight schedules to attend the workshop. However, the aim of the workshop – to identify areas of research and set up a road map – was well met in the last day and a half. NIMH is to be congratulated for this initiative. Hopefully the follow up will not be short-circuited by the need to accommodate influential mediocrity.

ATTENDING the workshop in my various hats, as a disability advocate, a parent, and a therapist, it was the therapist in me that was very taken by the presentation by Dr Theresa Hamlin of The Center for Discovery. It has been our experience that most centres in the developed world adhere strictly to any one particular method, resulting in a great deal of 'my way' and 'their way' debate. In contrast, under-resourced organisations like ours have been using an eclectic mix of strategies without tripping over rigid divisions. It was therefore a pleasant surprise to discover the excellent work being done at The Center for Discovery while using just such a mix of interventions. No wonder that the centre is considered somewhat controversial in the US.

CONTINUING on this note, after a number of workshops in India, Verbal Behaviour Analysis has been introduced in at least four schools in the country. Considering the number of bright young therapists from Bangalore, Chennai, Delhi, Goa, Mumbai, and other places that attended the workshops, it is clear that VB will be incorporated in the methods used at many centres. However, a stumbling block we are encountering is the insistence by some professionals that parents do not allow their children to learn sign language. "She makes so many sounds. If you let them teach her signs she will never speak." It often becomes an uphill task trying to convince families that teaching other modes of communication can only enhance the possibility of speech development. In this issue, the article *Making a Case for Using Signs to Teach Children with Autism*

(cont. on back page.18...)

Making a Case for Using Signs to Teach Children with Autism

Smitha Awasthi

Most of us become aware of autism in our children when we notice delays in speech and language. Apparent delays in language acquisition is often attributed to a history of delayed speech in the family, and ignored in the hope that language will soon arrive. However as time goes by, a lack of speech and / or a means of communication begins manifesting in the form of behavior problems and tantrums. Mild pulling of the parents hand and pushes for desired items gives way to more severe behavior forms. To quote Mark Sundberg & James Partington, “it’s not exactly clear why some children fail to acquire language. However it is clear that if language does not develop in a timely manner, negative or inappropriate behaviors like tantrums, self stimulation, property destruction, aggression or social withdrawal will occur.”

OFTEN nothing is done and precious time is lost in tackling the wide ranging issues related to autism while parents try to come to terms with their child’s diagnosis.

WE need to consider that often we ourselves may be inadequately equipped to teach language to a child who does not learn language the way everyone else does.

MOST early intervention programs begin with teaching the child to follow instructions. Do this, Clap hands, Wave bye, Bring your shoes, Sit down, Give me the pencil, Touch head…. are some of the innumerable commands which many programs start with. Teaching the child to follow receptive instructions however has very little use to the child. As Dr. Pat McGreevy says, if you teach Receptive Language without or before teaching Expressive Language “You’re stealing from them, without giving them back.” You end up telling the child, you listen to me and behave well. However I’m not going to teach you how to make me listen to you.

ONCE we realize, that teaching communication is all about teaching expressive language to our kids, and not about making them point to colors, shapes and letters of the alphabet, the next thing we need to figure out is what kind of communication methodology is most supported by science and will also help in bringing about vocalizations.

THE options available for teaching communication to kids with autism are:

a) teaching speech

b) picture exchange

c) sign language

d) textual communication

e) communication using other augmentative devices.

THE most desirable form of communication is speech and teaching it is the first step. However in many kids with autism this simple task may become daunting due to organic or non-organic causes. For those children where muscle control and echoing are too difficult, alternative ways of communication must be explored.

The Picture Exchange Communication system is an alternative teaching tool for children with autism. It is a selection based system where the child is taught to point, touch or exchange pictures as a way to communicate his needs, or reply to questions or comment.

Sign language is another alternative modality [Carr, 1982] for communication. It is a topography based communication system (Michael 1985; Sundberg & Sundberg 1990), in which the response for each word made by the student is different just the way we use different words for different items. This is one of the basic differences between Picture Exchange and Signing. In any Picture Exchange system, the motor response made by the student is always the same. Which is to first scan the picture from a large selection of pictures, select the correct picture, and then point to or exchange the picture. For example a person signing for home will put his hands together over his head, or when he signs for food he takes his hand to his mouth, however when a student uses Picture Exchange, he would select a picture of home and show, if he wants to say food he would again select a picture of food and show. Thus, the response made by the student when he is signing is closer to the way we use speech and language. However with picture exchange the response for selecting any picture is the same.

WHAT if a child wants to comment on something he sees in the environment? Look at the way a signer would respond. He will look at something and immediately make a sign and tell you what he is saying. Depending on the stage of his learning, he can sign using one word or use a chain of 2-4 words to communicate. A beginner can just sign "Aeroplane," while an advanced learner can sign "Mummy look aeroplane in the sky." What would a kid using the picture exchange system do? He would run to his picture box and pull out the picture. By the time he pulls the picture out and shows it to you, the aeroplane has flown away. You may not really know, (if you had not seen the aeroplane) if your child was commenting on what he saw or if he was requesting you to give him the toy aeroplane.

IF as a parent or teacher you follow what your child is trying to indicate, it's great for the child because he has been understood. However there may be many times when he is not understood and this can be very frustrating for the child. Thus showing a picture may not help the listener to understand if the picture is a comment on what he saw or is a request for what he wants. Let us assume that a child brings a picture of orange juice to you, how would you know if he is trying to say the orange juice is spilled, or I like orange juice or give me orange juice.

ANother aspect is the communication process that takes place between a child with autism and his teacher or parent, using these different ways of communication. When a child is using signs to communicate, you can join the child in his communication process at your natural speed whereas for the child using pictures the process slows down considerably.

LET'S look at a real life example:

Child with Autism (CA) signs: *"Open drawer."*

Therapist (T): *"Why do you want me to open the drawer?"*

CA signs: *"I want beads."*

T: *"What colour beads do you want?"*

CA signs: *"Red beads."*

T: *"What will you do with them?"*

CA signs: *"I want to play with beads."*

THE therapist gives the child what she wants and communication ends. Or it can continue. Imagine the same conversation using pictures. You will find the communication will be slower because in between the child will be searching for the picture. Replying "I want to play with beads," can be pretty complex using a picture where play and beads need to be put together to express the way we use language naturally.

TEACHING adjectives, pronouns, adverbs, is another case in point where, using pictures is not an easy job. To teach 'beautiful' to a signer you just sign 'beautiful' when you come across a beautiful baby, or beautiful flower or beautiful dress. Eventually we see the child with autism acquires it in his repertoire. A six year old girl I work with, while turning the pages of a magazine signs 'beautiful red dress' as spontaneously as we would comment. To teach an abstract word like beautiful by showing pictures, can probably mean little to the learner and you can never be sure if the child has really understood the meaning. In addition imagine the response effort required in picture exchanging, to spontaneously select a picture from the array of pictures just to say the same thing.

ONE of the most practical limitations with the picture exchange system is the issue of dependence on auxiliary equipment. When we introduce picture exchange in our early intervention programs, we also have to consider that when three year olds are leaving the house, they need to carry their picture card boxes with them. Active kids that age, have to learn to carry the cards, take the appropriate card out either for requesting or commenting and show it to an adult. However, a signer has his fingers and hands with him all the time.

A five year old signed 'pour water' to the waiter when she was having dinner with her parents in a restaurant. She did not have to go through her cards to say the same thing. And this was a generalized response she made to the waiter who had a water jug in his hand.

Advantages of Picture System

The biggest advantage of the picture system is, it is listener friendly. You and I do not need training to understand what the child is saying as long as he/she is saying it in simple words.

SECONDLY, once the child learns matching to sample, he may acquire words fairly quickly. Thus to learn each word no shaping is required. Example, once the response of picture selection is acquired, whether the child has to select a picture of 'ball' or that of 'cookie', the response would be the same.

FOR the therapist or parent, training differential responding (like pronouncing different words, or making different signs) is not required.

Advantages of Signs

Research has clear evidence that when signs have started with requests, there is very high probability of developing speech and vocalizations.

THE biggest advantage with signing is that it is speaker friendly. A signer can sign anywhere anytime, without depending on devices. It gives a child with autism a way to talk and allows listeners to immediately understand that something is being communicated to them.

TEACHING signs under motivational conditions help to shape the imitative response as well as helps in developing vocalizations.

SIGN language is conceptually similar to speech. Therefore teaching should start with requests which allow a child with autism to meet his needs, and can be acquired by children with poor imitative skills.

TEACHING sign language at an early stage, may help in avoiding a history of emotional reactions associated with trying to develop speech. Often getting kids with autism who have little language, to echo words is followed by emotional reactions. An emphasis on signs, followed by vocals, acts as a prompt for language.

SIGNS like speech are portable and free from mechanical devices for support.

THERAPISTS can physically prompt a sign, but cannot do so, if trying to teach language through echoics.

BY learning a system of signs, the child with autism, who prefers to be in his own world, perforce enters into social interactions with others.

Limitations of Using Picture Exchange

Let us look at disadvantages with a picture selection system.

TO communicate with success there is a need to carry auxiliary equipment.

PICTURES should be available to communicate.

THE person who uses pointing at pictures as a way to communicate will need a person in close proximity.

AS the child learns more and more, pictures and symbols become more and more abstract, and thus difficult to portray.

IN case of interactive communication, the response is very slow which alters the motivation of the speaker. Children who use this method, do not have an opportunity to imitate communicating behaviours from others in the natural environment as they use a system of communication different from what everyone around them uses.

AND even if a portable system is made, there will be times when it may be left at home or may get lost.

Limitations of Using Signs

The biggest drawback with signers is that a signing community is required to reinforce the use of signs. Parents and teachers need to learn signing, which of course requires a great deal of effort on their part.

EACH sign has to be taught individaully and the respective motor response shaped.

SIGN language is also not welcomed by most parents who are often reluctant to add an ‘odd’ feature to their child’s behavior.

Conclusion

Though research is heavily skewed in favour of teaching signing to children with autism as it helps in the development of vocal speech, we need to teach picture selection or textual communication (ie written words) as a back-up way to communicate with outsiders who would not understand signs.

SO if a child with autism goes to the shop to buy bread’, and the grocer does not understand the sign for bread or the child’s unclear articulation, there needs to be an alternative way for him to communicate with the grocer. In this case a picture of bread or a written text of the word ‘bread’ will help him to communicate, what he wants.

ALL studies report an increase in social awareness and a decrease in tantrums following the development of a system of communication.

WHATEVER the mode one selects for a child with autism to communicate effectively, it is our responsibility towards the child to ensure that we find the most effective tool for the purpose.

LETTERS

My name is Gareth Parkin. I am from the UK I am 19 years old. I was diagnosed with Aspergers Syndrome a mild form of autism at the very young age of seven. I have not had a terribly easy time over the past few years. What is worse is that people do not believe or understand the truth. I have had to spend most of my time clearing up all my terrible messes, without much success. Most of my ordinary situations feel just like a person with a morbid fear of heights having to climb the world's tallest building. Also I have been one of the most isolated people in the world, for over three years now, and I really do not like it. I thought you might like to hear from me.

Gareth Parkin
UK

I have gone through your Autism Network and find that each and every article is informative. Such informative articles on the subject like autism are very relevant and the need of the hour. Do you have this on your web page? If not please include all the articles in your web page so that it will be useful for the parents of the autistic children and the professionals in this area.

Manoj Kurian
NAB, TRIVANDRUM

Being a Montessori teacher I have come across a few cases of Autistic children in my day to day work. The details on your website are quite comprehensive and the training programmes sound interesting. I am keen to train myself in the same. Going through the AFA website has opened 'windows of opportunity' in my life.

Bindu Menon
DUBAI

I have found the magazine Autism Network very informative for professionals like us who are practicing in this field as I feel that there is a lack of right knowledge.

Dr Nandini Arora
BARODA

A Confounding Paradox: The Savant Syndrome

Neeraja Ravindran

(Continued from December 2003 Issue of Autism Network)

Train the talent or eliminate the defect?

Just as there many theories about the cause of the Savant Syndrome, there are also a number of viewpoints about the best approach to education, training and treatment of savants to allow them to have lives as productive, as independent and as fulfilling as possible, given their severe handicaps. According to Dr. Treffert, it is not a question of training the talent or eliminating the defect, it is merely the question of which to concentrate on, first. There is ample evidence to show that with appropriate approaches, understanding and patience on the part of those working with the savants, talents can be trained and as a part of that training process, some of the other defects will be lessened, albeit not altogether eliminated.

DR. Temple Grandin in her book *Emergence: Labeled Autistic,* feels, “Too many therapists and psychologically trained people believe that if the child is allowed to indulge in his fixations, irreparable harm will be done. I do not believe this is so in all cases… certain traits are beneficial.” Grandin herself is living proof that this may be the case and that there is hope. Hope for the autistic child, hope for all other children with some kind of disability. Hope that with constant care and understanding and setting of appropriately high expectations, adequate support and encouragement, we can provide them a foundation from which they can grow into being their own person and reach their potential.

Tito’s Wish...

Tito, in his book, talks about his dream of a matured society where nobody would be ‘normal’ or ‘abnormal’ but just human beings, accepting other human beings – a society where they are ready to grow together...

"A world of such
Can’t it be?
With acceptance and love
Not sympathy!
My story could touch
If your heart,
My ‘hope’ would get
The precious reward!"

HOPE University in California is quite famous as the only fine arts school set up exclusively for the gifted mentally retarded. With a student population of about 40, the University and the people in it seem to provide a sparkling example of what can happen if the talents are nurtured. Founded by Doris Walker, the school is a first of its kind. HI HOPES, a musical band formed under the guidance of Walker in 1972 and comprising of extremely talented and even prodigious savants as performers, aims at spreading the message of this wonderful school all over the world. The staff of this school believe that with students as talented as theirs, art can be a wonderful medium of instruction to teach a whole lot of academic subjects. Arts underlie all subjects of the curriculum at Hope University and are predominantly also used in the teaching of them. The kind of goals set out for students at Hope include development of problem solving skills, cultivation of real-life skills, learning co-operative work skills, communication skills, increasing motor dexterity, improving self-worth and self-esteem and even lessons in developing a good body image. Music, Dance and Movement, Art, Drama and Community Living Skills are some of the programs offered by this Fine Arts College. The staff of Hope University uses this kind of “fine art therapy” to “train the talent and diminish the defect.”

A student good in music may be given individual voice therapy sessions and theory and instrument lessons but music may also be used to teach math, reading and money skills. Rules of spelling may be taught to the students by making them write their own songs. Drama sessions are used to teach students lessons in role-playing, turn taking, acceptable behaviors and communication and conversation skills. Practice, rehearsal and performance are used to reinforce these areas. Using the students’ strengths in the arts helps their learning in other areas that are difficult for them. The school stresses “whole person development” and performing groups such as

HI HOPES acts as a platform for these individuals to showcase their talents and prove to the world that there is a bright splinter of brilliance in every individual that needs to be respected, nurtured and given its due.
THUS, the goal here would not be to eradicate the skills of a savant however bizarre and impractical they may seem. The goal is to patiently and creatively use them without fearing that in doing so, overall development will be hampered. Infact, such skills could become a mode of expression through which others can reach and interact with the savant, and consequently those skills can lead to the development of other related skills and communication. “The skills serve as a window to the world for the savant, and they serve as a window to the savant for the rest of us” (Treffert, *Extraordinary People.*)

DR. Edward Sequin, writing about the savant in 1866, said: “To explain the physical and physiological mysteries of such human beings is beyond the present power of any known science.” It is indeed true that the significance of the Savant Syndrome lies in our inability to explain it. The savant shows us how ignorant we are about ourselves and especially, about the functioning of our brain. I am in complete agreement with Dr. Treffert’s view that no model of brain function, particularly memory will be complete until it can include and account for this remarkable condition.

WE can learn a lot of lessons from the savant. The depths of human potential can never be understood completely and we can understand this best from the paradox this condition presents. The savant teaches us that where there is deficit there is also talent and where there is despondence there can also be hope. They teach us how to appreciate what is present rather than brood over what is absent and help us in understanding that greatness can coexist with impairment. Most importantly the savants teach us that love based on understanding can overcome any hurdle no matter how difficult, and belief and hope can propel an individual to great heights, no matter how impossible it may seem.

Sponsorship for
MOTHER CHILD PROGRAMME

The AFA Mother Child Programme seeks to maximize the benefits of the time that the mother spends with the child, teaching focused, one-on-one intervention on a daily basis over a three month period. The programme is aimed at training mothers to go back able to take charge of their child’s development.

AFA supported by the ADB will sponsor a few families to attend the programme. For families coming from outside of Delhi accommodation, travel and course costs will be entirely sponsored.

Criteria for applicants are as follows:
- household income less than Rs 7000 per month
- child with diagnosis of autism
- family currently has limited access to services

Please send applications marked ‘*Mother Child Sponsorship Scheme*’ to AFA indicating which course you wish to attend (July 04 / October 04 / January 05).

All applications should be accompanied by a letter of recommendation (from local NGO / school principal / paediatrician / psychiatrist or equivalent).

Trained Caregivers Available

AFA is happy to announce the completion of its first caregivers training programme for economically disadvantaged women in partnership with Janani.
The programme is aimed at creating new opportunities for income while providing a service to those with special needs. Women with little to no access to education have completed our six week intensive training. This offers them a unique and specialized skill; placing them in demand for employment assisting parents and professionals with special needs children.

A portion of the earnings will compulsorily be deposited in a savings account in the caregiver’s name. Families seeking trained caregivers can get in touch with:

Annie at AFA Tel: 29256469, 29256470

Librarian Required at AFA

AFA is seeking a volunteer to work in the library for 2-3 hours a day approximately three days a week.
Duties include:
- running the reading room
- issuing books
- organising library memberships
- ordering and cataloguing
- maintaining press cutting files.

Contact Aran Corrigan at AFA Tel: 29256469, 29256470

The Gift of Teaching

Debashis Paul

There was a strong wind. It was a hot summer morning in Kolkata. But the quiet and the magnificence of the sylvan green had enveloped us in a cheerful state of mind. The splendour of the Tollygunj Club Golf Course was pure delight to the eyes. So the 40 degrees did not seem to matter. And certainly not for our ten year old son, Noel.

I sat in the shade under a tree near the Chipping and Putting practice area where Noel was at his regular practice session with his golf instructor Amar Singh.

NOEL was a picture of concentration. Complying with every word that Amar said. Taking the correct stance. Trying his best to get the grip with both his hands. Focusing on the right degree of swing in every shot. He had been there chipping for more than half an hour.

IT was an unbelievable sight!

WHO would imagine that Noel was no regular child? An autistic boy who was displaying here a huge physical and mental effort like he has never done before. Noel suffers from hyperactivity, obsessive behaviour patterns, and communication impairments, characteristic manifestations of autism. Additionally, Noel has impaired motor co-ordination. His ability to modulate his hand grip according to the desired degree is severely affected.

YOU can now appreciate my disbelief at what I witnessed. Every time Noel executed a perfect shot, Amar would wave at me very excitedly, "*Dekhlen toh" (did you see that!), "excellent shot*!"

NOEL had started to play golf at the Tolly Club, only six days back. He was in Kolkata on vacation with his mother Pia, and Ahvana, his little sister. On a visit to Kolkata for a few days on official work I learnt from my wife that a golf instructor at the Tolly Club had been insisting that Noel learn golf under his guidance. When Pia told him that Noel had severe difficulties he agreed to take the entire responsibility of handling him. Amar was so confident that he told Pia that she need not be around for the hour of Noel's practice session.

IT seemed a bizarre situation to me and I was deeply anxious about how this arrangement was working out. The first thought that flashed through my mind was Noel's incorrigible obsession with the hard, dimpled surface of the golf ball when he was four. On almost every trip to the club he had slunk away and bought new golf balls from the club shop. I would come to know after the bill came to me.

I wondered too if the instructor was trying to make a quick buck by merely passing some time with Noel as so many people in Delhi have done. Was be scolding and mistreating him for his odd behaviour? Even if he was not, would Noel make any progress in a ball game requiring so much eye-muscle co-ordination, precision and concentration?

WELL, here was Noel, right before my eyes, looking smart in a bright yellow outfit, donning a Tolly Club Golf cap . Chipping away with precision. My apprehensions melted away.

I saw in Amar a naturally gifted teacher – that rare breed that Rita Jordan , the famous British special educator and author often writes about in her books and articles. Gifted to strike a rapport with a mentally handicapped child, with unbelievable power to deal with challenging behaviour and produce amazing results.

AMAR was exceedingly patient and calm. It did not matter to him how many times Noel made a mistake. While that is to be expected from an average coach Amar's innovative touch was his monologue while Noel was out in the middle of the practice course starting to take his shots. About how great the game of golf was. And how easily Noel could learn it. He talked about some history of the game, and how enjoyable it would be for Noel to play on the course when he learnt the game well. He kept up a gentle, natural, conversational tone, while helping Noel get his grip on the putter; striking a rapport and arousing Noel's curiosity. I realized the potential power of the right tone of voice in a teaching situation for a special child.

THE real insight, in my view , is that, Amar was able to gradually uncover Noel's desire of *doing something right.* And Noel beginning to derive pleasure in success. How easy it is to say this, but people who are connected with the subject of *ASD* know that motivation assumes such complex proportions. Lack of motivation is in itself a disability of the intellect and is very hard for most people like us to comprehend. Amar appeared to have a gut feel for this sort of thing. No impatience and no molly-coddling either.

AND elation when Noel got a good shot.

WATCHING the interaction between coach and student I could understand Noel's emotional state, apart from his apparent satisfaction at learning this new game. Noel felt wonderfully, unconditionally accepted by Amar. And this to my mind was the sheet anchor. He knew that his teacher respected him and his difference. Noel felt that Amar understood his inability to get things right even when he was genuinely trying hard. His coach did not bring upon him any performance anxiety whatsoever. Noel knew he had the freedom, yet he felt good that Amar was in control. This is a complex perceptional balance to arrive at, as the autistic person's mind generally holds a psychological craving for control over their immediate environment, which often leads to problematic behaviour.

NOEL made no attempt to run away in the middle of his shots, or begin to explore the dimpled surface of the balls with his hands. I had expected to see some of this but nothing like this happened !

I noticed that Noel liked to hold Amar's arm when they generally walked about in the club. It signified very high comfort levels and his trust in the man.

THE next few days that I was in Kolkata I went every morning to watch the practice sessions. It was a real joy for me to see Noel make rapid progress. Amar told me that he would procure second hand golf clubs for Noel so that he can continue his training in Delhi after the vacation. Also he said something that I will never forget, "Noel is God's special gift to all of us. All of us have to treat him with kindness and care and respect. Anybody who hurts him has to be an idiot! He would face the wrath of God ! Believe me, being with him has changed me – there is so much beauty in his innocence." Then suddenly he added "Sir, I have noticed that all of you educated people depend too much on medication. In Noel's case please don't depend on doctors . Through kindness, love and faith, we can bring a lot of change in him."

AMAR is forty. He has never been to school. He is poor. He is not confident how long he can support his son's school education. Since childhood he has spent his life on various golf courses earning on a daily basis. First, as a ball boy, then a caddie, and now an instructor. Over the years he has taught the upscale game of golf to the rich and the famous .

IF I had my way I would invite him to teach the well-educated people in our society about acceptance of the disabled, treating them with dignity and care. So that the new generation of well-educated children have an opportunity to gain a better influence at home. The respect, tolerance and kindness for the disabled is a sign of a higher state in community living and sophistication, and this realization is important for personality formation in the early years in life in an increasingly 'what's in it for me' world.

ALSO, for special educators it would be worthwhile to meet Amar to gain insights into some self-evolved *Applied Behaviour Analysis* techniques and see him in action with a handicapped child who cannot learn the conventional way.

A rewarding experience is assured.

Training Course in Music Therapy

Following the recent presentations in Delhi and Mumbai by London-based Music Therapist Margaret Lobo, there is a potential to bring a training in music therapy, leading to a qualification, to India.

Candidates would be required to fulfil a criteria as follows: high level of proficiency in and a love of music, some experience of working with children and adults with developmental disabilities, and a strong desire to unite their musical skills. This will be the first programme of its kind. For further information contact: *Aran Corrigan at 29256470*

तैयारी – परिर्वतन की

भाग –1

इन्दु चसवाल

हम ऐसे समाज में रहते हैं जहॉ स्थितियॉ निरन्तर बदलती रहती हैं। हम अपने पूर्व अनुभव, काल्पनिक शक्ति, और बातचीत द्वारा जानकारी एकत्रित करके बदलाव या परिवर्तन के साथ समझौता करके, अपने आप को नई परिस्थिति में इस तरह ढाल लेते है, जो कि सामाजिक तौर पे उचित हो।

उदाहारण के लिये एक ऐसी स्थिति की कल्पना करें जिसमें एक छोटा सा परिर्वतन हो। हम अगर अपने दफतर या विद्यालय किसी निशिचत रास्ते (route) से जाते हैं। एक दिन अचानक आधे रास्ते पहुॅचकर हमें ट्रैफिक पुलिस यदी रोक के कोइ्र दूसरा रास्ता पकडने को कहे तो हम आसानी से मानजाते है। इसके लिये हम बिना अहसास के अपने निम्नालिखित कौशल का प्रयोग करते है।

काल्पनिक शक्ति द्वारा हम अनुमान लगाने की कोशिश करते हैं 'शायद कोई वि.आई. पी. इस सड़क पर आ रहा है' या आगे रेत– रोडी पड़ी है, तो शायद सड़क पर काम चल रहा है।

हम सम्प्रेक्षण द्वारा (communication) जानकारी लेते है। हम ट्रैफिक पुलिश से या दूसरे लोगों से पूछते है 'यह रास्ता आज क्यों बन्द है' कब तक खुलेगा, इत्यादि।

परन्तु यदि हमारी काल्पनिक शक्ति और संप्रेक्षण (communication) सीमित है तो हम ना तो अनुमान या अन्दाजा लगा सकते हैं और ना बातचीत द्वारा जानकारी ले पायेगें। नतीजे के रूप में ऐसी स्थिति में व्यक्ति अपने आप को परिवर्तन के साथ नही चला पायेगा।

ऑटिज़्म से प्रभावित व्यक्ति में सीमित काल्पनिक और संप्रेक्षण क्षमताओं के कारण बदलाव को झेलने में कठिनाइयॉ आती हैं। इसलिये वह ऐसी स्थितियाँ प्रसन्द करते है जो एक समान रहे। अधिकतर इसका प्रणाम होता है– ऑटिस्तिक व्यक्ति सीमित क्रियाओं में रूचि लेते है, जो हमेशा एक समान रहती हैं । वह चाहते है कि उनकी दिनचर्या दिन प्रतिदिन स्थिर रहे।

बहुत से ऑटिस्टिक व्यक्ति अपने वातावरण में होने वाले प्रमुख परिवर्तन सह सकते है परन्तु उसी वातावरण में होने वाले छोटे और निरर्थक परिवर्तन को नही झेल पाते। उदाहरण के लिये – एक बालक छुट्टियाँ विताने के लिये नानी के घर आराम से जाता है। वही बालक खुशी से छुट्टियाँ काटकर जब वापस घर लौटता हैं तो अपने पलंग (bed) का स्थान बदला हुआ पाता। पलंग दीवार के साथ से हटाकर कमरे के बीच में पाता है। ऐसी स्थिती में वह फसाद खड़ा कर देता हैं, और तब तक शान्त नहीं होता जब तक वापस पलंग उस विशेष दीवार के साथ नही रख दिया जाता । ऐसा नही हैं कि ऑटिजम से प्रभावित व्यक्ति को बदलाव या परिवर्तन के साथ समझौता करना असम्भव है।

यदि हम उन्हे होने वाली घटनाओं और स्थितिओं की जानकारी पहले से स्पष्ट रूप से दें और साथ ही उन्हे यह जानकारी दें कि नई स्थिती में उन्हें क्या करना है, तो ऑटिस्टिक व्यक्ति को बहुत सहायता मिल सकती हैं और बदलाव होने पर वह घबरा या उलझ नही जायेगें।

जब हम किसी भी आम बच्चे को (जिसे ऑटिजम ना हो) कही ले जाते है तो वह बच्चा स्वयं सवाल पूछता हैं। जैसे कि "हम कहॉ जा रहे है" वहॉ कौन होगा "हम कब लौटेगे" इत्यादि इन प्रश्नो के उत्तर उन्हें बताते हैं कि क्या होने वाला हैं। ऐसे सवाल ऑटिस्टिक बच्चे नही पूछ पाते। हमें स्वयं यह जानकारी बच्चों को देनी है।

परिवर्तन के लिये तैयार करते समय याद रखे की शाब्दो का प्रयोग बहुत ध्यान से करे। सरल स्पषट, सकारात्मक भाषा का प्रयोग करे।

उदाहरणः– गुप्ता अँकल के घर में बदमाशी नही करना – यह कहना विल्कुल अनुचित होगा। इसकी जगह यह कहना उचित होगा – गुप्ता अंकल के घर में माँ के साथ बैठना। या गुप्ता अंकल के घर जाकर आप टी. वी. देख सकते है और अपनी किताब पढ सकते है।

होने वाली क्रियाओं या स्थिती के बारे में समझाते समय अच्छा होगा कि आप कुछ ऐसी सूचना दे जो दार्शिक रूप से स्पष्ट (visually clear) हो । याद रखियें, ऑटिस्टिक व्यक्ती दार्शिक जानकारी अधिक अच्छे ढंग से लेते हैं। इसलिये तसवीरे, कैलेन्डर, घडी, घंटी, इत्यादी अतयन्त उपयोगी हो सकते हैं दन साधनों का उपयोग कैसे किया जा सकता हैं, यह निम्नलिखित उदाहरणों मे दिया है।

यदि व्यक्ति किसी कारण से आने वाली स्थिती या घटना में अपने आप को ढालने में कठनाई पायेगा तो उसे धीरे–धीरे तैयारी करे।

कैलेन्डर पर तारीक पर गोला लगाये। उदाहरण – यदी व्यक्ती को बाल कटवाने में कठनाई हो, तो बाल कटने से लगभग 5.6 दिन पहले कैलेन्डरे पर बाल कटने वाली तिथी पर घेरा लगाऐ। उसे बताऐ– "हम 15 तारीक को बाल कटवायेगें"। हर रोज कैलेन्डर पर उस दिन की तिथी पर निशान लगवायें। व्यक्ती को नाई की दुकान में होने वाली स्थिती से परिचित करवाये। इसके लिये घर में उसे एक कुर्सी पर बिठाकर उसके गले से एक वस्त्र बॉधं जैसे कि नाई करता हैं।

बच्चे को कैची दिखाये सर पर पानी लगने का ऐहसास दिलाऐ। परिवार के किसी दूसरे व्यक्ती के बाल कटते हुए दिखाना इत्यादी।

बच्चे को सही जानकारी दे। यदी बच्चा डॉक्टर के पास सुई लगने के लिये जा रहा तो, उसे बताये की हल्की दर्द होगी ।

यदी किसी रिश्तेदार या मित्र के घर जा रहै हो, ता उन लोगें के फोटो, नाम इत्यादी के साथ कुछ ऐसे खिलौने या अन्य वस्तुऐ ले जाये जिससे बच्चा उस नई जगह पर कुछ परिचित वस्तुओं को देखे।

सफर में, किसी अन्य नये स्थान में सोने के लिये बच्चा घर से परिचित चादर, ताकिया इत्यादी ले जाये।

बच्चे के घर की दिनर्चचा या स्कूल में होने वाली क्रियाओं की सूची बनाये और इस सूची को चित्रों द्वारा बच्चे को प्रस्तुत करे। इस प्रकार उसे स्पष्ट जानकारी मिलेगी।

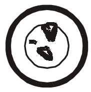
उदाहरण के लिये सूची में सुबहः–

सुबह उठकर नीचे दिये गये चित्र सूची द्वारा बच्चे को दिखाये – "क्या करना है"

दूध

नहाना

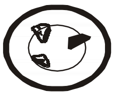
नाश्ता



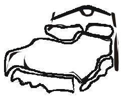
स्कूल

स्कूल से लौटने पर नीचे दी गई चित्र सूची दिखाये

दोपहर का खाना

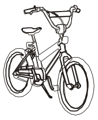


आराम करना



घूमने जाना

ाईकिल चलाना



जब भी आप अपने ऑटिस्टिक बच्चे के साथ कुछ कर रहे हो (जैसे नहलाना, खाना, कपडे पहनाना, पढ़ाना, खेलना, गाना इत्यादि) तो याद रखे कि यह सब क्रियाऐ बच्चों को अलग–अलग लोगों (माता– पिता बहन/भाई, रिश्तेदार) के साथ करनी जरूरी हैं घर के बाहर भी कोशिश करिये कि बच्चा किसी एक विशेष दुकान, सड़क, पार्क में जाने का आदी ना हो जाये।

इस लेख में हमने केवल कुछ विचार व्यक्त किये है। जो माता–पिता और अध्यापक बच्चे के साथ अधिक समय व्यतीत करते है। वह अपने बच्चे को भलीभाँती समझते है। यह लोग और भी सर्जनात्मक और रचनात्मक ठंग से ऑटिस्टिक व्यक्ति को परिवर्तन के लिये तैयार कर सकते है।

Book Review by Prof Shirshendu Chakrabarti, Professor of English
He is also the parent of a young man with autism

The Curious Incident of the Dog in the Night-time

By Mark Haddon

Published by Jonathan Cape: London 2003

This book is a triumph of imaginative sympathy, since it gives a compelling account of the world of an autistic young man written by a knowledgeable but non-autistic person. Unlike first-hand descriptions of the autistic universe, Haddon's is tidily constructed in accordance with shared conventions of communication.

At times, we may get the impression that Haddon begins with all the recognized diagnostic symptoms and works back to an individual representative rather than beginning with the latter and arriving at the disorder. But even if that is true, the sheer virtuosity with which he instils life into this theoretical model is breath-taking while the compassionate attention to concrete detail energetically dispels the myth that we cannot enter into the autistic consciousness from our familiar world.

THE hero and the first-person narrator of the novel, Christopher John Francis Boone, is an autistic child of working-class stock. His father, a boiler mechanic who runs his own business and his mother, who makes mistakes in spelling in the letters she writes to her son, enable Haddon to keep his subject uncluttered by specialized knowledge. The reader is thus moved to a simple acceptance of the behavioural 'eccentricities' of Christopher and even his mother's lack of patience is redeemed by love. If he dislikes some food because of its colour (a common sensory difficulty), he is allowed to change its colour with his own supply of ketchup. He has his choice of computer games and TV programmes and is even permitted to keep a pet rat at home.

CHRISTOPHER goes to a special school where he is fortunate to find a trained and sympathetic teacher, Siobhan, who helps him cope with the bewildering world of human communication. Christopher finds people confusing because they 'do a lot of talking without using any words'. As Siobhan admits, 'if you raise one eyebrow it can mean… "I want to do sex with you" and it can also mean "I think that what you just said was very stupid."'

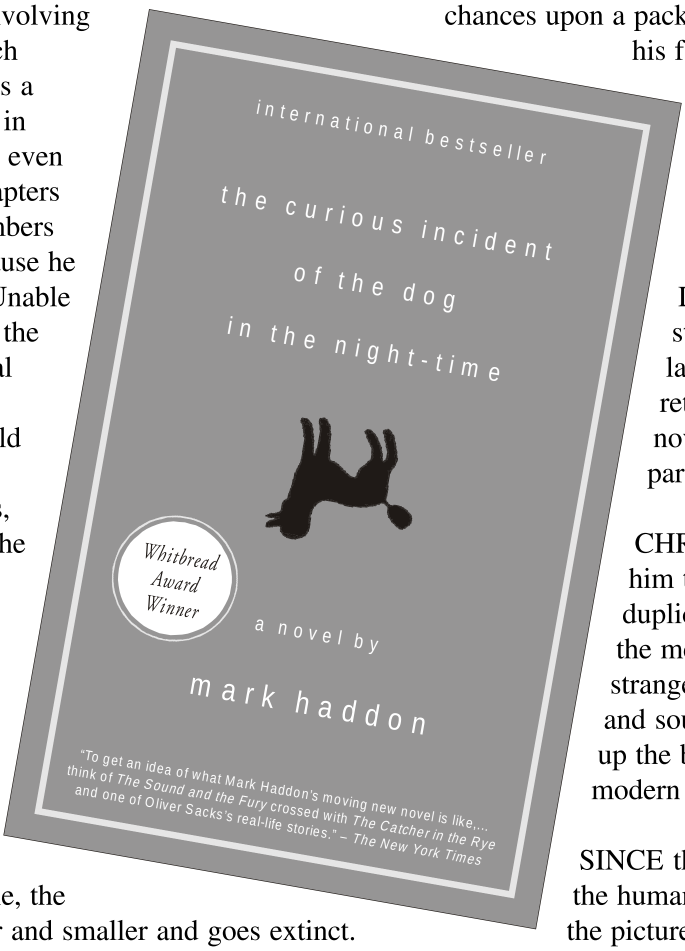
PEOPLE also use language without that literal precision that is indispensable to coherence in Christopher's life. Thus, while his mother thinks 'Christopher' a nice name because the story behind it is kind and helpful, Christopher does not want his name to mean any such story: '*I want my name to mean me*.'

WITH something approximating to clairvoyance, the writer of this novel enters in this way into the communicative logic peculiar to autism. The examples or illustrations that he chooses persuade us to acknowledge the sanity of apparently bizarre autistic behaviour. We discover that Christopher does not tell lies not because he is good (although his mother thinks so) but because he *cannot* tell lies. Lies disrupt his need for precise truth, for a cosmos of specificities from which the infinite and therefore bewildering possibilities of meaning or interpretation have been eliminated:

"A lie is when you say something happened which didn't happen. But there is only ever one thing which happened at a particular time and a particular place. And there are an infinite number of things which didn't happen at that that time and that place. And if I think about something which didn't happen I start thinking about all the other things which didn't happen."

THESE multiple possibilities of meaning make simple instructions incomprehensible to the autistic child who does not know what to do and is therefore generally misunderstood as disobedient.

PEOPLE often say "*Be quiet*" but do not tell you how long to be quiet for. A sign says 'Keep off the Grass' but Christopher feels it should say 'Keep off the Grass around this Sign' or 'Keep off all the Grass in this Park' because "*there is lots of grass you are allowed to walk on.*" When he is often asked to stay out of other people's business, he is confused since he does many things with other people, at school, in the shop, on the bus and so on; moreover, his father's job involves the maintenance of boilers in other people’s houses. Only Siobhan understands this problem for she gives exact instructions on what to do and what not. ‘For example, she once said, “You must never punch Sarah or hit her in any way, Christopher. Even if she hits you first. If she does hit you again, move away from her and stand still and count from 1 to 50, then come and tell me what she has done, or tell one of the other members of staff what she has done.’



CHRISTOPHER is an autistic savant who has an unusual proficiency in mathematics. He can solve in his head complicated quadratic equations or puzzles involving probability; in fact, such mental mathematics has a soothing effect on him in moments of stress. He even chooses to give the chapters of his novel prime numbers 2,3,5,7 and so on, because he likes prime numbers. Unable to understand properly the simplest forms of social interaction, he is comfortable in the world of numbers. Cold winters, cats, or herons, he admits, may cause the chaotically fluctuating population of frogs in the school pond, but the mystery has its own mathematics.

IN the formula for the population of frogs, when the constant is less than one, the population gets smaller and smaller and goes extinct. When it is between 1 and 3, the population gets bigger and stays stable and when it is between 3 and 3.57 the population goes in cycles. But when it is greater than 3.57 the population becomes chaotic: ‘it means that sometimes things are so complicated that it is impossible to predict what they are going to do next, but they are only obeying really simple rules.’

CHRISTOPHER does not like novels because in them people speak in a veiled, non-literal style. Thus, when Siobhan asks him to write something that he would want to read himself, he decides on a murder mystery novel because such novels have puzzles with specific clues that have to be separated from the red herrings, always leading to solution in the end. His admiration for Sherlock Holmes makes him borrow the title of his novel from Conan Doyle although he does not care for Doyle’s irrational beliefs.

THE curious incident of a neighbour’s murdered dog enables us to enter into Christopher’s mode of existence. As he starts writing down his investigations, his father orders him to stay away from ‘other people’s business’ and even confiscates the manuscript. Searching for it, he chances upon a packet of letters from his mother, which his father had kept hidden in his room. He discovers from them that his mother had not died two years ago and that his father had lied to him about her leaving home partly because of marital discord caused by her son’s difficulties. Christopher sets off for London to meet his mother and his strange experiences of the world at large are described vividly. His mother returns with him and at the end of the novel, there is just the hint of his parents patching up in the near future.

CHRISTOPHER’s detective work leads him to a world of discord, jealousy, duplicity and unruly passions. Apart from the menacing presence of dangerous strangers or drug addicts, even the sights and sounds around him cumulatively build up the bleak loneliness and brutalisation of modern urban life.

SINCE the novel simultaneously highlights the human values of tolerance and kindness, the picture that emerges is of a society that cannot cope with itself.

BY contrast, Christopher’s own universe invites a parallel with his two preoccupation: mathematics and the cosmos. We are thus left to wonder if the normal world is a viable alternative to the autistic one or if it is more deeply impaired in social and communicative skills than the latter.

NOTE: *This must-read book is available at most leading bookstores. But, if you cannot get a copy please contact AFA.*

AFA Sends Autistic Young Man to Mainstream Life

Shakuntala Joshi

Hemant is 25 years old. He has been working in a software company *Aerware* in Delhi for the last one year now. A volunteer picked him up from the Aadhar Work Skills Training Centre in Action For Autism (AFA) where he had been for about six months and introduced to *Aerware*. His parents were surprised when they were told that he was found suitable and had been offered a computer related job. Hemant had successfully completed his basic training in computer even before joining Adhar, and had acquired a fair degree of proficiency in typing. His parents were aware that he was capable of doing many computer related simple jobs under proper guidance yet they were doubtful about his capacity to work independently and, more than any thing else, his acceptance by a company employing technically qualified people.

HOWEVER having been given initial guidance and after supervising his work for about a month, Hemant has been working very well, handling his job independently by himself, and is fully accepted by co-workers. Initially he was given the job of simple data entry from a separate hand written form into computer format. Later he worked on 'Excel' for a while. Presently his work involves copying the data, updating it and transmitting it through the Internet. This is a totally paperless job demanding one hundred percent accuracy and a lot of concentration. He has been working as efficiently as any other normal employee of the company and there have been no complaints

LIKE any Autistic person Hemant has some peculiar habits and fixations. For example he does not like to write the figure '3'. So instead of '3'he would write '2+1' or 'n'. In a professional work environment such as his work place was, such playful acts were not accepted. This did create some problems in this job in the beginning. Once this problem came to light he was told not to do it and for sometime someone was constantly sitting with him to see he did not do this. He was constantly told that as long as he continued to do such acts his work will not be accepted and he will not be treated as a 'responsible' man. He was made to realize that he was not supposed to change any figure and that such acts were not acceptable at a work place. Slowly he gave up the habit.

AUTISTIC individuals have to be taught everything right from very basics upwards. They do not automatically adopt the things which all of us pick up naturally. We have to teach them everything and repeat it over and over again. But once taught properly they normally do not forget it for a long time. Particularly for those autistic individuals with normal intelligence with some effort they can be taught many skills which they can apply to their work.

WHILE autism is a disability, there are some areas where autistic individuals exhibit superior traits compared even to normal persons. Some of them like Hemant, possess a very good memory. Hemant is able to remember many things by heart. He remembers certain calendar tables used for calendar calculations and with the help of these he is able to calculate the day of the week of any calendar year 'orally' without using paper and pencil. Similarly he can also mentally perform multiplication of three and four digit numbers swiftly.

HEMANT is good in music also. He sings and plays Casio (synthesizer), and has performed at many functions at Action For Autism.

TODAY Hemant is completely independent in his personal chores. He is proud of standing on his own feet and earning. The feeling of being an earning member of the family has given him a sense of pride and self-esteem, which has further motivated him to behave like a normal member of the community. The changes that have been brought about in his personality, behavior and communication skills during the last one year due to constant application of mind and peer interaction in this job are very noticeable and only go to prove that such individuals should have opportunity of normal environment and social and interactive circles as possible.

WE are proud of Hemant and wish him every success and tons of good luck.

HELPLINE

ACTION FOR AUTISM

Q A is a six year old boy from Kolkata. He has been diagnosed autistic. He is being treated for delayed speech and ADHD. He receives speech therapy and is being taught at home by his mother and grand parents.

He is showing exceptional skills in arithmetic and language. We have taught him only the alphabet and numbers and nothing more, but he is writing sentences comprising difficult spellings without any mistake. He is also performing long additions and multiplications which are difficult without a calculator. He simply looks at the problem on paper and writes the correct answer within moments. He has not been taught any of these by us and the doctors are unable to explain the phenomena. He is attending a normal school as he lacks speech. We are at a loss to decide as to what to do for the proper nurturing and development of his talent.

I am working in Doha, Qatar where no special schools are available. I plan to bring them to Doha but this problem is delaying our decision.

A From your account it appears that A may have some exceptional skills that are quite often seen in individuals with Autism, known as savant skills. People with savant skills may excel in one or more area, in particular, in mathematical / calendric calculations, music or art. Researchers have proposed many reasons for the emergence of these skills, however the most acceptable explanation is that individuals with Autism are able to focus on one area phenomenally well due to the very nature of Autism and its core deficits.

In addition to this, it appears that your child is also exceptionally gifted in literacy skills. However, it is difficult to say how far a savant skill this is, as it could well be related to hyperlexia (an ability to read beyond one's level of comprehension) or an exceptional memory for words and sentences. If your child is being worked with following any particular intervention at home, perhaps his skill in literacy and numeracy could be tested in a variety of situations and his strengths assessed. It would be ideal for you to take your child to a specialist school for a full functional assessment of his skills.

There are currently no specialized centres in India for the development of savant skills. However, with the guidance of a special educator who has a sound understanding of autism you could hone A's skills using appropriate training methods. This needs to be carried out within the framework of an individual education plan that is based on his needs and learning style.

As A lives in Kolkata, you could contact the Autism Society West Bengal where you could receive training and guidance. In the meantime, we suggest you focus on developing alternative modes of communication for your child. You will need a special educator with experience of Autism to guide you. Speech therapy may help your child but success is limited within the Autism Spectrum.

Finally, If your child is on medication for ADHD, do ensure that he has been diagnosed with ADD or ADHD. Many individuals with Autism present hyperactivity due to reasons related to their autism, rather than clinical hyperactivity that may also be found in typically developing children. In such cases, medication may only be a temporary solution that will enable you to work with your child following appropriate training methods.

Q My daughter is 27 months old and still has a vocabulary of about 10 words. Recently she had some tests done in Ranchi (Jharkhand) for hearing as well as brain scanning as suggested by a neurophysician. She has been given medicines for Autism. We have not started the medicine still. I want to get my daughter diagnosed to ascertainwhether she really has Autism. Please suggest where we should we take her for diagnosis. Also if you can advise on Speech therapy centres in India.

A You can obtain a diagnosis for your daughter from NIMHANS in Bangalore, PGI Chandigarh, All India Institute of Medical Sciences Delhi, Ummeed in Mumbai, Hinduja Hospital Mumbai, as well as in most major hospitals. In addition there are many individual professionals who can give you a diagnosis. I would like to add that you do not require a brain scan for a diagnosis of autism; however the scan can help rule out other conditions. Also, there are no medications for Autism though there are medications to help counter some of the symptoms of autism.

While you want to get a diagnosis, it would be helpful to start teaching skills to your daughter as soon as possible.

Q Our four and half year old boy D has echolalia. He repeatedly utters one or two words like 'papi,' or 'tote,' but not otherwise speak. He has been receiving speech therapy daily since the last one and a half years.He was fully toilet trained and used to indicate his need by pulling us and saying 'susu.' But now he urinates at any place. He indicates his mischief by shying away and babbling.

We live in Mumbai where D attends a nursery school with one to one teacher attention and where his mother is also present. Recently the attention deficit and the impatient behavior have increased a lot. D is unwilling to sit in the class and follow instructions. When one insists it often leads to physical attack on the teacher or his mother like hitting and pulling the hair. This behaviour was not at all there even three months back.When he behaves like this we try to calm him down by explaining the situation but it does not seem to work. Emotional disbalance is also on the rise

We seek advice for his violent behviour. Can D's parents train at AFA on how to handle D?

A I am sure you have informed yourself about the ways autism affects an individual. One of these is the different ways from the norm that language develops as well as the persisting difficulties. So while many typically developing children go though a period when they echo speech, in children with autism echoing persists beyond age three when it typically stops. In addition children with autism do not merely have a limited vocabulary,rather there are difficulties with the understanding of language, with phonetics, with the rules of communication. It is almost as though they do not understand the purpose of language and how the rules of communication work. There are also difficulties in processing and understanding communication. The speech therapy D receives will have to be more oriented towards teaching him communication rather than focussing onarticulation.

Explaining things the way we do with regular children may not work with children with autism. In fact such explanations of why a behaviour is good, or bad, and so on, only adds to the child's frustration. It is difficult for me to say why exactly D exhibits the behaviours he does during one on one. But if I had to make a guess I would say that what you are seeing in your child is not so much emotional imbalance as frustration at not understanding what is expected of him and in not being able to convey his wants.

It would help to try and understand why D does not want to sit. Why he does not want to attend to the task. Is the task too easy? Too difficult? Are the instructions too confusing? Is there clarity and consistency of communication with D?

Regarding the renewed toileting accidents, we want to check out a number of things. Has there been a change in the environment? What happens before a toilet accident. What happens after? When do accidents usually happen? With whom? This will help us ascertain whether toilet accidents are due to sensory issues, control issues, a behaviour that has been inadvertently reinforced, and so on. However in the meantime you could try and put D on a toilet schedule.

For instance if he wets himself after approximately every two hours, then take him to the toilet after every one hour and 45 minutes. If he urinates in the pot, point to the urine in the pot and praise him. You may even give him a small reinforcer, which could be a candy, or a string, or whatever D likes. On the other hand when D wets himself is he reprimanded? Sometimes a reprimand can act as a reinforcer for a child. If that be the case you want to stop reprimanding D for toilet accidents while you maintain the toilet schedule.

Training yourself would of course be very helpful. You could indeed receive training at Action For Autism. This could be a week-long programming for your home, or it could be a three month Mother-child training programme. You could also benefit from attending our four-day training workshops in October.

New Section at OPEN DOOR

With growing awareness, more and more children with higher cognitive and academic skills are receiving a diagnosis. Many of them face difficulties in getting into mainstream schools and are unable to access appropriate educational services.

To reach out to such children between the ages of 5 and 10, AFA is starting a section that will work at moving these children toward the National Open School and / or mainstreaming.

For more information contact:
Indu Chaswal – Tel: 26094410

Annual Training Workshop for Parents & Professionals

INDIAN SOCIAL INSTITUTE, LODI INSTITUTIONAL AREA, NEW DELHI

October 14 – 17, 2004

AFA's annual workshops are an eagerly awaited event each year. The workshops build on an understanding of Autistic Spectrum Disorders and work through teaching various cognitive, communication, and daily living skills. The workshops are free of jargon, and illustrated with practical examples based on AFA's hands-on experience and exposure to children with autism of varying ages and across the spectrum and follow a format of lectures, a demonstration class, video clips, question and answer sessions and discussions.

Individual consultations on the last day of the workshop will be available at no extra charge to those families who book in advance.

Childcare will be available during workshop hours for families who find it difficult to leave their children at home. Please register in advance. Information about your child's spcial needs will have to be given at the time of booking so that adequate arrangements can be made.

Childcare will not be available to on-the-spot registrants.

Accommodation: *Limited number of rooms f*rom noon of 13 October to noon of 17 October at the ISI at Rs 1500/- per bed (twin sharing) and Rs 3000/- (double room) for a four night stay with breakfast

Registration Costs

PARENTS
Rs1750/- per parent attendee (Rs 1400/- for members)
Rs 3000/- per parent couple (Rs 2500/- for members)

NON-PARENTS
Rs 2500/- per non-parent attendee (Rs 2200/- for members)
Rs2300/- for each attendee from an organization that has taken membership if more than one person attends

DAYCARE CHARGES
Rs 200/- per child, per day

On the spot registration: Rs 3000/- Includes ALL attendees who pay for their registration on 14 October 2004.

For more details fill in the form below and mail with a self addressed stamped envelope to:
Action For Autism, T370F Chirag Dilli,
New Delhi 110017

— CUT HERE —

PRE REGISTRATION FORM

Fill this form in BLOCK LETTERS and mail, with a self-addressed stamped envelope to:
Action for Autism, T 370 F Chirag Dilli Gaon, New Delhi 110 017

Name ______________________ (*Tick relevant box*) Parent ☐ Professional ☐

Address ______________________

____

Tel ______________________ Email: ______________________

If parent, name of child ______________________ Child's DOB ______________________

If professional, name of organisation ______________________

Do you require accommodation YES/ NO Do you require childcare YES/ NO

(...cont. from page.1)

by Smitha Awasthi, hopes to dispel some of the concerns that parents and professionals often have about using AAC, and particularly about signing.

IN addition to all the professionals and parents who came as a part of the NIDRR delegation, (and Rita Jordan, who was here in December), the autism community saw Duncan Fennmore, Steven Ward, and Teresa Grimes, all in the past few months! This bounty of experts was topped by a visit from Prof Anthony Bailey, Patricia Howlin, and Rachel Pike – the first two being figures who, along with Rita Jordan, were among those who were my first teachers so to speak. Professionals whose work and writings influenced greatly the way AFA views the wonderful community we serve.

AS we go to press construction *finally* starts on the National Centre for Autism building. The first RCI recognised Diploma in Special Education nears completion. The 'disability certificate' that will help persons with autism access services seems closer to reality. The National Trust has been active on this issue, and we have been fortunate in having extremely supportive officials in the Ministry of Social Justice and Empowerment: both in Mrs Rajwant Sandhu earlier and Mrs Jayati Chandra now.

TO make a great start to the new year even better, AFA has received a special commendation for its work from the Rotary, which will be conferred by the Honourable Vice President in April.

> *" There were people at school that made fun of me... "*
>
> "Now...I feel sorry for them because
> they didn't understand.
> They just need to get educated, because
> what if they have a child one day
> with autism? What will they do then?
> Make fun of him?"
>
> – *Kent Schomber, 36-year-old self advocate*

B O O K P O S T

ACTION FOR AUTISM

If undelivered please return to:

The Editor, Autism Network,
T 370 F Chiragh Gaon, 3rd Floor, New Delhi - 110017

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.

AFA's own E-mail and Homepage

Action For Autism now has an *e-mail address* and its own *Homepage* on the Internet.
Our e-mail address and internet access details are:

autism@vsnl.com
http://www.autism-india.org