

autism network

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In referring to the child with autism, Autism Network often uses 'he', 'him', and 'his', not as a prejudice against the girl child with autism, but for reasons of simplicity and because the vast majority of children with autism are male. However, many articles also use 'she', 'her', and 'hers'.

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YOUR CONTRIBUTIONS

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Cover Illustration

'Dream House for His Sister'.
By Mohit Gupta, 14 years from Bhadoli (U.P.)

WISHLIST !

FOR THE SCHOOL

- Trampoline • Plastic indoor slide
- Board markers • Permanent markers
- Art materials such as : water colours, acrylic paints, cartridge paper, canvas
- A4 sheets • School exercise books
- Workbooks on writing exercises
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 - Musician to teach music

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PAGE ONE

When a family is gifted with a child with special needs, the family is mostly able to access a few programs and services to help and teach the child. There are also counsellors and training programs available to help the parents. But, in India at least, there is little if anything for siblings. This issue is a tribute to siblings: that oft neglected part of the family who often, unwittingly, play such an amazing role in helping children with special needs reach their full potential. We asked siblings to send in their thoughts. Some of the offerings from little ones are incredibly insightful.

This has been an eventful quarter at the National Centre. Action For Autism (AFA) and those working with or associated with AFA have won various awards and recognition in the past. In July, I was chosen, along with a few others, to receive the Heartspring Award for Innovation and Creativity in Special Education. Open Door School also became a sister school with Heartspring School in the USA. All this in the middle of a summer camp, the planning for the launch of a Music

Therapy Course, and the upcoming South Asian Conference and Post Conference Workshop on TEACCH in January. We also start a partnership with another wonderful organisation, AACTION Autism, in the USA.

We can no longer work in our little islands. The world is a global village, and our work cannot be restricted by geographical borders.

AFA has constantly striven to evolve methodologies that would be current and most helpful for our children. For some years we have tried to develop a combination of verbal behaviour and structured teaching. In my travels in the USA this summer it was incredibly exciting, for the first time, to chance upon schools that use just such a combination with confidence and success. A reiteration that we too are on the right track: which makes all our hard work worthwhile.

Exciting times ahead as we evolve and nurture the National Centre for Autism!

● I N M E M O R I A M

Rohan Sonalkar



In December 2001 Action For Autism initiated the launch of AUTISM WEEK, now observed as AUTISM MONTH across the subcontinent. That inaugural year we observed the week with a series of events including a hugely successful art show Views from Planet Autism at an art gallery at the India Habitat Centre. We were privileged to host a number of

talented artists on the Spectrum from across India. A memorable one was Rohan Sonalkar. We were enchanted by Rohan's work: his bold use of colour and the vividness of his canvases. I was fortunate later to visit Rohan at his home in Pune, and have breakfast sitting out in the garden with him and his wonderful family.

In March this year we suddenly lost Rohan after a brief illness. His family who ensured that Rohan has every opportunity to grow and develop his talent now want to start a small column to share their experiences on life with Rohan, which they hope will act as a motivator for parents of many other Rohans across the country. His sister-in-law Jahnavi starts the column with this issue.

My Brother Has Autism (...or my sister)

"You too are a valuable, developing individual human being. You too need to be recognized, to be loved and develop into the best person you can be. Your brother or sister with handicap needs to experience the most robust, risky, rough-but-kind interactions with you that he or she can tolerate-as close to normal sibling relationships as possible."

— Robert Perske 1981

Changing family scenario

In these the early years of the 21st century, society is going through accelerated changes. These changes understandably manifest in family structures and systems. Family size is decreasing. Couples 'plan' their children: they plan fewer children, and have them closer spaced. The typical Indian joint and extended families are giving way to nuclear families.

FURTHER, with changing economic possibilities, families exhibit greater mobility than ever before, with families often relocating to a new place, and thereby a new neighborhood, a new social set up, a new schools for the children with new classmates and new adjustments. Parents as well as children have to go through the process of adjustment. In addition, more and more mothers are seeking work outside the home.

WHILE families are driven by these compulsions of our times, these cannot but have an impact on all interpersonal relationships within the family, including relationships between siblings. Sibling relationships after all have a critical role to play in the family. In the individuals early years, siblings act as social agents. They provide the first peer interactions within the home and this forms the basis of later learning and personality formation. In any family, each sibling, and each relationship that siblings have, is unique, important and special. This relationship with its emotional and physical contents influences the individuals' personalities and has an impact throughout life. Brothers and sisters provide each other with an exposure to opportunities for sharing, expressing feelings, compromising, and understanding mutual collaboration.

Above all, as young children they learn to play among themselves forming the first close social network of life. As siblings grow and mature, they may become many things to each other – teacher, friend, companion, follower, protector, enemy, competitor, confidant, and role model.

WITH the support system and the social possibilities of the extended family no longer available, interdependency between siblings often become more intense. At the same time, without the distractions of the extended family, there is a sharper parental focus on children. In addition when family mobility leads to difficulties in developing new relationships outside the house, siblings come to rely more on each other. Or with both parents away at work and not easily available to

Many siblings have shared that their brother or sister with a disability actually groomed them to be better Human Beings with qualities like unconditional love, patience, empathy and generosity.

them as in the past, children tend to turn to each other and especially for emotional support.

LET us look at families where the changing dynamics are further impacted by the presence of members who have a disability and in particular a socially complex condition like autism.

Growing up with a sibling with special needs

At a conservative estimate there are 60 million individuals with a disability in India. Of these at least four million are individuals with autism. Many of these individuals have a brother or a sister WITHOUT autism. What has been, and is, the impact on these brothers and sisters of growing up with a sibling with autism? Each of us after all is shaped by the environment we grow up in: the early death of a parent, parents getting divorced, a mother who is a poet, a resident grandmother with Alzheimer's, a father with a drinking problem.

Similarly, having a sibling with special needs cannot but affect the person we become and the way we view ourselves.

VERY young children are often very may be accepting, since their sibling's special needs is all that they know and all that they grow up with. This is the stage when much of the child's attitudes towards the sibling with a special need is shaped by parental attitudes. Where parental attitudes are one of comfort and acceptance, children too hold similar views. But as children venture outside the home, they may encounter teasing from other children and become more conscious about their siblings' differences. They may become anxious and worried sometimes wondering whether they may have caused their siblings' condition, or whether they may also 'catch' the disorder. They may also resent the time and attention their parents give to the sibling with a handicap and feel neglected or even rejected. Children may wonder what is wrong with them that their parents love their sister or brother with a disability more. Feelings of jealousy or loneliness can arise.

ADOLESCENCE is a difficult age for any of us. The insecurities of the age drive adolescents to try very hard to 'fit in', to act and dress in the 'right way'. As a result adolescents may experience embarrassment of the autistic sibling's behavior or appearance. They may avoid contact with others, or not invite their friends home, and be embarrassed or ashamed that their friends may come to know of their autistic sibling. They may not want to participate in social activities for the same reason. Often there is also resentment that the sibling 'gets away with murder' or 'why cant I do that?' or 'why must I have to do this when he does not?' They may resent the caregiving responsibilities that they are made to take on, and worry that they might have to look after special needs siblings after their parents' death.

AS children enter adulthood, sibling concerns revolve more around the future and what would become of their brother or sister with a disability. There are concerns about how the people they socialize with, date, and later marry will accept their sibling with special needs. Additional issues faced by young adults may include genetic counseling when planning their own families, and coping with anxiety about future responsibilities.

Parental/family influences on sibling relationships

As mentioned earlier, the perceptions and attitudes, beliefs and opinions, of non-disabled siblings towards

their special needs sibling flow from parental example. Whether parents view the disability as tragic, or view it with acceptance, will all influence their children's views. A brother or a sister will feel comfortable and accepting when he or she has grown up in an atmosphere of happiness and acceptance. Parents who believe that the special child is not a burden or a source of stress, who try to enjoy life as any other family, can create a happy environment within the family that enable the other children to be accepting too. When parents display pity, disgust, irritation, or anger, towards the child with a special need, that colours the attitudes of the non-disabled sibling. How parents handle the situation of special needs in the family will determine how their children handle the situation.

HAVING a child with special needs in the family can strengthen parental bonds. However, it can also strain a marriage. In India, the opinion of the extended family, on a range of issues such as the 'cause' of the disability and how that child should be brought up, can all put additional pressure on the family unit. Pressures in the work place, health issues, lack of adequate support services, can all throw up challenges. Any or all of these cannot but impact on the children.

DIFFERENT families will of course deal differently with the scenario of having a child with special needs in the family. Sometimes the requirements of the child with special needs might take over the entire family and dictate their entire life. What they eat, where they go, what they do, the family's time money, resources, all go into caring for the special child, often to the neglect of the needs of the typically developing children. At the other extreme, the regular siblings can become the focus and the receptacle of all the parents' expectations. They are expected to excel at everything to almost make up for their special needs sibling. There is parental pressure on the regular child to over achieve and over compensate.

PARENTS may often expect the sibling to take care of the child with special needs well beyond the typical demands of sibship. There is additional pressure where the sibling is female, or where the typically developing sibling is older.

IN India there are families where after a child has received a diagnosis of special needs, couples go in for a second child primarily to have a caregiver for the first. The expectations of the second child, right from its birth, are that she or he will take care of their special needs

sibling for the rest of their lives. The pressures of such expectations and the stresses, resentment, anger, to guilt for wanting a life of their own, that these give rise to can often be extreme.

Facilitating positive sibling relationships

Having a child with autism impacts on the entire family. One cannot hide, or 'protect' the other children from the knowledge that their sibling has autism. Besides, hiding the information sends out a message of negative judgments about the condition. Hence disclosure is

important. When explaining the child's autism to the sibling it is best not to give too much information to a small child, which might just confuse the child. Neither does information have to be given at one solemn sit down major event, but through lived experiences – when the child with special needs does not play with his sibling, when he has difficulties with sleep, when a visit to a special needs school is planned, and so on. It is also important to be aware that the typically developing child understands the information being given.

(to be continued in the next issue)

ROHAN'S

COLUMN

Memories of a



Brother-in-Law

Janhavi Sonalkar

After my marriage I entered a new world full of surprises. I adjusted quickly to my new home: undemanding, not too many restrictions to follow, and not too many questions to answer. Yet, before the wedding I had often sensed an unspoken question in the minds of many people. How will you adjust to Rohan, your brother-in-law?

As part of my internship as a counselor in the making, I had worked with individuals with autism. But obviously never before had I a 24/7 experience with them. Now at 22, married to Rohan's brother, here was my opportunity to do so. I did have a few fears of how I would adjust to him, and more, how Rohan would adjust to another person living under the same roof!

As time passed and I interacted with him I realized that he was somebody who was much more than I had expected. All of 33 years of age, six feet tall, heavily built and aristocratically dressed, Rohan came to be my gentle giant and who with time came to occupy a deep niche in my heart; from whom I learnt a lot of things; and who made us all smile, laugh, and think. The Rohan I got to know was also someone who had no expectations from anyone around and was selfless in doing things for others.

Rohan liked to be perfect, which manifested in the round omelettes he made for himself every morning to the making of his own bed at night. It was always amazing

to watch him greet people with an enthusiasm and intensity that never changed for anyone irrespective of the class, the degree of relation, or friendship. Many a day I would find myself sitting at the dining table and singing songs with him as if we were kids in the midst of our summer vacations. And then quickly pretending to be in depths of meaningful conversations as we sensed my father-in-law approaching. This was on Rohan's good days. He had his good days and his bad days and we learnt to respond accordingly.

Rohan loved to sing and paint, both with the same intensity. With eight art exhibitions behind him, he tops my list of being the artist portraying splendid honesty and innocence in his paintings. From Rohan I got to learn the meaning of the word patience, as I watched him painstakingly sketch thousands of lines that made up a sea. Rohan has made me patient, flexible and sensitive. He taught me to let go off my pretensions and inhibitions. He taught me that life will not always be the way you want it to be, that life may not follow the paths which we choose to walk on. He taught me to respect wherever my life takes me. And moreover, he taught me that "if I with my autism can be happy, then why do you the so-called 'normal' always have something to be unhappy about?"

He touched a lot of hearts, made a lot of people smile, yet in many ways, Rohan will always remain an enigma and a mystery.

SUJIT

By Susmita Kurup

Susmita is 19 and doing her Computer Science Engineering at Thiruvananthapuram

I had always wanted a younger sibling. Because most of my friends had one. I thought, wouldn't it be fun to have someone to play with, have silly fights with, go to school with and...don't tell my mother this, but also someone to boss around as an elder sister!

IF you ask my parents, they'll tell you how much I pestered them about it. And finally I was holding a baby brother in my arms (albeit a bit awkwardly) as my seventh birthday present. I suggested we name him "Subhash" but thank God my mother didn't listen to me. She decided on "Sujit" and we all stuck with that.

INITIALLY, my seven-year-old mind was very disappointed. Baby Sujit, or Jeetu as we all affectionately call him, didn't talk, didn't walk, didn't even giggle when I tickled him. What's the point of having a brother when all he does is cry and drink milk?

"BE patient. He's too small. You can play with him when he's grown up a bit." My mother would tell me.

SO I waited. And before I realized it, baby Jeetu had grown into the cutest little 2-year-old. I've lost count of the number of times I've pulled his cheeks and pulled him into a hug because I couldn't resist his cuteness and his smile. Ask anyone who knows Jeetu and they'll tell you what a beautiful smile he has.

I was in the fifth standard when one of my friends told me about her little brother. "He's so cute! Especially when he calls me 'didi'!" She said.

"OH, I have a little brother too. He's also very sweet! But he hasn't started talking yet." I said.

"REALLY? Your brother must be very small then. Mine is only 18 months old."

18 months? I quickly calculated – that would mean 1 & ½ years. Jeetu was 2. Immediately I felt indignation. That was not fair! Why should her brother start talking earlier than mine? After reaching home I told my mother about it. She just gave me a worried look. Obviously, the

thought that Jeetu should have started saying at least a few words by now had crossed her mind before.

THE next couple of years are a haze to me. It mostly consisted of taking Jeetu from one hospital to another, one doctor to another. It wasn't a very pleasant experience for any of us. One incident stands out poignantly in my memory.

"THE doctors are saying he's partly MR and partly autistic." My mother told me, when she came back after an appointment with a doctor in a reputed hospital.

I frowned. "Is it possible for someone to be partly MR? And what is 'autistic'?"

AT that moment I had no idea that the word 'autistic' was going to become so integral to my life. I hadn't even heard of that word before.

WHILE my parents were leaving no stone unturned in trying to find Jeetu's problem, Jeetu himself was starting to show changes in his behaviour. He was becoming really naughty, or 'hyperactive' as the doctors put it. He loved jumping, swinging, running, climbing onto the highest places, breaking things. But he excluded me and everyone out of it. He was always lost in his own world.

DURING my vacations in 6th standard, we went to Bangalore. My parents wanted to take Jeetu to an institute there. It was there that the doctors diagnosed him as moderately autistic.

AUTISM isn't very common, I'd been told, and even doctors didn't know about it. That fact used to hurt me even more. Why *me*? Why did it have to be *my* brother?

"THIS is all my fault," I used to think. "If I hadn't insisted for a sibling none of this would have ever happened."

I slowly started detaching myself from Jeetu. I was sad, upset, disappointed and most of all embarrassed. I didn't tell my friends about his condition, never used to even

mention him. When they would ask me about him, I would answer with a cursory “He’s okay”

BUT my mother is a dedicated woman. Where my father and I had given up hope, she strove on...getting her hands on any information regarding autism, desperately trying to reach anyone who could help Jeetu. Coming across AFA was a huge leap for her and for Jeetu.

JEETU was five when he started going to a special school and at the same time going for intervention to AFA. My parents also arranged an Occupational Therapist for him.

“HE’s improving Mitu, can’t you see?” My mother would tell me. “If we all work with him, he’ll improve much more. Maybe he’ll even become normal!” I remained skeptical then. But I couldn’t help noticing the differences either.

THE previously indifferent Jeetu had become a very affectionate boy. He loved to be hugged and kissed (still does) when earlier, he used to push everyone away. He also started writing English alphabets, although that fact turned out pretty bad for the walls of our house.

HE didn’t like to play like other kids of his age. But he had a different way of playing. For some reason, he had a huge fascination for kitchen utensils, especially pressure cookers and mixers. He would pick up the pressure cooker, place it on a table and stare at it from all possible angles for hours! I used to find that odd about him, but slowly I started finding it endearing.

HE also made these odd, strange sounds. The loudness varied with his moods. I used to find that a very annoying habit and sensing my annoyance he started doing it more. In fact he loved annoying me in all ways. He would scribble over my homework so that I would have to do it all over again. He would snatch my Harry Potter book from me and run away giggling. I regret scolding him then because now as I think back, that was so adorable of him! He was trying to get my attention!

I started realizing what a bad sister I had been. I was ignoring my brother because he’s abnormal. But I soon realized he’s not abnormal. He’s special. He’s different.

JEETU loves a lot of things that other kids would find silly. For instance, he loves watching me draw, with a fascination for trees. He would insist that I draw

something and would watch me with rapt concentration. He also loves music. If you play his select favourite songs, he’ll sit still and listen for hours. He’s a big fan of A.R.Rehman and Himesh Reshammiya. He likes to hear me sing. My mother would tell you what a horrible singer I am. Jeetu, however, seems to think otherwise.

SLOWLY he got over his pressure cooker obsession and got a new one – spoons! He used to continuously tap the spoon on the table and floor and I found that even more annoying. Again, he sensed my annoyance and started doing it more.

ONE day, I was in a particularly foul mood and I snatched the spoon from him when he started tapping incessantly. “Jeetu! Stop it!” I yelled at him.

HE looked at me and shouted “Jeetu!” back at me.

IMAGINE my surprise. It was the first time he had said something legible in response. “Didi.” I corrected him.

“DIDI.” He repeated.

NEEDLESS to say, I was thrilled! Since that day, Jeetu, who never used to speak anything other than unintelligible sounds, started parroting words. It was a huge milestone for all of us. And I’m proud to say that I caused it (even though it was an accident)!

JEETU will be stepping into teens this August while I’ll be stepping out. Despite this sizable age gap and his condition, along the years we’ve come to share a close brother-sister bond, unlike any other. Our bond has to be different, because Jeetu is different. (My mother won’t agree with me on this, but Jeetu is most obedient with me than anyone else!)

THE closeness we share never impressed upon me, until I had to move 3000 miles away to do my engineering. I probably used to take it for granted as I was the one who spent the most amount of time with Jeetu. Even now as I’m typing, I miss Jeetu so much. I never realized how much he missed me too till I went to Delhi for my Christmas vacation last year. He wouldn’t let go of me.

LAST year, when I went to my new college my new friends asked me if I had any siblings, I replied, “Yes, I have a brother. His name is Sujit but I call him Jeetu. He’s 12 years old and he’s autistic. But he’s the most adorable and most loving brother you’ll ever find.”

MY BROTHER VISHU

Vibhu Pratyush

Vibhu is 12 and studies in Class VII,
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My brother Vishu is 10 years old. Being only two years younger to me I can't remember a time he wasn't there. Since we have always been so close I understand him very well and never feel sad that he is autistic. At times I do feel embarrassed when he misbehaves in public and I do scold him for doing so, but my love never reduced for him.

LET me describe Vishu a little. He is tall, thin, fair, with skinny legs and matchstick like fingers. Big shining black eyes full of innocence and a big, sweet smile which shows his big rabbit-like teeth. He is like an Angel when happy but worse than a devil, screaming and shouting and driving everyone crazy, when angry.

I love him most when I wake up in the morning and find him cuddled close against me with one leg thrown over my waist and his head on my chest. I enjoy going for a stroll and having a snack with him every evening and playing on the computer. I wish I could take him out to play with my friends, but due to his habit of running away I can't do so.

HE has changed a lot in the last five or six years. He was terrified of Diwali but now he is getting used to it and we can celebrate Diwali again. His favourite festival is Holi and he goes crazy playing with colours and water. He loves going out with me and Mummy, eating out and meeting friends. He loves doing art and craft and doesn't let anyone touch his scissors, not even Mummy.

VISHU has changed my life as he has in some way or the other made me aware of the problems of disabled people. I realise how difficult it must be for him to cope with the world and the social rules and regulations. I think the spirit he has of always being happy and loving us no matter what happens is something normal people should learn from him. He may be autistic but first and foremost he is my brother and I will always ensure that he is happy and safe.

BHARAT

Padmavathi Sundar

Padmavathi is Bharat's elder sister and lives in the USA

Autism – we did not realize what Bharat, now twenty six years old, had was this, when we first suspected that he may not be 'normal'. This was when he was three years old. We were a little concerned that he did not talk like a cousin his age did or as I had when I was that age, but attributed it to minor development delays. After two years of multiple visits to neurologists, pediatricians and special educators, Bharat was diagnosed with autism.

WE were devastated. When Bharat was born I was jealous of all the attention he got but as a ten year old I missed having a baby brother to play and interact with. I felt anger and embarrassment when children playing on the street made fun of him and his unusual mannerisms. Most of all I felt frustrated when we seemed unable to help him develop, despite numerous interventions via a special educator and homeopathic medicines.

HOWEVER, having a brother like Bharat has changed me positively in so many ways! It has made me sensitive

towards differently abled people and has taught me to not sympathize with them but to respect them and treat them as I would any other person. I also realized early on that Bharat was more skilled in some ways than many others. And I gradually developed the ability to appreciate those skills while overlooking the lack of others. For example, Bharat has a good ear for music and would often help me complete tunes that I was having a hard time remembering!

NOW that Bharat is an adult, it has become increasingly important for him to be independent and to be able to perform activities of daily living. I have been living away from him in the US but I am told that he is able to perform these activities satisfactorily. And he is blessed to have been born in a country like India where the constant companionship of neighbors and relatives gives him the opportunity to constantly develop his communication skills and to feel emotionally connected.

TODAY, I am a mother of a one year old and am looking forward to helping foster a warm relationship between my son and his 'mama' who lives 10,000 miles away!

AUTISM is now better defined and the importance of early intervention understood. Going forward, I see great hope for children with autism to develop skills that could eventually mainstream them in society.

उर्वशी की पूल यात्रा

उर्मिला तनेजा

आटिस्म एक ऐसा विकार है जिसमें क्षमता और इच्छा होने के बावजूद बच्चा कई काम नहीं कर सकता। इनका कारण संवेदिक दुष्क्रिया (Sensory Defensiveness) हो सकती है। कई बार प्रयास करने से इन कमियों से निकला जा सकता है जो कि उर्वशी की पूल यात्रा से समझा जा सकता है।

पानी से खेलना किसे अच्छा नहीं लगता और वो भी गर्मी के मौसम में। उर्वशी को भी पानी से खेलना बहुत अच्छा लगता है। उर्वशी 10 साल की आटिस्टिक लड़की है जो ओपन डोर (AFA) में पढ़ती है। उर्वशी को बचपन से ही पानी में खेलना अच्छा लगता था। कई बार तो पार्क में झील या तालाब देखकर वह उसी में जाने को तैयार हो जाती थी। मैं उर्वशी की भुआ बड़ी मुश्किल से उसे रोकती।

2006 में जब उर्वशी ने ओपन डोर में हुए पहले समर कैंप से भाग लिया तो वह pool में नहीं गई। दो तीन बार प्रयास किया गया पर उर्वशी pool के एक तरफ ही खड़ी रहती और बच्चों को पानी में खेलता हुआ देखकर खुश होती। जब उर्वशी के pool में न जाने की बात मुझे बताई गई तो मुझे बहुत हैरानी हुई। मैंने भी कोशिश की पर कोई सफलता हासिल नहीं हुई। मैंने पूल के समय उसे वही पर रखने के लिए कहा क्योंकि वह दूसरी बच्चों को पानी में देख कर बहुत खुश होती थी। समर कैंप के बाद जब जुलाई में स्कूल खुला तब भी उर्वशी अपनी क्लास के बच्चों के साथ पूल में नहीं गई। सभी ने अपनी राय दी। किसी ने कहा उसे इतने ज्यादा पानी में अच्छा नहीं लगता होगा, तो किसी ने कहा कि पूल की गहराई से उसे डर लगता होगा, तो किसी ने उँचाई को कारण बताया। पर मुझे धीरे-धीरे यह अहसास हो गया कि यह सिर्फ दूसरे बच्चों के पानी में खेलने की आवाज है जो उसे पानी में जाने से रोक रही है। उसका मन पानी में जाने को उछल रहा था पर बच्चों का

शोर उसे रोक रहा था। उसके बाद मैंने उर्वशी की अध्यापिका को उसे अकेले पूल में भेजने को कहा जब पूल के आसपास कोई न हो पर वह संभव नहीं हो पाया। 2006 की गर्मी का मौसम खत्म होते ही पूल भी बंद कर दिया गया। अब आया 2007 इस बार भी उर्वशी ने समर कैंप में भाग लिया। इस बार भी उर्वशी पहले दिन बच्चों के साथ पूल में नहीं गई। 2006 और 2007 में फर्क सिर्फ इतना था कि इस बार उर्वशी वैन में घर नहीं जा रही थी तो समर कैंप का समय खत्म होने के बाद भी, मेरे लिए रुकती थी। जब पहले दिन सब बच्चे चले गये तो मैंने उर्वशी के कपड़े बदल उसे पूल में भेज दिया और छुपकर उसे देखने लगी। पहले तो वह पूल के चारों तरफ घूमती रही और इधर उधर देखती रही। जब उसे कोई दिखाई नहीं दिया वह धीरे-धीरे पूल में उतर गई। पहले तो पूल के अन्दर उसने चक्कर लगाया और फिर वह बैठ गई और जो वह पानी में खेले वह दृश्य देखने लायक था। सभी हैरान थे कि अचानक उर्वशी पूल में कैसे चली गई। सलिला ने तो उर्वशी की फोटो भी खींच ली। जितना हम खुश थे उतनी ही उर्वशी भी खुश थी। बड़ी मुश्किल से मैंने थोड़ी देर बाद उसे पूल से निकाला। वह पूल से निकलना ही नहीं चाहती थी।

दो-चार दिन हमने उर्वशी के ग्रुप के पूल जाने के समय उसे ही पहले भेजा और फिर दूसरे बच्चों को एक-एक करके भेजा। पहले तो उर्वशी थोड़ा सहम कर किनारे हो गई पर वह पानी से निकल कर बाहर नहीं जाना चाहती थी। धीरे-धीरे उसने दूसरे बच्चों के साथ ही पूल में मजा लेना शुरू किया। उसके बाद तो कोई भी पूल में हो वह बेधडक पानी में घुस पानी का मजा लेती।

तो यह थी उर्वशी की पूल यात्रा। यह तो एक छोटी सी बढ़त है सफलता की ओर। अभी और भी मुकाम बाकी है।

मेरा भाई –सुजीत

सुस्मिता कुरूप

मुझे हमेशा एक छोटे भाई या बहन की चाह थी। शायद इसलिये क्योंकि मेरे सभी मित्रों के भाई-बहन थे। मैं सोचती, कितना मजा आयेगा जब किसी के साथ खेलने को, मस्ती में लड़ने को, स्कूल साथ जाने को और रोब जमाने को मिलेगा।

यदि आप मेरे माता पिता से बात करें तो आप जानेंगे कि इस इच्छा को पूरा करने के लिए मैं उनके पीछे कितना पड़ी थी और आखिरकार मेरे सातवें जन्मदिन के तोहफे के रूप में था मेरा नन्हा सा भाई मेरी गोद में। मेरा सुझाव था कि हम उसका नाम सुभाष रखें, पर सबने मिलकर सुजीत ही रखा।

शुरु में मेरा 7 वर्ष का मन बहुत ही निराश था। छोटा सुजीत, जिसे हम प्यार से जीतू बुलाते न बात करता, न ही गुदगुदाने पर हँसता। क्या फायदा ऐसे भाई का जो केवल रोता और दूध पीता हो। तब मम्मी बोली धीरज रखों, अभी यह छोटा है, कुछ और बड़ा होकर बोलेगा।

यह सुनकर मैं प्रतीक्षा करने लगी। देखते ही देखते जीतू 2 वर्ष का प्यारा बच्चा हो गया। मुझे याद नहीं मैं कितनी बार उसके गाल खींचकर उसे प्यार करती। मैं उसकी हँसी और प्यारे चहरे को देखती रहती। जो भी मेरे भाई को जानता है वह इस बात को मानेगा कि उसकी मुस्कान अत्यन्त सुन्दर है।

जब मैं पाँचवीं कक्षा में थी तो मेरी एक सहेली अपने भाई के बारे में बोली “ जब मेरा 18 महीने का भाई मुझे दीदी कहता है तो बहुत अच्छा लगता है” इस पर मैं सोच में पड़ गई और हिसाब लगाने लगी 18 महीने यानि 1 1/2 डेढ़ साल, पर सुजीत तो दो साल का है। मेरी सहेली का भाई कैसे बोला, इस सोच से उत्साहित और उत्तेजित होकर मैंने

घर पहुँचकर मम्मी का सामना किये बिना उनके चेहरे की परेशानी बोल रही थी कि यह सवाल मुझसे पहले उनके जहन में आया है।

अगले कुछ साल बहुत ही घुँघले रहे मेरी याद में। ज्यादा समय जीतू को एक डॉक्टर से दूसरे और फिर कई और डॉक्टरों के पास ले जाना एक बहुत ही दुख दाई अनुभव था। एक अनुभव जिसकी दर्द भरी याद अब तक मन है। माँ एक जाने माने अस्पताल से लौटी और कहा कि डॉक्टरों के अनुसार सुजीत में कुछ मन्द बुद्धि और कुछ ऑटिज्म है। मैंने माँ से पूछा क्या कोई थोड़ा मन्द बुद्धि हो सकता है और यह आटिज्म क्या है?

उस समय मैं यह नहीं जानती थी कि “ऑटिज्म” शब्द मेरे जीवन का एकग्र भाग बन जायेगा। ऐसा शब्द जो मैंने पहले कभी नहीं सुना था।

जब मेरे माता पिता जीतू की कठिनाइयों का समाधान ढूँढ रहे थे, वह स्वयं व्यवहार परिवर्तन दिख रहा था। वह शैतान हो रहा था, डाक्टरों के शब्द थे “ हाइपरऐक्टिव। कूदना, झूलना, दौड़ना- भागना, ऊँची वस्तुओं पर चढ़ना और सामान तोड़ना मानो उसे पसंद आने लगे। वह मुझे अपनी प्रत्येक गतिविधियों से अलग रखता, अपनी दुनिया में खोया रहता।

जब मैं छठी कक्षा में आई, तब हम सब बंगलोर गये। वहां एक संस्थान में सुजीत को औसत रूप से ऑटिस्टिक होने का निदान मिला।

यह भी पता चला कि यह आम पाई जाने वाली स्थिति नहीं है। डॉक्टर भी इसकी जानकारी नहीं रखते। यह बहुत ही दुखदाई था “ क्यो मेरा भाई ही ऐसा है?”

मुझमें एक अजीब भावना आने लगी। मैं ही भाई चाहती थी तो यह मेरा दोष है। अगर मैंने अपनी चाह माँ और पापा पर न थोपी होती तो ऐसा नहीं होता।

धीरे-धीरे मैं जीतू से दूर होती चली गई। मैं दुःखी, परेशान और निराश थी पर सब से अधिक शर्मिन्दा। मैं अपने भाई के बारे में बात न करती और कभी सहेलियाँ पूछती तो मैं कहती "वह ठीक है"।

मेरी माँ एक बहुत ही हिम्मत वाली स्त्री है। जब मैं और पापा हिम्मत हार चुके थे, तब माँ ने ही कदम आगे बढ़ाये। ऑटिजम संबंधित जानकारी एकत्रित कर सही दिशा ढूँढती रही। ऐसे में ऐक्शन फॉर आटिजम से मिलना उनके लिये एक बहुत महत्वपूर्ण कदम था।

5 साल की आयु में जीतू एक स्पेशल स्कूल में जाने लगा। साथ ही ऐक्शन फॉर ऑटिजम और ऑक्यूपेशन चिकित्सा का प्रबन्ध भी किया। माँ बोलती जीतू में सुधार आ रहा है, अगर हम सब मिलकर काम करें तो शायद वो सही हो जाये।

मैं मान तो नहीं सकती थी पर जीतू का सुधार भी दिख रहा था। वह अब स्नेह और आलिंगन स्वीकार करता, अंग्रेजी के अक्षर लिखता, घर की दीवारों पर भी!!

वह दूसरे बच्चों के साथ नहीं खेलता, रसोई घर के बर्तन ही उसके खिलौने थे। वह प्रेशर कूकर से खेलता। यह सब अटपटा था पर उस पर प्यार भी आता।

वह अजीब अजीब आवाजें निकालता। मेरी गृह पुस्तकों पर वह लकीरें मार देता। मेरी हैरी पॉटर की किताब लेकर भाग जाता। मैं उसे डॉटती पर आज सोचती हूँ तो लगता है कि वह मेरा ध्यान अपनी तरफ आकर्षित करना चाहता था।

मुझमें अहसास आया कि वह अजीब नहीं, विशेष है, अलग है। उसे दूसरे बच्चों की तरह छोटी-छोटी चीजे पसन्द

थी। मुझे वह पेपर और रंग देता और मुझे चित्र बनाते हुए देखता।

उसे संगीत पसंद है। ए आर रहमान और हिमेश रेशमिया उसके मनपसंद हैं। उसे मेरा गाना भी पसन्द है जब कि मम्मी कहती है कि मैं बिल्कुल बेसुरी हूँ। आहिस्ता, आहिस्ता सुजीत की रुचि प्रेशर कूकर से हटकर चम्मच पर अटकी जब वह टेबल या फर्श पर चमच्च बजाता, तो मुझे गुस्सा आता। वह और तेज बजाता क्योंकि वह मेरा ध्यान चाहता था।

एक दिन मैंने गुस्से में "जीतू" चिल्लाया और चम्मच खींच लिया। पलटकर वह भी बोला "जीतू" मैं हैरान थी। पहली बार उसके जायज प्रतिक्रिया मौखिक रूप से की।

मैंने उसे सही शब्द दिया "दीदी" तब वह भी बोला "दीदी" मैं खुशी से फूले नहीं समायी। उस दिन से सुजीत ने तोते की तरह शब्द दोहराना शुरू किया। इसके लिये मैं स्वयं को सफल मानती हूँ।

अगस्त में सुजीत तेरह साल का होगा और मैं बीसवें साल में प्रवेश करूंगी। हमारे में सात साल का अन्तर है पर हमारे बीच एक अनूठा बन्धन है। क्योंकि जीतू ही अनूठा है। माँ शायद न माने पर वह सबसे अधिक आज्ञाकारी मेरे साथ रहता है।

हमारे प्यार का अहसास उससे 3000 मील का दूर जाकर मुझे अधिक हो रहा है। मैं त्रिवेन्द्रम में इंजिनियरिंग कर रही हूँ। जीतू की कमी महसूस करती हूँ। विशेष रूप से यह सब लिखते हुए। पिछले साल जब दिसम्बर में मैं दिल्ली गई तो सुजीत मुझे छोड़ता नहीं था।

जब मैंने कॉलेज में प्रवेश किया तो नये मित्र बने। जब उन्होंने पूछा कि क्या मेरा भाई-बहन है? तब मैंने सबको बताया "हाँ मेरा भाई है सुजीत, उसे हम जीतू बोलते हैं। वह 12 वर्ष का ऑटिस्टिक बच्चा है, पर वह बहुत ही प्यारा और प्यार करने वाला भाई है। उस जैसा भाई कोई नहीं।

HELPLINE



Q I need some help in getting treatment for my 15 year old brother who is autistic. If you can help me in providing some information, it will be greatly appreciated. We are coming to Delhi and so I wanted to get started getting some information before we come there. Do you know what kind of alternatives are out there in Delhi or any part of India that possibly can cure a child who is normal in every sense but can not speak? Some people have told my mother that there maybe a cure in Delhi for her child, mainly surgery or something close to it, something so that my brother would not be depending on anyone else. Would there be such a way to cure the 'not speaking' part of him?

A I understand from your mail that your brother has a diagnosis of autism. I am sure you have read up quite a bit on the subject by now. Also spending time with your brother would have given you an insight into how autism can affect an individual.

You mention that your brother does not speak. Yes that does happen with some individuals with autism. But in addition to not speaking, have you noticed whether he uses gestures to communicate, eg shrugging the shoulders to indicate that he was not sure or that he did not care. Or lifting an eyebrow to say – are you kidding me. Consider whether he comes and tries to share through gestures, with those he loves, an account of a visit or a party or an outing. Something for instance that a deaf person without speech would do.

How about wanting to show you an interesting sight, or a familiar person who he spots on the road. Does he do these things?

Will he go to a shop and carry out a financial transaction like another fifteen year old?

If your answer to these questions are in the negative, then you would understand that your brother's diagnosis of autism goes beyond merely 'not speaking'.

Having said that, whether an individual with autism speaks or does not, they can all make significant progress and learn independent and functional skills. So

though you might come across people or websites that will claim to 'cure' autism, that is not what really happens. There is no surgery to make him speak. Its not as if his speech 'apparatus' is affected. Rather he has an impaired social understanding of how speech works in making connections with other people.

What we at AFA can offer is to observe your brother, assess his strengths and abilities, and guide you towards a programme that can help him develop communication, functional, independent, and work skills.

Q All members in my family treat my six year old autistic son well, but they find it easier to do everything for him instead of teaching him. His stepfather however believes that the child only has partial autism and treats him like normal but he is a bit too rough and severe with him in his words and attitude so the child avoids and fears his stepfather. I have told him many times that he needs to change and then the child will accept him. I no longer have him attending school as he constantly cries when he realizes that he is close to the school building. Is there any assistance for his schooling in my country?

PF
Trinidad and Tobago

A Your experience is similar to many families in India; it is sometimes hard for family members to understand autism and also to help the child become more self-sufficient. Perhaps with time, your family members will start to understand what is unique about your son. There are some different materials and brochures that are meant to help family members. We do not know if this information is correct, but we have one address for an organization in Trinidad:

Autistic Society of Trinidad and Tobago
St Helena Village, Via Caroni Post Office
TRINIDAD, WEST INDIES
Tel: 868 663 8397, 868 669 0462, Fax: 868 669 4720
E-mail: autismtt@excite.com

Please let us know how things turn out.

Q Please mail me details of food and diet for my son who has mild autism.

A As a rule you want to avoid excessive sugar intake, whether in sweets, chocolates, aerated drinks and so on. Also avoid processed foods like packaged flavoured noodles and packaged foods with preservative such as soups and ready to cook meals. Even for items like chips it is better to buy freshly made chips from the halwais or home fried chips, rather than uses the attractive branded packets that are full of chemicals. Essentially, as much fresh foods that your son eats, the better.

In addition you can also try out a diet free of gluten and casein referred to as a GFCF diet. Gluten is present in wheat and certain cereals and therefore will be present in rotis, and bread and biscuits, and cakes and so on.

Casein is present in dairy products including butter, paneer, cheese and chocolates and all milk based foods like mithais. However ghee does not have casein. The casein gets removed when milk is made into ghee. Before you start a GFCF diet it is worthwhile to keep a record of your son's skills and behaviours. When you continue this record after starting on a GFCF diet, it enables you to objectively assess whether the diet is helping your son or not. If it helps, you of course continue with it. If it does not, then you can discontinue.

For more information on gluten free and casein free diet (GFCF diet) you can check out our website (address below). Go to the back issues of Autism Network. You will find articles on the subject in issues of December 2000 and those preceding and following it.

When considering any diet, you want to also discuss it with your son's doctor to ensure that whatever diet he is on is wholesome and nourishing.

Q I am in my eighties. My son is 34. We have not found any homes where he can stay after I die. I have been to many of the homes but they do not have anyone who will understand my son. He stayed in one home when he was smaller. But he had a very difficult time. They insist he follow whatever they say. They don't understand he has autism. He became so frustrated he became violent sometimes. He became thin and withdrawn. I am lucky I have been able to make private arrangements for him. But what will happen to our children after us?

A I do understand your predicament and appreciate the difficulties you went through. Your son was diagnosed many years ago and the situation was quite different then. The scenario is different now and the situation for parents though nowhere rosy, is much more upbeat than at your time.

Viewing the situation in that context there are two things we have to keep in mind here.

First, we know that if parents wait for the government to set up services for our kids, we might wait forever! Of course the government will help facilitate citizen initiatives. So we, parents and other caregivers but primarily parents, will have to take proactive action.

Secondly, most parents do not realise the need to do anything about the future when they are themselves young. Yet that is the time when they have the most energy. Besides, from action to fruition takes a very long time. In addition many parents believe that 'my other children, or my brother's children, or other family members will take care of my child'. In the vast majority of cases that does not happen. Some even feel that 'if I can get my child married off that will solve the problem.'

I wont go into further implications of this as that can fill a book. In a different era all these scenarios might have been possibilities. Not in the 21st century.

The point I am trying to make is this. Action For Autism is a parent organisation. It has national membership. We have plans for setting up a range of model residences. We have tried innumerable times to start the initiative to plan for the future. Yet, each time we tried to interest parents in these initiatives, we have failed because the response has been faint. And there are many other organisations I am sure that face a similar situation.

What will happen to our children will be determined by what action we take! Especially action by those parents who are young and whose children are still young.

Q I am a clinical child psychologist wokring in PSG Hospital, Coimbatore. My work involves dealing with children with mental retardation, autism, learning disabilities, hyperactivity and emotional and behavioural diffculties. Majority of the cases are referred from the pediatrics department.

I was interested in learning more regarding training and identification of children with autism. this would be helpful for providing better care for the children who are referred to me.

Dr. Anuja S. Panicker

A Briefly put, for identification, the tool that is mostly used at AFA is the DSM IV. We had a psychologist trained in the ADOS as well, but she had to move on.

The crucial aspect in identification is to have a very good understanding of the complex ways autism affects and manifests in an individual. The greater the exposure to a wide range, the better one is able to identify.

For very young children we screen with the CHAT which helps to spot 'children at risk' of a subsequent diagnosis. While of course one cannot give a diagnosis to an 8 month old, the CHAT enables families to start work with the child right away, so that in time the child goes into a completely inclusive setup with only mild social difficulties.

We also refer children on to a developmental paediatrician when we are not sure if there are other issues as well.

For planning training we use an eclectic mix of evidence based approaches: primarily principles of applied behaviour analysis and the TEACCH approach. This means that we use verbal behavior analysis for instance. And of course address sensory issues as well. In the early years the focus is on functional communication and developing learning skills, and in an older child we move more towards functional academic and living skills, and independent work skills.

We also try and get our younger children into inclusive setups. However this is at a very nascent stage in India.

Additionally we provide parents information on alternate therapies like diets and auditory training, yoga and so on. But we also caution that these should be adjunct therapies and not become the prime focus of the training the child receives.

(...cont on page 18)

MERRY BARUA WINS HEARTSPRING AWARD for Innovation and Creativity in Special Education

Merry Barua is a 2007 recipient of the Heartspring Award for Innovation and Creativity in Special Education. Merry participated in the Heartspring Summer Session in July with five other winners, discussing ways to improve special education and resources around the world.

Open Door and Heartspring are sister schools

As a result of her positive experience with Heartspring, Merry has agreed to a sister school relationship with Heartspring, offering the opportunity for additional support through a cultural and informational exchange between Heartspring staff and the teachers at Open Door, Action for Autism.

"Having the opportunity to collaborate with Merry and Action for Autism significantly raises Heartspring's ability to change the lives of children with special needs worldwide. Working together, along with other organizations in Europe and Asia, we can disseminate knowledge to those around the world seeking a better life for children with special needs," said Gary Singleton, Heartspring President and CEO.

NEW PARTNERSHIPS

AACTION Autism

Another organization Action For Autism has recently been getting to know is AACTION Autism – Action Awareness Campaign Through International Organizations Networking. AACTION Autism is based in Chicago, IL, and shares AFA's commitment to serving families of children with autism and partnerships between organizations. The AACTION team will be in India in January sharing their expertise with those working in the area of special needs.

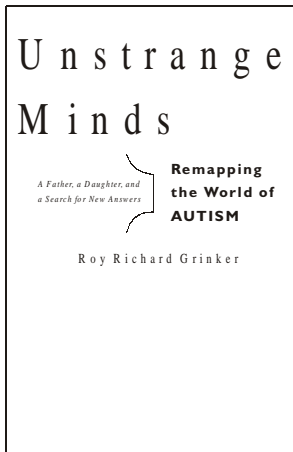
BOOK REVIEW

Unstrange Minds: Remapping the World of Autism

By Roy Richard Grinker

Published by: Basic Books, New York, 2007

Review by Shubhangi Vaidya. E-mail: shubhangi_v2000@yahoo.co.in



Is there an “autism epidemic” sweeping through the world? Why is it that a disorder considered very rare just a decade ago has become a household word in the USA and UK? Why is it that in countries as diverse as Peru and India, South Africa and South Korea growing numbers of children are being diagnosed autistic? Where did all these people come from? Is the

enigma we call autism the product of Western-style industrialization and emotionally disengaged parenting practices? After all, many cultures in the world do not even have a word for autism in their native languages.

R. Richard Grinker, anthropologist and parent of an autistic child is uniquely qualified to seek answers to these and other related questions. His academic discipline, anthropology, impels him to look at the intersection between culture and illness, especially mental illness, which is marked by varying cultural interpretations and understandings. The subjectivity and variability of psychiatric diagnoses both within and across cultures is the very stuff of anthropological research and analysis. Illnesses may be biological but they are never simply biological. Culture plays a critical role in recognizing and categorizing symptoms and prescribes ways to deal with them. Whether a person goes to a witch doctor or allopathic practitioner, dargah or psychiatrist to seek help for his problem, is greatly influenced by the cultural practices of his group and community.

In fact, the anthropological enterprise is curiously akin to the process of studying autism, as Grinker remarks, “...since the minds of people with autism are sometimes as hard to understand as foreign cultures. Anthropologists spend their days teaching about the customs of other cultures.... Our goal is to make the strange familiar...”

But cultural anthropologists also try to make the familiar strange, seeking to turn our gaze homeward and see our culture in a new light. And when we do, we find that scientists also belong to different cultures and that their research is often a product of their time and place, their community’s interests and values.” (p. 13).

Grinker the anthropologist takes us on an exciting journey. In the first part of the book, he chronicles the “discovery” of autism in the 1940’s – the socio-cultural and personal factors that actually enabled Leo Kanner to “see” a disorder that was probably as old as humanity but had never actually been labeled and named as one. The author traces the genesis of the infamous “refrigerator mother” theory provoked by the psychoanalytic drumbeat of Bruno Bettelheim and his ilk which caused untold misery and guilt to a whole generation of mothers of autistic children. He describes the shift in perception of autism as a form of schizophrenia to its present recognition as a neurodevelopmental disorder. Ironically, Kanner originally posited that autism was an innate or biological disorder but, as Grinker points out, it was a huge public-relations goof-up, as psychiatrists of that time would not buy the notion that a mental disorder could be an inborn one. After all, that would make the profession itself irrelevant! Marshalling facts and figures, the author analyses the changing prevalence rates of autism in the USA and presents new, exciting research findings that give us a fascinating glimpse into the biology and bio-chemistry of the condition.

In the second part of the book, Grinker takes us on a cross cultural quest across many lands – from the classrooms and clinics of his homeland to our own backyard in New Delhi – from the brutally competitive urban milieu of Seoul, South Korea to the violent, sprawling black townships on the outskirts of Cape Town, South Africa. We read the stories of Suzanna, Golden and “Big Boy”, Merry Barua and Neeraj, Seung-Mee and her daughter Soo-Yong, Maureen fanning and her two autistic sons who lost their father in the 9/11 disaster, and their ongoing struggles to make people around them understand autism. Through

these and several other stories, we share the experiences of parents fighting shame and stigma, rejection and ridicule. We utter a silent “hurrah” when oppressive social rules are bent or broken. As the author perceptively remarks, “when everything goes smoothly and expectations are met, the rules fade into the background of social life and become almost invisible. We learn more when things go wrong.” (p. 22)

Autism is fundamentally a rule-breaking disorder which turns social expectations virtually topsy-turvy. It breaches the predictability, the taken-for-grantedness of everyday life and forces parents, professionals and all those who encounter it to modify and improvise the rules of the game.

The stories Grinker tells amply illustrate this point. We learn of the mother who showed her teenage son a home-video of a man masturbating, so that he would learn how to alleviate his sexual tension. The author cannot resist remarking that this gives “hands on education” a whole new twist! We also read of a young mother from the hills of North India who picks up her little son and heads for Delhi determined to find help, in the process defying her husband’s wishes and outraging her in-laws. A bereaved wife flies against the face of religious taboos and performs her husband’s last rites in order to spare her autistic son the trauma.

Mention must be made of Grinker’s insightful analysis on South Korean society and culture and the place of disability within it. The maniacally competitive educational system, the obsessive desire for conformity to norms and the deep mistrust of difference conspire to marginalize those who are different and ascribe tremendous shame and guilt to their parents, in particular, the mother. This account of the stress of urban living and parenting an autistic child evokes a shock of recognition and one is made uncomfortably aware that “progress” and “development” often go hand in hand with intolerance and rejection of those labeled incompetent or different. The author reminds us of studies that indicate how people with mental disorders in small, rural communities tend to fare better than their counterparts in big cities. Perhaps this is because they retain their sense of social worth by contributing to work in the field or farm.

However, it is the story of Grinker, the father that lifts this book to an entirely different level. Whilst “remapping the world of autism” (the book’s sub-title) the author simultaneously takes us through deeply personal and intimate terrain; the impact of his daughter Isabel’s autism on their family, their struggle to obtain a diagnosis and

appropriate educational programmes, the impact on their careers, relationships, friendships, and routines. Despite the availability of inclusive classrooms and the empowerment experienced by American parents on account of the legislative and welfare measures in place the story of Isabel and her family reads like every autistic family’s story and this is what makes it so engaging. There are places in the narrative that are so evocative, that this reviewer was often times forced to stop short and wonder how on earth the author had captured her innermost feelings. Sample this:

“Sometimes, at night, Isabel has a hard time falling asleep. It helps her if I sit in a chair in her bedroom. Looking at her then, from across the room, I see two different Isabels. There is Isabel awake – often hyperactive and isolated, and Isabel asleep, a beautiful child drifting into a calm night. And then I realize something unsettling: I feel more affection for the sleeping Isabel. She looks so peaceful and relaxed. And I wonder what this says about me. Do I love her less when she’s a real person, awake and in the world?...

...Before I leave her room I kiss her cheek... I think about how much she has to struggle every day, just to deal with what to her must be chaos, and what to most of us is simply everyday life.” (p.23)

And this: “Isabel has taught me that the unexpected, even the beautiful, can emerge from the undesirable, like a lotus growing out of the mud, its beauty and purity unsullied by its origin. That beauty can be found in a single person, inside of whom there is something – no, not something “normal”. But a brilliant light or an inner truth struggling to blossom.” (p.35)

There are many children like Isabel in the world. Perhaps they do not as yet have access to the same sorts of facilities that she does, but the seeds of change have already been sown. The book sensitizes us to the work done by numerous committed individuals – parents, teachers, clinicians researchers, social activists, media people – to make autism less strange, less foreign. The new awareness of autism across the world and its growing visibility, the burgeoning of community organizations, research foundations, charities and parent groups surely bode well for the future of our children.

Appropriately enough, the book ends with a quote from the anthropologist Margaret Mead. “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.”

SOUTH ASIAN REGIONAL CONFERENCE ON AUTISM: BUILDING BRIDGES

India International Center, New Delhi • 15 & 16 January 2008

&

POST CONFERENCE WORKSHOP: TRAINING IN STRUCTURED TEACHING

National Centre for Autism • 17 & 18 January 2008

The Conference will showcase national and international presenters who are leaders in their fields. It will also open the conference to practitioners in different sectors from South Asia, and provide an opportunity to share developments that are taking place in different parts of India and other countries in the region. **The Conference is proud to host several autistic speakers including STEPHEN SHORE, author, educator, and self advocate with autism.**

KEYNOTE SPEAKERS: Keynote presentations from eminent national and international professionals include:

Adam Feinstein, UK

Dr Bhisnadev Chakrabarti, Autism Research Unit,
Cambridge, UK

Christopher Flint, Have Dreams, USA

Dr E Knust Potter, COS, Germany

Dr Jitender Nagpal, VIMHANS, Delhi

Margaret Lobo, Otakar Kraus Music Therapy Trust UK

Dr Pawan Sinha, MIT, USA

Dr RK Sabharwal, The Epilepsy Clinic, Delhi

Dr Shobha Srinath, NIMHANS, Bangalore

Stephen Shore, Self Advocate, AutismAsperger.net, USA

Dr Thomas Owley, UIC, USA

Thorkil Sonne, Specialisterne, Denmark

Dr Vibha Krishnamurthy, Ummeed, Mumbai

WHO SHOULD ATTEND

Individuals living with ASD, Medical Practitioners, Allied Health Practitioners, Education Practitioners, Lifestyle Support Workers, Academicians, Researchers, Students, Parents and other caregivers.

CALL FOR PAPERS

Action for Autism invites individuals or organisations engaged in research, teaching, and/or clinical practice to submit papers based on their experiences or research on topics that include, but are not limited to: Biochemical Interventions, Communication, Diagnostic Practices, Education, Early Intervention, Employment, Ethics, Inclusion, Legal Issues and Advocacy, Personal and Family Accounts, Research Findings, Self-Advocacy, Sibling Issues, Social Aspects of Autism and Understanding ASD. We are particularly interested in topics that contribute to the broad span of concerns related to autism spectrum disorders. Research studies, technical presentations, case studies, program descriptions, commentaries and reviews of methodological, legal, ethical, social, philosophical, and historical issues are welcome, as are presentations in areas such as behavioural sciences, behavioral pharmacology, behavioral neuroscience, physiology, biology, psychology, and education.

Each submission will undergo a peer-review conducted by a panel of qualified individuals in the field. Selections will be based on quality and practicality of the proposed material and the need for balanced content. **Those wishing to submit a contribution should send an abstract consisting of not more than 300 words, with single line spacing, in English and should include:**

Full title of the paper.

Title, full name, affiliations, address, phone number and email address of one author for all correspondence.

Title, full name, affiliations, address, phone number and email address for each author & co-author(s).

A brief CV of the author(s)

Please email the above to Purba Sen: purbasen@gmail.com

DEADLINES

Submission of abstract and CV:	15 October 2007	Submission of final written paper:	30 November 2007
Notification of selected papers:	1 November 2007	Submission of visual presentation:	15 December 2007

CONFERENCE REGISTRATION

For information on registration charges, registration forms, accommodation and general enquiries please log on to www.autism-india.org or write to Purba Sen purbasen@gmail.com

For a hardcopy of the information, send a self addressed stamped envelope to Purba Sen, Action for Autism, Sector 5, Jasola Vihar, Behind Sai Niketan, New Delhi 110025. Tel: +91 11 4054 0991, 4054 0992

POST CONFERENCE WORKSHOP: TRAINING IN STRUCTURED TEACHING

National Centre for Autism • 17 & 18 January 2008

RESOURCE PERSON: CHRISTOPHER FLINT

The Conference will be followed by a two-day training on TEACCH and using structure with a lifespan perspective. TEACCH, an approach that is internationally used, developed the concept of the 'Culture of Autism' as a way of thinking about the characteristic patterns of thinking and behavior seen in individuals with ASD. The TEACCH approach is a family-centered, evidence-based practice for autism, based on a theoretical conceptualization of autism, supported by empirical research, enriched by extensive clinical expertise, and notable for its flexible and person-centered support of individuals of all ages and skill levels, from individuals with significant impairment to those with superior intelligence and academic achievement.

The TEACCH approach uses Structured Teaching that can be provided in any educational setting, including regular education classrooms, 'specials' such as music, art, physical education, foreign language, speech/language and occupational therapy sessions. Services based on the TEACCH approach are also used in settings such as families' homes, residential programs, and private housing; play and other social groups; in the cafeteria, school bus, and playground; summer camps and other recreation programs; individual and group counseling sessions; and both competitive and sheltered employment sites.

Structured Teaching fosters the development of independence as well as the development of enjoyable social interactions and meaningful social relationships which are important priorities. Structured teaching can be an excellent foundation for facilitating social activities that would otherwise be too unpredictable and confusing for students with ASD.

Christopher and his team will provide an overview of Structured Teaching philosophy and implementation as it applies to children with ASD. Christopher will present the information in an interactive video format where participants have a chance to watch children with ASD engaged using the principles of structure. Participants will have the opportunity to see and learn about schedules, learning tasks, assessment, communication, leisure, and behavior management. Also, participants will practice making structured activities involving a variety of skills.

For information on registration charges, registration forms, accommodation and general enquiries please log on to <www.autism-india.org> or write to Purba Sen <purbasen@gmail.com>

For a hardcopy of the information, send a self addressed stamped envelope to Nidhi Singhal, Action for Autism, Sector 5, Jasola Vihar, Behind Sai Niketan, New Delhi 110025. Tel: +91 11 4054 0991, 4054 0992



I was shocked to read so much negative publicity about vaccinations in India. It is disheartening to read that thimerosal, a mercury preservative is used in Indian vaccines. In spite of knowing that mercury is a neuro-toxin and causes autism it is still being used in India, in spite of countries like USA banning them.

I've just given my two year old daughter her booster DTP and MMR doses. And I am beating my head against the floor for putting my only child at risk. Had I known this earlier, I would not have allowed any vaccinations to be given to her. But one thing is definite; none of my future children will ever be given any vaccinations. EVER.

Priya K, GOA

Ed: The following is a response to the letter above:

I am taking the liberty of writing to you as I am a developmental pediatrician, and have some knowledge about vaccines and autism. Although the buzz is tremendous regarding vaccines and autism, the fact remains that NONE of the claims re vaccines causing autism are substantiated. In fact there have been some fairly large studies that disprove the link between MMR and Autism. Particularly in the Indian context, we need to keep in mind that vaccine-preventable diseases are still prevalent, and can cause tremendous morbidity as well as death. The danger from these diseases is real, and the need for vaccination crucial. While we do not want under any circumstances to increase the prevalence of autism, we cannot ignore the lack of data pointing to vaccines. I think you did a wise thing by immunizing your child and need to continue to do so. The search for causes of autism needs to continue and we all need to keep abreast of developments.

Vibha Krishnamurti

(cont from page 13...)

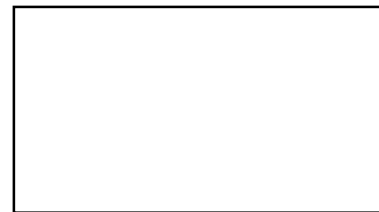
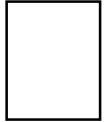
Q I am a Surgeon and have two identical twin girls with ASD. Is there any role of Gluten or Casein in Autism ? Is there any role of chelating agents for heavy metals in Autism ?

A Some studies have suggested that intense opioid activity that has an affect on the central nervous system in individuals with Autism may be due to the incomplete and improper metabolism of Gluten and Casein. The dietary method is still at an experimental stage and no promise is made for positive results. However, anecdotal reports suggest that the results are positive in some children. The process of implementing the diet can be difficult for some families to follow, but if implemented under proper directions of a dietician, is harmless. Therefore many families try putting their children on a diet that is free of gluten and casein. In our practice we have met a few families who feel that a GFCF diet may have contributed to their child's progress, but we have not received a significant positive feedback regarding chelation in Autism. For more information you can write to Autism Research Unit, School of Health Sciences, University of Sunderland, Sunderland, Great Britain SR27EE. You can also secure information on Chelation from the same source.

Q My daughter is four and has been receiving VB training. She has shown very good progress. We are in the US and will be returning to India in January 2008. Are there any VB facilities in India.

A You have not mentioned which part of India you will be relocating to. There are three schools that we know of which practice VB. **Dikshan, Autism Society, West Bengal** (autismsocietywb@hotmail.com) is in Kolkata, **Sai** (kamini108@rediffmail.com) is in Mumbai, and **We Can** (wecantrust@rediffmail.com) is in Chennai. Other special needs schools also practice VB – such as **Open Door** in Delhi. But the first three are the only strictly VB based schools that we know of. In addition there are two trained Behaviour Analysts in India practicing VBA. Ann Varavukala (annjosevaravukala@hotmail.com) is based in Delhi, and the other is Kamini Lakhani (kamini108@rediffmail.com) who is based in Mumbai. Both provide consults and trainings. There is also Smita Awasthi (awasthi@emirates.net.ae). Smita is based in the Middle East but travels to India several times in the year. Again there may be others based in India and we welcome information on them.

BOOK POST



If undelivered please return to:

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