

autism network

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YOUR CONTRIBUTIONS

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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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Cover Illustration

'Craftwork' by Tuhin,
student of the Intermediate Section at Open Door

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PAGE ONE

In 1998 Action For Autism (AFA) created the slogan 'Different... and proud of it,' which evolved out of the philosophy of AFA. Most individuals with autism grow up believing they have to somehow be embarrassed about being the person they are, that they must hide their autism. Society tells them that autism is something terrible, sad, tragic, something to be ashamed of. We wanted to counter this commonly held notion.

This was firmly in our minds when we planned the *South Asian Regional Conference: Building Bridges* (SARC:BD) in Delhi this January. As a result the SARC:BD was unique and special in various ways. Most importantly it was marked by the presence of several self advocates, individuals with autism who spoke of their lives, their work, their achievements and their difficulties; and they spoke independently and without external facilitation. For conference attendees it was a moving first opportunity to listen to, meet with, interact, be enriched and take away an insight into the autistic culture.

If we profess to want inclusion in education and in society, then understanding the autistic culture is the first step. Because autism *IS* truly a culture that is distinct from the neurotypical way of life.

What presentations at the conference brought into focus, and articles in this issue of Autism Network reaffirm, is that being able to 'speak' and 'get into a mainstream school' and become a 'graduate' does not mean a 'cure from autism'. With all the hype about 'cures' floating around it is so important for us to acknowledge that negating the autistic condition and 'wishing it would go away' is equivalent to wishing that all these wonderful individuals never existed. Of all the bridges that we have to build, - between the professional community and parents and persons with ASD, between the different kinds of services that are often at cross purposes, between special needs services and mainstream

services, between aspirations and reality, among others; none is as crucial as the bridge between the autism community and the non autistic neurotypical world. The conference provided a fitting occasion to release the *Charter of Rights for Persons with Autism*.

We from the non-disabled world often find it hard to get rid of our predictable mindsets, even when we are being sensitive. The film *Taare Zameen Par* released this year, gave an insightful portrayal of learning disability. It nevertheless fell into the same trap that most of our films do: the person with disability needing to have a special skill, be exceptional in some manner, achieve some sort of distinction, in order to almost redeem himself for having the disability. Its like saying: "I have a disability, but see how smart I am despite that." Why can the person with disability not be just a regular Joe. Just an average anybody. Not some child with exceptional drawing skills or singing skills, or save someone's life, or capture a murderer! How many of us non-disabled people do any of the above?

But I suppose we must be patient. Filmmakers appear to not view disability as a distasteful topic any more. And even as we go to press, several new films that touch on disability are in production.

So 2008 has begun with some promise. This is also the first year that the World Autism Awareness Day will be celebrated across the world. AFA is making every effort to encourage partners to ensure that autism is brought into focus in every manner possible. International media giants like the CNN and BBC have promised extensive coverage, and we hope our national and regional media will be equally forthcoming in spreading awareness.

The UNCRPD, too, is on its way to being ratified. So though the road ahead is still very long, complex and difficult, there are many good developments to bring cheer along the way.

ANNOUNCEMENT

Training in
Fundamentals of Structured Teaching

By Christopher Flint and Team

In January, a lucky few had the invaluable opportunity to attend a Training Workshop on the Fundamentals of Structured Teaching conducted and supported by **Autism Awareness for Campaign Through International**

Organisations Networking from Chicago. Seats were limited and we had to turn away many disappointed participants. We had promised at the time that we will do our best to arrange for the training one more time. We are delighted to share that Christopher and his team will be back for another two-day training in Delhi in late September. The two-day training is mandatory for anyone wanting to join the five-day trainers program.

For more information on this workshop send a SASE marked 'AACTION Workshop'. Once dates are finalised, the information will be on our website <www.autism-india.org>.

Asperger Syndrome - An Indian Perspective

Indrani Basu

President, Autism Society West Bengal, India

Asperger Syndrome (AS) is a neurobiological condition that is part of a group of diagnosis known as Autism Spectrum Disorders. Like with all persons with autism, the areas of impairment are communication, social skills, restricted patterns of interest and behavior. Persons with Asperger Syndrome demonstrate good formal language with good grammar and vocabulary. Yet they do not truly understand the nuances of language and have difficulties in areas of pragmatics.

THERE is an assumption that all those that have Asperger Syndrome have superior intelligence. This impression has probably been derived from movies such as the Rain Man and the few wonderful individuals with Asperger Syndrome who have come to be widely known for their exceptional intelligence. However, this does not mean that hiding within all individuals with Asperger Syndrome there is a genius. Like the rest of us who are not on the spectrum, there are a few geniuses, some very intelligent, and the rest intellectually very ordinary mortals. And with most of them, despite good language, social interaction remains a major area of difficulty, especially when it comes to rules governing social behaviors.

ASPERGER Syndrome is, in many ways, an invisible disorder. In India Asperger Syndrome is a condition that is often missed out in diagnosis or is diagnosed quite late, often when the child is in the teens or even in adult life. The following is an attempt to address some of the common situations that individuals with Asperger Syndrome and their families in India find themselves in.

School

For some parents, when the child is very little, they do not notice anything that causes concern. For others there is a small nagging

feeling which parents are tempted to ignore in the hope that it would somehow make whatever the difficulty is, go away. If the child is a single child, then there is a feeling that school and companions will sort things out. It is when the child starts going to school that there is full realization that there is something 'wrong' or different about their child even though the child is talking. There is no escape and those nagging feelings have now to be faced.

IN school the child is perceived to have 'problems'. Some of these are that the child will not sit, tends to wander off, will not follow class routines, is not interested in listening to stories, and so on. The commonest complaint from school would be that the child does not mix with his peers. However, after a few months many of the children appear to settle down.

AFTER settling down in class, the child with AS appears to do well when academics are introduced. They learn their letters and numbers and rhymes fast, often faster than the other children. At this stage the learning required is simple, and the children, with their phenomenal memory, do exceptionally well. When writing is introduced there are a few hiccups; many of the children seem to face a problem mastering this skill. Finally, after much effort and practice when the children eventually master the art of writing, the class moves on from printing letters to cursive writing, and the child has to learn writing all over again. At this stage there might even be 'tests' that the children have to participate in. These tests invariably have direct questions

that the children with their strong memories usually excel at.

PARENTS soon feel that they appear to go through a cycle. Just as their children appear to have settled down and are doing well, a new situation crops up. So they go through a cycle: the child stumbles;

Children with Aspergers Syndrome learn better when they are exposed to concrete experiences that develop concepts. For example using objects to get the feel of how numbers increase when one is adding and how they decrease when one is subtracting. When learning about plants the child needs to handle them, to grow them in a pot. The child with Asperger Syndrome needs visuals, and to handle materials where ever possible. This, of course, is the best way of learning for all children!

parent and child work very hard on all the issues; and towards the end of the academic year things appear to fall into place and everyone breaths a sigh of relief. Then the new academic year starts with a new class, new books, new environment, new teacher, with perhaps differences in the way of teaching. For many children with Asperger Syndrome and their parents this means that the struggle starts all over again.

AS they grow older many parents begin to feel that the demands placed on their child are overwhelming. Coupled with that the school may express doubts as to whether their child will be promoted to the next class. Suddenly, the inadequacies of our education system become clear when one is parenting a child with AS.

Learning style versus teaching methods

The teaching followed in most schools in India is still very bookish, with a lot of stress on learning by rote and little stress on experiential learning. Much of the difficulties in academics faced by those with Asperger Syndrome arise from this as it does not account for their learning style.

PERSONS with AS are good visual learners. Many are hyperlexic. They appear to excel at learning by rote. Often the child with Asperger Syndrome is at the top of his nursery class. Both parents and teachers feel happy at the child's performance. It is very difficult for them to fathom that even though the little one in the kindergarten class is reading fluently and answering questions he may have very little idea about the content and meaning of what he has read.

THEIR sharp memory is a strength. And the child with AS often uses it to cope with having to learn something he has not really understood. As the child moves to higher classes, he builds on this shaky foundation. And suddenly after a few years, usually when he is in the fourth or fifth grade, he is not able to cope. As academics becomes more complex the child starts to stumble. There was so much he did not really learn in the lower classes, the concepts and meaning that he missed, and as a result there are yawning gaps in his understanding of many concepts.

THE curriculum followed in schools can be rigid. An additional difficulty arises with the two, and in some cases three, languages to be studied. Families of children with Asperger Syndrome who are in English medium schools are advised to create an English speaking

environment at home. Most say they cannot because it is uncomfortable for the adults in the house. So the child with Asperger Syndrome who has a communication disorder is expected to undergo an English medium education, but speak in Hindi, Bangla, Tamil, or whatever may be the mother tongue at home.

OF course even children who attend schools where the method of instruction is the child's mother tongue are rarely provided the kind of support children with AS need.

SOME of the most pressing issues from the AS perspective often appear to be insignificant to the non-autistic learner, but to a child with Asperger Syndrome they can become huge hurdles they have to overcome.

To give just a few examples:

- A lot of schools when teaching numbers, teach '1 and 1 is eleven' and '1 and 2 is twelve', and so on; but it's not '10 and 1 is eleven'. For a child with Asperger Syndrome it often leads to incorrect learning, followed by having to un-learn and then learn again.
 - Learning reading phonetically can be confusing for some children with Asperger Syndrome. Many children teach themselves to read through 'sight-reading' and they do not face any problem in spelling out words. When reading starts with phonetic exercises it can be frustrating and confusing since they may not be able to relate the exercise with reading.
 - Being able to ask the teacher for help or say "I didn't understand".
 - Dealing with interruptions in the middle of class time can be difficult. For instance, the child with Asperger Syndrome is listening attentively while the teacher is taking class. There is a sudden interruption as can happen in any regular classroom. Once the teacher resumes teaching after the interruption, the child may not be able to pick up the thread from where they left off.
 - If the child with Asperger Syndrome cannot complete his class work during class time, sensitive and caring teachers often take the student aside after class and help him complete the class work. A child with AS may therefore come to the conclusion that class work is to be done after class, one-on-one with the teacher.
- OF course not all children with Asperger Syndrome face challenges in academics; but a great many do and it is best to anticipate this, address the possible areas of concern,

and prepare the child by strengthening different skill areas, enhancing language skills and working on social understanding.

THE child with AS definitely benefits from a regular school education, but he may not have the emotional strength to cope with the non-autistic learning and social environment of the class room *if sufficient accommodation is not made to adapt to his specific needs.*

WHAT is urgently needed is firstly, the acceptance that those with AS are different from the non-autistic population, and cannot be expected to fit into the non-autistic mould. So in terms of schooling those on the autistic spectrum require some flexibility. For instance, just as for those who are hearing impaired, or visually impaired, or have dyslexia, or cerebral palsy, persons with Asperger Syndrome may be allowed the option to skip learning one language. Flexibility in choosing some subjects is something all children will benefit from, not just those on the spectrum. Also flexibility with such things as hand writing; for the authorities to just accept that children on the spectrum may not have a good handwriting. Or that they may even not be able to write their exams by hand. Some children with Asperger Syndrome may need 'writers' or scribes for their exams, or be allowed to give their exams using a computer.

SOMETIMES simple things like being allowed to use schedules or a token system can make a huge difference. Giving the child something to do when he has finished his class work, since that's the time he may become restless, can help the child keep himself occupied and not slip into behaviors that might be disturbing for the rest of the class. When giving instructions the teacher can on occasion use the child's name to help him focus.

THERE is of course the attitude of his peers, and much of that depends on the attitude of the teachers and the parents of the child with AS. If the child is treated as a 'poor thing' then that will be attitude of the other children. If the teacher and the parents feel the child with AS is a 'problem' then that too is the way the other

children will treat him. And if the adults treats the child as some one who needs support then suddenly there will be a number of 'mother hens' willing to adopt the child with AS.

CERTAINLY, schooling is not the only issue. As the child with Asperger Syndrome grows up there can be difficult times ahead. Many desire peer interaction; and then there is the attraction towards the opposite sex. And all of this gets mixed up and gives rise to often unusual and at times difficult behaviors which are misunderstood by the non-autistic world.

Friendship

As children, some may not show interest in peer

interaction or friendship and not have a clear concept of what a 'friend' is. As young children some may avoid peers altogether while other's may try to initiate peer interaction through inappropriate ways. For some little ones in Kindergarten a way to interact is to push and shove the classmates. In the early years many socially unacceptable overtures in class are quickly forgiven in the light of the child's excellent 'academic performance'. But it gets less and less so as the child grows older.

IT is very difficult to explain and teach friendship. No one taught those of us in the non-autistic world these extremely abstract concepts. Here are two examples of two different young men and their attempts at friendship.

FIRST is Sandeep who is 23, and who has assumed that young men of his age will just turn up to his door and they will become his friends. He came to this conclusion because one of Sandeep's cousins came to visit with a friend. This friend of the cousin was a kind young man who decided to befriend Sandeep. So on occasion he would come to Sandeep's house for a chat or take him out. But the young man eventually got a job and went away and that left Sandeep confused as to how he could get another friend. He resorted to standing on the street and waiting for likely candidates to turn up. Also while travelling by train he resorted to demanding friendship from some of the fellow passengers, with consequences not always pleasant for him or his family. It took some time for him to understand that this will not work. But he still is not sure how the whole

For many children with Asperger Syndrome the bulk of the school work is done at home, with parental support and with extra time spent on studies to keep the child with AS at par with his classmates if not ahead of his class. When the most significant interaction between the parent and the child is at study time, then the relationship of the child and the parents becomes that of a teacher and student. For both parents and the child this can be emotionally draining.

business of 'friendship' works. Sandeep is still working on this riddle but in a more appropriate way.

THEN there is Gaurav who is 18 and in standard twelve. Gaurav is an Aspie who is good at his studies. He also wants friends and according to him, has friends. He counts the boys hanging around the barber shop near his home to be his friends. The boys do not treat him as a friend but allow him to hang around them. The young man who works at the local tea stall is, as far as Gaurav is concerned, his friend. This young man at the tea shop at times teases Gaurav but to Gaurav this is what friendship is about. On the other hand Gaurav's parents find it very difficult to accept Gaurav's friends. They assume that Gaurav should mix with those of his class who are also good students.

Adult Life

There are adults with Aspergers Syndrome who are coping and living independent lives in India, as elsewhere in the world, but there is no data available to show how many are actually doing so. Therefore one can only talk from ones experience. Those that we as professionals do get see are individuals whose lives are not working out too well. And the number seems to be rising. For adults with Asperger Syndrome, the scenario in India is not very good.

MUCH of their formative years are spent trying to just keep up with school and therefore it leaves them little or no time, or opportunities, to develop emotionally. Most children and adolescents with Aspergers Syndrome appear to lead lives where they just go to school and then come home and study or go for additional classes. So do most children in India some would say. But the non-autistic population gets to interact and play in between classes, traveling on the school bus, during school vacations. Neurotypical children manage to snatch those moments when they need it. We all did. We knew how to carve out those moments for ourselves. But for the person with Asperger Syndrome they may not even know they need those moments let alone how to get them. They have little opportunities to learn coping skills, like how to relax, or to ask for help, or calm oneself when angry.

THOSE children with Asperger Syndrome who do finish their education, which in the Indian context usually means become a Graduate, may not necessarily get a job let alone keep a job; since all this requires a lot of social skills. One young man with a Post Graduate degree has

retreated to his home and refuses to go to work ever since the company he worked for shifted premises. There is another young man also a graduate who – not having a job - spends most of his time traveling on local trains and taking foodstuff from vendors.

WHO are the ones doing well? Those lucky to be in a supportive environment, whether it is schools, home, or place of work; where it is accepted that Aspies are different and may not fit into the 'normal' mould. Doing well has nothing to do with academic education. It has to do with a supportive environment that adapts and accommodates to the differing needs of those with Asperger Syndrome.

WHAT is needed now is to ensure that the supportive environment is not dependent on luck. Young children with Asperger Syndrome may need communication therapy not necessarily speech therapy. They may need help in academics. They need help in understanding the social world around them and will require help in navigating their way around them. But mostly early diagnosis is so that persons with Asperger Syndrome can benefit from strategies and techniques that are available in this country, which most people think individuals with Asperger Syndrome don't need. If this is not done now another generation will grow up into unhappy, isolated and confused adults.

- *indranibas55@gmail.com*

Diploma in Special Education (Autistic Spectrum Disorder)

~ Training Course 2008-2009 ~

Admissions are open for Action for Autism's RCI recognised course in Autism starting July 2008. There are limited seats. As in past years successful candidates receive placements in leading organizations in India.

Eligibility

Energetic and enthusiastic candidates who are creative, logical, intelligent, open to learning and willing to work hard are invited to apply. Graduates in Psychology, Education, Child Development preferred, though 10+2 pass with 50% may also apply. Prospectus and application forms available from Action for Autism for Rs. 150/- (payable by cash/ DD), plus Rs 20/- for pp. Last date for submission of application with bio-data 31 May 2008. Please send completed forms to:

*Training Coordinator, National Centre for Autism
Pocket 7 & 8 Jasola Vihar, New Delhi 110025*

Please mark envelopes 'DSE (ASD) 2008-09'

Voices from the Spectrum

Shubhangi Vaidya

Shubhangi, a sociologist by training, is doing research on families of children on the autism spectrum. She works as an Assistant Director in the Regional Services Division of Indira Gandhi National Open University, New Delhi.

The South Asian Regional conference on Autism held in New Delhi on 15 and 16 January 2008 was appropriately subtitled 'Building Bridges'. And building bridges is precisely what the event succeeded in doing: bridges between personal experience and professional practice, between the neuro-sciences and behavioural ones, between the theoreticians and hands-on practitioners. But perhaps one of the greatest achievements of the conference was that it helped to bridge the divide between those who actually inhabit the Autism spectrum and us so-called normals; or as the autistic population prefer to call us – 'neurotypicals'.

FOR the first time in India, a number of autistic individuals spoke about their experiences of growing up 'different'; the challenges they faced at school, in the play ground, the workplace, and the wider society. They spoke of their families, of stigma and labels, social and emotional difficulties, and most heart-warmingly about the way they negotiated a confusing and erratic world and attempted to adjust to it.

DR Stephen Shore, a keynote speaker at the conference, is a Ph.D. in special education and the author of three well-received books based upon his personal experiences and advocacy work. His presentation, 'Employing Strengths, Interests, and Negotiating Relationships in the Workplace: Observations on Promoting Success', dealt with the important issue of meeting the social challenges involved with obtaining, keeping and even departing a job for people on the Autistic Spectrum. Sharing his personal and professional experiences as an adult living with Autism, Dr Shore discussed the strategies he used to secure and meet the expectations of his employees. His second presentation, 'Sexuality and Intimate Relations for People on the Autism Spectrum: An Inside View for Success' dealt with the delicate and much – misunderstood topic of sexuality and people on the autism spectrum. Busting some of the myths about people with disabilities being 'asexual' beings, Dr Shore discussed both the physical as well as emotional aspects of sexuality. What was remarkable about both his

presentations was the insight they offered us neurotypicals, into the inner worlds of autistic people; their deepest thoughts, feelings and emotions. This is terrain that is often quite inaccessible to the rest of us, due to the difficulties our children have with language and communicating abstract thoughts. We thus 'freeze' them in childhood, naively believing that despite their bodily growth, they remain little children on the inside: Dr Shore's presentations were also marked by a delightful and dry wit: an unexpected attribute in an individual on the Spectrum. From being written off as a hopeless case needing institutionalised care, to a highly qualified and sought after public speaker and writer, Dr Shore's success story is inspirational.

NO less inspirational is the story of a quiet self-effacing young man by the name of Achyutanal Guha. Visitors to Action for Autism will immediately recall the genial bespectacled young man in the office who epitomises the phrase 'service with a smile'. Mr Guha spoke about the efforts of his mother to enable him to lead a regular life, his relatives, spouse, siblings and friends, and his experiences at Action for Autism. What was striking about the presentation was the confidence with which Mr Guha stood up before a large audience and declared that he is autistic. We marvel at his courage and dignity and the social changes that are increasingly making it possible for individuals to make this sort of disclosure. The autism movement in India, it appears, is finally coming of age, with focus slowly shifting from families as 'voices' of the autistic, to self-advocacy on the part of people with autism themselves. We in India can be justly proud that the robust autism movement here has resulted in growing public awareness and improving diagnostic skills and facilities, and most importantly, doing away with the 'stigma' and 'shame' of disability.

QAZI Fazli Azeem, a young man from Pakistan, grew up without receiving a formal diagnosis and spent 25 years of his life trying out unorthodox self-devised methods for coping with his oddities and adapting himself to the world. His presentation, 'Unconventional

Strategies for Living with Asperger Syndrome' was a remarkable testimony of his lone struggle to understand himself. Some of the 'unconventional strategies' that worked for him included his own version of vitamin therapy, personal chelation, improving eye contact, devising techniques to control his hyperactivity, dealing with sensory overload, directing his obsessions and islands of ability to develop expertise in computers and becoming a successful professional.

QAZI shared that eleven other members of his family have been diagnosed with ASD since. Like other self advocates, Qazi has helped many children and adults with autism and their families understand and deal with their autism.

AMITAVA Basu, a young man from Kolkata, shared experiences of his school days. He described how confusing he found school rules, his difficulties in the classroom with sensory issues, particularly the noise. At

the same time he said he was happy he had the opportunity to make friends and learn from teachers who were kind and helpful, even though they did not exactly know or understand what his condition was.

AMITAVA is representative of a community of young people with autism whose condition remain undiagnosed for a number of years, and who are faced with complex situations as a result. The scenario in our metropolitan centres at least is much better today, and Action for Autism has played a pioneering role in this regard. Conferences such as these help to bring together expertise in various fields in the service of a common cause. The disclosures and sharing of experiences by persons on the Autism Spectrum helps to throw new light on how they attempt to make sense of a world that is yet to acknowledge and honour their unique gifts and their courage in the face of this most complex and misunderstand condition.

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LETTERS

ED: A reader forwarded this mail from an elist. I thought it was a perfect example to share with readers:

Deepti Havila's mother is a lesson in acceptance and understanding going back 30 years! This letter is a must read for every parent who agonises over each ignorant comment that others make about their child.

I have a brother with Downs who is 32. My mom told me when I was three years old that I have a special brother. And that God specially chose me to be his sister (she told me the old story of God searching the whole wide world to look for somebody strong enough). I believed it that day, and I still believe it. She told me that people might sometimes tease (and they did, including throwing stones at us while coming back from school). She told me that he needed loads of love and though sometimes he did stuff that was unreasonable, he did it coz he doesn't realise it is unacceptable.

To keep it short, she was honest and very plain about it. And 30 years back in a small town in India, it was very difficult but she made it very easy. She never got upset about kids teasing us. She just told (me) that they only do it because they don't know how special he is.

I think kids have more understanding then we give them credit for sometimes.

Deepti Havila

*Escape to Cyprus and help guide
a Musical Talent with Asperger's!*

She is a 27 year old talented musician with Asperger's Syndrome. Based in Nicosia, Cyprus, this interesting young woman is fairly independent and self-motivated, with the ability to communicate and make friends.

She requires a patient, persevering and if possible fellow music lover, qualified in Psychology and/ or Education to educate and enhance her behavioural and social skills.

If you have experience in attending to the development of individuals with Asperger's, if you believe you are the right person for this role and would value the opportunity of support from a leading global expert in the field of Asperger's pack up and escape to Cyprus! For more information, to apply online and prepare to embark on a truly fulfilling opportunity please click on the link: www.sfsct.com .

- Serena Malayatoor



My Story

Achyutanal Guha

I was born and brought up in Delhi. My father was a journalist and my mother is a retired HR personnel. My family includes my mother and my wife. I have a younger sister who is married and has two children. My father expired in 1996. It was my mother who took care of my needs and upbringing.

I am an adult with Autism Spectrum Disorder. I received a diagnosis of Aspergers Syndrome when I was in my early teens, by Dr BN Roy of the Dr BC Roy Memorial Trust in Kolkata in the early 1970s. Dr Roy was running an organisation for individuals with special needs in Kakurgachi in Kolkata. In those days autism was unknown to most of the doctors. When we met Dr Roy, he knew about autism as he used to travel abroad for his work. In 1985, when I was 18 years old, Dr Roy assured my mother that she could help me develop my skills towards a career of my choice.

AFTER completing school, I did some short-term courses to further develop my skills. I started my career as an apprentice in a TV company in 1986. In 1990, I worked in a newspaper office and in 1994 I joined a marketing organisation. In 1997, I joined a magazine office as an office assistant and learnt to use the computer. Here I discovered that I was good at computers.

IN 1999, I came to know about the organisation Action for Autism (AFA) and joined them as an office assistant. Here I learnt to do many kinds of administrative work including keeping accounts. Now I maintain all the day-to-day accounts of the organisation. Over the years, I have also become the IT troubleshooter and assist others in the planning and organizing of different events of the organisation.

I work better when the job is explained to me in a clear direct manner and I am given a time frame. The work can be easy or tough but breaking it into small simple steps makes it less complicated.

SOMETIMES, it is difficult for me to handle loud and unwanted sounds, negative remarks, harsh words and anger around me. When a situation like this occurs, depending upon the situation, I try to control myself, talk to people about it, or listen to music. Sometimes going out for a walk helps me de-stress. While walking I go over what happened, try to overcome it and re-plan the work that I was doing.

I have difficulties in social understanding because of which I have had difficulties at home, at school and also later at work. After coming to AFA the meaning of life has changed for me. People in my office know I have autism and accept me as I am. Several persons at AFA have helped me in different ways to understand myself. I like to interact with people, but my circle of friends continues to be limited and most of my friends are from AFA. At AFA I have learnt to be patient, learnt about ways to overcome my difficulties (including problems of attitude and body language) and be more focused in my work.

TIME spent with friends and family members often involves serious issues; at other times it is exciting, fun and fruitful. My relatives including my wife and my sister do not know that I am autistic, but they know that I am different and they see me as a regular person. My sister and brother-in-law are like my friends and so are my mother, nephew and niece. My relationship with my wife is good, enjoyable and meaningful though sometimes it is stressful especially in matters concerning the household. At home I generally help my wife to keep all washed clothes and utensils neatly arranged in their proper place. I also do the monthly household shopping. We do have misunderstandings and occasionally we lose patience with each other, but we resolve our quarrels sooner or later.

I am also a self-advocate for autism. I help in spreading awareness about autism and about AFA. I share my experiences with other students with autism coming to AFA. I also speak about my diagnosis and experiences to other parents and professionals during AFA workshops and conferences and on national television. When I become comfortable with new people I tell them about myself. For example, some people in our bank know I have autism. This helps them understand me better.

IN my free time, I enjoy watching news channels, surfing the Internet, listening to music, exploring new places and markets and watching movies on TV or at film theaters.

ऑटिज़म और भावनाओं का सीमित ज्ञान

इन्दु चसवाल

ऑटिज़म एक जटिल विकार है, जिसमें व्यक्ति समाजिक रूप से पिछड़पन दिखाता है और समाजिक संसार में ठीक तरह से नहीं बैठ पाता। आधुनिक समय के मनोवैज्ञानिकों ने ऑटिज़म में सीमित या क्षतिहीन "थिओरी ऑफ माइन्ड" का वर्णन किया है। दूसरे शब्दों में कहा जा सकता है कि मन पढ़ने का सिद्धान्त जो आम लोगों में पाया जाता, वह ऑटिज़म में बहुत सीमित होता है।

हर एक इंसान अपने आप को अपने सामाजिक पर्यावरण के अनुसार ढालता है। वह समझता है कि दूसरे व्यक्ति की अपनी भावनाएं होती हैं। बहुत कम आयु से ही बच्चा दूसरों के मन में क्या चल रहा है, यह जानने की कोशिश करता है। इस प्रकार वह एक माइन्ड रीडर या 'मन पाठक' होता है। दूसरों के मन को पढ़ वह स्वयं के व्यवहार और आचरण रचता है जो कि उस विशेष स्थिति में विशेष व्यक्ति के हिसाब से होते हैं।

उदाहरण – एक बहुत छोटा बालक (2 वर्ष की आयु पर) यदि कोई ऐसी वस्तु उठा लेता है जो निषेध हो, तो वह उसे छिपाने की कोशिश करता है ताकि कोई देख न ले।

यदि बच्चा एक सुन्दर चित्र बनाता है तो वह किसी और को दिखाते समय चित्र को घुमाएगा ताकि दूसरे व्यक्ति को सीधा दिखे। ऑटिज़म रहने से बच्चों में इन बातों का सीमित ज्ञान होगा—

1. दूसरे व्यक्ति को चित्र सीधा उलटाने पर ही दिखेगा या किसी वस्तु को चुराया है तो छिपाने पर दूसरे व्यक्ति से छिपेगी। ऑटिस्टिक बच्चे यह मानकर चलते हैं कि सभी को वही सब मालूम है जो उन्हें मालूम है। इसलिए वह स्वाभाविक रूप से कोई भी अभिव्यक्ति नहीं करते। वह कोई भी घटना जो स्कूल में घटी हो उसे घर लौटकर नहीं सुनाते क्योंकि उन्हें यह बोध ही नहीं होता कि घर के लोग जो उस घटना स्थल पर उपस्थित नहीं थे, उन्हें उस बारे में कुछ नहीं मालूम।

बहुत बार जब ऑटिस्टिक बच्चों का कुछ खो जाता है, तो वह घबराते हैं, बेचैन होते हैं और किसी बड़े को परेशान करने लगते

हैं क्योंकि वह यही समझते हैं कि उस बड़े व्यक्ति को भी मालूम है कि मेरा कुछ सामान नहीं मिल रहा।

सैली-ऐन प्रयोग :

जैसे कि पहले बताया है, मन को पढ़ने का सिद्धान्त हमारे ब्रेन का फंक्शन है जो विकास के साथ पुष्ट होता है। इसके द्वारा हम दूसरों के विचारों, इरादों, भावनाओं इत्यादि को समझते भी हैं और उनका सही तात्पर्य क्या है यह ज्ञान भी प्राप्त करते हैं। 18-30 माह के आम बच्चों में विकसित होने लगता है और लगभग 3 – 4 वर्ष तक इसका अच्छा विकास हो जाता है। विमर और परनर नामक मनोवैज्ञानिकों ने इस माइन्ड रीडिंग सिद्धान्त को एक प्रयोग द्वारा सिद्ध किया।

1. सैली के पास एक टोकरी है ऐन के पास एक बक्सा है।
2. सैली अपना एक कंचा (मारबल) टोकरी में डालकर कमरे से बाहर निकली।
3. नटखट ऐनी ने सैली के जाने के बाद टोकरी से कंचा निकालकर अपने बक्से में डाल दिया।
4. अब लौटकर सैली कंचा कहां से पाने की कोशिश करेगी।

चार वर्ष की आयु के बच्चे सही उत्तर देंगे – सैली टोकरी में देखेगी। यह इसलिए, क्योंकि वह स्वयं को सैली के स्थान पर रखकर सोच सकते हैं। उन्हें यह ज्ञान है कि सैली की अनुपस्थिति में ऐन ने कंचा हटाया था इसलिए सैली की सोच यही है कि कंचा टोकरी में है। इस प्रकार 4 वर्ष के बच्चे में दूसरे का मन पढ़ने की क्षमता होती है परन्तु ऑटिस्टिक बच्चा या ऑटिस्टिक किशोर बालक इसका उत्तर देंगे— बॉक्स में क्योंकि उन्हें मालूम है कि कंचा बॉक्स में है, तो वह समझते हैं कि सैली को भी मालूम है।

जैसे व्यक्ति बड़ा होता है वह इस मान्ड रीडिंग या मन-पठन द्वारा सामाजिक संसार में समायोजित और व्यवस्थित होता है। दूसरों द्वारा किये जाने वाली क्रियाओं का और व्यवहारों का अर्थ समझता है और उसी समाजिक बोध द्वारा अपने आस पास के लोगों के साथ प्रभावशाली क्रिया स्थापित करता है। ऑटिज़म रहने से इस क्षेत्र में क्षती होने के कारण निम्नलिखित कठिनाईयां हो सकती हैं :-

1. दूसरों की भावनाओं को समझने में असमर्थता।
2. दूसरों के पास क्या सूचना या समझ है! दूसरे किस चीज से या अभिज्ञ है। इन बातों का सीमित बोध।
3. दोस्ती के समझौते, आदान प्रदान व सौदे जो मित्र के माइन्ड को पढकर किये जाते हैं, वह अति सीमित हो जाते हैं।
4. दूसरा व्यक्ति उनकी बातों में रूचि रखता है या नहीं, उनके लिये समझना कठिन है।
5. दूसरों की बात का भावार्थ समझने में कठिनाई।
उदाहरण :- बच्चे को कहा गया " एक बार फिर गिलास गिराकर तो दिखाओ" तो उसने शब्दों का अर्थ को ही समझ फिर गिलास तो दिया।

6. दूसरा व्यक्ति उनके द्वारा किये गये ऐक्शन (क्रिया) का क्या अर्थ निकालेंगे, नहीं समझ पाते।

उदाहरण – एक किशोरावस्था में प्रवेश किया लड़का गर्मी लगने पर कपड़े उतारना शुरू कर देता था। ऐसा एक बार उसने एक बस में महिला के साथ बैठे हुए किया।

7. गलतफहमी को न समझ पाना।

8. दूसरों को धोखा न दे पाना और दूसरों द्वारा धोखेधड़ी व छल को न समझ पाना।

अगले अंक, यानी कि अगस्त अंक में हम चर्चा करेंगे इन परेशानियों और सीमित गुणों में ट्रेनिंग की।

प्रसिद्ध असपर्गर व्यक्ति

1. टेम्पल ग्रन्डिन हार्ड और फक्शनिंग ऑटिज़म

टेम्पल ग्रन्डिन का पालन ऐसे समय में हुआ जब ऑटिज़म की जानकारी बहुत सीमित थी। इन्होंने अपनी बैचेलर डिग्री (बी.ए.) मनोविज्ञान में 1970 में प्राप्त की और 1975 में पशुविज्ञान में की। आज यह एक सफल अभिकल्पक है, जो पशुधन की डिजाइनिंग करती है। अपने जीवन के अनुभवों द्वारा उन्होंने अनेक कार्यशालाओं में और कई लेख, पुस्तकें इत्यादि लिखे। उन्होंने अनेक कार्यशालाओं में और सम्मेलनों में भाग लिया है। आज भी टेम्पल 'ऑटिस्टिक' है।

2. स्टीफन शोर

स्टीफन शोर को चार साल की आयु में ऑटिज़म का निदान मिला। उन्हें अती रोगी बताया गया। और इस कारण प्रारंभिक प्रशिक्षण में कठिनाई हुई, आज स्पेशल शिक्षा में डाक्टरेट हासिल कर ऑटिज़म ट्रेनिंग और ऐडवोकेसी (अधिवक्ता) में कार्य कर रहे हैं। स्टीफन अनेक सम्मेलनों में वक्ता रूप में शामिल होते हैं। जनवरी में वह भारत (नई दिल्ली) आये और ए.एफ.ए. द्वारा आयोजित कॉन्फ्रेंस में भाग लिया।

3. जिम सिन्कलेयर, कैथी ग्रान्ट, डोना विलियम

इन तीनों ने एक साथ मिलकर "ऑटिज़म नेटवर्क अन्तर्राष्ट्रीय 1992 का निर्माण किया। वह पिछले अधिवक्ता के रूप में ऑटिज़म क्षेत्र में आयोडोना विलियम ने भी अनेक किताबें लिखी, जिनमें ऑटिज़म की अन्तर्राष्ट्रीय प्रस्तुत की गई।

और अन्य प्रसिद्ध नाम:

1. कार्य अरसिन्के— बेसबॉल खिलाड़ी
2. रामानुजन
3. अल्बर्ट आइन्स्टाइन
4. अडॉल्फ हिटलर
5. जार्ज इलियट —लेखक

ऐसा माना गया है कि इन व्यक्तियों में असपर्गर अथवा हार्ड फक्शनिंग ऑटिज़म के अनेक लक्षण थे परन्तु औपचारिक निदान नहीं मिला।

असपर्गर सिन्ड्रोम

असपर्गर संलक्षण या असपर्गर डिसार्डर एक जैविक विकारता है जो मस्तिष्क संबन्धित कारणों से होता है। इसे 1944 में पहली बार हैन्स असपर्गर नाम के चिकित्सक ने समझाया और अपने पेपर पेश किये। असपर्गर विना में जन्में चिकित्सक थे जिनका नाम ऑटिज़म स्पेक्ट्रम विकार के क्षेत्र में जाना माना है। असपर्गर ने कुछ बच्चों (मुख्य रूप से लड़कों) के व्यवहार पढ़े और फिर उनका उल्लेख किया। असपर्गर के वर्णन के अनुसार बालकों में ऑटिज़म जैसे लक्षण होते हैं, पर इनमें कम्युनिकेशन (मौखिक संचारण या अभिव्यक्ति) ऑटिस्टिक बालकों से अधिक रहती है। असपर्गर सिन्ड्रोम में पाया जाता है कि उनका बौद्धिक स्तर सामान्य रहता है, भाषा का भी अच्छा विकास होता है परन्तु अन्य ऑटिस्टिक व्यवहार एवं लक्षण भी दिखते हैं।

असपर्गर डिसार्डर के लक्षण क्या हैं ?

असपर्गर से प्रभावित लोगों में जो लक्षण आमतौर पे पाये जाते हैं, वह अस प्रकार है:-

1. असपर्गर डिसार्डर होने पर, बच्चा दो वर्ष की आयु होने तक एक शब्द प्रयोग कर या तीन वर्ष की आयु तक दो-तीन शब्दों के वाक्यांश द्वारा दूसरों के साथ कम्युनिकेट करने लगता है। पर भाषा का प्रयोग 'अटपटा' रहता है।
2. 3-5 वर्ष की आयु तक विकास सामान्य रूप का दिखता है। कोई भी वैधानिक विलम्ब नहीं होता।
3. अमौखिक व्यवहार द्वारा सम्पर्क बनाने में सस्पष्ट रूप से क्षति। यह व्यवहार आँख मिलाना, चेहरे के भाव, शारीरिक मुद्रा, इशारों का प्रयोग इत्यादि हो सकते हैं। ऐसे व्यवहारों में अर्थ समझकर सामाजिक क्रिया करने में अत्यन्त कभी होती है।
4. अपने हम उम्र या अभिजात लोगों से सम्पर्क स्थापित करने में और बनाये रखने में कठिनाई।
5. स्वाभाविक रूप से अपनी रूची, उपलब्धी एवं आनन्द को दूसरों के साथ बाँटने व अभिव्यक्त करने में कमी।
6. शारीरिक रूप से ढीलापन। जूतों के लेस बाँधने में, कमीज के बटन लगाने में, पेज-कस प्रयोग करने में या अन्य दूसरे खेल जैसे बैडमिन्टन इत्यादि में कठिनाई होती है। चाल, दौड़ने का अन्दाज, इत्यादि अटपटे लगते हैं।

7. असपर्गर बच्चे अधिकतर अकेलेपन का शिकार होने लगते हैं क्योंकि उनमें तीव्र स्वभाव दिखते हैं। वह किसी विषय (जैसे रेल, क्रिकेट, कार इत्यादि) में, या वस्तु में इतनी अत्यधिक रुचि रखते हैं कि वह अन्य दूसरी बातों में और वस्तुओं में ध्यान नहीं लगा पाते। दूसरों द्वारा बोली जा रही बात पर बिल्कुल भी ध्यान न देकर अपनी ही बात किये जाते हैं।

8. सामाजिक रूप से यह अत्यधिक फुर्तीले या ऐक्टिव होते हैं पर इनका सामाजिक व्यवहार या सामाजिक क्रिया बिल्कुल अटपटी होती है।

9. अक्सर असपर्गर व्यक्ति अपनी दिनचर्या में बहुत ही रूढ़िवादी व्यवहार दिखाते हैं और बदलाव को आसानी से नहीं अपनाते।

10. लगातार एक ही तरह की बात करना, बातचीत बनाये रखने में कठिनाई, बात करते समय आवाज़के स्वर, ध्वनि, लहजेपर नियन्त्रण न रख पाना, बात के भाव को न समझ पाना, यह सब असपर्गर व्यक्ति के मौखिक व्यवहार में पाये जाने वाले लक्षण हैं।

11. असपर्गर डिसार्डर होने के फलस्वरूप व्यक्ति बोलता तो बहुत है, परन्तु शाब्दिकता का ही ज्ञान रखता है और अधिकतर शब्दों के अर्थ को गहराई या भावनात्मक रूप से नहीं समझ पाता। जैसे- चुटकुले, मुहावरे, व्यंग इत्यादि समझ में नहीं आ पाते।

असपर्गर डिसार्डर क्यों होता है?

इसका कारण अभी तक स्थापित नहीं है। बहुत से परिवारों में (जिनमें किसी व्यक्ति को "असपर्गर" निदान मिला है) अन्य और लोग पाये गये हैं जिनमें सामाजिक पिछड़ापन या अटपटे सामाजिक व्यवहार हों। इस प्रकार जनेटिक या अनुवांशिक कारण हो सकते हैं पर आज तक कोई भी ऐसा 'जीन' नहीं पहचाना गया जो असपर्गर डिसार्डर के लिये उत्तरदायी हो। एक बात स्पष्ट है- असपर्गर रहने से व्यक्ति के ब्रेन में कुछ कार्यात्मक एवं संरचनात्मक भिन्नताएं होती हैं। बहुत से वैज्ञानिक असपर्गर और भौतिक वातावरण में सम्बन्ध या वैरूपिक (टिरेटोजेन या हानिकारक पदार्थ जो गर्भ में प्राप्त हो) पर अनुसंधान कर रहे हैं पर अभी तक कुछ नतीजा नहीं पाया।

असपर्गर डिस्ऑर्डर का पूर्वानुमान या प्रॉग्नोसिस

2007 तक अध्ययन के अनुसार कोई भी अजीवन निष्कर्ष नहीं हुआ। असपर्गर व्यक्ति की आयु अवधि सामान्य होती है, साथ में मनोवैज्ञानिक और मनोरोग संबंधित रोग हो सकते हैं।

बहुत से ऐसे असपर्गर व्यक्ति भी हैं जिन्होंने स्पेशल शिक्षा व ट्रेनिंग द्वारा अपनी रुचियों को सही प्रयोग में ढाला ओर उनके आधार पर जीवन में उपलब्धी प्राप्त की।

असपर्गर के लिये कुछ कार्यक्रम संबंधी सुझाव

1. उनके लिये एक सुरक्षित और भविष्यवाची (प्रडिक्टेबल) ढाँचा बनाया जाये।
2. दिनचर्या उनके लिये स्पष्ट हो, दार्शिक सहारे जैसे चित्र लेखा, इत्यादि का प्रयोग करें।
3. अधिक आश्चर्यजनक स्थितियों का परिहार करें
4. नवीन स्थिति के लिये तैयार करें
5. भावनाओं का ज्ञान दें।
6. समझदार मित्रों को ढूँढ़ें और फ्रेंड्स क्लब बनाये।
7. व्यवहार परिवर्तन के सिद्धान्त समझकर लागू करें।
जैसे— अच्छे व्यवहार की सराहना और इनाम दें।
बुरे व्यवहार को समझे, फिर परिवर्तन करे।
दण्ड का प्रयोग न करे।
8. उचित सामाजिक नियम सरल रूप से समझाएँ।
9. बहुत ज्यादा नकारात्मक बातें न करे; धमकी या लालच देकर काम करवाना बहुत दूर तक काम नहीं आयेगा।
10. लोगों से बात करने।

UN Convention on the Rights of Persons with Disabilities UNCRPD

India was one of the first countries to ratify the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) on 1 October 2007. The Convention will enter into force on the thirtieth day after the 20th ratification or accession. The Optional Protocol will enter into force on the thirtieth day after the tenth ratification or accession.

By the time we go into print, the Convention will have received at least 20 or more ratifications and be on its way to becoming an International Law on the Rights of Persons with Disabilities.

The convention marks a major step toward changing the perception of disability and ensures that societies recognise that all people must be provided with the opportunities to lead a life to their fullest potential.

The eight guiding principles that underlie the Convention and each one of its specific articles are:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

We hope too that in the coming months the disability legislations in India are aligned with the UNCRPD.

ROHAN'S

COLUMN

A Brother



Remembers

Ketan Sonalker

Thoughts of my brother Rohan bring forth streams of memories that I treasure through my life. If anybody ever asks me which is the saddest day of my life, my answer shall always remain the same.... that very harrowing day that we lost Rohan all of a sudden.

ROHAN, my elder brother, was the person who has shaped my life and decisions for the past 30 years. Being older by five years he was the protective brother anyone would have. Taking my side if anyone was to bully me, covering up for me time to time, and never once complaining against me even if I were to be the one to start a fight or argument.

AS I grew up, I realised that Rohan was 'different'. But at the same time he too had started comprehending that he was different, and this had made him choose a different path at each step in his growing years.

BY diagnosis, Rohan was autistic. But to us, his family, he shall always be remembered for the person he was, for his uniqueness and to make us all laugh at the smallest of his actions or jokes.

ROHAN had his own inimitable way of doing things. There has been no one in my knowledge so genuine, and enthusiastic about greeting someone, who remembered and recalled even the tiniest detail, like the colour of the shirt, date, etc of people he had met only once

ROHAN influenced a lot of my decisions in life. It was keeping him in mind that I chose to plan my life and stay on with my family in Pune, rather than go overseas on the strength of my qualification and degree.

WHEN it came to my marriage, there was always a question that I and my parents had to face: 'How would my wife accept Rohan?' But on the other hand, there was yet another question: 'How would Rohan accept my wife?' I am sure this question would be part of every person who has a differently-abled sibling. This was a situation none of us could foresee the results of. Prior to our engagement, I had told my wife that you meet Rohan once and then decide. However from the first time they met, they bonded so well that eventually it was the two of them versus me, with Rohan always siding with my wife in every situation!

ROHAN'S uniqueness lay in the fact that he touched peoples' lives in so many ways. Due to the grace of God, his talent for art really took him far. When God takes away something from one hand he always puts something in the other. In Rohan's case it was his talent for Art which was discovered during his adolescent years and which he channelised to touch the hearts of people. He used to send people handmade greeting cards on their birthdays and anniversaries, and ensure that they were posted so that the cards reached exactly on the date. He would calculate this including the public holidays when the post office was closed and then post them. His hand-made cards reached people across the globe and even people who had rare contact with him were the beneficiaries of his cards. So much so that we always used to joke in the house that, "He is the only person in the family who is internationally known".

ONE of his talents that was not known to many people is that he could tell a day of any year within a few seconds. For instance, if one told Rohan that one was born on the "x" day of March 1980, he could tell us what day of the week it was. When we asked him how he could say it so fast, the answer always was, "I have calculated it."

AS a brother, he was always supportive and not once did he refuse anything if I ever asked him. Whether it was an ordinary pencil or an expensive shirt to wear for an occasion, his heart was large, large enough to fit in every demand that I put across, never once being questioned about it.

AS a sibling I was often asked by people as to how different it was being Rohan's brother. My reply has always been that it was never too different from the rest. For me he was the only brother I knew, and he did play the role of an elder brother such as any other would have. His absolutely unique way of reaching out to people, his art, and other talents, were all things which made me look up to him like any other proud younger brother would.

ROHAN was 35 when he left us. I do not question God's ways, but hope and pray everyday that he is peaceful, wherever he is. Here as we come to terms with his passing away I realise that in his lifetime he has taught me things that will help me for the rest of my lifetime.

A 'Normal' Autistic Person

Indrani (Nano) Basu

As the mother of a 15-year-old boy with Autism, Nano, there have been so many varied responses to my 'Nano has autism'. These range from, "Autism, what is that?" (The yet to be aware); to "Autism. Oh! I've heard a bit about it." (The just aware); to "Autism!! Really!! And what is Nano's special skill?" (The super aware, thanks to the Rain Man and its ilk). And that makes me realize that we still have such a long way to go before we can give to our children a society that can truly understand them for what they are.

THERE are those who have not even heard of Autism yet, though its incidence is said to be as high as 1 in 150; and amongst those who have heard about it, a large number view it as this glamorous, mythical disability, where every single individual with autism MUST have a savant skill, be superlative at something, be it at math, writing, music, art and so on. This myth exists not only in the general population, but also in parents who have children with autism. The media, the Internet, as well as some professionals in the field continue to perpetuate the myth, that autism and savant skills are almost synonymous. When you try and tell someone that your autistic child does not have any superlative skills, one is met with astonishment and often told that he MUST have one, that its just undiscovered as of yet...and that 'you must find THAT skill, catch it and then you'll just see your child blossom!!!!' Implying, that we as parents, either don't know our children well enough or haven't bothered to put in the effort to find the genius that is just waiting to see the light of the day! As if that skill is lurking somewhere, and all we need do is to hunt it down, and once it emerges in all its glory, our children will be fine!

HOWEVER, there is danger in this belief. Because, often as parents, instead of focusing on teaching our children to communicate better, develop more appropriate social and leisure skills, be as independent as possible; we may end up losing precious time, focusing all attention, efforts in the quest of that superlative skill that may continue to be elusive for a long, long time, maybe forever...And this, at times, is just what happens...Sometimes a child might have a skill that is not outstanding in itself, but seems outstanding in the light of the child's autism. A child may be able to recite

long poems from memory, may be able to do complicated math, which is wonderful of course. But that sometimes takes parental focus away from teaching basic skills so that the child may not be able to communicate his basic needs, may not be able to do simple, basic things for himself, like wash his own bottom-for instance.

COMING back to "And, what is Nano's special skill, his savant skill?"...Well, he doesn't have one! He is just a normal autistic person. And, I use the word normal with responsibility! Normal is defined as *conforming to the usual standard, type or function*.

AND, the standard person with Autism DOES NOT have any savant skills. Just as is in the case with us normal, 'normal' people. How many people in the general population are geniuses??? How many Picassos or Mozarts do we know of? For every one Picasso, there are millions of people for whom art began and ended in art class in school; for every Mozart, there are millions of people who are content to vent their musical abilities in the shower.

SO, why should it be any different for people with Autism? Each one of us has strengths and weaknesses. Some of us may be good at math, others may not be able to even add large sums mentally; some of us may have excellent people skills, others may be comfortable with limited contact with people. We all use our strengths and try to minimize our weaknesses, to function to the best of our abilities. We don't expect to be geniuses ourselves, we just try to do our very best, given our abilities.

SO, why should it be any different for our children? Should not, they, too, be encouraged to use their individual strengths and minimize their difficulties, to function to the best of their abilities? If they have a special skill, fine. If not, that's fine, too!

WHY can't our children be just normal people with autism? Why do they HAVE to have a savant skill for them to be special? Is it because, at some level we expect a special skill to absolve our children of their Autism? But, do our children need absolution? Are they not special and unique, just the way they are; NOT by virtue of their autism, or their savant skills, BUT, by virtue of just being human, like all of us!

Workshop Announcement

BEHAVIOUR MODIFICATION
 ...at Home, at School and in the Community

DATE: Tuesday 6 May 2007

Understanding why we do some things and not do others can enable us to increase those behaviours that we want more of, and help bring down behaviours that we would not want repeated.

Behaviour modification is used with all children, but plays a particularly significant role in the management of children with various developmental disabilities. The difficulties faced by individuals on the autistic spectrum in particular often manifest as complex and challenging behaviours to the non-autistic world. Behaviour modification with the reinforcing of wanted behaviours is the cornerstone of management of autism: in changing behaviours as well as in teaching skills. Behaviour modification is used in teaching children to 'attend', control 'temper tantrums', and for helping the child learn appropriate and socially accepted behaviours.

The workshop will cover an understanding of the reasons behind behaviours, assessment and management procedures. Though it will focus on autism spectrum disorders, the methods to be covered are equally effective with children with developmental delays.

The workshop will incorporate question answer sessions where participants will be encouraged to problem solve. The workshop is open, but not limited, to anyone who works with children with developmental disabilities on a day-to-day basis; and may include parents and teachers of both children with and without specific needs.

Venue:

The National Centre for Autism, Pocket 7 & 8 Jasola Vihar, New Delhi - 110025

Timings: 10:00 am to 4:00 pm.

Registration (including refreshments & handouts)

- Rs 400 per Person
- Rs 300 for *Full Members* and *Life Members*
- Rs 325 for each attendee from an organization that has taken *Institutional Membership* if more than one person attends
- Rs 500 for spot registrations

Childcare at Rs 200/- per child, including meals, will be available during workshop hours.

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REGISTRATION FORM

Do fill this form in **BLOCK LETTERS** and mail, with a self-addressed stamped envelope to:
Action For Autism, Pocket 7&8 Jasola Vihar, New Delhi 110025

Name _____ (Tick relevant box) Parent Professional

Address _____

Tel _____ Email: _____

If parent, name of child _____ Male Female DOB _____

If professional, name & address of organisation _____

Please find enclosed a Demand Draft No _____

dated _____ drawn on _____ (Bank)

Workshop Announcement

ENABLING COMMUNICATION

DATE: Wednesday 7 May 2008

Unlike other developmental disabilities, language and communication take completely different developmental paths in autism. Speech does not equate with communication. While some individuals with autism develop no speech, others may be vocal at different levels. Language may develop with the child having little idea how to use it for communication or even to understand how others use language for communication.

Much of the inappropriate behaviours in autism have their root in these difficulties. Children with autism are often therefore mistakenly perceived to be 'stubborn' or 'willful'.

The workshop will cover an understanding of differences in the development of communication in autism and ways to teach communicative function and the use of both speech as well as assistive and augmentative modes of communication.

The workshop will incorporate question answer sessions and interactive demonstrations. The workshop is open to

parents, professionals and anyone who works with children with developmental disabilities on a day-to-day basis.

Venue: The National Centre for Autism, Pocket 7 & 8 Jasola Vihar, New Delhi - 110025

Timings: 10:00 am to 4:00 pm

Registration (including refreshments & handouts)

- Rs 400 per Person
- Rs 300 for *Full Members* and *Life Members*
- Rs 325 for each attendee from an organization that has taken *Institutional Membership*, if more than one person attends
- Rs 500 for spot registrations

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Name _____ (Tick relevant box) Parent Professional

Address _____

Tel _____ Email: _____

If parent, name of child _____ Male Female DOB _____

If professional, name & address of organisation _____

Please find enclosed a Demand Draft No _____

dated _____ drawn on _____ Bank _____

Understanding & Teaching Children with ASD

An RCI CRE Programme

DATE: Wednesday 1 - Sunday 5 October 2008

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

Individual consultation available at no extra charge on the last day of the workshop to those who book in advance .

Reading material: Books & handouts on understanding autism, interventions, and personal accounts on sale.

Childcare will be available during workshop hours for families who find it difficult to leave their children at home. It is open to children with special needs as well as their siblings. Information about your child's special needs will have to be given at the time of booking so that adequate arrangements can be made.

Please register in advance. *Last date to register is 5th October. Childcare will not be available to on-the-spot registrants.*

Registration Costs

- *Parents*
 - ~ Rs 2000/- per parent attendee (Rs 1650/- for life members & full annual members)
 - ~ Rs 3500/- per parent couple (Rs 2500/- for life members & full annual members)
- *Non-parents*
 - ~ Rs 3000/- per non-parent attendee (Rs 2500/- for life members & full annual members)
 - ~ Rs 2700/- for each attendee from an organization that has taken membership if more than one person attends
- *Registrations received after 14 September 2008*
 - ~ Parent 3000/- , Non-Parent Rs 3500/-

Daycare charges

- Rs 200/- per child, per day

Venue: The National Centre for Autism, Pocket 7 & 8 Jasola Vihar, New Delhi - 110025

Accommodation

Limited number of places of shared accommodation on first come first served basis, from noon of 30 September to noon of 5 October at Rs 1000/- per person for a five-night stay without food. *Last date for booking accommodation: 21 September 2008.*

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PRE-REGISTRATION FORM

Do fill this form in **BLOCK LETTERS** and mail, with a self-addressed stamped envelope to:
Action For Autism, Pocket 7&8 Jasola Vihar, New Delhi 110025

Name _____ (Tick relevant box) Parent Professional

Address _____

Tel _____ Email: _____

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

Please find enclosed a Demand Draft No _____

dated _____ drawn on _____ Bank _____

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

The South Asian Regional Conference on Autism: *Building Bridges*

A Brief Report

Annie Tyhurst

BOOK POST



The South East Asian Regional Conference on Autism was held recently in New Delhi with the title, '*Building Bridges*'. Bringing together professionals, researchers and families from across India, Bangladesh, Sri Lanka, Singapore, The Maldives, Vietnam and Pakistan speakers covered a range of topics: child-based interventions, individual reports from participating countries, employment, neurological, diagnostic & medical issues, and several first person accounts from adults with ASD.

THE opening address was given by Anand Sharma, MoS for External Affairs who as a parent of a child with autism has played a prominent role in supporting the work of *Action for Autism*. Thorkil Sonne, a parent from Denmark, described his creation of an IT company, 'Specialisterne' that provides opportunities for meaningful work competing at market rates for high functioning individuals with ASD. Of the several self advocates, author Dr Stephen Shore shared some of the strategies that he had used to gain employment as well as on sexuality and intimate relations. Several speakers touched on current pharmacological approaches to treating ASD. Dr. Thomas Owley, University of Chicago, encouraged **minimal psychopharmacological approach** as an adjunct to other treatments targeting specific symptoms, such as anxiety, hyperactivity, obsessional behaviour, aggression and sleep difficulties. Sociologist & mother of an autistic son Shubhangi Vaidya, examined the social construction of mothering in the context of having a child with ASD. Dr. Bhismadev Chakrabarti of the Autism Research Centre, University of Cambridge proposed that future studies should focus on specific symptoms and described his recent studies on empathy.

LISTENING to the accounts of individual pioneers in countries like Pakistan and Bangladesh, countries where disability legislation is almost non-existent, and autism frequently not even regarded as a specific diagnosis was a humbling experience. I felt that my own presentation, (where I made a case for clinical work in music therapy to be informed by a greater understanding of physiological function and sensory information processing) made a small contribution towards 'bridge building'.

- *annietyhurst@hotmail.com*



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