autism network

APRIL 2009 **VOL 4 ISSUE 1**

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

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INFORMATION
For information on receiving the Autism Network write to:
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New Delhi - 110025. Tel: 40540991/2

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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

'Calming orderliness of a block of flats'
by Abhishek Sarkar, Student of Dikshan,
Autism Society, W. Bengal, Kolkata

WISHLIST !

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Autism is a condition that is unique in many ways. The very fact that it is an invisible condition means that at first sight, many kids may not be seen as having a disability, at all. This, then leads to situations that do not arise in many other conditions. For instance, there is no question of a parent 'hiding' the disability from a child who has a visual impairment. Or concealing the disability from a child with locomotor impairment.

The very unusualness of the autistic condition throws up a situation where, to tell or not to tell becomes an issue that is debated intensely.

One of the reasons put forth for not telling individuals with autism about their diagnosis is to avoid 'labelling'. Yet a label is just a word; it is the sentiment and beliefs of the user of the 'label' that determines the positive or negative impact of the label.

So do we tell our child that she or he has autism? Will it damage her or empower her to understand herself and seek and establish her individual identity? This issue of Autism Network focuses on the debatable issue of disclosure.

The wheels of advocacy move slow, but they do bring results. The year started on a positive note with a notification from the Central Board of Secondary Education (CBSE) on accommodations extended to students with autism appearing for their boards. Autism is acknowledged to be a complex condition and many do have significant difficulties. However there are children with Autism Spectrum Disorders who attend regular schools, some of whom may even not have been identified as having autism.

According to the UN Convention for the Rights of Persons with Disabilities, the Universal Declaration of Human Rights, and the Declaration of the Rights of the Child, every member of society has an equal right and the opportunity for education without discrimination. The CBSE notification will bring cheer to all students with autism who are in mainstream classrooms. We applaud the initiative of the CBSE but remind ourselves that we still have to work on allowing students with autism to use computers for writing: not all kids want an amanuensis. And the other national and state school boards have still to be made aware of the needs of students with autism. As with all else this is a work in progress.

As we go to print, it is time for the second World Autism Awareness Day (WAAD), and month. We have been receiving information from organisations across India, the SAARC countries and beyond, of activities planned throughout the month to create awareness of autism. Creating awareness has to be an ongoing project, and we are far from having reached the levels of awareness required. So, it is with great pleasure that we receive information on innovative and interesting awareness activities.

Finally, on savant skills. While we do find savant skills interesting, nay enigmatic, yet we do realise they are very often what Rita Jordan once called 'so what' skills. At the same time we cannot help but be fascinated with every child we meet who has exceptional skills. Abhishek Sarkar is one such. Whenever he sits 'idle', his fingers are busy with bits of paper, tearing the paper 'randomly'. However the result of his random tearing results in the most fascinating creations, some of which were featured on the cover of the last issue of Autism Network. This issue again features Abhishek on our cover, though this time it is his drawing. He draws in perspective, buildings he has seen on a visit, travel, or just in passing, as well as everyday objects around us – collapsible gates, fans, pumpsets, balustrades. His buildings reminding us very much of the work of Stephen Wiltshire, Gilles Trehin, and Jessy Park, among others. And, we can only look and marvel!

The Central Board of Secondary Education *makes* Accommodations in Examinations for Students with Autism

The Central Board of Secondary Education (CBSE) posted a notification dated 2 January 2009 by Mr MC Sharma, Controller of Examinations, that informs several amendments/ additions that have been made in the CBSE Examination Bye-laws. Amongst these are the following:

(i) Candidates with Autism appearing for the Secondary School Examination or Senior School Certificate Examination are permitted to use an amanuensis and shall be allowed an additional time as given below:

- For paper of 3 hours duration: 60 minutes
- For paper of 2½ hours duration: 50 minutes
- For paper of 2 hours duration: 40 minutes
- For paper of 1½ hours duration: 30 minutes

(iii) Candidates with Autism have the option of studying one compulsory language as against two. This language should be in consonance with the overall spirit of the Three Language Formula prescribed by the Board. Besides one language any four of the following subjects be offered:

Mathematics, Science, Social Science, another language, Music, Painting, Home Science, Introductory Information Technology, Commerce(Elements of Business) & Commerce (Elements of Book Keeping and Accountancy).

To Tell or Not To Tell

Indrani Basu & Merry Barua

To tell or not to tell….that is the question. Do we tell our children that they have autism? Do we use the 'A' word? There are many decisions that affect our children's lives that we discuss and debate on: Do we introduce an assistive and augmentative mode of communication or insist that he learn to speak. Do we go for a mainstream school or have him attend an autism specific environment. Yet interestingly, on the topic of disclosure: Do we tell our child he has autism, there is strangely little debate in India. It is a topic that most parents and carers appear not to have given much thought to. An often initial reaction is "Do you think we should?!" This is followed by an interesting mix of opinions. Some feel that their children certainly have to be told. Others feel they would want to but do not know how. And yet others believe it is a subject best avoided.

THE web as always hosts a vast array of views. An article on the internet 'A Different Perspective' gives an interesting angle on the 'not to tell' viewpoint. Here is what Becca, a parent herself given a label of Minimal Brain Damage, has to say. "Hmmm. Let's see if I can say this right... but as a labeled child (Minimal Brain Damage they called it at the time) who never appreciated knowing that label and never will, I can definitely offer an alternate perspective.

"FIRST off I feel comfortable with M knowing that she is autistic partially because she doesn't really know what that means. Nor does she understand other people's inner reactions to that word. The openness in the family about autism has been more for the benefit of my other children than for M herself. Were she to become more aware in the future I cannot guarantee that she would not experience immense discomfort at knowing her differences.

"SECONDLY, I would like to say that knowing one's label can become a self-fulfilling prophecy. A person autistic or not is far more than the label that they have been given. But as a labeled person myself, just knowing my label limits me inwardly. You see I was taught that I was brain damaged and thus incapable of achieving certain things. When anything was inconsistent with that label I didn't need anyone to discourage me I limited myself. Being anything but that label made me feel like a fraud. It also stopped me from asserting myself and pushing my limits to the max. Furthermore it instilled a deep sense of inferiority where I knew before trying I had already failed to measure up. Were I to go back all those years ago, I would never have wished to know my label and would have appreciated it greatly had it been kept from me."

JEN D from the same site says in 'We Agree in NOT telling', "He already struggles with low self-esteem and the last thing we need to do is to give him an excuse to exercise inappropriate behaviors and our patience or just another excuse to NOT clean his room."

Another common argument in favour of the 'not to tell' perspective is that children with autism already have a communication impairment, and there is no need to burden them with further information that is of no use to them. And then there is the argument that is raised by Becca in the preceding: Do they even understand what that means?

AT the other end of the spectrum is the perspective that our children may or may not understand what 'autism' means, but, irrespective of their functioning levels, they do recognise at some level that they are 'different'. Many experts in the field seem to share this view as do many adults with autism. Furthermore, the argument goes, even if parents avoid speaking to them about their autism, the children cannot be shielded from ever hearing about their autism. To draw an analogy, when parents balk at the idea of speaking to their children about the facts of life, it does not keep those kids from hearing about sex. Instead they learn through snippets and sniggers and end up having an ambiguous and confused view of things. When a parent or some other responsible adult acquaints them with the 'facts of life', they have a clear and healthier picture. Similarly children with autism who are not told about their autism nevertheless hear veiled and not-so-veiled references to their condition, oftentimes negative or derogatory. They then grow up believing they have some terrible disease or infirmity that they often feel embarrassed about and wish they never had. Furthermore, they often feel isolated and alone, believing they are the only person with the difficulties they experience.

WHAT the individual with autism feels is in some ways a mirror of parent experiences. In the early years before the child receives a diagnosis, most parents wonder what is 'wrong' with their child. Why does he not respond? Why does he not talk? Why does he like to be on his own? Am I doing something wrong? Did we neglect him in some way that has led to this problem? Most parents are plagued by these questions along with feelings of bewilderment, alienation, anger, frustration, and helplessness. When finally the child receives the diagnosis of autism, along with the shock of the diagnosis is often a feeling of relief, of at least knowing what was behind the child's behaviours and knowing that the child was not a deliberately defiant indisciplined child, but that he did a lot of things he did because he had autism; and knowing that one was not a terrible parent but that it was autism that was the cause of the child's non-compliance!

ONE of the most empowering feelings for parents at that point is to learn that they are not the only people facing the situation; that there were hundreds like them out there; that they are not alone.

A very similar sentiment is echoed by many adults on the spectrum, especially those who have received a late diagnosis as adolescents or adults. The relief of finally knowing why they are the way they are; that there was a reason to their 'quirks' and for the difficulties that they encountered in so many areas. That they were not 'weird'. They just had an Autism Spectrum Condition!

DISCLOSURE therefore has its place. So while some parents and caregivers feel that it can only lead to problems, some of which have been narrated earlier in this piece, there are others who believe that it is important to speak to the child about his condition.

WHEN we give the label of 'autism' to our children, we have the opportunity to attribute the word with any connotation that we want to. Perhaps the negative experiences of disclosure recounted by some parents arise from the connotations of negativity imputed to autism based on the parent or caregiver's personal attitude to autism. Does the parent or carer view autism as a dreadful tragedy, a shame, etc. Is it a 'problem' because of which their 'poor' child has to live a 'sad' life of deprivation? When the parent or carer has a negative view of the condition, then invariably the child picks up on those sentiments. Regardless of whether she/ he is told about their autism or not the child develops negative self perceptions.

AS Cathy Warner Weatherford said, "What you teach your children is what you really believe in." So when the parent talks to the child abut autism, their personal beliefs naturally colour the disclosure. The child can learn that he has something called autism which is somehow shameful, is a tragedy, and a curse, and that he has thereby blighted his parents' life. Or the child learns that we all have various differences and difficulties and so do they. And that they also have abilities just the same as others. So children learn to see that having autism is just a different way of being. It is not something they have to be ashamed of.

IN addition, autism is not an 'excuse'. It is an excuse if we let it be one! So if children use their autism 'to not clean (his) room', they are using their autism as an excuse just the same as most of us try and use an excuse to get out of doing something that we don't want to. Many of us have feigned a stomach ache on the day of that tough math test in school. If our parents bought into that and we got out of appearing for the test, then we continued to have a 'stomach ache' on other occasions. Had our parents caught on, given us medication and packed us off for the test then we ceased having 'stomach aches' on exam days! If our children use their autism to exercise inappropriate behaviours, we can do what we do to deal with any inappropriate behaviour…..make sure that the behaviour does not get reinforced.

When do we tell our children that they have autism?

For parents who want to speak to their children about their autism there is often the question of 'when'. When do we tell our children? This is a decision that needs to be made depending on the individual child, his environment, and the personal family circumstances. In some cases we may want to tell the child about his autism, the moment we feel that he is beginning to realize that he is different. Speaking from personal experience, one of the writers, Indrani Basu, started speaking to her son about his autism when he was around seven years old. This was the fallout of a particular incident.

"WE had gone to the park one day. He was playing on the swings whilst I was talking to some friends. I noticed a few children pointing out at my son, laughing at him and making jokes about him. He got down from the swings and came to me crying. Was it because he realized that he was different and the other children were ridiculing him? I have no idea. But, I decided, whatever be the cause of his crying, it was time to tell him about his autism and his being different."

SO the answer to "When do we tell our children that they have autism?" Is ideally "Now!" But at a more practical level the discussion on autism can be introduced as soon as the parent or carer herself or himself has come to some level of comfort about the diagnosis, since that will determine how the child will perceive his autism.

How do we tell our children that they have autism?
The manner of communicating this information to the child will have to take into account the child's level of functioning, as well as the quality of his receptive and expressive communication. In addition, the language used by the adult for the telling will have to be simple, direct, and easiest for the child to understand.

MORE to the point, this is not to be a 'teaching session', but done in a casual, happy manner, where both, we and our children are completely relaxed and comfortable. If our children are very close to someone else, like a grandparent or an aunt, they may be good people to get involved in the conversation. We could start with talking about differences, about the fact that everybody is different. We could point out differences in physical attributes, maybe using photographs and then talk about how each of us is different. If the child has experiences of others with special needs, this would be a good time to draw his attention to their difficulties. For instance we can tell him that Mother needs to wear spectacles because she has difficulty in seeing. Grandfather cannot walk without his stick. He has difficulty walking. Some people cannot see at all; they are blind. Some people have difficulties in controlling how they move; because they have cerebral palsy. In the same way, he has difficulties in getting people to understand what he wants, or that he has difficulties in speaking, and so on; because he has autism. At this time we may want to draw his attention to other people he knows who also have autism.

IT would be important to speak about strengths as well. We may want to tell them that each of us has strengths and difficulties and they too have lots of things that they can do well. If they can read, or are strong visual learners, a kind of matrix tabulating each of our strengths and difficulties may help.

THE key thing to remember would be to make the telling, the disclosure, a positive experience, to keep the language, the tone of voice, positive, light and easy. We want our children to perceive their autism not as a 'problem' or a tragedy, but as a difference, a special way of being. It is also helpful to let the child experience that the autism does not affect the parents feelings towards the child. This could be done with a simple, "I love you", or whatever personal manner of showing and reiterating affection that parents might have. Some parents have brought in silliness and humour into the disclosure so that the child is actually able in time to laugh and see the lighter side of their condition.

IT is crucial to remember this is not accomplished in one serious sit-down session after which we think, "Okay disclosure done," and wash our hands of the matter. This is an ongoing process. There will be many opportunities to discuss, review, and reinforce autism as a positive experience. To give an example: If a child remembers the direction to a place he is visiting after three years, or some little detail from a melody heard several years ago, or an incident from long ago that most others cannot recall, we can express our astonishment and acknowledge how people with autism often have this amazing ability to recall things that most non-autistic people cannot.

ON the flip side there would be occasions when someone says in the child's presence,
"What's wrong with him?"
There can be different responses to this, but something along the lines of,
"There is nothing wrong with him. He just has autism."
And turning to the child and commenting,
"He (the questioner) does not know anything about autism!" So that the child sees that you are on 'his side'.

OR someone says,
"Why does he rock?" Can be answered with, "He has autism".
And to the child with a smile,
"Don't you! You rock!!"
Then adding to the questioner,
"People with autism sometimes need to rock."

OUR children have autism! It cannot be wished away. That is who they are. We may choose 'to tell or not to tell'. But as Alex Noble says "The best way to be spectacular is to be yourself". How can our children be themselves if they don't know who they are?

REFERENCES

Website*: http:// www.bbbautism.com/pros_and_cons_plaintext.htmi*

Open It: A Mother's Perspective on Disclosure

Sudhanshu Grover

My son, Bunny was diagnosed with ASD when he was three years old. I never thought of telling him about his autism. I thought "How does it matter? Will he even understand the difference it will make? Why should I? Get it, shut it – I am never going to disclose!"

THEN I got thinking that, as parents, we all put in a lot of effort in deciding what we are going to name our child. For a lot of us, this quest begins even before our child is born. I remember going through a fat Sanskrit dictionary, a priceless possession of my father-in-law's, as soon as I had been given my pregnancy report. Can we imagine anything without a name, a label?

IMAGINE you went out for dinner, tried out an exquisite dish, enjoyed every bit of it, polished off every morsel, but didn't know what it was called .You want to talk about this great dish, tell your friends about it, but don't know its name. And, suppose your friends talked about the same dish, described it and also named it, you would now know that it was the same dish that YOU had also been wanting to talk about!

CAN we think of anything – just anything without a name? Then how could I deny Bunny from knowing about his 'autism'? I also thought that if he hears us talking about it or if he ever reads his report – wouldn't he think he has got something terrible, something horrible and shameful. I would want Bunny to stand up and fight for his rights, be a self advocate, but how could I expect him to do so, if I didn't tell him about his autism? Yes, I had to –I couldn't keep it shut, I had to open up, for him to know about his autism. And why shouldn't I: it wasn't something bad, obnoxious, sinful or shameful!

SO, the sooner the better. I had to tell him now! It seemed like a daunting task but hasn't been one at all.

I started by telling him about differences and difficulties. I showed him my contact lenses and told him that Mom has a difficulty in seeing, just as his Daadi has a difficulty in hearing. Raj Uncle has a difficulty walking and he uses a walking stick to help him walk better. Everyone has some difficulties and it is absolutely okay to have them. People who have difficulties in some areas are okay in other areas. Gradually, I started talking about his difficulties, like looking at people, speaking in long sentences, making friends, understanding what others are thinking. At the same time, I talked about his abilities, his strengths – he could tell the names of all 40 classmates along with their surname, roll number wise! He could remember complex songs just by having heard them once! He knew the name of the song, the movie it belonged to AND the name of the artiste who had sung it!

I don't think he comprehended at first but then gradually with time, I think my words did sink in.

BUNNY is now a 12-year-old young lad buzzing with energy and confidence .He knows he has his unique strengths and weaknesses just as we all do. I so am glad I did 'Open It'.

PS: I just wanted to share that Bunny has done the proof reading of this article for me.

Teaching Positions at AFA

Action For Autism invites energetic and enthusiastic individuals who are creative, logical, intelligent, and willing to work hard, to apply for various teaching positions at Open Door School. The positions offer exciting opportunities to therapists and teachers to work with individuals with autism and communication differences, in what is one of the most challenging and exciting areas of special needs education.

Action For Autism is a premier organisation that has pioneered teaching strategies based on extensive practical experience and internationally validated teaching principles, adapted to the Indian situation. We offer an enriching work experience in a positive environment, where work days are exciting and something to look forward to on a daily basis; with many opportunities for continuing training.

Applications are invited from those who have experience in teaching mainstream classrooms, those who have completed DSE (ASD) / BEd / DSE (MR), graduates in Psychology, Education, Child Development or those interested in working with individuals with autism.

Interested candidates may send their CV to:

Teaching Positions At AFA
Ms Reeta Sabharwal, Director , HR
The National Centre for Autism
Sector 7 & 8 Jasola Vihar, New Delhi 110025

Do I Tell my Son that He has ASD?

Parul Kumtha

My sixteen year old son Kabir has difficulties. Who doesn't? It can be said that perhaps his difficulties are more profound than those of other's. He attends a special school where he is being trained in skills that will help him settle into a sheltered vocational workshop for adults with special needs. This is because he cannot cope with academics. His articulation and speech is also very limited, although, over the years, Kabir has learnt to adjust to these shortcomings as best as he can. Everyday, he tries to overcome the hurdles faced due to his shortcomings. Diagnostically, Kabir suffers from brain injury and ASD.

ONE day, some years ago, when talking to the parent of a child with better academic and intellectual abilities and ASD, I heard out in painful detail the dilemma of the mother who was wondering if, when and how she should break the news to her child about his ASD status. This got me thinking…. I thought about my particular child and I thought about other, more able, special children…. And the more I thought, the more I came to realise that perhaps it doesn't really matter how intellectually able the person is or how profoundly incapacitated – everybody needs to know the truth about themselves.

BUT as I am not a professional in the field of special care, education, psychology or any other related field and as my area of expertise in this matter is related to my son, I thought that I'd dwell on his case.

DO I need to tell Kabir? What do I need to tell him? And when? And how? Taking into consideration that he has more profound difficulties with cognition than most, does it even matter whether I do or not? Will he even understand?

Do I need to tell him?

Unquestionably my son is aware that he is different from his cousins or the other boys and girls he meets in our Co-operative Housing Society. He is also acutely aware that, although he is a great singer and can pick up a tune in one listening, he is not like the many young children, some half his age and size, who perform so effortlessly in the many reality shows he watches on TV or the concerts we take him to. On reaching adolescence, he has often reacted as strongly as any regular teenager to his 'faults' being pointed out and he is as insulted as anyone if he is laughed at. It is clear that he is very aware of his shortcomings and the fact that he is different.

What do I need to tell him?

For sure, Kabir has many shortcomings. But he has many strong points too. In as many ways that he is different from you and me, in just so many ways he is just like you and me.

WHEN I was his age, I was stupid enough to believe that I could do anything I choose to. In my middle-class, cocooned world, anything was possible to achieve for a person of average ability such as me, with an encouraging nudge from average, loving parents such as mine – the world was mine for the taking, or so I thought. It was only much later in life, when I met people with immeasurable talent caught in unfortunate circumstances, which may have been in any form: physical, emotional, financial…. that I became acutely aware of, on the one hand my 'average ness' and on the other, my good fortune. I can hardly remember having to struggle too hard to achieve anything I wanted, despite how boringly, averagely, 'normal' I was.

BUT my special son belongs to a very different set of people – people who have had to struggle to achieve the simplest of things – things you and I take for granted – like eye-contact, language, speech, play, shared attention, togetherness, independence…and like so many who belong to this special group, he is so much wiser than I was at his age. He has always known that there are things he cannot do. That he needs to learn the ways of the world in order to fit in. That life is full of duties and compromises….

So then, what does he need to know about himself, what do I need to tell him?

He needs to know that even if he is different, he can achieve what he wants to – perhaps he will do so differently. He needs to know that he has as many or more strong points than he has shortcomings. He needs to know that he is no less than the next person and deserves as much in life. He needs to know that to his parents and family he is not a

(cont on page 7...)

· . · . · THE LIGHTER SIDE OF AUTISM· . · . ·

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A is an extremely able young man with Aspergers Syndrome. He knows about his autism and is completely comfortable about it (in fact he wears it like a 'badge of honour'). He is also an extremely friendly lad. He likes meeting new people, striking up conversations with them and getting to know them better. Of course, being on the spectrum, A's conversations sometimes may tend to have a slight 'copy and paste' flavour to them, along with a 'slightly' repetitive nature, where he can go on asking the same question over and over, till those being quizzed by him want to bleat "Mercy!"

A helps out in a centre that provides services to people with autism, and hence meets a lot of parents who have children with autism. In keeping with his 'copy paste' leanings….

A may ask "Has your child been diagnosed with autism?" If the answer is "Yes", then there is a big smile and many at our centre can see his thoughts rising like a balloon…. 'Another one in my tribe'! And, if the diagnosis is that of 'Autism with Aspergers Syndrome', as he prefers to call them, the grin is even wider!

BUT, for those hapless parents whose children do not have 'Autism with Asperger's Syndrome', A would ask "Does your child have any behaviour problems?" The answer is often a "Yes" and A impresses upon them "You must do some thing about their behavior problems. You must; you see he has to learn"

HAVING overheard one of these exchanges, one day one of our therapists asked A "So, do you have any behaviour problems?" With a benign smile, A said "that's very difficult to say...yeah I do...may be...I think" The therapist asked him "Do you know what they are?" The smile disappeared, as there was a perplexed "No, I don't know". The therapist reminded him "What about when you ask the same question repeatedly?" And the benign smile was back, as A said, "Oh, but that's not a behaviour problem, I do that because I'm not getting the right answer!"

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?? Your Son ??

Another one with A as the star. Like most NGOs, we at AFA, too get our share of people who want to volunteer their time with us. Around six months back, when A was visiting us, a couple of young high school students came in to look at some options to volunteer their time at AFA. The young lady in question was very much a quintessential high school girl, well turned out, coiffed hair, makeup in place, bright clothes, matching accessories….et al. And her boyfriend? Well, he was just a casually dressed young boy, who may have looked a wee bit younger to his girlfriend. We were sitting at our cafeteria, discussing options, when A sauntered in, and started chatting up the young lady, completely ignoring the boy. Now, wait a minute, we thought, this is highly unusual for A. A prefers interacting with young men because he considers them to be his peers, his 'friends'. We let it pass though. There were the usual exchange of names with the young lady, a few other questions thrown in, when A looked enquiringly at the young lady's boyfriend and asked her "And, who is this? Your son??!!" A kaleidoscope of expressions flitted on different faces in the cafeteria…… A's beatific smile, our poker faces as we tried desperately to control our chuckles and the young girl's expression of sheer, unadulterated horror! She emphatically said "NO!!", as they fled before any more such assumptions were voiced by anyone else. Rest assured that was the last time we ever saw or heard of this particular 'mother and child' duo!

(...cont from page 6)

person with the label of a disability, but a loved, cherished and respected young man. He needs to know that he can be a contributing part of the family and society. He needs to know that just as he can and has shaped his life for the last sixteen years, he can shape and give direction to his future. He needs to know that the world needs him because he makes a difference.

When and how does he need to know this?

He needs to know this all the time and in every possible way. This is because he does understand when he is discriminated against, and he does understand when he is accepted for who he is.

In this, he is very regular, 'normal', average, standard….. whatever adjectives you choose to use – in this, he is just like all of us.

I am sure you'll agree that even though I dwell only on the case of my child, Kabir, every child, every special child and most definitely every child with ASD falls in this category.

वर्तमान में प्रयोग होने वाली चिकित्साएं

एलिजेबथ के गेरलाक

1960 के प्रारम्भिक वर्षों में डाक्टर बर्नारड रिमलैण्ड को ऑटिस्टिक बच्चों के माता–पिता द्वारा सूचना मिली कि बच्चों द्वारा कुछ विशेष बिटामिन लेने के पूर्व उनमें सुधार पाया गया। डाक्टर रिमलैण्ड ऑटिज़्म अनुसंधान संस्थान के निर्देशक हैं। डॉक्टर रिमलैण्ड और अन्य साईसदानों ने जांच किया और पाया कि यह मान्यताएं सही है। इसके फलस्वरूप उन्होंने बिटामिन एवं मिनरल थैरेपी का विकास किया, जो कि कुछ ऑटिस्टिक बच्चों से सुधार के लिए प्रभावशाली पाई गई है। खोज कर्त्ताओं ने पाया है कि मैग्नीशियम के साथ बी–6 बिटामिन (जैसे– पोरिडॉक्सिन) की भारी खुराक 40–45 प्रतिशत बच्चों में प्रभावशाली सिद्ध हुई हें। कई वैज्ञानिक अध्ययनों ने भी यही सिद्ध किया है।

1. बिटामिन बी–6 और मैगनीशियम पानी में घुल जाते हैं ओर इस कारण शरीर में चरबी के साथ ठहरते नहीं है। इस कारण यह महत्वपूर्ण हो जाता है कि उन्हें अन्य बिटामिनों के साथ भारी मात्रा में लिया जाय जिससे बिटामिन बी–6 और मैगनीशियम का सही मेटाबॉटलज़म हो। कर्कमैन लेबोरट्री में ऐसे बिटामिन बी–6 एवं मैगनीशियम का सही मिश्रण बनाया जाता है। इसे गोली और पाउडर के रूप में खाद्य पूरक के रूप में लिया जाता है। गोलियों को सम्भालना सरल होता है पर यदि बच्चा गोलियां नहीं ले पायें तो उन्हें पाउडर रूप से पालन किया जाये। खुराक बच्चे के शरीर में भार के आधार पर निर्धारित होती हेट ''ऑटिज़्म अनुसंधान संस्थान'' (ऑटिज़्म रिसर्च इन्सटीट्ट) एक पत्र और फार्म प्रदान करता है जिसमें बिटामिन थैरेपी के विषय में पूर्ण सूचना और खुराक संबंधित जानकारी एक सूची के रूप में दी जाती है। इस संदर्भिका का अध्ययन करने के बाद ही बिटामिन थैरेपी आरम्भ करने का सुझााव है।

2. डाईमिथइल (डी0एम0जी) पूरक ग्लाईसीन :

इस का नाम बहुत ही टेक्निकल सुनाई देता है, परन्तु डी एम जी भी खाद्य पदार्थ है। इसका रसायन ढांचा पानी में घुल जाने वाले अन्य बिटामिन जैसा है। इसमें मुख्य बिटामिन बी–15 होता है। यह अमरीका में स्वास्थ्य खाद्य पदार्थ के रूप में आम बिकता है और इसे खरीदने के लिए किसी विशेष चिकित्सक आदेश की आवश्यकता नहीं होती। यह छोटी गोलियों के आकार में मिलती है, आसानी में मुंह में घुल जाती है और स्वाद में अच्छी होती हैं। तीस गोलियों के पैक की कीमत लग भग दस अमरीकी डालर होती है।

डी. एम. जी. की सफलता किसी भी प्रकार से वैज्ञानिक दृष्टिकोण से परिमाणित नहीं है परन्तु अभिभावकों ने इससे होने वाले निम्नलिखित लाभ बतलाए हैं–
मौखिक भाषा और आंख से सम्पर्क बनाना सामाजिक व्यवहार और अवधान में सुधार हो जाता है। पाउडर को खाने में या दूध और अन्य रसों में मिलाया जा सकता है।

इस पूरक में कोई बनावटी रंग या परिरक्षक रसायन नहीं होते। इसमें बी–6 के अलावा अन्य दूसरे बिटामिन भी होते हैं।

बिटामिन थैरेपी का मुख्य उद्देश्य शरीर के मेटाबॉलिज़्म को सामान्य करना होता है जिसके फलस्वरूप व्यवहार में सुधार होता है। अध्ययन द्वारा पता चला है बी–6 और मैगनीशियम मस्तिष्क लहर को सामान्य करता है, अति सम्बेदिक क्रिया और मूत्र रसायन को कर आम व्यवहार पर अच्छा प्रभाव डालता है। यह एलर्जी प्रतिक्रिया पर रोक लगाकर शरीर के प्रतिरक्षक पद्धति को मजबूत करते हैं। इस थैरेपी से होने वाले सुधार निश्चित नहीं है, परन्तु बहुत से बच्चों के माता–पिता ने मैगनीशियम एवं बिटामिन बी–6 से होने वाले जो सुधार बताये हैं, वह इस प्रकार हैः

1. मौखिक भाषा में सुधार
2. सोने के नियम में सुधार
3. उत्तेजनशील व्यवहार में घटौती
4. अवधान में सुधार
5. सीखने की इच्छा का बढ़ना
6. स्वहानिकारक और स्वप्रेरक व्यवहार में कमी
(सेल्फ इन्जरी एवं सेल्फ स्टिम्यूलेशन)
7. आम रूप से स्वास्थ्य में समस्त सुधार।

कुछ केस ऐसे पाये गये जिनमें बिटामिन थैरेपी के आरम्भ करने के कुछ ही दिन के पश्चात् व्यवहार में सुधार पाये गये। परन्तु आम तौर पर इसके परिणाम दो से तीन महीनों में दिखते हैं। यह आवश्यक है कि थैरेपी का नियमित ऐसा माना जाता है कि एक छोटे बच्चे 125 एम0जी0 की आधी गोली नाश्ते के साथ कुछ दिनों के लिए दी जाती है। बड़े बच्चों को एक गोली और वयस्क को दो–तीन गोलियां प्रतिदिन दी जाती हैं। यदि डी0एम0जी0 की खुराक जरूरत से अधिक हो तो बच्चे में अत्यधिक क्रियाशीलता आ जाती है और इसके अतिरिक्त और कोई हानिकारक परिणाम नहीं पाये गए हैं।

3. ऑटिज़्म के उपचार सम्बन्धित चिकित्सा (मेडिकल) :

ऑटिज़्म के उपचार के लिए कोई भी प्राथमिक चिकित्सा का प्रयोग नहीं किया जाता। कुछ विशेष लक्षण जो कि बहुत तीव्रता से बच्चे के लिए बाधा बन रहे हों और किसी कारण व्यवहार परिवर्तन जैसे मनोवैज्ञानिक इन्टरवेशन द्वारा सुधारे नहीं जा रहे हों, दवाई द्वारा कम किये जा सकते हैं। स्वहानिकारक व्यवहार, आक्रमणशाली व्यवहार, दौरे पड़ना, डिप्रेशन, अति अत्सुकता, हाइपर ऐक्टिविटी, ओ0सी0डी0 इत्यादि। परन्तु यह जान लेना आवश्यक है कि दवा देने से ऑटिज़्म लुप्त नहीं होगा बल्कि दवा के साथ यदि सही तरह हस्तक्षेप और व्यवहार प्रबंधन के उचित तरीकों का प्रयोग न किया जाये तो पूरा लाभ नहीं मिलेगा।

दवा के साथ–साथ बच्चे के वातावरण में परिवर्तन और सकारात्मक सहयोग सर्विस की आवश्यकता होती है। अभिभावकों को दवा से सम्बन्धित जानकारी दी जानी चाहिए। दवा के साथ यह जान लेना आवश्यक है कि इसकी सुरक्षा सीमाएं क्या हैं। माता–पिता को पता लगाना चाहिए कि सम्भावित जोखिम या खतरे और हानिकारक पक्ष क्या हैं। उन्हें स्वयं निर्णय लेना होगा कि सम्भावित फायदे और नुकसान में क्या अनुपात है। माता–पिता, चिकित्सक और अध्यापकों के बीच अच्छा तालमेल होना चाहिए। सही डाटा (दत्त उपात्र या रिकार्ड) रखना भी आवश्यक होता है।

निम्नलिखित दवाएं आटिज़्म के लक्षण के उपचार के लिए दी जाती है परन्तु केवल डाक्टर की सलाह से :–

1. ऐन्टी साइकोटिकस (प्रति–मनोविकृत)

यह प्रशान्तक दवाएं हैं और तीव्र व्यवहार होने पर सुझाये जाते हैं। इनके लेने पर जो साइड–इफेक्ट हो सकते हैं, वह अति निद्रा, कांपना और मांसपेसियों में झटका लगना है। मेलारिल, हेलडॉल और थोराजी के नाम से यह दवाएं मिलती हैं।

2. ऐन्टी कन्वल्सेन्ट (प्रति ऐंठन)

यह दवाएं दौरे पड़ने पर नियंत्रण रखती हैं। इन दवाओं से होने वाले साईड–इफेक्ट में नशीलापन, मसूड़ों का फूलना, नकारात्मक व्यवहार और बौद्धिक प्रदर्शन में कमी होती है। टेग्रिटॉल ऐसी दवा है।

3. ऐन्टी एग्लाईटी (प्रति–उत्सुकता)

यह दवा उत्सुकता से शान्ति होने के लिए दी जाती है। इनके लेने से कई बार व्यवहार सम्बन्धित परेशानियां हो सकती हैं। वेलियम, लिब्रियम, ट्रोफानिल और इलाविल के नाम से यह दवा मिलती है।

4. ऐन्टी डिप्रेशन (प्रति उन्माद)

यह दवाएं डिप्रेशन और बाध्यकर (कम्पल्सिव) व्यवहार होने पर दी जाती है। प्रीज़ेक, एनाफ्रानिल, लीथियम और डीपाकोट, एन्टी उन्माद दवाएं हैं। इनके साईड–इफेक्ट हैं– नींद कम आना, भूख कम लगना और क्रियाशीलता में अधिकता होना।

5. बीटा ब्लाकर :

यह अधिकतर रक्तचाप को नियंत्रण में लाने के लिए होती है परन्तु कुछ लोगों में तीव्र व्यवहार (जो कि अधिवक्ता या एड्रिनालिन के बढ़ने से होते हैं) में दी जाती हैं। इन्ड्राल, खिज़्मा और रक्तचाप का गिरना हो सकता है।

7. उपियेट ब्लॉकर (स्वापक अवरोधक दवाए)

कई बच्चों में स्वहानिकारक (सेल्फ इंजीनियर्स) व्यवहार देखे जाते हैं। स्वयं को शारीरिक चोट पहुंचाने से इन्हें सुखद आभास होता है। ऐसी मन्द करने वाली रसायन क्रियाओं को रोकने के लिए ''नेलट्रॉक्सिन'' जैसी दवाएं दी जाती हैं, इनसे सामाजिक व्यवहार और आम तौर से अच्छा अहसास होने में सुधार आता है।

8. उपशामक :

यह दवांए नींद सम्बन्धित परेशानी के लिए दी जाती हैं। परन्तु इनके सेवन का उल्टा असर भी हो सकता है। ''बेनाड्रिल'' और ''नॉक्टेक'' इसके उदाहरण हैं।

9. स्टिम्यूलेन्ट्स (उधिपति) :

यह हाइपर ऐक्टीविटी और अवधान सम्बन्धित परेशानियों के लिए दी जाती है। ''रिटेलिन'' ऐसी दवा है। इसके साइड इफेक्ट में भूख कम लगना, फसाद करना और दुःखी रहना इसके उदाहरण हैं।

एक बार फिर यह दोहराना आवश्यक है कि चिकित्सक हस्तक्षेप किसी भी तरह से ऑटिज़्म को दूर नहीं कर सकता और केवल कुछ लक्षण में सुधार दिखा सकता है। इनका सेवन केवल डाक्टरी सलाह के बाद होना चाहिए। खुराक और हानिकारक साईड–इफेक्ट की जानकारी है और इन सब दवाओं का लम्बे समय तक सेवन सही नहीं होना चाहिए।

रंगों का ज्ञान

वीना सिंह

रंग जो कि हमारे वातारण को खुशनुमा बनाते हैं। कल्पना कीजिए कि यदि ये रंग नहीं होते तो जिन्दगी कितनी उदास और सूनी होती। इन रंगों का ज्ञान और पहचान सामान्य बच्चे बहुत आसानी से कर लेते हैं। अपने वातावरण को देखकर और लोगों से सुनकर सामान्य बच्चे ये सीख जाते हैं कि लाल रंग की लालिमा क्या है और हमे रंग की हरितिमा क्या है ? लेकिन एक बच्चा जिसको आटिज़्म है उसके लिए रंगों का ज्ञान थोड़ा मुश्किल होता है। सेब की लालिमा और टमाटर की लालिमा को समझना थोड़ा मुश्किल होता है। अतः आटिस्टिक बच्चों को रंग सिखाने का तरीका थोड़ा अलग होता है।

रंगों को सिखाने के मुख्य दो चरण हैं :
1. रंगों के भेद
2. रंगों की पहचान (रंग का नाम– लाल, नीला इत्यादि)

1. रंगों के भेद

इस चरण में ये जरूरी है कि बच्चा एक जैसी चीजें एक साथ रखना जानता हो मैचिंग। तब हम दो या तीन रंगों की एक जैसे सामान बच्चे को वे देंगे और उसको बोलेंगे कि एक जैसे एक साथ रखो।

उदाहरण के लिए **–** लाल और नीला वीड **(**मोती**)** बच्चे को दिया और बच्चा उनको अलग–अलग करेगा, लाल को लाल के साथ रखेगा और नीले को नीले के साथ रखेगा।

2. रंगों की पहचान

इस चरण को हम कई छोटे–छोटे चरणों में बांट सकते हैं, जो निम्नलिखित हैं–

क – पहला चरण (कार्ड द्वारा) :

सबसे पहले हम जो रंग सिखाना चाहते हैं उस रंग का कार्ड लेकर बच्चे को दिखाते हैं। उदाहरण के लिए– जैसे हम बच्चे को लाल रंग की पहचान करवाना चाहते हैं तो हम लाल रंग का कार्ड लेकर बच्चे को दिखाएंगे। हम साथ में ये भी बोल सकते हैं कि लाल छू लो या ला दे दो। (बच्चे को पहले से “दे दो”, “ले लो” जैसे आदेश का पालन करना आता हो।

ख – दूसरा चरण :

कार्ड दिखाने के बाद दूसरे चरण में हम अलग–अलग तरह की चीजें इकट्ठा करते हैं जिनका रंग एक जैसा होता है। उदाहरण के लिए– अगर हम बच्चे को लाल रंग सिखा रहे हैं तो हम लाल रंग का कोई खिलौना, लाल ऊन, लाल पेपर, लाल कपड़ा, लाल लकड़ी का सामान इत्यादि इकट्ठा करते हैं। यहां पर हमें ध्यान रखना है। कि उपरोक्त सामान पूरी तरह से लाल होना चाहिए। जो भी सामान हम ले रहे हैं उनके सिर्फ आकार में, संरचना में और स्पर्श में अन्तर हो पर रंग बिल्कुल एक सा होना चाहिए जिससे बच्चे को पता चले कि लाल रंग की लालिमा क्या है।

इन चीजों को हम एक डिब्बे में डलवाते हैं, डिब्बे को भी हम बाहर से लाल पेपर से ढक देते हैं और बच्चे को बोलते हैं कि “लाल डालो”।

ग– तृतीय चरण :

इस चरण में हम लाल सामान के अलावा थोड़ा सा अलग रंगों का भी सामान रखते हैं जैसे – हरे और नीले रंग का कोई खिलौना या ब्लॉक। अब हम बच्चे को उपरोक्त चरण की तरह ही बोलते हैं– “लाल डालो” और डिब्बे में डलवाते हैं। जैसे ही बच्चा दूसरे रंग का सामान उठाता है हम बोलते हैं “लाल नहीं है” और उसको अलग रख देते हैं। ऐसा हम तब तक करते हैं जब तक बच्चा अपने आपसे (बिना सहायता के) केवल लाल डालता है और दूसरा रंग छोड़ देता है।

घ – चौथा चरण :

इस चरण में हम एक जैसे सामान का जोड़ा लेते हैं जिनका केवल रंग अलग होता है। उदाहरण के लिए– लाल और नीला बीड या ब्लाक आदि जो आकार, संरचना और छूने में सामान होते हैं।

इस चरण में हम अलग–अलग रंग के कार्ड लेते हैं और बच्चे को बोलते हैं “लाल दे दो” या “लाल छू लो”।

(cont on page 11...)

परिवर्तन कितना जरूरी

उर्मिला तनेजा

परिवर्तन जीवन का एक अहम अंग है। परिवर्तन हमारे जीवन में एक नया बदलाव लाता है। सभी परिवर्तन को लेकर काफी रोमांचित रहते हैं। परन्तु आटिस्टिक बच्चों का परिवर्तन को लेकर एक अलग ही नजरिया होता है। परिवर्तन आते ही उनमें कुछ बदलाव नजर आता है और वह कुछ अलग तरीके से व्यवहार करते हैं। एक तरह से कहा जाए तो परिवर्तन उन्हें पसन्द नहीं है क्योंकि किसी भी चीज में परिवर्तन आते ही वह किस तरह अपने में बदलाव लाएंगे यह उन्हें नहीं पता होता।

किसी भी परिवर्तन के आने से पहले हमें उन्हें तैयार कर लेना चाहिए। परिवर्तन में क्या–क्या चीजों में बदलाव आएंगे, उन्हें बता देना चाहिए। उनसे खुल कर परिवर्तन के बारे में बात करनी चाहिए। हमें उनको यह भी बताना चाहिए कि परिवर्तन जीवन का एक हिस्सा है और परिवर्तन आना एक आम सी बात है।
दूसरे शब्दों में –
“इट्स ओके”

किसी भी परिवर्तन के बारे में हम अगर उन्हें पहले ही तैयार कर पाएंगे तो परिवर्तन से वह घबराएंगे नहीं। परिवर्तन को एक आम सी चीज मानकर उसे आसानी से अपना लेंगे।

परिवर्तन के बारे में बात करने के साथ–साथ हमें जान बूझकर बच्चों के टाइम–टेबल में परिवर्तन करते रहना चाहिए ताकि अचानक कभी परिवर्तन होने से या किसी क्रियाकलाप (एक्टीविटी) के न होने सो वह परेशान न हो और आसानी से अपने सभी काम करते रहें।

परिवर्तन की बात जहां हो वहां बच्चे की फंसने की बात न हो यह हो नहीं सकता। कई बार हम जाने अनजाने कुछ तस तरह काम तय कर देते हैं कि वह एक दूसरे के साथ जुड़ जाते हैं और उनको अलग कर पाना मुश्किल हो जाता है। क्रियाओं या काम को कुछ इस तरह तय करें कि वह एक दूसरे के साथ जुड़ न जाए।

उदाहरण के लिए हम बच्चे को हर ब्रेक के लिए प्ले एरिया में भेजनते हैं। कभी वह किसी दूसरी जगह भी जाना चाहता है और टीचर की सहमति के बाद भी वह प्ले ऐरिया में रहता है क्योंकि यह उसका रूटीन बन गया है। किसी भी क्रिया को स्थिर समय पर न होने दें। टाईम–टाईम पर बदलते रहें। खाली समय के लिए भी एक एक्टीविटी न रखकर विभिन्न क्रिओं को रखें ताकि बच्चे के पास कई क्रियाएं हों और वह बोर भी न हों।

क्रियाओं में परिवर्तन के साथ जो कार्य हम बच्चे के लिए तैयार करते हैं चाहे वह कोई क्रिया सिखाने के लिए हो या अपने आप करने के लिए, कार्य प्रस्तुत करने का ढंग भी बदले उदाहरण के लिए – कार्य प्रस्तुत करने में हमेशा एक वर्कट्रैप, वर्कशीट, एक स्टिचिग मैट हो। कार्य भी बदलते रहें और कार्य पेश करने का ढंग भी।

इन तरीकों को अपना कर हम परिवर्तन को अपने बच्चों के लिए एक आम सी चीज बना पाएंगे। यदि तरीकों को अपनाने के बाद भी कोई मुश्किल आनी है तो परिवर्तन प्रक्रिया के दौरान आप बिल्कुल आराम से (कम्फर्टटेबल) और फोकस रहें।

(...cont from page 10)

एक बार जब बच्चा रंग सीख जाता है तो हम अपने आसपास के वातावरण में उसे बताते हैं या पूछ सकते हैं कि लाल शर्ट लाओ या लाल गेंद दे दो। इसी तरह से हम बाकी रंग भी सिखा सकते हैं। एक बात हमें और भी ध्यान में रखनी है कि यदि आपने रंग सीखना शुरू ही किया हे तो जो भी आदेश आप बच्चे को दे रहे हैं (“डालो”, “छू लो”, या “दे दो”) उसका पाल हमें बच्चे को पूरी सहायता देकर करवाना है। जैसे यदि हम बोल रहे हैं “लाल डालो” तो बच्चे को शुरूआत में उसका हाथ पकड़कर डलवा सकते हैं। बाद में धीरे–धीरे उस सहायता को कम करना है ताकि बच्चा अपने आप करे।

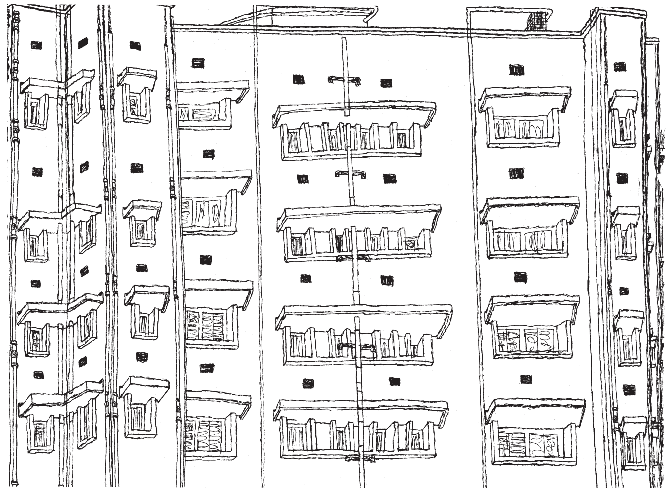
Abhishek - The Artist

Soma Sarkar

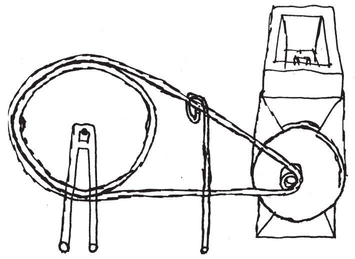
The cover of Autism Network (December 2009) carried a picture of a rabbit and a giraffe which was made by tearing paper. It was done by my 16 year old son Abhishek Sarkar.

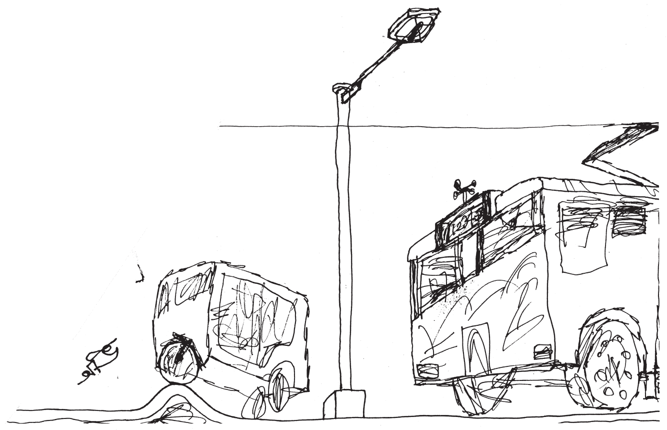
ABHISHEK is a student of the pre-vocational unit at Dikshan, a school run by Autism Society West Bengal. Abhishek does not use scissors. He just tears the paper with his hands to create different things like a giraffe, cow, elephant or trees. Abhishek also draws pictures and has been able to do so for a long time. However, he doesn't draw pictures on our request. The only time that he is willing to create something on other people's request is if he is asked to make something by tearing paper.

ABHISHEK draws things that he has seen himself. They could be something that he has seen when he had gone out, or maybe seen on the TV. He doesn't draw the whole picture depicting all that he saw, but only parts of the 'whole picture', the parts that **he** liked. When Abhishek is inspired by anything, he keeps it in his head for a while and draws it later. For instance we had gone to Dakshineshwar, a suburb of Kolkata, to visit some temples and months later, Abhishek drew some spires. Thinking that he had drawn something meaningless, I asked him what he had drawn. He immediately told me that those were the temples at Dakshineshwar!



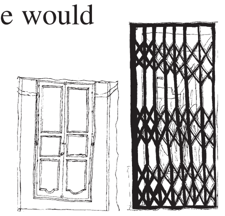
EVERYTHING that Abhishek draws has some meaning to him. It could be things that bother him, like the sound of pumps or the bumpy rickshaw rides, or things that he finds pleasing, like the straight, symmetrical lines of a block of flats or of the collapsible gate of a lift.





ONE such example is the drawing of the facade of a building, titled 'Calming orderliness of a block of flats', which is on the cover of this issue of the Autism Network. He never asks for paper to draw on. Instead he uses what ever is near at hand, like a copy of the news paper or some scraps of paper lying around the house.

WHEN Abhishek was little I thought he would learn to draw and paint pretty landscapes or portraits. But he didn't. He stayed true to his art which springs from the unique perception of an artist who has autism.



3rd South Asian Regional Conference: A Synopsis

Dr. Nidhi Singhal - Clinical Psychologist

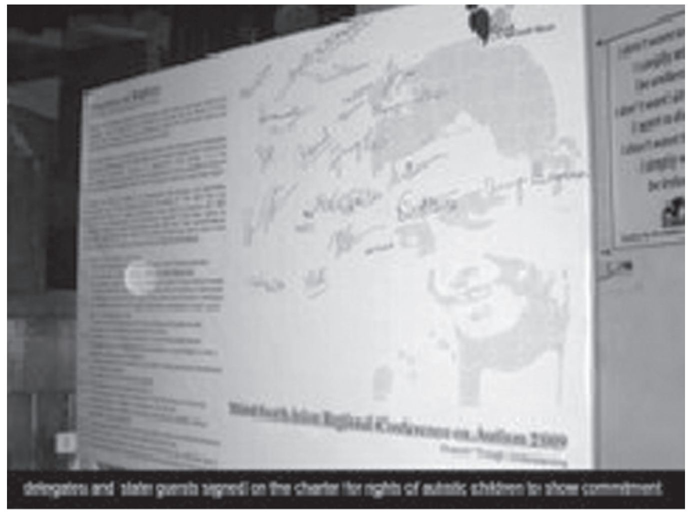
Director (Research & Trainings), Action For Autism

It is heartening to see that the initiative first taken by Rukhsana Shah, founder Ramaq Centre for Awareness and Social Responsibility, Lahore, Pakistan in December 2005, through the 1st South Asian Regional Conference on Autism, being sustained as we continue to work together towards a common objective of spreading awareness and building services for people with autism. After the big success of *2nd South Asian Regional Conference on Autism: Building Bridges*, organised by Action for Autism in January 2008; Bangladesh took charge of the *3rd South Asian Regional Conference: Support through Understanding* on 16 & 17 January 2009. The event, organised by Society for the Welfare of Autistic Children (SWAC), was yet another milestone in the autism community worldwide.

ATTENDED by a large number of parents and professionals, the conference was a well balanced mix of sessions on practical strategies on intervention and management of children with autism; updates on diagnostic, medical and research developments in autism in South Asia and personal accounts by self-advocates. In addition to speakers from Bangladesh, representatives from India and Pakistan presented papers and there were also video presentations by Dr Stephen Shore, the self-advocate from US.

THREE speakers from AFA were invited to represent the Indian subcontinent and made several presentations over the two days. Merry Barua presented the country paper and apprised the audience of the developments over the past year and the current scenario of autism in India. Her invigorating session on the issues and strategies that parents and professionals may use to facilitate the transition from adolescence to adulthood for a person with autism and those living with him or her was well received. The session was further enriched by valuable inputs from self-advocates Qazi Fazli Aseem, from Pakistan and Dr Stephen Shore. Kaneez Mustary from Bangladesh, and Dr Leedy Haque from England. Indu Chaswal shared strategies that may be used to work through inattention, hyperactivity and repetitive behaviours during a learning session. Merry and Indu presented the inclusion practices being carried out in India and shared their experiences about the practical difficulties that parents face in raising a child with autism and effective strategies that may be implemented. Dr Nidhi Singhal focused on the importance of screening and early diagnosis in autism and shared the development and implementation of the Assessment Kit for Autism, a screening instrument developed at Action For Autism. Designed for children aged 18 months and above the tool can be administered by anyone interacting with children including community-based rehabilitation professionals, special educators, and teachers and in a variety of settings such as day-care centres, child guidance clinics, schools, and homes. There were several presentations by medical professionals on the role of medication in associated conditions such as epilepsy and hyperactivity.

AS we all went back with a deeper insight into autism; we look forward to the synergy of this interaction continuing at Sri Lanka during the next South Asian Regional Conference.



delegates and state guests signed on the charter for rights of autistic children to show commitment

HELPLINE

ACTION FOR AUTISM

Q I am the mother of a 2 1/2 year old kid diagnosed with autism and mild developmental delay. My son achieved most of his milestones on time except for crawling after which he very soon switched to standing and he was walking just one week before his first birthday. Later we noticed that he always put his head down and never much noticed his surroundings when taken out. Physically he has no problems, his bonding with us his parents is natural and very good but we observed that his eye contact, communication skills and social skills were completely lacking. He never looked at what we pointed out nor did he point out at things. I have gone through your site and it has really touched me. No site provides so much information and the 'Original AFA articles' are really good. Reading your articles has made me think and now I have a few concerns and feel that I will find answers from AFA.

1. His eye contact is improving gradually but the main concern is his concentration. He has learned to stack blocks and rings long before we got his diagnosis. I have been asked to teach him beading and putting shapes into an insert box. He loves to play with beads but when it comes to putting them onto a string he has no idea how to do it. When I do the activity he hardly observes it and mostly stares into the space or will try to get into my lap to lie down. How do I make him sit, observe and concentrate? I am aware that it cannot happen in a day nor will he sit at a stretch. But how do I go about it and how can I make him sit for longer periods and observe things?

2. He has not developed speech yet except for a few words: says around 15 meaningless words and two or three meaningful words, has not yet called mummy and daddy. What is the best way to develop speech and how to stimulate him to speak?

3. He is very hyperactive and has also been diagnosed with mild ADHD, and has this habit of climbing up and down the steps. Whenever we go out and the moment he sees steps, he becomes uncontrollable. At home too he has the habit of climbing up the chairs and tables and also the slopes outside. How do we make him get rid of this habit?

4. He hates it when I brush his teeth. I just don't know which technique to adopt to make him brush. Please help.

5. He likes to play with older kids but when gets excited or happy or angry bites them or pinches them. Kids fear to come near him because of this. Is this a sensory issue and how to tackle it?

I would like to know whether any workshops will be conducted this year and when that would be. I would definitely like to attend any workshops.

A Thank you for letting us know that you found our website to be helpful. It is indeed heartening to know the same.

Autism is a condition in which the child attains milestones in a somewhat irregular fashion as compared to children who do not have autism. The areas that are most affected are the ability to communicate, connect with other people, areas of interest and play. These areas are often late to develop, but more importantly, they develop in unusual ways.

Milestones like turning over, crawling, walking are often achieved at appropriate ages in children with autism. The delay, as well as deviance usually happens in the areas of language and social interaction, where precursors like pointing, (both the child pointing and the child following another's point), joint attention, response to name, eye contact, babbling may be impaired. It takes some time for us to begin to understand the condition, and the more we do so, the better equipped we become to help our children progress.

Many children with autism also have different ways of 'sensing' their world. Some may not like being touched gently but prefer a firm hold. Others may have difficulty in brushing their teeth or having a hair cut. Some may keep seeking movement of a particular kind like running up and down a room 'aimlessly', or climbing on stairs or furniture. Many may seem unaware of the world around them and prefer to be left alone to their own devices. So, you see, your son's behaviours are quite typical of a child with autism.

Whilst interacting with and teaching children with autism, we need to use a lot of high energy, exaggerated gestures and excitement, making the learning process a fun and enjoyable one for the child, a process which the child will begin to look forward to. For instance, if we want the child to look at us more frequently, have better eye contact, we could make our faces and bodies exaggerated and alive, whenever the child looks, so that the child finds that something fun and interesting happens whenever he looks at us. This may encourage the child to look more.

1. For a lot of our children, 'work' may not be particularly reinforcing. Hence, they may be inattentive or unwilling to do the things that we would like them to do. For increasing our children's concentration and willingness to work, we need to make work time, enjoyable and reinforcing. Whilst teaching your child try to have fun with your child, sing to him, do things that he enjoys, so that work time is a fun time for him. Start with the child's interests and keep the demands on him very low.

When you are introducing a new activity, keep the activity short and prompt the child through the activity by physically guiding him, AND **follow it up with very big praise**. For instance, you've mentioned that he likes playing with beads. So, when you are working with him, you could start with him playing with the beads. Then get him to string just maybe 2 beads; help him string the beads with hand on hand prompt, praise him big and then let him go back to playing with beads. You could start with beads with big holes and a stiff wire, to make the activity easier for him, so that he achieves success quickly and can be reinforced for that success. As he learns, you could slowly increase the complexity of work and demands on him.

2. We know that children with autism are often not consciously aware that they can get things done by speaking; that they can get attention, or a toy, or food by speaking, we have to model speech in a very concrete fashion. So for example, if your son takes your hand and places it on a bottle when thirsty, you could say 'Water' before handing him the glass of water. He will begin to make the connection, that when the sound 'water' happens, I then get a drink. After awhile, you could say water and pause for a couple of seconds to see if he repeats it. If he does, please praise him, if he doesn't, still give him the water and continue with this pausing bit. However, please don't use 'say water'. If we use the word "say…." all the time the child becomes dependent on the word "say". So he will not speak until some one tells him "say water". Or he will say, "say water", when he wants water. You could try using the same technique before giving him anything that he wants.

3. You've mentioned that your son likes climbing stairs and chairs etc. This may be a sensory input that he needs, that he is seeking; something that may help him integrate his senses; something that helps him function better. Thus, getting 'rid' of the habit may not be a viable option. Instead we could try to provide him with appropriate alternatives for the inputs that he is seeking. You could engage him in activities that involve climbing, like a game of an obstacle course where he would have to climb on chairs, tables etc to reach a particular object or a goal. At the park he could climb on the jungle gym or a climbing frame. Walking on bricks or an elevated path is also an option. So you see we will be providing for something that he is seeking, but, in a structured, meaningful manner.

With regards to his wanting to go up and down the stairs when you go out, you could try to meet him halfway, i.e., you could tell him that he can climb the stairs maybe one or two times and then after that climbing stairs is going to be over. He may protest initially, but, if you are consistent, you will see that he will get the idea and begin complying. Once he is used to this, you could slowly wean him off this and let him climb stairs when you go out, only if he needs to do the same, i.e, say you are visiting someone and they live on the 2nd floor, so he can climb stairs. On the other hand if you are visiting someone who lives on the ground floor, that day, he goes straight inside the house without climbing the stairs. Prepare him in advance and praise him a lot when he complies.

4. Difficulty in brushing teeth may also be a sensory issue. A lot of our children find it difficult to brush their teeth. For making brushing teeth easier, you could try:
Different kinds of toothbrushes and toothpastes. There are toothpastes with different flavours available in the market that you may want to experiment with. Before using a new toothbrush, you could try to soak it in water. A vibrating toothbrush may also be of help. You could try to massage his gums just before the brushing to desensitise his gums. If using a toothbrush is still very aversive, you could massage his teeth with your fingers for the time being and slowly re-introduce the toothbrush.

It is important to remember to keep 'brushing time' enjoyable and fun and to acknowledge and praise your son for every effort that he makes whilst brushing, however small that may be.

In addition to this, an Occupational Therapist who has experience in dealing with sensory issues of children with autism may be able to help with further suggestions for the above mentioned difficulties.

5. You've mentioned that your son likes playing with older children, but when he gets excited or happy or angry he bites them or pinches them. This may be his way of interacting with them. It could also be a form of communication when the interaction is not very pleasant or too overwhelming for him. We could try to teach him appropriate ways of interacting with other children, the concept of taking turns, waiting for his turn, moving away if the games or the interaction becomes to overwhelming for him. You may want to teach these skills by replicating a play situation at home with a few, very familiar children who are comfortable with your son and vice versa. Once your son has learnt these skills and is comfortable, you could move similar games into a real play situation.

Playing games that would be of interest to him is a good place to start, for instance devising a game revolving around climbing, like the obstacle course, in which all the children could participate. Your being part of the group and facilitating your son when he is with his friends may also help your son learn better. In the meantime while you are still trying to teach your son appropriate social interaction, when you see your son getting excited or angry, try and move him away before he bites or pinches other children. In case you are not able to avoid the situation and he ends up pinching for instance, then, move your son away without comment (that is try not to pay undue attention to your son), briefly comfort the child who has been pinched (that is pay attention to the child who has been pinched). Do not give your son a long explanation on how bad he has been and how pinching and biting is bad and so on and so forth.

You mention that you may be interested in attending some of our workshops. Details of all our upcoming workshops are available on our website:www.autism-india.org

Q My son is 12 years old and diagnosed as autistic. I want to know about the residential schools in India, where proper care may be ensured.

A The National Trust Act (for the welfare of Persons with Autism, Cerebral Palsy, Mental retardation and Multiple disabilities) supports various organisations which provide both short term (respite care) and long term (prolonged care) for people who have the above disabilities. Two schemes supported by the National Trust

1. SAMARTH Centre Based Scheme: (http://thenationaltrust.in/NewWeb/Schemes.html)

This Centre Based Scheme which was introduced in July 2005 for residential services - both short term (respite care) and long term (prolonged care). Activities in a Samarth Centre should include early intervention, special education or integrated school, open school, pre-vocational and vocation training, employment oriented training, recreation sports etc. The facilities in the home shall be available to both- men and women- on 50-50% basis and shall cover all the four disabilities under the National Trust. The list of all the Samarth Centres is available on the website mentioned above.

2. GHARAUNDA: (http://thenationaltrust.in/NewWeb/Schemes.html)

The Gharaunda is a new scheme for providing Life Long Shelter & Care to Persons with Disabilities in Group Homes. The organizations which are part of the Gharaunda scheme are:
1. Open Learning System, Bhubaneshwar, Orissa
2. Karnataka Parents Association for Mentally retarded Children, Bangalore, Karnataka
3. Prayas Community Living Centre, Kolkata, W. Bengal
4. Partner Hooghly, Hooghly, W. Bengal

More detailed information on both these schemes is available on the internet.

Q My son aged 3 years, does not speak, does not respond to his name, has a lot of difficulties with changes, does not play with toys. Does he have autism? How can I find out? Where can I find services for my son?

A We understand your confusion about the difficulties that your son seems to be facing. You perhaps want to consult someone for a diagnosis, so that it is easier for you to help your son with techniques that are specific to his needs. A clinical psychologist, pediatrician, or a child and adolescent psychiatrist should be able to help you with an accurate diagnosis.

Please check, http://www.autism-india.org for a comprehensive list of organizations providing autism specific services across India.

Action For Autism's
UPCOMING TRAINING/ WORKSHOP

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Diploma in Special Education: Autism Spectrum Disorder

DSE - ASD (2009 - 2010)

Admissions are open for Action for Autism's (AFA's) RCI recognized course in Autism starting July 2009.

A premier organization training therapists and teachers to work with individuals with autism and communication handicaps, AFA offers training in one of the most challenging and exciting areas of Special Education. AFA has pioneered teaching strategies based on extensive practical experience and internationally used sound behavioural principles, adapted to Indian condition.

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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, and Social Work preferred, though others including10+2 pass with 50% may also apply.

Seats limited. Last date for submission of application is 29 May 2009.

For prospectus, application forms, or further queries contact:

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

Tel: 91 11 65347422, 40540991/92
Email: shikha.afa@gmail.com
Website: http://www.autism-india.org

Please mark envelopes 'DSE (ASD) 2009-10'

Workshop: Teaching Children with ASD

September 16 - 19, 2009

The workshop is aimed at teachers, both mainstream and special educators, and other carers covering a wide range of topics. These include The Culture of Autism, Communication Strategies: Going Beyond Speech, Applied Behaviour Analysis: Helping Children Learn, Addressing Challenging Behaviors, Visual Strategies to Enhance Learning, Developing Social Understanding, Play, and Leisure Skills, Children with Autism in the Mainstream Classroom, and Adaptive Daily Living Skills.

One of the series of AFA's much awaited workshops it will be illustrated with practical examples based on the AFA's hands-on experience and exposure to children with autism of varying ages and abilities. The workshop will follow a format of lecture, demonstration classes, video clips, question and answer sessions and discussions.

Childcare will be available during workshop hours for participants who have young children needing supervision.

Reading Material and books on Autism will be available at the workshop site

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

For further details contact:-
Shikha Bhardwaj, Training Coordinator
National Centre for Autism
Pocket 7 & 8 Jasola Vihar
New Delhi 110025

Tel: 91 11 65347422, 40540991/92
Email: shikha.afa@gmail.com
Website: http://www.autism-india.org
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MEMBERSHIP TO AFA

To continue to receive ‘Autism Network’ please complete the application below, cut or photocopy, and return it to us as soon as possible.

MEMBERSHIP DETAILS
Parents: *Associate Member* – Annual: Rs 150/- *Full Member* – Annual: Rs 500/- *Life Member*: Rs 5000/-
Professionals: *Associate Member* – Annual: Rs 150/-
Full Member – Annual: Rs 1000/- *Institutional Member* – Annual: Rs 2000/- *Overseas Membership* – Parents $ 30, Professionals $ 50
Associate Members receive copies of Autism Network and information on all upcoming events and activities. Full Members, Life Members, Overseas Members and Institutional Members are in addition, entitled to concessionary rates for AFA events and workshops.

☐ New ☐ Renewal Date

Name

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State Pin/Zip

Phone Email

I am a: (tick all that apply)

☐ Parent ☐ Relative

☐ Professional

☐ Other

If you are a parent of a person with autism, please answer:

Child’s name Sex

Date of birth

Diagnosis (if known)

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

☐ Rs 150/- ☐ Rs 500/- ☐ Rs 1000/- ☐ Rs 2000/-
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The Editor, Autism Network,
Pocket 7&8, Jasola Vihar, Behind Sai Niketan,
Opp. Gate 6, Sector 8, SFS Flats, New Delhi - 110025

Published & printed by Merry Barua
on behalf of Action for Autism (AFA) from
Pocket 7&8, Jasola Vihar, New Delhi - 110025

Tel: 91 11 40540991, 91 11 65347422
Email: actionforautism@gmail.com
Website: http://www.autism-india.org

Printed at:
Niyogi Offset Private Limited
D-78 Okhla Industrial Area Phase I,
New Delhi - 110020
Tel: 26816301/26813350/51/52 Fax: 26813830

Editor: Merry Barua