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INFORMATION

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

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The Editor, Autism Network, T 370 F Chiragh Dilli Gaon, 3rd. Floor, New Delhi - 110 017. E-mail: autism@vsnl.com Homepage: http://www.autism-india.org

<u>Editor:</u> Merry Barua <u>Editorial Board:</u> Ann Varavukala, Indu Chaswal, Aran Corrigan <u>Design & Production:</u> Bindu Badshah, Sudhir Pillai

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Cover Illustration

'Dahi Handi' (Breaking the Curd Pots), by Samarpan Mondol, Age 8 years

WISHI IST ! FOR THE STUDENTS o The use of a room for one year to store AFA's printed materials o A minibus or van o A Video Camera/ Cassettes o Still Camera o Rolls of film o Audio Cassettes of soothing music o Blank audio cassettes o Children's tricycles/ slides/ swings/ seesaws o Paper to recycle for children's worksheets o Mattresses o Gymnastic balls o Bean bags of all sizes o REAMS of A4 paper FOR THE OFFICE o A Scanner o Two fast printers for computers 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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PAGE ONE

Towards the end of November an event significant to Americans with autism took place in Washington DC. An Autism Summit Conference was held, at which the federal government for the first time mapped out a 10-year Autism Research Roadmap, addressing the growing 'problem' of autism in the United States. This is a landmark step for the Autism Society of America (ASA), which has long advocated for a major government commitment to autism. In addition, it seems that by the middle of January the US Congress will in all probability approve a further \$3 million budget for autism activities at the Centers for Disease Control and Prevention (CDC).

While we in India do not have such dramatic events to report, the small steps we have taken have not been insignificant. A very important recent achievement has been the launch of the Diploma in Special Education in Autism by the Rehabilitation Council of India (RCI). Action For Autism has advocated for such a course for many years, fully aware of the fact that unless a rehabilitation training had RCI certification, only a few would want to train. Finally, overcoming great odds and much misinformation, AFA has succeeded in its efforts and the course has been started on a pilot basis. The autism community is deeply grateful to the Rehabilitation Council of India for this important step.

Nearly a year ago AFA was visited by Pawan Sinha, Professor of Brain and Cognitive Sciences at MIT. An accomplished yet wonderfully humane academician, Dr Sinha spent the time at AFA learning about the situation in India for persons with autism. Pawan Sinha's work focuses on how the human brain interprets visual information and recognises objects and faces, which Sinha theorises is a holistic process.

A scientist who considers it important that his work have applied value, Sinha has put his research to work for the blind. A project close to Sinha's heart is Project Prakash in India, which has arisen out of Sinha's interest in understanding how the human brain learns to recognize objects and making his research interest work in the real world. Project Prakash studies children who have regained sight following congenital blindness, and systematically characterizes the development of their visual skills. This Sinha hopes will assist visually impaired children to be eventually mainstreamed. The project is hoped to improve the lives of many children while at the same time answer some of the fundamental questions of neuroscience regarding brain plasticity and cognitive development. Prof Sinha has expressed an interest in undertaking a project in which Action For Autism is privileged to play a part, involving impairment in face processing in children with autism. In this issue Professor Sinha writes on the project that should start early next year.

Neeraja Ravindran is a psychologist from Bangalore whose area of interest is Autistic Savants. Tito Mukhopadyaya the gifted young poet and author from Bangalore has fuelled immense interest in talented persons with autism who are otherwise severely impaired. Neeraja shares with our readers her interest in this fascinating segment of the autistic population

As we go to press Dr Rita Jordan has been travelling across India giving workshops in a collaborative effort between autism organizations in different parts of the country. In another such partnership ASHA of Bangalore are taking *Gloomy Rabbit* – a play on autism especially written by Vijay Nair – to five centres including Delhi.

While the year ends on this very encouraging note of partnering, 2004 promises to be exciting as well. The year starts with workshops on Verbal Behaviour Analysis taking place everywhere! Autism Network has carried articles on the subject in past issues. Based on extensive research, Verbal Behaviour (VB) is increasingly becoming the preferred mode for teaching children with autism. VB uses Natural Environmental Training which helps in the generalization of skills learnt. But more importantly, VB builds compliance. For many teachers struggling with compliance issues , the biggest treat is to watch their children comply with every instruction in every setting and with every instructor.

V Suresh a parent in Dubai has been bringing in VB trainers to Dubai for more than a year. He is now hosting a workshop by Behaviour Analyst Patrick McGreevy. In January Chennai has Duncan Fennemore whose earlier workshop at Mumbai many of us were fortunate to attend. In February Behaviour Analysts Steve Ward and Teresa Grimes will give workshops in Kolkata and Delhi. It is wonderful that organizations everywhere are able to take steps to keep abreast with the latest developments in the field. It bodes well for the autism movement in India.

By mid 2004, God and our supporters willing, Action For Autism will move to its new premises at Jasola behind Apollo Hospital. We share this happiness with our readers and wish you all a splendid year ahead!

Characterizing and Improving Face-processing Skills in Children with Autism

Prof Pawan Sinha

Department of Brain and Cognitive Sciences, Massachusetts Institute of Technology, Cambridge, MA 02139, USA

SUMMARY -

Introduction: An integral component of a child's mental health is the ability to correctly interpret visual information about other people in the environment. Deficiencies in these skills can have devastating consequences. Indeed, one of the most marked correlates of autism is 'an impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction' (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition). In order to understand the causes and consequences of such visual impairments and to design rehabilitation procedures for mitigating them, it is imperative that we precisely characterize the visual skills of the affected children. With this motivation, we have undertaken a research project that seeks to improve the lives of children with autism.

Goal: We shall focus our studies on the face-perception skills of children suffering from autistic disorders. Preliminary experimental data suggest that such children may have impaired face processing abilities. This jeopardizes their interpretation of non-verbal cues, compromises effective social interactions and may lead to emotional disturbance and depression. Our goal is to experimentally characterize the nature and extent of face-perception impairments, to determine the processing deficiencies that may cause the observed impairments, and to refine and test VisTA (Visual Training and Assessment), a novel tool to help the children overcome their visual impairments.

Impact: This project will be the first to provide us with a comprehensive set of data regarding impairments in facial processing for autistic children. The data will be invaluable for understanding the precise nature of the deficits, evaluating the effectiveness of VisTA, and guiding the design of other treatment interventions.

Face-processing skills in children with autism

Autism is a pervasive neuro-developmental disorder associated with marked deficits in a child's social and

communicative abilities. Impairments in social skills are typically accompanied by emotional disturbances and severe problems in adjustment, making autism one of the most disruptive disabilities for a child's life. Its prevalence is estimated to be at least 1:1000 children (Centers for Disease Control and Prevention, 1997). More recent estimates have suggested an incidence as high as 1:500, making autism even more common than Down's syndrome. Given its prevalence and its devastating consequences on the lives of the children affected and, indeed, their families, our general lack of understanding of autism's causes and options for ameliorative interventions, is of grave concern.

WE propose to focus on a hallmark deficit of autism – difficulties in social interactions. Specifically, we shall investigate whether this deficit is caused, at least in part, due to problems in high-level visual processing. Most person to person interactions are contingent on an exchange and interpretation of subtle facial cues. It is, therefore, conceivable that an inability to effectively process facial signals would manifest itself as impairments in social skills. Investigating this possibility is important since it has major implications for the design of treatment programs.

THERE is already some experimental evidence in support of this idea. Researchers such as Hobson (1986a, 1986b), Tantam et al. (1989), Gepner et al. (1994), Loveland et al. (1995), Celani et al. (1999), and Dawson et al. (2002), have reported that children with autism exhibit impairments relative to normal controls at tasks involving interpretation of facial emotions in images. While these findings have not gone uncontested (Ozonoff et al. (1990); Davies et al. (1994)), they serve as an excellent starting point for our investigations into the visual correlates of the social impairments in autism.

OUR work has three specific goals:

1. To identify core deficits in face processing by autistic children.

2. To determine the processing abnormalities that might cause the visual deficits.

3. To design training routines for improving visual skills.

WE next describe the motivation for these goals and our planned approach for achieving them.

Goal 1: To identify core deficits in face processing

Establishing the basic face-processing deficits associated with autism is important from many perspectives; it is a pre-requisite for diagnostic purposes, for guiding the course of treatment and for constraining the search for causes. Past work, mentioned above, has made a beginning in this direction. However, the focus has been almost exclusively on the perception of basic facial expressions. Several other face perception tasks are largely unstudied. Four of the most important ones needed for normal social interactions are:

1 Face localization in complex scenes (the first step in analyzing facial signals),

2 Classification of complex expressions (for instance pride, shame and affection, common in everyday interactions),

3 Assessment of attentional locus (a pre-requisite for shared attention tasks), and

4 Facial identification across changes in viewpoint (as might occur during a normal interaction).

WE shall test two groups of children on these four tasks. The first group will include autistic children and the second will be a control set comprising normal, agematched children. Children will be diagnosed for autism at the collaborating hospitals using DSM-IV criteria and their syndrome severity will be assessed using the Childhood Autism Rating Scale (CARS) (Schopler et al., 1988). The children will participate individually in psychophysical experiments designed to probe performance on each face perception task. Psychophysical sessions will be augmented with ERP recordings whenever feasible to permit more comprehensive comparisons between experimental and control groups.

Goal 2. To determine the processing abnormalities underlying deficits in face perception

By identifying the core deficits in face processing, as described above, we expect to improve our understanding of the causes of at least some of the social impairments exhibited by autistic children. To understand the genesis of the face processing deficits themselves, it is imperative that we explore another level of causation - what underlying visual processing deficits might lead to the observed problems in face perception? We shall address this question in a hypothesis driven fashion. Our hypothesis is derived from an observation that several high-functioning autistic individuals have made in describing their sensory experience (VanDalen, 1995; Williams, 1999). The world, to them, appears fragmented and lacks the 'built-in form of coherence' (Frith, 1989). We shall explore whether 'fragmented perception', or alternatively, the lack of configural processing, is a plausible causal factor for the observed deficits in face perception tasks. Our approach will involve psychophysical studies with autistic and normal children. The facial stimuli used in these experiments will be transformed so as to selectively influence piecemeal or configural processing (transformations will include Gaussian blurring, vertical inversion and image part permutations that preserve the features but not their configuration). By measuring the influence of these transformations on performance and face-specific ERP signals, we shall be able to infer the nature of visual processing deficits that might underlie face perception impairments in autism.

Goal 3. To design training routines for improving visual skills

Goals 1 and 2 seek to uncover the causes of social skill impairments in autistic children. Goal 3 is meant to apply this knowledge towards the design of methods that can alleviate the deficits. To the best of our knowledge, there are currently no interventions for improving visual processing by children with autism. We propose a novel approach, VisTA (Visual Training and Assessment) to address this need. VisTA has several of the characteristics considered desirable for autism related interventions (McConnell, 2002) such as the ability to involve both children with autism and their normally developing peers, portability for use in various settings throughout the day and easy monitoring of progress.

VisTA is based on a technique for image presentation we have recently developed called RISE (Random Image Structure Evolution) (Sadr and Sinha, 2001, 2003; Pollak and Sinha, 2002). RISE enables the presentation of images as time-series while carefully controlling potentially confounding influences from low-level image parameters. In a RISE sequence, images gradually evolve and become progressively more recognizable. An observer's point of perceptual object onset in such a sequence serves as a quantifiable marker for object perception proficiency. We have used RISE for assessing object perception skills of children with different developmental histories (Pollak and Sinha, 2002), for studying phenomena such as object priming and for identifying object-specific neural responses (Sadr and Sinha, 2001, 2003).

VisTA extends the usage of RISE to the domain of visual training. VisTA presents time series showing face images evolving from randomness. The task of the observer is to try to determine what the evolving image depicts (say, a particular expression or a specific individual) as soon as possible after the beginning of the sequence. Since the image is very degraded near sequence onset, the observer is forced to use overall configural information rather than relying on piecemeal cues. Our pilot experiments with normal observers suggest that they find the task engaging, in the nature of a game, and show significant improvements in their ability to recognize objects using partial information after a few training sessions. We believe that the same procedure when conducted with children with autism, using appropriate facial stimuli, can mitigate their tendency to rely on fragmentary information and improve their ability to use overall facial configuration. This would translate into better performance at many of the socially relevant face-perception tasks such as recognition of subtle facial expressions.

Logistics: We plan to conduct our experimental studies at two institutions that draw a significant population of children with autism.

1. Children's Hospital in Boston

The Children's Hospital in Boston is a 300-bed comprehensive center for pediatric health care. The Hospital's Department of Psychiatry evaluates and treats children with a wide range of emotional and behavioral disorders, including autism. It typically records more than 15,000 outpatient visits and 400 inpatient admissions each year, making it one of the largest pediatric psychiatric services in New England. The Department develops interventions for various complex psychiatric problems using cognitive, behavioral, group, and biological methods.

2. The OpenDoor Center for Autistic Children in New Delhi, India

This center is operated by Action For Autism (AFA), a founding member of the World Autism Organization.

AFA provides counseling, assessment and educational programs. Children diagnosed with autism are referred to AFA by prominent national hospitals such as the All India Institute of Medical Sciences and the National Institute of Mental Health and Neurosciences. AFA received 123 referrals in 2001. The OpenDoor Center is the first specialized school for children with autism in South Asia.

OUR decision to work with AFA besides the Children's Hospital is driven by two considerations:

FIRST, it stands out in terms of the dedication of its members and their willingness to collaborate on such a project. The staff, in particular, have impressed me greatly with their deep passion for helping children with autism and the very welcoming attitude towards this undertaking.

SECOND, it serves to bring much-needed attention to the problem of autism in India. India is estimated to have more than 2 million children with autism and yet public awareness of this disorder and governmental resources directed towards it are insignificant.

WE hope that reports of this work for the scientific and lay audiences will play an effective role in improving the state of knowledge in India regarding autism and possible interventions. This is necessary for improving the quality of life for the many children with autism in India who may otherwise be treated as social outcasts.

IN summary, we propose to characterize face-processing deficits that may contribute to the social impairments observed in children with autism. We also seek to improve the children's face-perception skills through the use of a novel training technique, VisTA. The prospect of helping the many children who have to overcome challenges imposed on them by autism is a very compelling one and we look forward to getting the project underway by the beginning of year 2004.

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December is Autism Month!

Kolkata

- 2 December
- Training Workshop By Dr Rita Jordan
- Heritage Tram Ride
- Picnic
- Christmas Party
- Parents Perspective: A Workshop/Discussion on Parent 20 December initiative to meet lack of services

New Delhi

- 3 December
- World Disability Day Walk to Freedom at India Gate ▼ 6 - 7 December
- Workshop by Dr Rita Jordan at IIC, supported by The British Council:

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

- 8 December
- Inauguration By Dr Rita Jordan of AFA's Diploma in Special Education: Autism 2003 - 2004 Training
- 11 December
- Dinner for families and supporters.

14 December

• 'Gloomy Rabbit'

- A play on autism in collaboration with ASHA, Bangalore at the Shri Ram Centre (part of a five city tour).
- 16 December
- Picnic at The Garden of Five Senses
- Christmas Party at Open Door
- 28 December

• Innovative Communication Programming Workshop at the IIC by Dolly Bhargava Speech Language Pathologist

Mumbai

• Talk on Stress Management for parents of autistic children: Dr. Harish Shetty

- Talk on Sexual Issues in Autism
- ◆ 21 December
- Dinner Party for children and parents. Sponsored by Kamini Lakhani : information on venue and timing from Forum For Autism Library

Why Verbal Behaviour

<u>Indrani Basu</u>

Children diagnosed with an Autistic Spectrum Disorder do not learn to communicate in a way that is characteristic of typical children. Some do not develop any speech at all; others may develop speech which is idiosyncratic and repetitive. These are complex impairments, which hinder the child's learning and progress in all areas of development.

WE all want our children to talk. But before a child can develop 'conversational' speech she must acquire certain pre-requisite skills .She must for instance be able to ask for things, label things, receptively identify things .To acquire all such skills she needs to imitate both motor and vocal behavior.

Verbal behavior (VB) is a programme that is based on an assessment of the language deficit of each child and thereby providing a training programme to teach skills necessary to use language in everyday life.

EACH language skill is taught separately, and once mastered a child is then taught more advanced speech skills like conversation. Verbal Behavior is being used successfully in the US in teaching children with autism and other communication disorders to acquire functional language.

AS we are aware, Applied Behaviour Analysis (ABA) has been widely used in the US. So how is it different from VB? To quote a parent who has successfully switched her son from ABA to VB: "VB is ABA fine-tuned" .VB is more flexible with a lot of **Natural Environmental Training** .The reason why VB is so successful is that it uses the child's likes and interests to motivate so that she will **want to** communicate in an appropriate manner.

On Working as a Special Educator Using Verbal Behavior

When I first met R he was two and half years old. R cried a lot and the only thing that soothed him was the swing. R's mother A and I worked out a programme and R started to improve. He learnt to sit at the table, we taught him some basic instructions which he learnt to follow. He even started to verbalize a little. However,

his verbalization was not consistent . It seemed to come and go and was not always meaningful. There were still phases when he was stressed and would cry a lot. R was progressing, but slowly.

SHORTLY thereafter A and R went the US where R was put on an intensive programme based on Verbal Behavior. During their three months there A received training so that she could work with R herself, and also train others to work with him, on their return to India.

BY the time they returned the change in R was huge. He was asking for things he wanted. He could receptively identify a number of things from an array of at least five to six pictures. He could label a number of items from pictures, or in the environment. He could do the same using a book containing 10-20 different pictures. His imitation had improved greatly: not only motor but also vocal and even facial expressions. What this change told me was how much more connected and aware R was. And he was a much happier little boy. He still has his crying phases but much shorter and less intense. He is a lot more independent in such things as toileting, eating and dressing. He is compliant and follows instructions with all those around him. He enjoys learning.

WHAT I really like when I work with him now is thatwhen he does something right he looks right at me and smiles. We don't just work at the table: we work sitting on the floor, in the garden, on the balcony. Play is an important part of the intervention program so that R learns to play appropriately. Toys are brought to the tabletop so the table is a fun place.

I don't want to give the impression that it is all smooth sailing; it is a lot of hard work. But the progress is apparent to all who know R. R has just turned four; it is now five months since their return from the US. R is slowly being introduced to learning in a small group. He can now ask not only for things he wants but things he needs for an activity he wants to do, like a brush to paint with, or a spoon to eat with.

R still has a long way to go but he has made a great beginning and is ready to learn. VB has enabled little R to learn how to learn.

A Confounding Paradox: The Savant Syndrome

Neeraja Ravindran

A psychologist and special educator based in Bangalore

Jeremy can stand at the side of the railroad tracks and give you the cumulative total of the numbers on the boxcars, however many, as the end of the train rolls by. But he is severely autistic and cannot count.

THE central core of the brain includes the lower brainstem, the medulla oblongata, pons, parts of the thalamus and hypothalamus and the cerebellum. The most popular theory about the formation of the universe is the Big Bang theory. 24,628 * 35,482 = 8,73,85,0696. No, these are not facts and figures I am reeling out of my head. These are answers to relevant questions that were posed to Samarth. Answers that were given in less than a minute, with no manual, textual or mathematical aid. Samarth is all of 6 years old and he is autistic.

ALL of us are familiar with Tito's name. His books are being read the world over and almost everyone who is familiar with Tito's writings will agree that the thoughts, style and comprehension that goes into each of his lines can only be described as phenomenal. Such talent can be viewed as marvelous and unbelievable even in a normal adult, let alone a severely autistic teenager.

HOW many of us, as parents and special educators of children with autism are left flabbergasted by a sudden revelation of some stupendous skill or ability in our child? How many times are we left standing in dumbstruck astonishment at our child's ability to do complex mental mathematical operations or exhibit mastery and adeptness at music or drawing or display a phenomenal memory? How many times are we left wondering about how come a child, who can barely take care of his needs, who can hardly even indicate a need to use the toilet or tell us that he is hungry, who seems to take a zillion years to grasp just the first three letters of the alphabet, still excels to such mind blowing proportions in some particular area?

JEREMY, Samarth, Tito and all other such people you might be familiar with are called *savants*. (Earlier described as the "idiot savants" by Dr. Langdon Down) And their condition over the last few years has been described as the Savant Syndrome. "Savant Syndrome is an extremely rare condition in which persons with serious mental handicaps either from Mental Retardation, Early Infantile Autism or major mental illnesses (Schizophrenia), have spectacular islands of ability or brilliance which stand in stark, markedly incongruous contrast to the handicap. In some, the savant skills are remarkable simply in contrast to the handicap (*talented savants* or *savant I*) while in the other, rarer form of the condition, the ability or brilliance is not only spectacular in contrast to the handicap, but would be spectacular even if viewed in a normal person (*prodigious savants* or *savant II*)." (Dr. Darold Treffert, *Extraordinary People*)

THE condition can be congenital or it can be acquired and develop in an otherwise normal person following injury or disease to the nervous system. It occurs in males more often than females in an approximate ratio of 6:1. The skills often appear suddenly, without explanation, and can disappear just as suddenly.

THE ability or brilliance, while spectacular, occurs within a very narrow range, considering all the skills in the human repertoire. It occurs generally in one of the following areas: calendar calculating; music, almost exclusively limited to the piano, violin or the flute; lightning calculating and mathematics; art, including painting, drawing or sculpting; mechanical ability; prodigious memory (mnemonism); or very rarely, unusual sensory discrimination or extrasensory perception.

SAVANT Syndrome is very rare and studies have placed the incidence at 1:2000 in an institutionalized, developmentally disabled population. The incidence of this syndrome is seen to be much higher in patients with Early Infantile Autism – it occurs in almost 10% of the cases. Similarly, talented savants are found to be more common than prodigious savants – less than 100 cases of prodigious savants have been reported in all the world literature during the last 100 years.

The Autistic Savant

Raymond Babbitt was probably the person most responsible for making the term "autistic savant" a household term. This brilliant and accurate portrayal of an autistic savant by Dustin Hoffman in the Academy award winning movie Rain Man was largely responsible for creating an awareness – about not just the condition of autism but also in giving a wonderful picture of the special, hidden and truly remarkable abilities that some of these individuals might possess, in spite of their handicap. Dr. Treffert defines the term "autistic savant" in the simplest way possible:

Autistic disorder + extraordinary special skills + remarkable memory = Autistic Savant

However, it should be remembered that not all autistic persons are savants and not all savants are autistic. Approximately 10% of people with Autistic Spectrum Disorder (ASD) have Savant Syndrome at a "splinter skill", "talented" or "prodigious" level, with the splinter skills being the most common representation by far. As said before, Savant Syndrome can also occur in other forms of Developmental Disabilities such as Mental Retardation (MR), but with much less frequency. Since MR is more common than ASD and since the frequency of savant skills in that group is much lower than in persons with autism, it turns out that approximately 50% of persons with Savant Syndrome have Autistic Disorders and 50% have some other form of developmental disability including Mental Retardation.

AMONG the 10% of persons who are autistic, there is a wide spectrum of savant abilities. Most common are what are called "splinter skills", such as obsessive preoccupation with and memorization of obscure facts such as sports trivia, license plates, the city's bus systems or with things as bizarre as motor sounds of various electrical gadgets. "Talented" savants are those people whose special abilities are more specialized and honed, making those skills spectacular when seen against the person's overall disability. Finally, "prodigious savants" are those individuals whose skills and abilities are so spectacular that they would be obvious even if they were to occur in a non-disabled person. There are fewer than maybe, 50 persons living worldwide who would meet the criteria of a prodigious savant and approximately 50% of that group would be autistic savants.

THE skills in the autistic savant continue to be seen within a very narrow but remarkably constant range of human abilities such as music, usually piano and almost always with perfect pitch; art, typically drawing, painting or sculpting; lightning calculating; calendar calculating; mechanical abilities and spatial skills. Map memorizing, remarkable sense of direction, unusual sensory discriminations such as an enhanced sense of smell or touch and perfect appreciation of passing time without knowledge of a clock face are some of the other less frequently reported skills in these individuals. In most autistic savants, a single special skill exists while in others multiple skills occur. The skills tend to be mostly right hemisphere in type – non-symbolic, concrete and directly perceived – in contrast to the left hemisphere skills that are more sequential, logical and symbolic, including language specialization. In a recent research conducted by Dr. Trevor Clark (Autism Association of New South Wales, Sydney), autistic savants also seem to show exceptional adeptness in areas of memory, hyperlexia (i.e. the exceptional ability to read, spell or write), athletic performance and computer abilities, in addition to the range of skills already mentioned.

Now comes the really intriguing question:

How do they do it?

This is the first question that leaps up in all our minds the minute we encounter the paradox that is the savant. And there have been about as many theories to answer this question, as there have been investigators. Theories that have been suggested thus far as possible etiologies for the Savant Syndrome include:

• Presence of an *eidetic or photographic memory* in the savants which can account for their ability to remember even obscure things with remarkable precision

• Possible genetic link that could result in the savant skills being *inherited*

• Sensory deprivation and social isolation factors which makes it possible for the savant to be extremely aware of even minor changes in the environment and also produces intense concentration and preoccupation with other bizarre endeavors such as studying calendars or almanacs or memorizing motor sounds

• *Concrete thinking and inability to reason abstractly*: According to Scheerer, Rothmann and Goldstein, the limitation to concrete thinking, with the natural human desire to achieve optimum capability, creates in the savants a continual expansion in his repertoire of these repetitive and narrow skills because "it is the only way he can come to terms with the world that is beyond his grasp". This concentration of skills and channelising of energies into such abnormally limited methods of retention and expression creates abilities, which on the surface seem miraculous. Yet, given the narrow outlets for the expression of these abilities, the abilities are not so astounding (Scheerer et al).

• *Compensatory activity and the search for reinforcement* have been seen as major factors that seem to influence the Savant Syndrome. Dr. LaFontaine stresses positive reinforcement as a powerful motivator for the intense concentration, skills and practice seen in the savants. According to Dr. Edward Hoffman, in an institutionalized setting especially, for the savant, "his mental feats are immensely socially reinforcing; he will receive a great deal of attention and interest that a normal retardate would not." Essentially, the savant uses the reinforcement from others to meet needs for selfesteem and the special skills acts as a compensation for the inferiority they might otherwise feel.

• Left brain injury and right brain compensation – In recent years, this has been a theory that provides one of the most plausible explanations for the condition of the savants. According to one researcher, since the skills most often seen in an autistic savant are those associated with right hemisphere functions and the skills most lacking tend to be those associated with the left hemisphere, left brain injury with right brain compensation seems to be a very plausible explanation

to the condition. Another researcher, Bernard Rimland, has also highlighted the simultaneous nature of right brain activities in contrast to the sequential nature of left-brain activities seen in the autistic savant. Several brain imaging studies such as PET and CAT scan report findings in several cases also seem to strengthen this theory.

THOUGH all these theories do seem correct in their own right, they can all still be considered valid as only *descriptions* of the various traits seen in the syndrome and cannot be considered as the *cause* of it. There have been a lot more recent findings that seem to shed more light on the etiological factors; yet, there has not been *a* definitive theory that can explain the Savant Syndrome. The savant continues to remain an enigma to most people who come across him. As LaFonatine concludes, "the behavior of the idiot savant appears to be complex and truly difficult to comprehend."

AFA Initiates Mother & Child Sponsorship Programme

AFA has been running its Mother Child Programme for three years with great success.

THE 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. Mothers form a group where they work with their children under the guidance of an experienced, trained therapist. They are given extensive feedback and an opportunity to compare perspectives and forge links with parents experiencing similar difficulties.

FROM January 2004 AFA is initiating a sponsorship scheme in order to reach families from disadvantaged socio-economic groups. AFA will sponsor one mother and child from outside of Delhi and one mother and child from within Delhi to attend the programme. For the mother coming from outside of Delhi accommodation, travel and course costs will be entirely sponsored by AFA.

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 in 2004:January, July or October.

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

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.

The librarians duties include:
running the reading room

issuing books

organising library memberships

ordering and cataloguing
new books and publications
maintaining press cutting files.

If you are interested in this position please contact Merry Barua at: Action For Autism T 370 F Chiragh Dilli Gaon, 3rd Floor, New Delhi - 110017 Tel: 29256469, 29256470 E-mail:**autism@vsnl.com**

खाने की उचित आदतों को विकासित करना भाग -2

<u> हिनदी अनुवाद : अभय नाथ साह</u>

हम लोग औटिज्म नेटवर्क के संस्करण, संख्या 02 में यह चर्चा कियें थे कि भोजन किस प्रकार ज्यादातर भारतीय परिवारिक सभ्यता का एक महत्वपूर्ण भाग (अंश) है। इसलिए औटिस्टिक लोगों के खाने की उचित आदत, माता–पिता तथा देखभाल करने वालों के लिए बहुत ही महत्वपूर्ण पहलू है।

हम लोग यह भी चर्चा किये थे कि किस प्रकार विभिन्न परिस्थितियों में भोजन के समय का बच्चों तथा माता – पिता दोनों पर नाकारात्मक प्रभाव पड़ता है। प्रायः ऐसा किया जाता है और बच्चें को खाने के लिए मजबूर किया जाता है और बच्चा प्रतिकार (इन्कार) तबतक करता रहता है, जबतक कि बस्तुतः कुछ भी खिलाना उसे असम्भव न हो जायें। परन्तु यह परिस्थिति किसी भी बच्चे को पसन्द नहीं, इसलिए हम उन्हें सिखा सकते हैं कि कैसे, खाने और उचित तरीकें से खाने में, मजा है। बच्चें को अच्छे से खिलाने का समाजिक वास्तव में जो कठिनाईयाँ होंती है, उसके बावजूद भी हमें खिलाना सिखाने के कार्य को आनन्दायक बनाना है।

खाने की उचित आदत की विकसित करने से पूर्व हम यह चर्चा करना चाहते है कि भारतीय लोगों के खाने के आदत जितना हम सोच सकते हैं, उससे कहीं ज्यादा भिन्न होता है। विभिन्न परिवार में भेजन करने के विभिन्न तरीकों का प्रयोग किया जाता है और वही तरीका उपयोगी माना जाता है। उदाहरण के तौर पर, स्पष्ट अन्तर यह है कि कुछ परिवार खाने के लिए काँटा – चम्मच का आदि का प्रयोग करते हैं तो अन्य दायें हाथ का। चाहे कोई खाने में कटलरी कुछ खाद्य पदार्थ (भोजन) का मतलब होता है कि कुछ अन्य खाद्य पदार्थ के साथ प्रयोग करना। जैसे – रोटी, पराठा या पूरी के एक टुकड़ा को कुछ अन्य खाद्य सामग्री के साथ प्रयोग किया जाता है। कुछ व्यंजन जैसे – चावल – दाल को आवश्यकता होती है हाथ से मिलाने की। चूँकि आप उद्घृत सलाह पढ़ते हैं। इसलिए यह ध्यान रहें कि जितनी भोजन की मात्रा आपका बच्चा खाता है उतना ही बर्तन में होनी चाहिए या हाथ में कौर भी उसी मुताबिक होनी चाहिए। साथ ही प्रारम्भ में वही भोजन (व्यंजन) आप लें जो आपके बच्चें के स्वाद के अनुकुल हो।

खाने की मात्रा, जिससे आप शुरूआत करके सेशन पर लागू करना चाहते हैं, जैसा कि हमने हपले ही साफ कर दिया है कि बच्चे के स्वयं खाने सिखाने से पहले, बिलकुल तैयार स्थिति में होने चाहिए। खाने के तरीके, जिस पर हमें जोर देना चाहिए। वह यह है कि सभी (स्टेप) पहलू बिलकुल एक फॉरमूला की तरह नहीं है जिसे पूर्णतया कठोर ढ़ग से एक के बाद एक करके अनुकरण किया जायें। माता–पिता और देखभाल करने वालों के लिए यह आवश्यकत होगा कि वह स्वयं निर्णय लें कि बच्चों के लिए क्या (लेवल) पैमाना उचित है जिसे बच्चा सक्षम है प्रयोग में लाने को और उसे अनुकरण करने को ताकि वह खाने के आदत का शुरूआत कर सकें।

जब बच्चा आरामदायक ढ़ग से, 10–15 मिनट लगातार बैठ रहा हो, तब उसे स्वयं भोजन खाना सिखाना शुरू करें। बच्चे के पीछे या बिलकुल बगल में खड़े हो जाये, और अपने हाथ का बच्चे क हाथ पर चढा दें। फिर उसके हाथ को पेट के साथ मोड़ लें। या फिर उसके उगली को भोजन के कौर (टुकडें) पर उचित तरीके से पकड़ा दें। अब भोजन के टुकड़े को उठाकर मुँह तक ले जाने के कार्य को प्रारम्भ करें। उस तरह, आप हमेशा बच्चें को जब कभी कुछ भी खिला रहें हो तो इसी तरीके का प्रयोग करें।

कुछ दिनों तक लगातार उपरोक्त विधि को प्रयोग करने के बाद, आप महसूस करने लगेंगे कि बच्चा स्वयं खाने के चेष्टा या गति के प्रति : ज्यादा प्रयास कर रहा है और आपको अपना हाथ उसी मुताबिक कम घुमाने पड़ रहे है। यह सब बच्चे के जिसका कोई पूर्व निर्धारित पैमाना नहीं है, के कारण होता है अब आप बच्चे के मुँह से लगभग 2 (दो) इन्च पहले काँटा, चम्मच या उंगली पर से (ग्रिप) पकड़ हटा लें। पुनः धीरे – धीरे पकड़ हटाने का क्रम, मुँह से दूरी को बढ़ाते हुए क्रम में जारी रखें। परन्तु यह ध्यान कि दबाव के साथ (परोमटिंग) खाना पकड़तें हुए थाली से मुँह तक ले जायें। यानि आप हाथ को, भेजन और मुँह के बीच साधारणतया निर्देशित करें आप पायेंगे कि आपके उंगली के इशारे ही काफी है उक्त कार्य के लिए।

अब यह भी महत्वपूर्ण है कि धीर—धीरे (अपनी) पकड़ को कम करें, क्योंकि बच्चा को यदी सहारे की आदत बन गइ तो यह कुछ भी तबतक नहीं खाएगा जबतक कि उसे सहारा देकर खिलाया न जाए।

इस प्रकार, यह पुनः एक खाने के समय का नई उलझन होगा। इसलिए पकड़ को कम करने के लिए प्रारम्भ में, सिर्फ हाथ को स्पर्श करें, फिर सिर्फ केहुनी को स्पर्श करें, फिर कंधे को स्पर्श करके ही बच्चे को खाने के लिए निर्देशित करें। फिर बाद में यह पकड़ बिलकुल बन्द कर दें। जब पकड़ आप बन्द करेंगे तो सम्भव है कि शुरू में, बच्चा खाना कम कर देगा या बहुत सारा खाना छींट देगा या खाना वर्बाद करेगा। परन्तु आप इससे तनिक भी विचलित न हो और अपनी स्थिति पर कायम रहें। क्योंकि बच्चा जब एक बार स्वयं चम्मच या अपने हाथ से खाने का आदि हो जाएगा। तो पुनः आप एक बार फिर से साफ – सुथरे ढ़ग से खाने सिखाने के लिए प्रयास कर सकते है।

याद रहे कि हम उस समय सिर्फ एक पहलू पर जोर डाल रहें है स्वयं खाने की स्वतंत्रता (आदत) न कि साफ – सुथरे ढ़ंग से खाने की आदत। एक बार जब बच्चा भोजन की कुछ मात्रा स्वयं खाने योग्य बन जाए तब हम अगलें पहलु (साफ–सुथरे ढ़ग से खाने) पर ध्यान देंगे। अतः हमारा पहला उद्देश्य बच्चे को स्वयं (प्दकमचमदकमदजसल) खाने की आदत डालना है।

अब जब बच्चा स्वयं आराम से कुछ खाने लगा हो तब हम अपनी प्रयास को साफ – सुथरे वाले पहलू पर केन्द्रित कर सकते है। हमारे स्कूल के एक बच्चा का आदत था कि वा खाने का एक टुकड़ा उठाता था, फिर उसे कई टुकड़ों में विभाजित करता था, फिर एक टुकड़ा खाता और अन्य को दरवाजे पर फेंक देता था। एक दूसरा लड़का जिसे हम जानते है वह अपना सारा खाना पाँच मिनट से भी कम समय में समाप्त कर लेता है क्योंकि वह खाना अपने मुँह में भरता जाता है यानि मुँह का खाना समाप्त किए बिना मुँह में डाल लेता है। बहुत परिवार ऐसे बच्चों को रेस्टुरेन्ट या विशेष अवसर से अलग ररवते हैं, पर बच्चों को साथ रखकर उसके ऐसे स्थिति के लिए सिखायें। साथ ही साफ – सुथरे ढ़ग से भी सिखा सकते हैं, परन्तु यहाँ भी ध् यान रहें कि एक बार में सिर्फ एक पहलू पर ही जोर डालना है।

वातावरण की संरचना : साफ – सुथरे ढ़ग से खाना सिखाने के लिए, हम सर्वप्रथम वातावरण (खाने के स्थान) को इस तरह तैयार करते है कि बच्चे खाते समय खाना फैलाकर गन्दा न करें। बच्चे को इस तरह बैठायें कि वह भोजन को टेबल या फर्श पर न छितरायें। या फिर वह कुर्सी को धकेल कर टेबुल पर न चढ़ जाए। यानि शरीर बिलकुल टेबल के बराबर में रहना चाहिए। खाना के लिए प्लेट ले जो किनारे से उठा हो, और चम्मच छिछला रैंसिसवू) लें ताकि भोजन उठाकर आसानी से मुँह में रखा जा सके। कुछ माता–पिता ने पाया कि बच्चें किनारे वाले प्याले से अच्छें तरह खा लेते हैं। खाने के सभी व्यंजन परोसे और पुन– परसन तब तक न दें, जबतक कि बच्चा थाली या प्लेट का खाना पूरा समाप्त न कर लें। यह स्पष्ट है कि यदि प्लेट का खाना समाप्त किए बिना अगर पुनः प्लेट भर दिया जाता है तो सम्भावना है कि बच्च कुछ खाना खाये और कुछ प्लेट में हो छोड़कर चल दें।

सफाई से दाल चावल खाने में प्लेट के स्थान में एक ढौंगा का प्रयोग लाभदायक हो सकता है। चपाती खाते समय ध्यान रखें कि खाना के कौर (टुकड़ा) छोटे होने चाहिए। क्योंकि अगर आप खाने का टुकड़ा बड़ा रखेंगे तो बच्चा वह पूरा टुकड़ा एक ही बार मुँह में डाल लेगा और यह सम्भावना बन जाता है कि उसे चबाकर खाने के बजाए भकोसने की आदत बन जाएगी या वह खाना का ज्यादा मात्रा एक ही बार मुँह में डाल लेगा।

सिर्फ एक हाथ से खाना सिखानाः-

अगर बच्चा दाये हाथ का ज्यादा प्रयोग करता है। तो आप निर्देश दें कि वह दायें हाथ से खायें। अगर आपका बच्चा बायें हाथ का ज्यादा प्रयोग करता है यानि वॉया हाथ वाला तो आप खाने के लिए निर्देश दें कि वह बायें हाथ से ही खायें। बायें हाथ का प्रयोग करने वाले बच्चों को दायें हाथ से खाने के लिए मजबूर न करें। अगर दूसरा हाथ भी खाने के लिए प्रयोग करता है तो बड़े आराम से दूसरे हाथ को अलग कर दें। और इसी तरह उसक निर्देशित करते रहें। यहाँ पुनः हम बताना चाहेंगे कि अच्छे परिणाम के लिए आपमें स्थिरता आवश्यक है। अपने निर्देश दुहराते रहें और बच्चों को शारीरिक सहायता तब तक देते रहें। जबतक कि वह एक हाथ से खाना नहीं सिख लेता।

अगर बच्चों की यह याद न रह पाता है कि खाते समय एक हाथ नीचे रखना है तो आप उसके एक हाथ को पॉकेट में या जाँघ के नीचे रखवाकर खिलाने की कोशिश कर सकते हैं। परन्तु कभी भी वल का प्रयोग न करें।

ध्यान केन्द्रित और चौकस रहनाः–

यह बिलकुल ठीक होगा कि यदि बच्चा कुछ फेंक दे और उसके बाद की स्थिति का हम सामना करें उससे पहले ही उसका हाथ पकड़ ले। अगर खाने के क्रम में कुछ गिर जाता है तो इसकी हम चर्चा न करें। परन्तु यदि बच्चा जान – बूझ कर ध्यान आकर्षित करने के लिए खाना गिराया है या फेंकता है तो बच्चे से प्रत्येक फेंके या गिरायें हुए टुकड़े को जमीन से उठवायें। और बड़े इतमिनान से साफ और स्पष्ट निर्देश दें कि "उठाओ" जबकि कभी–कभी बच्चा इस तरह खाना उठाने की विधि से मजा करता है तो स्वभावतः आप इसे रोंके। अर्थात् यदि गिरायें हुए खाना, उठाना उसे दण्ड लगता है तो उसे उठाने का निर्देश देकर आप इस आदत को कम कर सकते है।

यह दूसरा अंक, हमारे (।नजपेजपब) बच्चे को बिना मदद के, साफ सुथरे ढंग से खाने के पहलू पर प्रकाश डालता है निष्कर्ष के तौर पर हम अगले अंक में कुछ शेष बिन्दुओं पर प्रकाश डालेंगे। अगर आप इससे समबन्धित कोई सवाल सामिल करना चाहते है तो हमें अवश्य लिखें। हम जहाँ तक सम्भव होगा, इसे अवश्य सामिल करेंगे।

HELPLINE

 \mathcal{Q} I am a father of a seven year old son who has autism. I came to know that you are helping the parents of autistic children In this regards I would like to know the following from you. What are the schools with hostel facility that train autistic children. Secondly the list of doctors with their addresses who are curing autism through Herbal/ Ayurvedic Medicine, Acupuncture, Allopathic and Homeopathic treatment.

 \mathcal{A} There are no residential schools in India that are trained to handle children with autism. There are some special schools with hostel facility, but not for autism. Families of children with autism use them mostly when they have no option but to leave their child there. Otherwise if a child's progress is the motivation, then these schools are not an option.

To answer your second question, there is no medical cure for autism. There are periodic claims by practitioners of various kinds who claim a cure. None of these are unfortunately proven or true. The truth is that

autism cannot be cured. However with proper training all children can progress significantly.

 \mathcal{Q} I have a son with autism. I came to know that I am pregnant again. I want to know what the chances of Autism are and are there any other parents who had a child with autism but still had a normal next child. Please guide as soon as possible.

${\mathcal A}$ First of all

congratulations! I can only

imagine that your are experiencing many mixed feelings right now, but among those, happiness and excitement. Of course, there are many, many families with one autistic child and other children who are not autistic, Moreover, because autism is believed to be at least in part of a genetic disorder, you are also correct that there is a higher likelihood of a second child also being autistic. I have heard different estimates, but 1 in 20 is often cited, or slightly higher , because oftentimes families with autistic children choose not to have a second child, and we do not know whether those children would also be autistic.

So there is no easy answer to this question. I would suggest that you access research in this area on the internet. But most importantly discuss it with your husband. I am not sure whether speaking with a genetic counselor would be of any help, if there are such people, because the genetics of autism are still so unknown. As mentioned, though there are many families who choose to have additional children and while it is of course a very difficult decision, no one can make it except for you and your husband.

 \mathcal{Q} My son is three and half years old and has been diagnosed with ASD (Moderate). We are at present residing in Singapore. We have been taking him for speech and occupational therapy since March 2003. He also receives modulated music therapy for sound

sensitivity. This is basically based on Mozart and western classical music.

We are planning to visit India, Chennai and Bangalore, next month and would be staying there for some months. We would like to continue with his therapies in India.

Is there any kind of music therapy available in India with classical music – Carnatic or Hindustani – as my son loves carnatic music very much. Ever

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

A Two-day Intensive and Interactive Workshop by **Rita Jordan PhD** Reader in Autism Studies at The University of Birmingham

> 6 and 7 December 2003, India International Centre, New Delhi

> > For information call Annie at: 29256469 29256470 or Email: **autism@vsnl.com**

> > > since my son was diagnosed with autism we have been getting a lot of information and details regarding various kinds of treatments and therapies. What kind of treatment would be best in this case, to integrate my son into the mainstream?

 \mathcal{A} It is good to learn that you have found good speech and occupational therapy services for your son. He must



of course be receiving structured teaching along with. Early and appropriate intervention can lead to quite significant progress. During your visit to India you will find that there are a number of good services for children with autism in Bangalore as well as Chennai.

I am not sure what modulated music therapy is, that you mention you are using for your son's sound sensitivity. For sound sensitivity you also use what are known as EASe CDs. EASe CDs are a set of four CDs. They can be played at home on a good CD player, they do not require any specialized training, and help children deal with sound sensitivities. They are a form of what is commonly known as Auditory Integration Therapy (AIT), and do the same job as and at a fraction of the cost of the more expensive AIT that are given by AIT practitioners.

As for Carnatic music, there can be no dearth of facilities in either Chennai or Bangalore. Music per se is therapeutic for most children including children with autism. Most of them love music, can spend hours listening to music, and appear calmer when doing so.

As you rightly observe there is now a flood of information on therapies that benefit children with autism. Included in this are yoga, reiki, reflexology and acupressure. All of these can be beneficial to all people. But none of them are proven to be especially suited to children with autism. So while it is okay to give these therapies to children with autism, articulately when they seem to enjoy them, they must not be at the cost of well established methodologies which use structure and an understanding of autism and are based on behvioural principles.

 \mathcal{Q} I am a mother of an autistic child who is exactly four years old. He was diagnosed last year in June. But after coming to Bahrain a lady who is working for an organisation carried out a check on the CARS with him. She says that according to the CARS he scores non autistic but has behaviour problems which can be dealt with and sorted out. My son has some meaningful words.

 \mathcal{A} Your situation – of receiving mixed information about diagnosis – is a very common one in many places, especially with younger children. It is important to educate yourself on the most common behaviours and characteristics of autism so that you can monitor your son's behaviour and come to some decision yourself as to whether you feel he meets the criteria. Professionals, of course, can be extremely useful in providing an objective opinion, but it depends on their experience and expertise, whether they observed you son on a 'typical' day, whether they have a sophisticated understanding of autism, etc.

It is preferable to not rely on the CARS as the only indicator of diagnosis, though it should not be ignored, either. Because your son is younger, it may be somewhat less reliable. I would suggest that you learn as much as possible so that you are in a better position to understand his behaviour and know how to work with it, whether he is autistic or not. You could also try to seek out a professional in Bahrain whom you feel has a lot of experience and does not rely on a questionnaire such as the CARS. The only contact information we have available for someone in Bahrain is the Bahrain Autistic Society sarc@batelco.com.bh. I am sure you have already spent some time looking, but some sources on the internet you could learn more about autism are the: National Autistic Society: http://www.nas.org.uk and Autism Society of America: http://www.autismsociety.org. There is also information on our site that you may find helpful http://www.autism-india.org

 \mathcal{Q} I have a query about my daughters behaviour. For the past few months she gets excited and turns aggressive when she goes to play with other children. At times she shouts and beats other children. We have written a social story on her playing quietly in the park. She likes to listen to the story but does not stop beating her peers in the park I know these are attention gaining behaviours but how do I control them. Please advice.

 \mathcal{A} Perhaps you could write us about what happens before a behaviour takes place. What happens after? Since you feel the behaviours are attention getting, you want to look at the consequences to you daughter and see if you can change them. Write and tell us: Who is there with her. In what situation does she hit? What exactly was happening before the behaviour? What do the children do when she exhibits this behaviour? What do the adults do or say to her. This will help us to answer your query better.

We regret not carrying our letters column in this issue due to lack of space. Our apologies to those who wrote in to share their views.

Sachu Anita Pradeep

There was excitement in the house. Everyone was awaiting the arrival of my second child. Rohit, my elder son, 5yrs old at that time was the most thrilled. He had already decided on a name - Sachu. On 20 September 1993 I gave birth to a beautiful baby boy and we called him Sachu. When Sachu was six months old we flew to Muscat to join my husband. Sachu was the perfect child: a very cheerful baby, he threw no tantrums. He crawled, stood up and walked at the right time. His milestones were all normal. But something was wrong. Two years passed by but not a word came from him. All our friends told us that some children speak late. That reasoning consoled us at that juncture. Sachu was cute, chubby and with big round eyes. Nobody found anything amiss in him. But during that time he started becoming aloof. He could sit for hours together playing with a toy or even just an empty Pepsi can.

SACHU was sensitive to certain sounds, was attached to objects rather than people. He was terrified of sitting on the toilet seat. By now quite hyperactive, he had self stimulatory habits like hand flapping, and worst of all he was still not toilet trained. But he had a fantastic memory.

BY then we were panicky. We came back to India to consult the doctors here. Our journey consulting doctor after doctor ended at the All India Institute of Speech and Hearing, Mysore where Sachu was diagnosed Autistic and we were given a home based training schedule. AFTER the initial shock and disbelief, we got a hold on our emotions because we had another child who needed our attention.

WE received a lot of support from people though some blamed Sachu's behaviours on our parenting.

BACK home with the help of Raksha, a special school in Cochin, Sachu achieved many goals. Elizabeth Philip the Psychologist and Jayadevi his special teacher gave their unconditional support, love and encouragement. Sachu started responding to us, made eye contact and also started interacting with his brother and cousins. In the meantime, Sachu attended a playschool and completed his preschool, LKG and UKG. Simultaneously, his home based training schedule continued. He learnt skills like brushing, bathing, dressing etc. Toilet training took almost a year and that was one major achievement. His speech started picking up – from small sounds to words and finally to sentences and vocalising his needs.

WE heard of Dr Subramaniam a homeopathic doctor in Changanacherry who treats differently abled children. Since then Sachu has been under his treatment for all his ailments and we found considerable improvement.

THEN started our search for the next school to continue his education. We were advised to put him in a regular school where he would be able to interact and socialize with children of his age and adults. We were able to secure admission for him in a wonderful school - The Choice School where he was accepted and was showered with so much of love and affection from the teachers, students and the support staff. Being uncertain of his new surroundings, he got a bit apprehensive and anxious, which made him a little aggressive. He would pinch the teachers who tried to make conversation with him. But he never ever harmed any child. Since he didn't take the initiative to talk to his classmates, they would come out of their way to talk to him and included him in everything. After the initial hiccups, Sachu settled in quite well. He got used to the teachers and the hustle and bustle of the school atmosphere. Now he is able to read, write and speak. He has a good memory. He is fascinated by computers, vehicles and the people who drive them. He loves music and musical instruments. He is still sensitive to certain sounds and certain musical notes especially high pitched notes. Sachu is in Std 3 now. For him, his school is a home away from his real home.

THE one person who is a major influence and who played the key role in Sachu's progress is his brother Rohit. Initially, he was very hurt, troubled and disappointed that his brother couldn't speak. He missed all the fun that brothers have – fights, games and the usual boyish pranks. It was almost as if his world had come crumbling down. He cried secretly and would keep small notes under his pillow to Jesus and the tooth fairy- asking them to make his brother speak. He was too little to hear a lecture on Autism, so we had to explain in the simplest way. We told him that Sachu was very special to God and he wanted a nice loving brother to look after him and that was why God gave him to us. He wants us to give him

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

AFA's Workshops

Innovative Communication Programming

A Full-day Workshop by Dolly Bhargava SLP with Ylana Bloom

INDIA INTERNATIONAL CENTRE, NEW DELHI

December 28, 2003, 6.15 pm

Dolly Bhargava is a speech language pathologist and an augmentative communication consultant working in Sydney Australia. She has worked with children and adults with intellectual and/or multiple disabilities in a variety of settings, including schools, home, group home, day care centre and day programs. Dolly Bhargava has coauthored a number of books and teaches online courses. She has presented seminars nationally and internationally.

Workshop Topics

- Introduction to AAC
- Assessment of Intentional and Symbolic Communicators

• Using Visual Connectors and Question Maps to determine the types of communication systems that would be needed for any given activity, identify the vocabulary that is needed to be included in the communication systems, and a map for the communication partner to know how and when to use the communicative systems to scaffold the individual's receptive and expressive skills

• Using commercially available books to develop literacy skills in children with communication difficulties. Creating your own personalized material to develop literacy skills in older children and adults with communication difficulties • Using positive behavior support to minimize challenging behaviour, promote environmental management and skill building

Registration Costs:

PARENTS

Rs. 300/- per parent attendee (Rs. 250/- for members)Rs. 550/- per parent couple (Rs. 450/- for members)

NON-PARENTS

- Rs. 400/- per non-parent attendee (Rs. 300/- for members)

- Rs. 350/- for each attendee from an organisation that has taken membership if more than one person attends ON THE SPOT REGISTRATION

- Parent Rs. 400/ and Non-Parent Rs. 450/

We regret that cancellations for this workshop will not be refunded.

Please fill in the form below and mail with a SASE to: Action For Autism, T370F Chirag Dilli Gaon, New Delhi 110017, Or download a form from our website at: <u>http://www.autism-india.org</u>

- CUT HERE

DOLLY BHARGAVA WORKSHOP 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	(7	Tick relevant box) Parent] Professional
Address			
Tel	Email:		
If parent, name of child			
If professional name of enconingtion			
If professional, name of organization			
Do you require accommodation YES/ No	D	o you require childcare	YES/ NO

VERBAL BEHAVIOUR

Advanced Training Programme to Train Resource Persons by Steve Ward MA CABA and Teresa Grimes MS BCBA February 11 – 15, 2004, Kolkata

The Organizers: ASWB

Autism Society West Bengal (ASWB) focuses on bringing to the notice of parents and professionals the need to use appropriate methods of teaching persons with ASD. ASWB has implemented the VB model. The progress has been remarkable considering the programme has been running only since August. Some children have started to verbalize and some have developed echoic skills. But the biggest change has been in compliance. This makes teaching easier and therefore children progress. Older children who had lot of idiosyncratic use of language have improved, are more focused and are now learning conversational skills. With the implementation of VB, parents find they can now teach their children skills they thought they would never be able to.

The Trainers:

ASWB is proud to present certified behaviour analysts **Steve Ward** and **Teresa Grimes** from the US. Steve and Teresa have been working with R and his family is still consulting with them for R's continuing VB program (see *'Why Verbal Behaviour'*). Both Steve and Teresa have trained under Dr Carbone and worked with Dr Partington and Dr. Sundberg. They have over 15 years' xperience as behaviour analysts and over the last six years they have been focusing specifically on children with ASD. There will be two training workshops.

NOTE: Accommodation and Childcare available for both programmes. Charges not included in registration.

WORKSHOP ONE: Seats available: 30

Advanced Training Programme: 'Understanding of behavioural principals for the implementation of Verbal Behaviour'

- 5 day Training Programme 11 –15 February
- Registration Charges Rs 6,500/-
- Early Bird Concession Rs 5,500/- (By 30th December).

WORKSHOP TWO: Seats available: 20

'Workable Introduction to Verbal Behaviour–Understanding of basic Principles and its Practice'

- 3 days Training Programme 11 13 February
- Registration Charges Rs 3,500/-.

Some of the topics to be covered:

- Assessment (ABLLS)
- Framing an IEP
- The different components of verbal behaviour:
 - Compliance
 - Teaching Strategies
 - Teaching Language Skills
 - Natural Environment Training
 - Advanced Language Skills
- Functional analysis of Problem Behaviour and its management
- Direct instructional training on reading and Math
- Teaching Play

NOTE: Participants will receive a letter of participation on completion of the training programme.

PRE REGISTRATION FORM Verbal Behaviour: Advanced Training Programme				
Fill this form in BLOCK LETTERS and mail, wi Mrs.Roma Basu (coordinator), Autism Society WB, 22 Anju	ith a self-addressed stamped envelope to: Iman Ara Begum Row, Tollygunge, Kolkata 700033			
Name	(<i>Tick relevant box</i>) 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			
I wish to register for (<i>Tick relevant box</i>): WORKSHOP ONE	WORKSHOP TWO			

VERBAL BEHAVIOUR: From Theory to Practice Understanding of Basic Principles of VB and its Practice

by Steve Ward MA CABA and Teresa Grimes MS BCBA

Initiated by and in partnership with West Bengal Autism Society
 February 27, 28 & 29 2004, New Delhi

Steve Ward and Teresa Grimes have trained under Vincent J Carbone and worked under researchers Drs Mark Sundberg and Jim Partington (authors of the **ABLLS** and **Teaching Language to Children with Autism and Other Developmental Disabilities**) and have many years experience working in the field of behavior analysis specifically focusing on children with autism.

Those working with children with autism are aware of the difficulties in teaching them to attend and follow instructions and enjoy the process of learning. It is therefore important that children learn that learning is fun and that communication is powerful. **Verbal Behaviour** is empirically verified and one of the latest and most effective methods used in teaching children with Autism. Teaching takes place in the child's natural environment making it easier for the child to apply his learnt skills in everyday life.

Participants will learn teaching strategies based on the science of behaviour analysis. Participants will learn to think and behave as behaviour analysts and understand how to increase desired behaviours, decrease undesired behaviours, and teach new skills.

The workshop is planned for parents, special needs professionals, speech pathologists, psychologists, and anyone working with children with autism. The Workshop will be limited to 40 participants only. Seats available strictly on a first come first served basis.

Topics will include:

- Assessment (ABLLS)
- Framing an IEP
- Compliance Training
- Teaching Strategies
- Teaching Language Skills
- Natural Environment Training (NET)
- Advanced Language Skills.

Registration before 15 January 2004:

- AFA Members: Rs 3,500/-
- Non Members: Rs 4,000/-

Registration after 15 January 2004:

- AFA Members: Rs 4,000/-
- Non Members: Rs 4,500/-

Accommodation: Rooms with breakfast from noon of 26 February to noon of 29 February 2004 Childcare: Childcare will be available only to those participants who register in advance. *Childcare will not be available to on-the-spot registrants*.

For information on registration, etc fill in the form below or download after 20 December, 2003 from the AFA website: http://www.autism-india.org

NOTE: Participants will receive a certificate of participation on completion of training.

PRE REGISTRATION FORM Verbal Behaviour: From Theory to Practice				
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	(<i>Tick relevant box</i>) Parent Professional			
Address				
Tel ——— E	mail:			
If parent, name of child	Child's DOB			
If professional, name of organisation				
Do you require accommodation YES/ NO	Do you require childcare YES/ N)			

CUT HERE — -

Activities planned in the coming year by:

Forum For Autism, Mumbai

January 2004

• Walk for Autism. Volunteers please register

11th January

• *Talk* on Financial Planning-Taxation, Insurance Policies, Getting Certificate for Qualification under Income Tax, Investment avenues for the future of the child by a parent Mr S Ranganathan at Shishuvihar Dadar

February 2004

• Picnic to Alibaug:

Volunteers please register for 25th and 26th January, 2004

• *Siblings workshop* (follow-up) by: Ms. Sunita Kulkarni at Shishuvihar, Dadar

• What options do we have?

Discussion with Mr. Vasant Thakkar of Savali (Shelter for CP children) on various models of residential care for adult autistics.

(...cont. from page.14)

lots and lots of love and care so that one day he would say "Thank you, Achacha". God has been great. Sachu is blessed with such a wonderful brother. There is good rapport between them and Sachu adores his big brother. They talk, play games, sing and go for walks together. Rohit now understands what Autism is and fully accepts his brother's condition. He is in Std 10 now. With the help of Navjyothi Centre, Kakkanad, we have formed a parent group named Anugraha Society for Autism. The dedicated and able team consisting of Dr. Sitalakshmi, Dr. George, Fanny Palathinkal and the Sisters of Navjyothi have arranged for parents and professionals to attend training programmes which have helped us to understand our child better.

WE know that this is the just the beginning. We have a long way to go with our little Sachu. As we tread this path, with a different and special child – we know God is with us and he has a special plan for him. We thank God for Sachu – who has brought out the best in each one of us. We have been blessed with family and friends and a lot of wonderful people who have accepted Sachu and have helped us to find information on Autism and have supported us in every step of our journey.

BOOK POST







If undelivered please return to:

The Editor, Autism Network, T 370 F Chiragh Dilli 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