

# autism

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**A**ction For Autism is a registered, non-profit, national parent organisation. Autism Network is published by Action For Autism to provide information on education, therapy, care, and to provide interaction for families and professionals across the country.

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### Cover Illustration

'Stencil Stanta'  
by Sujit Kurup, 8 years, a student at Open Door

## WISHLIST !

### FOR ALL STUDENTS

- o A minibus or van
- o A Video Camera/ Cassettes
- o Still Camera
- o Board Markers & Felt Pens
- o Glossy/ Weekend Newspapers for craftwork
- o Children's tricycles/ slides/ swings/ seesaws
- o Paper to recycle for children's worksheets:
  - o A4 sheets of paper used on one side
    - First Aid Items: Band Aid, Dettol, Cotton etc
  - o Shampoo pouches/ Soap

### FOR THE OFFICE

- o Loan of a Laptop for 3 months
- o A Scanner
- o Two fast printers for computers

### FOR THE NATIONAL CENTRE

- o Support for components of the NC Building

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## PAGE ONE

When Open Door opened its doors nearly nine years ago, it was the only school imparting specialized training to children with autism. It is exciting to note that many more schools have opened up since, and continue to do so. It is also exciting to see some of those professionals who have trained at AFA doing great jobs around the country. Recently, we have had heartening reports of Bansham Lyndoh in Shillong. Good to hear of your work Bansham!

The year got off to an interesting start with the visit of Dr Anthony Bailey, recently appointed to the Cheryl and Reece Scott Chair in Psychiatry at Oxford. Dr Bailey's area of specialisation is related to understanding the biological and cognitive basis of autism and researching potential treatments. His seminar clearly underscored the very specific needs of those with ASDs from those with global developmental delay alone. Regrettably, the highly restricted attendance deprived many who were eager to hear him. His comments on the incidence of autism would have been extra beneficial if more generally broadcast.

The first quarter also saw the release of 'An Introduction to Neuro Developmental Disorders of Children' by the National Trust. Written by Dr Mervyn A Fox as a 'labour of love' it is an authoritative volume and the first of its kind published in India.

This year the National Trust had formulated a scheme for Social Security for persons from low-income groups. However, disappointingly, the scheme to provide a security net to this most marginalized group was not included in the Union Budget. It is now up to parents' organisations to take up this issue and ensure its inclusion in the next budget.

Last autumn, AFA started plans for a workshop tour of India by Rita Jordan. We now look forward to welcoming Rita at four locations during November and December 2003. Rita holds a special place for AFA. She was the catalyst 11 years ago that formally propelled the organization onto its present path.

On the subject of educational issues, there seems to be much confusion about ABA, DTT, & TEACCH; which is better, which is best and so on. In this issue we carry excerpts of an interview with Dr Julie Donnelly, associate professor and highly respected autism consultant, based in the USA. Her interviewer Adam Feinstein is Editor of 'Autismconnect' as well as a parent of a 7 year old with autism.

Finally, it seems that in July 2003 the Rehabilitation Council of India will launch a Diploma in Special Education (Autism) Course and AFA's long efforts will have paid off. That is much to rejoice. It has not been an easy road. We have gone through

"Give up your pointless campaigns. *"Kitne hai autistic? Nothing will happen,"* to "Why are you quoting these numbers? These are not true for India. Autism does not happen in the subcontinent," to "Why have you come to me? *Yeh to parents keh wajah say hota hai.*" We have carried on doggedly till perceptions were changed, and minds opened up. But the tougher arguments were still to come! A big one was that since people with autism often have MR why do we need any different teaching for them? Such an argument obviously does not take into account that children with autism have an impaired theory of mind and executive function as well as central coherence deficits.

The next argument against was: "You want a training course but where are the trainers?" Even if one discounts the fact that AFA has been running an enormously successful training course for several years (and parents are the best judge of that) as has KPMARC, surely we can not NOT have a training course now "because there are no trainers!" We do not have trainers so we do not train; and because we do not train we will never have enough trainers! Should we not start with what we have?!

More recently, critics argue that since inclusion is what the world is moving towards, why is AFA advocating a course that would be exclusionary! The understanding being that if we are going to include children in mainstream schools why do we need a specialized teacher training. Such arguments of course come from a lack of awareness of ground realities. Who does not think inclusion? There is not a parent who would not want their child to be in a regular school.

But we do not live in a perfect world. The simple fact is that most children with autism are not in *any* school – even special needs schools. Most turn away the more severely impaired (read those with more challenging behaviours). And as for regular schools, even the physically impaired often get turned away. So how do those with autism stand a chance?! Many children with ASD could be mainstreamed if there were trained therapists to help them. But bar a handful there are no trained therapists. Why? Because there is no RCI training. And why is that? Because it is believed there is no one to train them....

The whole situation is like a dog chasing its tail.

But now, we are truly grateful that the Rehabilitation Council of India is putting a DSE (Autism) Course together. It has been a long hard struggle. And a long wait for parents desperate that their child receive an education. We have a diagnostic explosion staring us in the face. It is time we stopped debating what action to take. There are those who act and there are those who critique without action. Let us be amongst those who act.

# Verbal Behaviour in Practice: A Brief Overview

Ann Jose Varavukala

When it comes to therapy options for working with a person with a complex developmental disability like autism, there can sometimes seem to be a bewildering array of choices. So far there has been an absence of a conceptually sound and cohesive framework, on which therapy option recommendations are made. Professionals and parents often use experiential or anecdotal evidence for recommending a line of action, based on the topography i.e. the form of the target skill, instead of a function analytic and scientific approach. Advances that have been made in our understanding of behavioral principles rarely find their way into clinical practice.

IT is therefore heartening to know that **Verbal Behavior (VB)** – a therapy system, that is founded on sound well established principles of Applied Behavior Analysis, and draws together relevant streams of current research, is gaining acceptance and popularity.

WHILE the huge and growing demand for VB is new, VB itself is not. VB is based on teaching procedures that exploit the principles and concepts of Applied Behavior Analysis, first set out in B.F. Skinner's book: '*The Behavior of Organisms*' in 1938. In this book Skinner laid out the principles of **Operant Conditioning**<sup>1</sup> for the first time. Put simply Operant Conditioning is the process by which behaviors of an organism get strengthened or weakened by the consequence immediately following the behavior. For example: the behavior of jumping traffic lights would tend to be weakened if a strict and stringent fine system was implemented, or the behavior of taking an aspirin for a headache is strengthened because the headache is reduced.

IN addition Skinner laid out his methodology for studying and changing behavior – namely single subject design instead of statistical analysis of large groups, inductive process instead of deductive etc. Understanding the process of Operant Conditioning led to the analysis of

the impact of schedules of reinforcement, the process of extinction, stimulus discrimination and generalization, motivation etc – all crucial factors that need to be taken into account in any teaching situation and particularly when teaching children with a complex handicap. These principles shall be discussed at length in a later article. The methodology Skinner laid out led to the realization of the need for the '*teacher to be a strategic scientist*', letting the student's reaction guide the moment-to-moment interaction, using the known principles of Behaviourism as a framework.

IN 1957 Skinner published his seminal work entitled '*Verbal Behavior*' where he laid out his analysis of language itself as a behavior, and therefore shaped by the laws of Operant Conditioning. According to his analysis, the word was not the unit of language. In fact Verbal Behavior is not limited to vocal behavior – but any behavior which is mediated by a competent listener. For example, a child asking for water or a nonverbal child signing for water, or using a picture card to ask for water, or pointing to a bottle, or engaging in a tantrum when thirsty, when a familiar person is present – would all be examples of verbal behavior. Language needed to be looked at not just structurally, i.e. its syntax and semantics, but functionally.

SKINNER outlined several functional classes of language or **verbal operands**, the key ones being:

- **Mand:** A motivation driven demand: e.g. a child asks (or signs, or gestures or screams or hits his head) for water when thirsty).
- **Tact:** Labelling an object, event etc. – for example saying 'its raining' when looking out of the window.
- **Echoic:** Imitating someone else's vocal behavior – for e.g. a child saying 'water' after you have pointed out a glass of water to him and said 'water'.

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<sup>1</sup> For those seeking to understand the principles of Behavior Analysis, a good basic text is '*Behavior Modification: Principles and Procedures*' by Raymond G Miltenberger. This book is available in the resource section of the AFA library

- **Mimetic:** Mimicking someone's motor actions – e.g. clapping when someone else claps.
- **Intraverbal:** Answering questions or filling in blanks, i.e. verbal behavior controlled by others, vocal behaviour e.g. a child saying 'lamb' when you pause after saying 'Mary had a little ...' or answering 'pink' when asked 'What's your least favourite colour?'
- **Textual:** Reading written words e.g. saying 'water' because you see the word written word 'water'.
- **Written:** Writing or spelling out a word that you hear spoken.

USING Skinner's analysis of language as a behavior that is under the influence of the variables of operant conditioning, gives us a viable model for helping individuals with a language deficit. *VB Therapists focus strongly on teaching language across its functional classes leading to a more spontaneous and complex language development.*

DR. Jack Michael, and his students Mark Sundberg and James Partington, have extended Skinner's research and applied it with great success to language-handicapped individuals, in particular children with autism. Jack Michael's work on Establishing Operations or motivation has also had a huge influence.

IN 1998 Drs Sundberg and Partington published a manual '*Teaching Language to Children with Autism and other Developmental Disabilities*' outlining the teaching procedures that are most effective in teaching these functional classes, as well as an effective behavioral language evaluation tool '*The Assessment of Basic Language and Learning Skills (ABLLS)*' again based on Skinner's analysis of Verbal Behavior<sup>2</sup>. In addition to providing an excellent assessment tool that leads naturally to an optimal functional intervention plan Drs. Sundberg and Partington have made Skinner's hard to understand analysis of Verbal Behavior accessible and usable.

USING research that has flowed out from Skinner's analysis over the years, Dr Carbone and his associates

have outlined and popularized certain **teaching procedures**, that have encapsulated the findings in areas like fluency, concurrent schedules of reinforcement and joint control. Briefly these include

1. The teacher strongly 'pairing' herself with the child's current reinforcement, thereby increasing the probability of on-task behavior as opposed to escape motivated or self-stimulatory behavior.
2. Using 'Error Less Teaching' Procedures, and a high ratio of mastered to difficult goals, to reduce learner errors and keep the rate of reinforcement high.
3. Mixing and varying tasks during intensive teaching schedules, to keep motivation high and encourage generalization and better stimulus control.
4. Using a variable schedule of reinforcement, short inter-trial intervals, to keep the rate of responding high.
5. Teaching to fluency so that more spontaneous use of the mastered goals is displayed.
6. Extinction for off-task behaviors, but a stronger reliance on the use of competitive reinforcers, so that the teaching situation does not become aversive.
7. Prompt fading over the dimensions of space and time.

THESE will be explained in greater detail in a subsequent article.

IN addition VB practitioners<sup>3</sup> use the literature on **Functional Analysis** to determine the most optimal way to work at decreasing challenging behaviors. Instead of using the topography of the behavior, i.e. its form to determine the strategy to reduce it, they try to determine the function of the behavior using established experimental analysis methodology. For example, if a child tends to scream a lot during sessions, they will attempt to figure out, by isolating the possible variables, and measuring the behavior in different combinations of these variables, whether the child's screaming is for task avoidance (socially mediated negative reinforcement), or for attention or some specific item (socially mediated

<sup>2</sup> A review of these books has appeared in the August 2000 issue of the Autism Network.

<sup>3</sup> The term VB Practitioners is used in this article to refer to those professionals within the Applied Behavior Analyst Community, who use Skinner's analysis of Verbal Behavior and the teaching methods that have been shown to be effective in Applied Behavior Research. It would be more accurate to simply call them ABA practitioners which is what they are, but because of the strong association of the term ABA with those following a more narrow Discrete Trial Therapy (DTT) focused approach, the distinction had to be made.

positive reinforcement), or because it gives the child some sensory pleasure (automatic positive reinforcement) or because of some medical condition like pain (automatic negative reinforcement). Once the function of the behavior has been isolated, a strategy to reduce the behavior is drawn out which will again use the principles of Applied Behavior Analysis, and will include extinction, manipulation of the Establishing Operation (EO) or motivation, and the teaching of an alternate more acceptable behavior.

VB Practitioners in contrast to other therapy lines that draw their roots from Applied Behavior Analysis – for e.g. practitioners of Discrete Trial Therapy (DTT) inspired by Ivar Lovaas's study, give a lot of importance to teaching in the Natural Environment (**NET – Natural Environment Training**). NET may look like free play to a casual observer, but when done well, will manipulate constantly changing EO or motivation on a moment-to-moment basis, to target the child's goals across the functional classes of language.

IN addition VB Practitioners are responsible for bringing **sign language** into focus, as a means of augmentative communication especially for non-verbal children. Previously Picture Exchange System (PECS) had been the method of choice for non verbal children with autism. With their focus on spontaneity, maintaining flow, and using language across functional classes, PECS was felt to be too limiting. It is recommended only for those children with an extremely low imitative repertoire due to some physical limitations caused by a concurrent medical condition. It has been seen that merely having poor motor imitation does not necessarily preclude a learner from using sign as a response form, and if a good attempt at teaching sign is attempted using error less teaching procedures and focusing first on the most motivating things in the child's life (i.e. on 'mands') motor imitation often improves. Even for verbal children, teaching sign along with the word has been shown to dramatically improve retention and spontaneous use.

IT should come as no surprise, that when we evaluate procedures that have been used successfully in the past to change problem behavior or teach new skills, we find that they have been consistent with the principles of

Applied Behavior Analysis. It is analogous to realizing that efficient everyday tools like the hammer or a pair of scissors are those that exploit Newtonian laws. To effectively design new tools, or to use them in new situations it is certainly helpful to understand the laws of mechanics and this is only more true in a complex situation. In a similar fashion understanding the principles of Applied Behavior Analysis and its application to the teaching of Verbal Behavior and behavior modification, help to design optimal ways to teach new behaviors or skills for everyone, and in particular for the community of people with autism. The community of people involved in helping individuals with autism, owe a debt of gratitude to the practitioners of Verbal Behavior for the work they do, in making this possible.<sup>4</sup>

## Diploma in Special Education (Autism)

### TRAINING COURSE 2002 - 2003

Action For Autism offers training in one of the most challenging and exciting areas of Special Education. Admissions are now open for the next training session.

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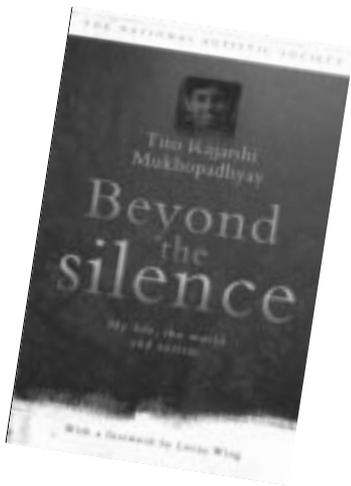
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*Please mark envelopes 'DSE (Autism) Training Course'  
Last date for receiving applications 20 May 2003.*

<sup>4</sup> The author would like to place on record her deep gratitude to P.O.A.C( Parents of Children with Autism, New Jersey) whose generosity enabled her to attend an intensive and fascinating course given by Dr. Carbone, covering the principles of Behavior Analysis, and their continuing support. Dr. Carbone and Thomas Caffery of P.O.A.C have made several helpful suggestions and corrections to this article.



**Book Review: Professor Shirshendu Chakrabarti, Delhi University**

## Beyond the Silence: My life, the World and Autism

(London: The National Autistic Society, 2000)

Tito Rajarshi Mukhopadhyay.

This 'inside' story of autism is truly remarkable because the disability is marked by significant communicative impairment and because the author is a very young boy barely verbal due to his autism. The first two sections of the book, 'The Voice of Silence' (written when Tito was eight years old) and 'Beyond the Silence' (written when he was eleven), present a compelling picture of groping and surfacing through cognitive bewilderment. With savant-like linguistic proficiency, Tito offers us in these two sections a unique glimpse into his expanding consciousness of himself and the world. Such communicative and cognitive ability is no doubt atypical of autism but perhaps, as Tito himself puts it, the autistic person has it inside him; only, he does not know how to 'use' it in a 'socially acceptable way'.

THE final section: 'The Mind Tree' and 'Poems from Tito's Story', achieves a clarity that suggests unusual social accommodation and adaptation. But its poetic beauty does not have the haunting strangeness of 'The Voice of Silence', which, true to its title, speaks to us from the precipitous brink of language.

PERHAPS we ought to accept autism as an alternative, autonomous cosmos on which our codes of socialization may be applied only with caution and introspection. Tito looks forward to such tolerance: 'One day I dream that we can grow in a matured society where nobody would be "normal or abnormal" but just human beings, accepting any other human being – ready to grow together'.

TITO'S language has the repetitive quality distinctive of even high functioning autistic persons: it imposes stability on the potentially disintegrating world of autism. By describing the 'continuous flow of happenings' observed by the 'mind tree', he is able to see himself from a distance undisturbed by that flow. The tree represents the

somewhere that he has reached; it is location in time and space, while its interlinked branches, trunk, roots and the very heart of the earth exemplify triumph over fragmentation.

TITO'S attempts to cope with his experiences took him towards withdrawal, to a world of shadows and dream staircases. For instance, he felt secure in the company of the shadow of his flapping or fluttering hand, and as the shadow vanished at night in darkness, his world would be on the verge of collapse. He could relate to the picture of a dog but not an actual street dog. People were voices for him, that is, he had to acquire slowly and with help the concept of the relationship between voices, people and their lips.

UNCERTAINTY was so central to his world that having memorized the previous day's sky he was upset to find a different map of clouds the following day. Tito learnt to 'time travel', replaying the past events repeatedly, so that they remained unchanging, within his control.

AFTER his grandfather's death, Tito plunged into fantasies believing himself to be a bodiless spirit who could enter the world inside the mirror. Such was his sense of physical fragmentation that when he was hurt he was unable to point at the place of pain. Perhaps autistic hyperactivity is the product of an ongoing struggle with fragmentation:

*He spun round and round to be faster than the fan. He felt so that way!*

*He got the idea of spinning from the fan as he saw that its blades that were otherwise separate joined together to a complete circle, when they turned in speed.*

*The boy went to an ecstasy as he rotated himself faster and faster. If anybody tried to stop him he felt scattered again.*

*A new environment became very difficult to cope with, as he felt that he was not able to find his body. Only if he ran fast or flapped his hands he was able to find his presence.*

HAVING learnt to read and write with the help of a writing board, he was unable to point at his body parts when the doctors at Vellore (in South India) asked him to. This was not because he was ignorant of the parts of the human body but he could not point and identify them in his own self. However, he could do the reverse: when the doctors touched his hand and legs and so on, he easily pointed at them on the board.

TITO could not speak because he could not relate his voice to his capacity for speech: 'The problem of autism was making him feel that his voice was a distant substance that was required to be collected and put somewhere inside his throat. But he was unable to find it. He wept for it'. Similarly, although Tito knew that balls could be caught or hit with a bat or kicked, he could not use his limbs to that effect. 'Knowledge and the

application of the knowledge were like the two ends of a string, which were distinctly separated by a distance called 'relation' and it is this relation which is so elusive to the autistic person.

TITO'S autobiography is far from being an exercise in self-absorption for he warmly acknowledges the nurturing and soothing influence of friends and professionals like Dr. Pratibha Karanth, Roopa Rao and Veronica Mathias. Above all, it is the presence of his mother, in all her strengths and weaknesses, that shines through the entire narrative and is as much her story as his.

THE autistic person is thus not unaware of the social basis of human existence, not a wasp trapped in a bottle; his problem is the lack of coordination between 'what' and 'how.' Ultimately, Tito's story is a deeply social gesture directed at entrenched attitudes of apathy, intolerance and rejection:

*I must make the point clear that it is not lack of social understanding which causes the weird behaviour, but it is lack of getting to use oneself in the socially acceptable way, which causes the weird or the undesirable behaviour.*

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## Do You Do TEACCH or ABA?

*A question we are asked often is: Do you do TEACCH? Or do you do Options? Or do you do ABA? And we try to explain that we do not use any one method rigidly and in isolation; we try and use an eclectic mix.*

*We use TEACCH, Options, Communication Therapy, Sensory Integration and the principles of Applied Behaviour Analysis.*

*We carry a few excerpts from an interview that Adam Feinstein the Editor of Autismconnect had with respected autism consultant and author Dr Julie Donnelly which expands on this issue.*

**AF: How did you become involved with autism in the first place?**

**JD:** When I was twenty years old I had a son...at the age of three he was diagnosed with autism and that's what got me involved. He is thirty one years old now.

THEY wanted to put him in the hospital for an indefinite stay, which was an institution and I couldn't do it. I ended up working with him in the home very, very intensely. It was one of the first home programmes – and made some progress with him.

I didn't know anything about Lovaas. We did behavioural programmes in natural settings. So it would be about dressing himself or it would be about communicating to get through or participating in the family, doing the things that a typical three or four year old would need to do. So we did use a behavioural method but it wasn't a discrete trial programme.

**On Lovaas.**

IT was popular in the sixties and it is now very popular in the States. It is a very good intensive type technique and it does work with a lot of children, but there is a

*(cont. on page 7..)*

(...cont. from page.6)

certain artificiality about it, being that it is usually across the table and many times students learn a lot of things but they don't learn about adult settings and they are unable to generalise them. I consider it a very good tool and it is one tool I use.

I use the discrete trial training technique in my work with other children but it's only one of my tools. If you only have a hammer, everything starts looking like a nail. And sometimes a screwdriver would be the better tool – so you have a toolbox full of tools.

(Lovaas) is a good technique – it's just not the one and only. The research definitely supports that there are a lot of other good techniques out there.

**...the whole approach (with Lovaas)...is to eject autism from the child, which is very different, say, from the Options or TEACCH approach.**

THEY say that they will cure autism or be able to make people normal... there are some children

who really do benefit from this technique...my problem with it is not in the parents. Parents are desperate to find something to try and I understand that the parents jump on this treatment or jump on that treatment, but... some of the consultants who sell this to parents and would sell it by blowing it out of proportion about what it does, by making claims that this will cure their child and every child and that this is the only technique that is good for kids with autism.

... it is exciting ... (that now) we have choices: we can use this technique or that technique or a combination of some different techniques, and that's wonderful.

**Lovaas is now more currently known as applied behaviour analysis**

I think it is very confusing because ... applied behavioural analysis (ABA) is a main part of the entire field of behaviourism. So it is confusing that they take the name of the larger field and they put it on a

technique that's just one behavioural technique. I do ABA, everyone does ABA, teachers do ABA.

**Lovaas as compared with ABA. Are there a many differences?**

LOVAAS started working with that technique in the Sixties. Some people in various places have allowed the technique to evolve and are more eclectic. For instance, use occupational therapy, and speech and language therapy, ... Sensory. But when you work with people who are very strict Lovaas in the old style way, you're

not allowed to have language therapy or occupational therapy. They consider that the discrete trial technique can teach everything, and that's where I disagree.

**What is your view of the famous 1987 statistic?**

HE [Lovaas] said that he has never used the word "cure" but lots of people that followed him used the word "cure".

(The) research (was) on 19 children: 47% is (only) 9 children. (Also)... the selection of children... tended to make it a higher

functioning group to begin with, and the way that he measured the outcome was also problematic. The other issue was being placed in a regular classroom. In the United States, we place a lot of kids in a regular classroom and you can't judge recovery from that. Although it was a very good study and there is good follow up, it was experimental.

WITH research you can't base a conclusion on one study. There are some replication sites ... but ... none of the replication sites are doing pure Lovaas – it wouldn't make sense to do that. I mean this is 2000 and Lovaas is the old technique. For instance, one of the replication sites is doing a project... and they said: "We don't just do discrete trial training, we do sensory integration and we do TEACCH. We're eclectic, we're not purists." That's good for the kids, but as far as the research is concerned, we are not replicating the originals of Lovaas protocol so they're not going to be able to say we have replicated and approve it.

### **AFA Receives First Ever 'Nina Sibal Award'**

On March 5th, Action for Autism received the first ever Nina Sibal Memorial Award for *innovative methods of education* from the All India Women's Education Fund Association.

AIWEFA is a voluntary organisation that works, in consultation with the United Nations, to promote women's empowerment through education, information and knowledge. The award was presented by Dr Najma Heptullah at Parliament House. We are delighted that AFA's contribution has been recognised.

## My Son Kartik

Chandrashekar

**K**artik joined for intervention at Action for Autism in 1997 when he was five and a half years old. Kartik had been diagnosed as having cerebral palsy with mental retardation at AIIMS and was undergoing special education with children with mental retardation at Samadhan. He was also getting speech therapy.

THOSE methods were not able to help Kartik much. We were at a loss as to the appropriate focus by which we could help Kartik to settle down and learn.

WHEN Kartik had joined Action For Autism he would not sit at any place for even a second except while he was eating something. Even then it was for only one minute or so. His eye contact was minimal – just for a fraction of a second. He would be continuously running around making one sound ‘eeeeee’. He would only sit and listen to music. He would not sleep properly in the night. He had to be constantly watched to avoid hurting himself. He did not have any interest in toys and was always occupied with his cycle’s wheels making them go round and round. His recognition skills were minimal. His language skills were also not present. He could not even communicate his needs. Kartik could not hold himself straight while walking and needed a lot of support on roads and on staircases. His gait was also awkward and it felt that his upper and lower body was disjointed. His gross motor skills were very poor though he had a tight grip. He resisted changes. He would cry for hours for no reason. He was sensitive to loud sounds such as those of the cooker and the mixi which hampered his learning process. He did not like to bathe.

WHEN he started at Action For Autism, Indu Chaswal worked one to one with him. All the teaching was hand on hand. I too worked with him at home following the same methods. We found Kartik responding more with this method. He could sit in one place for 10-15 minutes at a stretch and his eye contact also improved. We found that if the instructions were simple and consistent he was able to understand and follow it. ALSO if we sang the instructions in a soft tone he would listen more.

IF the whole process of bathing, for example, was broken down into simple procedures he was able to understand and follow. We found that if we were **consistent** in our instructions, behaviour, routine and more important if the promises made were kept and **response and praise** given **immediately** – we were able to get him to do things and he learnt quickly.

LATER Kartik joined the Open Door Day Program and he has been going there for four years now. There has been tremendous change in these four years. His cognition skills have improved to unimaginable levels.

He started showing interest in the world around him. He became interested in books. He liked to look at books. He was given small story books with pictures. He has picked up number concepts quickly. He has learnt to read. He has developed an interest in cricket. He likes to go for walks and to the park. He adapts to changes now without tantrums. He is still sensitive to loud sounds but

is able to cope by closing his ears with his hands. He is learning to use PECS for communication at school and follow-up at home.

NOW he takes his bath and goes to the toilet on his own. He can indicate his wants by touching a finger, when a choice is offered to him using the fingers of the hand. The school is following the curriculum followed by normal children and Kartik is being taught science, maths, social studies, English etc.

HE has started attending the vocational center AADHAR at Action For Autism as a part of his pre-vocational training. He is well behaved while going out. He also takes interest in people coming at home and tries to interact with them. Kartik has grown into a boy who has his own views and can exercise his option.

WE are grateful to the teachers at Open Door whose **undaunting** efforts have helped Kartik to grow to this level. Our family thanks AFA for starting a place where our children can receive proper guidance and grow.

*“To you, autism might  
be a terrible tragedy.  
For many of us  
on the spectrum,  
it is just the way we are.”*

# LETTERS

Autism Network is very informative and a platform where parents, special educators & others can share their experiences and thoughts.

I would like to share an improvement in my son Abhishek. As you know our kids have the problem of brushing teeth. I could overcome this by using a Colgate toothpaste for the kids – bubble fruit flavour. Initially I started using this paste both in the morning and night before sleeping. Due to the sweet flavour my son was allowing me to brush his teeth though with lots of anxiety. If I forgot to do so, he would point at the paste. Gradually I have started to use the normal promise paste in the mornings and colgate bubble fruit flavour in the nights. The improvement is that he now allows me to brush his teeth willingly and relaxed.

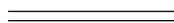
I hope this will help other parents who are facing a similar problem with their kids.

Anuradha  
CHENNAI



Our sincere thanks for maintaining such a wonderful site for autistic children of India. It is really impressive and the information provided in your journals is very handy.

Jyoti Kennedy  
YEMEN



As a mother of a 3+ old autistic child, I have my own share of challenges and victories. I don't claim to be perfect in the way I am dealing with life but I would still like to share some thoughts with you all. Maybe, just maybe, my way of thinking helps anyone who needs some positive thinking.

First of all, PROBLEM is not the word when we deal with your child. CHALLENGE is. Remember all our dreams of an adventurous life full of challenges. Well God has given us one such life, through our child. The nature and intensity of challenge is however different for every one of us. Each and every day although much the same, is also different as our child may or may not show any progress and we don't know what lies ahead.

Every day we are working on our children, some times without any positive outcome and getting frustrated and some times being happy at their progress. But we have to understand that our society does not understand and accept any change easily. So it's our duty to make this society understand our child's needs. Don't expect others to be helpful as every one today is facing a difficult life in some way or other.

Most parents keep trying to send their children to regular schools till their hopes have faded. Please stop humiliating yourself and your child again and again. If your child is going to school then make sure he/she completely understands whatever is being taught. If you have not been able to get your child in a school don't panic. First observe and make note of his or her hobbies or the activities they are most interested in, and then try and make out a way to develop these skills. For example, if your child likes dance and has a good sense of rhythm then when they grow up a little they can be sent to a good dance academy.

For your child's sake do not be shy of being in public. The more you cut yourself off from society, the more difficult it will be for you to make others aware of your child's condition. Take your child along on visits to shops and banks. Do the calculations in front of your child. Ignore other people, as you are teaching your child one of the valuable lessons of life, you don't have to be ashamed of anything.

Most of the autistic children don't pretend play. Well don't wait for them to do so. Initiate and show your child how to play. For instance, if your child loves airplanes then make noises and run the plane in front of him. Or if your child loves dolls then dress up the doll in different cloths, give bath to the doll and anything you can think of. While doing these activities involve your child in the play. At first your child may not be very keen in joining you but if you keep doing these activities, your child will also start doing these and will also do some thing new he or she observes.

Don't be reluctant in showing anger to your child if they are wrong. But showing anger does not mean slapping or screaming. In a firm and low tone repeat to them where they have gone wrong and what they should actually do. Remember none of the activities written above will bring out a sudden change in your child. You have to go on and keep repeating these and more activities to help your child.

S. Mukherji, UP  
EMAIL: smukherji@adityabirla.com

## अपने ऑटिस्टिक बच्चे से बातें कैसे करें

समस्या: बहुत से ऑटिस्टिक बच्चे अपनी रोजमर्रा की जिन्दगी में देखकर या सुनकर काफी बातें समझते हैं। लेकिन, जैसा कि हम सभी जानते हैं, इन बच्चों में भाषा से सम्बन्धित कई तरह की मुश्किलें होती हैं, जिसकी वजह से कोई बात ठीक तरह से समझने में मुश्किल होती है और व्यग्रता का कारण बनता है।

1. बच्चे अपना ध्यान एक जगह केंद्रित न कर पाने की वजह से सामने होने वाली घटना की अधूरी जानकारी ही हासिल कर पाते हैं।

2. यह बच्चे किसी शब्द के शाब्दिक अर्थ और उसके भावार्थ के अन्तर को समझने में असमर्थ होते हैं।

3. ऑटिस्टिक बच्चे शब्दों को उसके शाब्दिक अर्थ के रूप में ही समझते हैं, इसीलिये द्विअर्थीय शब्द या ऐसे शब्द जिनका मतलब प्रसंग के अनुसार बदल जाता है, को समझने में उन्हें मुश्किल होती है।

उदाहरण: नीचे, कल, तुम, वहाँ आदि।

4. किसी घटना को समयानुसार सिलसिलेवार रूप में ध्यान रखना उनके लिये मुश्किल होता है। इस वजह से यह बच्चे नयी घटनाओं के लिये तैयार नहीं हो पाते।

भाषा समझने में अपने बच्चे की सहायता कैसे करें:

(1) सकारात्मक भाषा बोलें: बच्चे को जो काम नहीं करना उसे बताने के बजाय जो काम करना है वह बतायें।

उदाहरण: "कुर्सी पर बैठ जाओ" न कि "कुर्सी से मत उठो।"

- "चलो" न कि "दौड़ो मत"

- "जैसे ही तुम कोट पहनोगे, तुम बाहर जाकर खेल सकते हो।" न कि "अगर तुमने कोट नहीं पहना तो तुम बाहर नहीं जा सकते"

(2) अपनी बात या विचार पूर्णरूप से व्यक्त करें।

उदाहरण: "अब हम स्टोर जा रहे हैं /न कि/"अब हम जा रहे हैं।"

(3) साधारण भाषा में और शाब्दिक अर्थों को ध्यान में रख कर बात करें।

उदाहरण: "यह केले का चित्र है" न कि "यह केला है।"

- "किताब मेज पर रख दो" न कि "इसे वहाँ रख दो"

- "यह पेंसिल लाल है" न कि "यह लाल है।"

(4) अपने बच्चे से सिर्फ तभी प्रश्न पूछें जब उसे मानने या न मानने की छूट हो। और आप भी बच्चे के उत्तर को मानने के लिये तैयार हों। जैसे कि यदि 'क्या तुम्हें अभी खाना है? यदि बच्चा कहे 'नहीं' तो आपको उसके इस उत्तर को स्वीकार करना होगा। यह इसलिये क्योंकि आपने उसे खाने के लिये निर्देश नहीं दिया है, केवल एक सवाल पूछा है, "क्या तुम्हें भोजन खाना है और इसलिये उसके उत्तर का सम्मान करना पड़ेगा।

अब इस सवाल को एक दूसरी स्थिति में देखें।

आप पूछें "क्या तुम अभी खाना खाने के लिए तैयार हो" और बच्चा खाना खाने के लिये खाने की मेज़ पर नहीं आता तो आप सोच लेते हैं कि शायद बच्चे का जवाब "ना" है। यदि आप बच्चे को ज़बरदस्ती खाने

के मेज़ पर लाने की कोशिश करते हैं तो वो परेशान होगा या किसी और तरीके से अपनी नाराज़गी प्रकट करेगा। बेहतर होगा यदि आप कहें “खाने का समय हो रहा है”। कुछ मिनटों के बाद कहिये “खाने की मेज़ पर आ जाओ, खाने का समय हो गया है।” या फिर आप कह सकते हैं, “ओ. के. मैं टाइमर सैट कर रही हूँ और उसके बाद खाने का समय होगा।” या आप कर सकते हैं कि “मैं पहले बोटल में पानी लूँ और फिर खाने का समय होगा”।

(5) जो बात आप कहें उसे जरूर पूरा करें। यह जरूरी है कि बच्चा जाने कि जो बात आप कर रहे हैं उसका कुछ मतलब है। उदाहरण: “खाने के बाद हम जाकर आइसक्रीम खायेंगे” यह कहने के बाद यदि घर पर कुछ मेहमान आ भी जायें तब भी आप जायें और बच्चे को आइसक्रीम दिलवायें। यदि ऐसा नहीं करेंगे तो बच्चे को आप पर विश्वास नहीं रहेगा और “खाने के बाद हम जाकर आइसक्रीम खायेंगे” - इस वाक्य का मतलब भी नहीं समझ आयेगा।

(6) बच्चे से बात करते समय वाक्य पूरा व सामान्य गति के साथ बोलें। जिससे बच्चा दूसरों की बात समझ पाये। यदि आप कोई नया कॉन्सेप्ट (विषय वस्तु) बता रहे हैं तो उसे प्रमाण सहित वर्णन करें या वह ऑब्जेक्ट (वस्तु) दिखाने के साथ सही शब्द का इस्तेमाल करें या उस वस्तु को लेबिल करें।

(7) निर्देश देना:

- बच्चे का ध्यान अपनी तरफ आकर्षित करें।
- कुछ देर रुकने के बाद-छोटे और साधारण वाक्यों में अपनी बात कहें।
- बच्चे को समझाने के लिए शारीरिक, मौखिक व दर्शनीय संकेतों का उपयोग करें।
- अगर जरूरी हो तो शुरूआत व समाप्ति को स्पष्ट रूप से बतायें।

उदाहरण: बच्चे को अपने कमरे में अंदर रहने के लिये उसके कमरे के दरवाज़े पर एक टेप लाइन लगाना।

- काम शुरू करने के लिए स्पष्ट संकेत दें। जैसे “ओ. के. अब शुरू करो।” यदि बच्चा आपके कहने से पहले दौड़ना शुरू कर दे, तो उसे रोकें और पहले उसका ध्यान दोबारा अपनी तरफ करने की कोशिश करें और तब तक उसे आगे के निर्देश ना दें।
- सुनिश्चित करें कि आप जो बात कह रहे हैं उसे पूरा करें और बच्चा भी उसे सही तरीके से करे।
- कार्य पूरा होने पर उसे शाबाशी दें (या बात को उसके मन में पक्की करने का प्रयत्न करें)।

(8) अपने बच्चे को ‘नयी’ या ‘अगली’ होने वाली घटना के लिये तैयार करें, जैसे कि कहें “पहले हम ----- करेंगे और फिर तुम ----- करोगे।

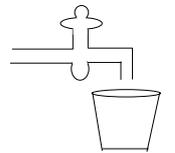
ऑटिस्टिक बच्चों में देखकर सीखने की क्षमता अच्छी होती है। इसीलिए कई बार अलग-अलग स्टेप्स को लिखकर या चित्र बना कर दिखाने से बहुत सहायता मिलती है। उदाहरण के तौर पर:

- दस बजे बाथरूम जाओ
- कोट पहनो
- बस में जाओ आदि। या ...



दस बजे घड़ी का चित्र बनाये

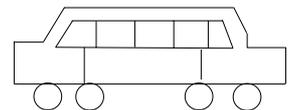
- बाथरूम का चित्र बनाये



- कोट का चित्र बनाये



- बस का चित्र बनाये।



# Understanding David

*Sushila Ailawadi*

“**Y**our son has Downs syndrome”. The doctor, a personal friend, went on to observe that he did not seem to have all the features of a classic Downs child. “Mosaic” was the term used to explain the sprinkling of Down’s features that we recognized in him.

WE grappled with this reality for over fourteen years, most of which were spent in a rural area, far removed from the opportunities afforded by the larger city. Some characteristics of Down’s children were evident, but others had us puzzled. The lack of eye contact. His very limited use of speech. His mannerisms. His extreme reaction to change in routine. His overreaction to certain stimuli. Seemingly lost in a world of his own, with limited social skills.

AFTER moving to Delhi our search for an appropriate school for our son began. It was during this period that we began to hear another label attached to our son. “Have you ever considered that your son may be autistic”, the experts asked us. We had not. Was that why? The many unexplained characteristics we had noticed suddenly began to be understood with a new and alarming insight.

THERE is often despair in the face of such a situation. The diagnosis of one’s child being irrevocably handicapped can be final and terrifying for parents. The realization that one is powerless, that academic qualifications, money, or treatment cannot bring about any permanent change.

IT wasn’t easy to come to terms with what seemed another huge obstacle to understanding David and helping him to have a quality life. Only the thought that he was after all the same little boy we had always known and not some new and terrifying mystery helped us keep a sense of balance.

NONE of the places we went to seemed competent to help us understand and develop a program to serve our son’s needs. Eventually, after going through numerous organizations, there was a glimmer of hope at a well-known school for special kids. The lady we spoke to suggested that we start with a home program. A trained

teacher would come once a week and work with David. The plan was that he would eventually be prepared through the relationship that developed with the teacher to join in regular classes.

THE teacher, a good-natured young man with the best of intentions seemed at a loss to know how to proceed. We watched each week as he came and lectured us at length on how we should be with our son but seemed unable himself to build up any relationship after a month.

THIS was a dismaying observation and it was clear that paying two hundred rupees an hour for such a service was a futile exercise.

IN the meantime we met up with a friend who had trained at Action For Autism (AFA) for a number of years. To our amazement at the first meeting she established a rapport with David and seemed very comfortable with his non-verbal withdrawn state. Eventually we got to know the AFA family and discovered what was for us an oasis of hope in a desert of ignorance.

WE found a place where caring and sincere people worked hard to break through the thick impenetrable layers of the world of the autistic. Classes are small and every child is accepted and valued as a unique and special individual. The program is tailor-made for each child, and constantly evaluated to make the difference. The evaluation is participatory and inclusive of parents, which is a new dimension of work with these children. Frequent parent’s meetings in the school, provide a supportive practical network, besides being an emotional and psychological help. The teachers themselves receive many inputs through in-service seminars, workshops and lectures. This environ encourages development and growth and is healthy for any educational institution.

ONE of the programs that I have greatly benefited from is the Mother Child Intervention program. It is encouraging to see young mothers equipped to work with their children. The most healing aspect is the joy of being in a comfortable atmosphere of acceptance and understanding. As an educationist, I was amazed to see

how these mothers function with the efficiency and effectiveness of trained teachers. With the love and commitment they already have, they are taught ways to reach out into the world of their autistic child, and minimize obstacles in the pathway of learning.

THIS program confronts the despair that parents have and brings with it a new sense of hope and expectation. It gives practical ways of moving forward step by step. It equips parents and thus helps them to have confidence.

WE have since learnt that Autism is a complex condition. It is difficult to contain within any definition, and research in this field is as yet relatively in its infancy. So many unknown factors and dynamics make it all the harder to understand the mind of the autistic person.

THE need for a center in India is urgent. Such a programme would have the multi-faceted role of :

- educating the public regarding this condition;
- de-mystifying its seeming impenetrability;
- training professionals; and as we have experienced;
- training lay people and parents to face the disability with a sense of hope.

IT is time suitable training courses are made available to train professionals. Our experience suggests that a normal course on mental disability will not be enough, possibly just a beginning.

AFA is a forerunner in this endeavor, and should definitely be encouraged in all possible ways to continue.

## The Special Picnic

Viji Srinivas

Generally Sundays are spent leisurely in the company of family members, a much needed respite from the weekly schedule. But Sunday, the 8th of December 2002 saw a group of thirteen families boarding a bus as early as 6.00 am on their way to Mandva Beach, Alibaug.

PLANNED meticulously with each member involved in organizing it, the group of enthusiastic picnickers was having a blast. "It's been years since I have been on a picnic. *Ati Uttam*" exclaimed Mr. Punjabi. As Mrs. Punjabi nodded happily in agreement, Mrs. Taneja added, "It is a great stress-reliever. I am very much at ease in spite of the large group."

ALL of us go on picnics and enjoy ourselves. What makes this picnic more special and worth mentioning is that it was organized by the families of the Parents' Support Group for autistic children [PSG].

THIS group formed by like-minded parents in Chembur and Navi, Mumbai has been active for nearly two years now. Apart from providing information regarding professional help and resources to help fight Autism in their child, the group also tries to bring the families together by organizing get togethers, outings and picnics. Mrs. Kare, a new member, was happy that at

last she had a set of friends in whom she could confide her fears and anxieties about her child's future.

THE group of families without any inhibitions participated in all the fun. The fathers were heard joking amongst themselves while they happily sang during the *antakshari*. The siblings of the special children enjoyed as they participated in the musical chair and such games along with their parents. The special children too had fun as they played around in the water and sand always under the watchful eye of one or the other parent.

FOR the mothers it was a relief. They could be themselves for a day and not worry about their special child. In fact, right in the beginning, they had promised themselves that they would be 'normal' parents, forget all about Autism and just be carefree. That all kept their promise was clearly visible on their tired but happy faces as they watched the sun set on the beach. As they boarded their bus homebound, Mr. Punjabi was already planning a long trip to Goa.

MRS. Shubangi Auluck, friend and guide of the PSG, summed up at the end, "Slowly we are achieving the objective behind forming the PSG: to give moral, social and emotional support to one another."

# HELP LINE



*Q.* I am sending F to a new school since July 2002 which is near my house. In his school they put a lot of stress on writing exercises. F does not like writing, at the most he scribbles and puts the pen down as soon as he can. Is he dyslexic? What am I supposed to do?

Secondly the teachers insist I teach F reading capital and small letters before teaching him to sight-read. Otherwise they say he won't progress much further in learning to read. I have tried to explain to them the method I use i.e. using F's strength at sight-reading but to no avail. What should I do, please guide me.

And thirdly, teachers want me to prevent F from playing with strings. Initially, sometimes they used to snatch the string away from him as soon as he entered school and he cried the whole day. However a new behaviour, i.e. mouthing and licking has started. Is the new behaviour the result of the suppression?

*A.* Many children with autism have difficulties with various motor functions. From our experience we find that many have a difficulty writing, though they may be quite willing to type on a computer.

F's situation might be such. On the other hand from what you say he is not averse to using a pen. Maybe you could try and keep writing sessions brief and pleasurable, following it up with a reinforcing activity. Also make sure he sees and understands clearly what and how much he is expected to do. So may be you draw a flower and a flower pot below and F has to join the two. So it is clear what he has to do. Then again maybe you have three such sets drawn and ready so he knows 'how much'.

Finally at the conclusion of the activity he could know that he would get to play with his favourite toy or get to do something that he really enjoys. In addition maybe he could do exercises on a vertical writing surface.

If you cannot get the teachers to understand what you want them to do with F and why, maybe you just let it be and teach him sight-reading at home. When you cannot change something that you have to live with, do the best you can. Since explaining is not helping, use

your energies to teaching F rather than getting frustrated about what you cannot change.

It is very difficult for me to say why the mouthing and licking has started without having a background to the situation. Behaviours do not happen in isolation. So it would not be fair to F, you, or the school to comment without having more information. Incidentally, F's fascination with strings is something that could actually be used to motivate him to learn

*Q.* Recently we came to know that our five-year-old son is autistic. The symptoms are as follows:

He learnt to speak very late, at three to four. Now he is five. He can't speak fluently and often speaks in the third person. He can't mix with other children and plays with unusual things, like a small stick or paper pieces or broken wheel of his toy train and spends almost the whole day with that. If he is asked ten questions, he answers only one or two, either properly or improperly in spite of knowing the proper answer. He does not respond to outsiders, does not even make contact with them with his eyes. He protests if wearing a new shirt or a pair of new shoes, or following a new path to his school or to taste a new food. He likes to strike objects with his fingers creating a sound and occasionally is found, rubbing both his jaws together. He shows little interest in learning anything new, as a result, neither can he sip water or milk, nor can he spit water out from his mouth after brushing his teeth. He cannot tolerate the sounds of horns. He is very restless, inside his home, but very calm outside. Sometimes he laughs without any apparent reason and sobs for minor causes.

His memory is good and he seems quite intelligent. At the beginning of his school, teachers complained about his non-cooperation. However, at present, he is co-operative with them. He reads in nursery and doing well with his studies in a regular school.

But after knowing about his autism, we became anxious about his education and future life. There is no special school in our town and we don't want him to get admitted in Kolkata, far away from us. Kindly help us

with your advice for continuing his studies in the normal school he is attending and regarding his other deficiencies.

From the internet, we found the name of a book, "*Biological Treatment for Autism and PDD*", authored by U.S. based scientist, William Shaw, Ph.D, which claims dramatic improvement of autistic child by biological treatment.

*A.* As you can figure from observing your son, autism, unlike mental retardation, is not a global developmental delay. Your son is young and of course the best course is for you to educate yourself about autism in order to facilitate your sons progress.

Autism primarily affects the areas of communication, social skills, and thought and behaviour. For instance your son cannot play with other children or respond to adults. He appears to have difficulty looking at people when addressed or when addressing them to get his needs met. He has good speech, yet answers questions infrequently, and that too sometimes incorrectly.

Play is also affected, so that a child might not play appropriately with toys and which is why M keeps himself occupied with sticks and odd bits and pieces. Many individuals with autism have a good memory. Others may be of average or above average intelligence. There is also often a need for sameness. Which is why M has difficulty taking a new route or trying new food. There may be differences in the use of sensory modalities. So your son finds it difficult to tolerate some sounds, yet enjoys striking notes and listening to them. Or rubbing his jaws together.

Your son appears to be managing well in a regular school. Rather than look for a special needs school to send him to, you want to focus on helping him continue in his current setup. Take note of his strengths and work to minimise his deficits.

On improving his communication skills check the issue of Autism Network Vol IV No 3 December 1997. M might have speech, know the answer to a question, and yet when queried may not be able to come up with a reply on every occasion. What you want to do is to provide the correct response, so that he understands the function of speech. Example:.

"How many biscuits do you have?"

"Three."

Supposing you know that he will say "One," incorrectly when he actually has three, you pre-empt his "One" with your "Three".

Above all, avoid asking him needless questions. For instance if he knows his name and can answer "M" when asked his name, then you do not want to ask him his name. Only let outsiders and visitors do so. And if he then does not respond prompt him as mentioned earlier. There is an entire range of exercises as well as things you can do in the course of daily interaction with SR to help his communication.

To help develop his ability to look at people when addressed try the following:

When giving an instruction or telling him something first take his name, pause for a couple of seconds, and then say the rest. For instance, "M?" pause, "come have dinner."

When giving him something – rather than just handing it to him – hold the object between your and your sons eyes in the line of vision, such that in order to look at the object and reach for it he has to inadvertently look in your eyes. When addressing him, whenever you can, lower yourself to his eye level in order to make it easier for him to look at you. And whenever you get a spontaneous look from him acknowledge it. Avoid telling him "Look", "Look", repeatedly. We often fail to realise how irritating it can be for a child to be continuously told to look when it is actually difficult and sometimes painful for him to do so.

From your account M is doing well in his class. As he learns and grows be aware of a couple of issues. M has good memory. This is a strength that you want to use and that will also enable him to learn well. At the same time, good memory in our children can mask a learning disability. So while he might learn to read and calculate, you want to be aware to ensure that simultaneously his concepts are clear and that he is not doing these things by rote, as a mechanical ability.

There is currently a great deal of research being carried out on the biological basis of autism. Some children have improved with changes in diets and allied methods. Some do not show much improvement. You could give those a try if you want to.

We do not have the book by William Shaw. However we do have something on the subject by Paul Shattock

which you can access at the AFA library. You could also check out the following issues of Autism Network: Vol VII No 3 December 2000, and Vol VIII No 3 December 2001.

**Q.** After six years of marriage God blessed us with a beautiful daughter L. We are thankful to God for the precious gift he has given to us. Now she is three and a half years old. From the fourth month onwards my daughter was suffering from seizure disorder – epileptic attack – it was regular and for long periods. Through the medication and medicines it is now under control. Now this epileptic attack happens only once in 5-6 months.

After one year of age she was trying to talk. Then it stopped and we noticed some of her actions are different. We felt something else is wrong with her. After a check up and assessment from Hinduja Hospital Mumbai we learnt she is autistic. We are again thankful to God for throwing a special challenge in our life. It is his wish and his decision. He will have his own plans....

We wish to have your support and help to go through the special challenge in our life. Kindly give us the information that will shape her future about teaching speech, medicines, and schools in Mumbai.

**A.** It was humbling to read your letter of total acceptance of your daughter. Most of us have so much difficulty in accepting our children. We believe we love the child we have when actually we love the image of what we want our child to be. Your total acceptance of the 'special challenge in your life' is very special, an example to families, and will enable you to help your daughter far more effectively.

The main areas of difficulty for a child with autism are communication (not just speech), social interaction, and imagination. In addition children have difficulties in processing sensory information. Your daughter had speech but lost it with the manifestation of Autism. What you will want to work on is teaching her communication. You can teach her to communicate with a cause and effect approach, so that she comprehends the function behind speech..

For example, a child might bang on the door when he wants to go out. Usually, as soon as we have figured out what the child wants we provide the want. So when the child cries so as to be taken out, she is at once taken out.

This reinforces the behaviour which means the child learns that when I want to go out I have to cry. Instead, when the child bangs on the door I first provide the word/words that should be said, and then provide the consequence. The child then learns that these words precede the need being met. So child bangs on the door: I first say "Go out." **Then** I open the door.

Again, say the child takes my hand to the water bottle to indicate that she wants water:  
I first say "Paani." **Then** I give some water.

At the same time, whenever I make a request or give an instruction I ensure that the child follows through. We might need to prompt the response in the initial stages. For instance I ask the child to "sit" and she continues standing. I then 'follow through' on my request by making her sit and then of course always reinforce the behaviour.

Acknowledged teaching techniques that are effective with children with autism are based on principles of behaviour analysis. Every child needs a structured behavioural program keeping in sight the individual's strengths and needs. There is no medication to treat autism. Medication can be used to alleviate symptoms of the condition if it comes in the way of the child learning skills, and *along with* structured behavioral teaching. Medication cannot be used *in place of* teaching.

In Mumbai there are a number of schools that take in children with Autism. For detailed information you would be best served by contacting the local, very active parents group:

*Forum for Autism, 2<sup>nd</sup> Floor, Block A, Jyeshtharam Baug, Dr.Ambedkar Road, Dadar, Mumbai 400014, Email: forumforautism@hotmail.com*

They would be able to give you more information about services available in Mumbai.

**Q.** I am the mother of an autistic boy aged 9 years, based at Chennai. I would like to start the CFGF diet for my son. I request you to answer the following questions:

1. Is there any pediatrician/doctor in Chennai, who knows about the Dan protocol, and CFGF diet and can guide me? If so, please give me their address.
2. Is the peptide testing done in India (especially in Chennai). If so please furnish their address.

3. What is the dairy alternate that is available in our country? I read even soya milk contains gluten. Is rice milk available here.

4. I am a South Indian, vegetarian. Rice is the major component of our food. I would like to have a list of gluten free grains/cereals that can be used. I would also like to know if vanaspati/dalda can be used for cooking.

5. If you have the address or e-mail of parents who follow the CFGF diet in India, especially in Chennai, please give them to me so that I can get their views.

*A.* 1. We do not have information on physicians in Chennai who have information on the diet though I am sure there must be some who do. Perhaps you could check with your son's pediatrician.

2. The same goes for the peptide testing. We really have no information on places in Chennai doing it.

3. Soya is indeed considered the dairy alternative available. However as you yourself observe it is now believed that soya too contains traces of gluten. As for rice-milk parents make the milk themselves. If your child is not particularly keen on milk and otherwise eats a range of foods I don't think you need to worry too much about the consumption of milk. However, ensure he gets a balanced diet.

4. South Indian vegetarians are the luckiest! Their diets are largely gluten free!! Even your savouries like *murrukkus* are gluten free. For a list of Cereals and grains please check out Autism Network Vol VII No 3 December 2000.

Vanaspati, dalda as well as ghee are all GF/CF. Ghee though, derived from dairy, is casein free.

5. We don't have a list of families following a GF/CF diet. However we will forward your mail to parent groups and ask them to get in touch with you if there are parent members who follow the diet.

I hope these answer your queries. Finally may I add a note. Follow a GF/CF diet for your child if you can. The diet may or may not help. Those who do report changes usually find small ones. There will not be a miracle. But whether you follow the diet or not you want to focus strongly on structured behavioural teaching. That is really what will give results.

*Q.* We are parents of a three-year-old son diagnosed with autism from Hinduja Hospital. We have been running from pillar to post and are feeling helpless. We have given him occupational therapy for more than three months but there is no change. Now his therapist has told us of a new treatment for autism called G-therapy. Please advise and guide us. Will the medicine G-therapy make him lead a near normal life?

*A.* Occupational Therapy is certainly helpful particularly when it takes the individual child's specific needs into account. The therapist is probably doing sensory integration which can be very helpful.

Perhaps you want to discuss with the therapist what exercises are being done and most importantly why. You know your child best and can give the therapist valuable inputs. However I must add that occupational or sensory therapy in isolation is not an appropriate treatment option. As you must be aware a diagnosis of autism implies impairment in communication and social skills. Occupational therapy will not teach him communication and social skills, though under a good therapist it can enhance his ability to learn these skills. Your son needs special education in addition to the therapy he is currently receiving.

Please get in touch with the support group *Forum for Autism* (details elsewhere in Helpline). They will be able to give you information on services available in Mumbai and Pune. With appropriate therapy provided early and intensively some children with autism can come to leading a close to 'normal' life. By which it means that they will be able to participate in day to day life without too much additional and specialized support.

Many parents have asked us about G Therapy. But I am afraid G therapy will not accomplish this. Neither is G therapy a new therapy. It has been advocated by one individual in Pune for more than ten years. While it may have its merits no studies have ever been carried out to judge its efficacy. Neither are there any families who have used it long term and reported any remarkable improvement.

While it is a fact hard to accept, the truth is that there are no medications that can 'cure' autism. Not in allopathy, not in homeopathy, not in ayurveda, despite claims that are periodically made. The only effective treatment is structured teaching and therapies that address the impairments.

# AFA's Diary of CONTINUING EDUCATION PROGRAMMES

## Open Door Outreach Programme

Monday – Friday: 12.30 – 1.30pm & Second Saturdays: 9.30 – 1.00pm

This programme includes sessions on:

- PECS (Picture Exchange Communication Systems)
  - Academic Skills
  - Sensory Motor Activities
  - Communication Therapy

We also provide Functional Assessments and CARS

## Dealing with Challenging Behaviours

INDIA INTERNATIONAL CENTRE, NEW DELHI

June 4, 2003

- Full-Day Workshop to help parents and other carers devise strategies to help their children

Behaviour management is an essential component of educating children with autism. The difficulties faced by individuals on the spectrum often manifest as complex and challenging behaviours.

The workshop will cover an understanding of the reasons behind such behaviours, assessments and management procedures. It will present a scientific approach to behaviour management based on well-established methods.

### Registration Costs:

- PARENTS: Rs. 300/- (Rs 200/- for members) • NON-PARENTS: Rs. 350/- (Rs. 250/- for members)
- CHILDCARE: Rs 200/- per child

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### CHALLENGING BEHAVIOUR WORKSHOP REGISTRATION FORM

Fill in BLOCK LETTERS and mail, with a self-addressed stamped envelope to:

Action for Autism, T 370 F Chirag Gaon, New Delhi 110 017

Name \_\_\_\_\_ Parent  Professional  (please tick relevant box)

Address \_\_\_\_\_

\_\_\_\_\_ Tel No \_\_\_\_\_ Email \_\_\_\_\_

If Parent, Name of Child \_\_\_\_\_ DOB \_\_\_\_\_

If Professional, Name of Organisation \_\_\_\_\_

Do you require childcare? \_\_\_\_\_ For how many children \_\_\_\_\_

PLEASE NOTE: If you have replied 'Yes' to the 'childcare' question, please remember to fill in and submit a childcare form WELL IN ADVANCE OF THE WORKSHOP. You can receive a form from the AFA office or you can download a form from workshop link on our website.

# Annual Training Workshop for Parents & Professionals

INDIAN SOCIAL INSTITUTE, LODI INSTITUTIONAL AREA, NEW DELHI

September 25 – 28, 2003

The workshop is open to anyone who wants to understand Autism, the myriad ways it affects individuals, the methods used to teach them cognitive, self-help, communication and social skills, and most important how these skills can be taught. Like all AFA seminars and workshops, the sessions will be free of jargon, and will be illustrated with practical examples based on AFA's hands-on experience and exposure to children with autism of varying ages and across the spectrum.

- **Individual consultation** for families, at no extra charge, will be provided on the last day of the workshop. The consultations will be available to those families who make prior bookings – so do book well in advance.

- **Childcare** will be provided during workshop hours for those who find it difficult to leave their children at home. AFA will collect the children from the Indian Social Institute, take them to the daycare venue, and bring them back to their parents at the end of the day.

Information about your child's special needs will need to be given at the time of booking so that adequate preparations can be made.

- **Registration Costs:\***

PARENTS

- Rs. 1500/- per parent attendee (Rs 1100/- for members)

- Rs. 2500/- per parent couple (Rs 2000/- for members)

NON-PARENTS

- Rs. 2000/- per non-parent attendee (Rs. 1700/- for members)

- Rs. 1800/- for each attendee from an organisation that has taken membership if more than one person attends.

DAYCARE CHARGES

- Rs. 200/- per child, per day.

- **Accommodation:**

At the ISI for a limited number of attendees on a priority basis. Rooms from noon of 24th to noon of 28th, at Rs. 1500/- per bed (twin sharing) and Rs. 3000/- (double room) for a **four-night stay with breakfast.**

Last date for booking rooms: **10 September 2001.**

- **On-the-spot registration:**

Parent Rs 2000/- and Non-Parent Rs 2500/

- **Cancellations:**

Cancellations upto 1 September 2003 will receive refunds after deducting Rs 100/- as handling charges. We regret that cancellations after 1 September 2003 will not be refunded.

*NOTE:\**

*Only those who have taken a membership of Action For Autism are eligible for the discounted 'members' rate.*

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## 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 Gaon, New Delhi 110 017**

*Last date for registration : 15th August, 2003*

Name \_\_\_\_\_

Address \_\_\_\_\_

Tel: \_\_\_\_\_

Are you a Parent or a Professional \_\_\_\_\_

If a parent, would childcare be required during the workshop (circle one)      YES      NO

For how many children \_\_\_\_\_

Any other information you want to offer \_\_\_\_\_

# Planning and Executing an Educational Curriculum with a Focus on Communication and Behaviours

A Two-day Intensive and Interactive Workshop by Rita Jordan PhD

INDIA INTERNATIONAL CENTRE, NEW DELHI

December 6 – 7, 2003

**RITA JORDAN** is one of the most widely known and respected figures in the field of education for persons with Autism Spectrum Disorders. She has many years' hands on experience with children with ASD. Rita Jordan has a degree in Psychology, Masters in Child Development, as well as a Masters in Linguistics. Her doctorate was in pronoun development in autism. Rita Jordan has researched curriculum development and parent training for those with profound and multiple disabilities. Currently, Rita is Reader in Autism studies at 'The University of Birmingham' where she runs programmes of study (campus-based and by distance) for professionals and parents working with individuals with autistic spectrum disorders. She has written and researched on many aspects of autism, is widely published, read and has been involved in training events, consultations and conferences across the world.

Rita Jordan's workshops are compelling due as much to their presentation from the perspective of the person with an ASD as well as the parental perspective as much as they are due to her depth of knowledge and experience. The Workshop covers

**DAY ONE:** • Special needs of children with Autism Spectrum Disorders • Developing an eclectic Curriculum Inclusion and Autism Spectrum Disorders • Developing communication and language

**DAY TWO:** • Challenging behaviour and the individual with Autism Spectrum Disorders • Sexual and emotional problems in ASDs

Registration Costs:

- PARENTS: Rs. 1500/- per parent attendee (Rs 1200/- for members)
- PARENT COUPLE: Rs. 2500/- per couple (Rs 2000/- for members)
- NON-PARENTS: Rs. 1750/- per non-parent attendee (Rs. 1450/- for members)
- Rs. 1500/- for each attendee from an organisation that has membership if more than one person attends
- ON THE SPOT REGISTRATION: Parent Rs 1750/- and Non-Parent Rs 2000/
- DAYCARE CHARGES: Rs. 200/- per child, per day.

Accommodation: Rooms with breakfast within walking distance from the ISI, available from noon of 5 December to noon of 7 December, at Rs. 750/- per bed (twin sharing) and Rs. 1,500/- for a double room for a two-night stay. Last date for booking accommodation: 31 October 2003.

Registration cancellations upto 31 October 03 will receive refunds after deducting Rs 100/- as handling charges. Cancellations after that date will not be refunded.

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## RITA JORDAN WORKSHOP REGISTRATION FORM

Fill in BLOCK LETTERS and mail, with a self-addressed stamped envelope to:

Action for Autism, T 370 F Chirag Gaon, New Delhi 110 017

Name \_\_\_\_\_ Parent  Professional  (please tick relevant box)

Address \_\_\_\_\_

\_\_\_\_\_ Tel No \_\_\_\_\_ Email \_\_\_\_\_

If Parent, Name of Child \_\_\_\_\_ DOB \_\_\_\_\_

If Professional, Name of Organisation \_\_\_\_\_

Do you require Accommodation? (circle one) YES NO Do you require Childcare? YES NO

PLEASE NOTE: If you have replied 'Yes' to the 'childcare' question, please remember to fill in and submit a childcare form WELL IN ADVANCE OF THE WORKSHOP. You can receive a form from the AFA office or you can download a form from workshop link on our website.

## Teaching an Alternative Mode of Communication

A Workshop on Makaton by Dr Rubina Lal

INDIA INTERNATIONAL CENTRE

June 29, 2003

Sign language is increasingly gaining focus, as a means of augmentative communication especially for non-verbal children with autism. It has several advantages over PECS (Picture Exchange System).

Sign language is conceptually closer to speech than PECS and is easily portable across locations in the child's environment. Sign Language facilitates spontaneity, maintaining flow, and the use of language in a truly functional manner.

Contrary to popular belief, it has been seen that merely having poor motor imitation does not necessarily preclude a learner from using sign as a response form, and if a good attempt at teaching sign is attempted using error-less teaching procedures and focusing first on the most motivating things in the child's life, motor imitation often improves. Even for verbal children, teaching sign along with the word has been shown to dramatically improve retention and spontaneous use of words.

### *Registration Costs:*

- PARENTS: Rs. 300/- (Rs 200/- for members) • NON-PARENTS: Rs. 350/- (Rs. 250/- for members)
- CHILDCARE: Rs 200/- per child

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### MAKATON REGISTRATION FORM

Fill in BLOCK LETTERS and mail, with a self-addressed stamped envelope to:

**Action for Autism, T 370 F Chirag Gaon, New Delhi 110 017**

Name \_\_\_\_\_ Parent  Professional  (*please tick relevant box*)

Address \_\_\_\_\_

\_\_\_\_\_ Tel No \_\_\_\_\_ Email \_\_\_\_\_

If Parent, Name of Child \_\_\_\_\_ DOB \_\_\_\_\_

If Professional, Name of Organisation \_\_\_\_\_

Do you require childcare? \_\_\_\_\_ Yes / No \_\_\_\_\_

**NOTE:** If you have replied 'Yes' to the 'childcare' question, please fill in and submit a childcare form *WELL IN ADVANCE OF THE WORKSHOP*. You can receive a form from the AFA office or download it from the workshop link on our website.

### **AFA National Centre for Advocacy, Research, Rehabilitation and Training**

AFA sees an average of two new families every working day – an indication of the number of children requiring help and the pressure on our services. The physical space at AFA is stretched beyond imagination.

We are happy to announce that work on the construction of the **National Centre** will begin this summer.

*Please contact Aran Corrigan at AFA if you wish to support this venture in any way.*

☀ MEMBERSHIP TO AFA ☀

To continue to receive 'Autism Network' please complete the application below and return it to us as soon as possible

**Or, become a Member of Action for Autism?**

Membership entitles you to concessionary rates for AFA events, workshops and library membership. You will also receive 'Autism Network' three times a year. Members are kept informed of all AFA events and activities.

**Membership privileges:**

- Parents may become Annual Members at Rs 500/- or upgrade to Life Membership at Rs 5000/-
- Professionals may avail of Annual Membership at Rs 1000/-
- Institutions may avail of Annual Membership at Rs 2000/-

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 receive three issues of 'Autism Network' and enclose Rs150/- as Annual Contribution for 2003

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

Rs 500/-     Rs 1000/-     Rs 2000/-     Rs 5000/-

(Please send Bank Drafts Only) Draft No: \_\_\_\_\_

Dated \_\_\_\_\_ On Bank \_\_\_\_\_

Amount in words \_\_\_\_\_

• I wish to give a contribution to AFA \_\_\_\_\_

Amount in words \_\_\_\_\_

Mail cheque or demand draft payable to:

**Action for Autism**

**T 370 F Chiragh Dilli Gaon, 3rd Floor, New Delhi - 110**

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

**BOOK POST**



**If undelivered please return to:**

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

**AFA Mission Statement**

*To create an environment where children and adults with autism spectrum disorders and their families can live as fully participating members of their 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**