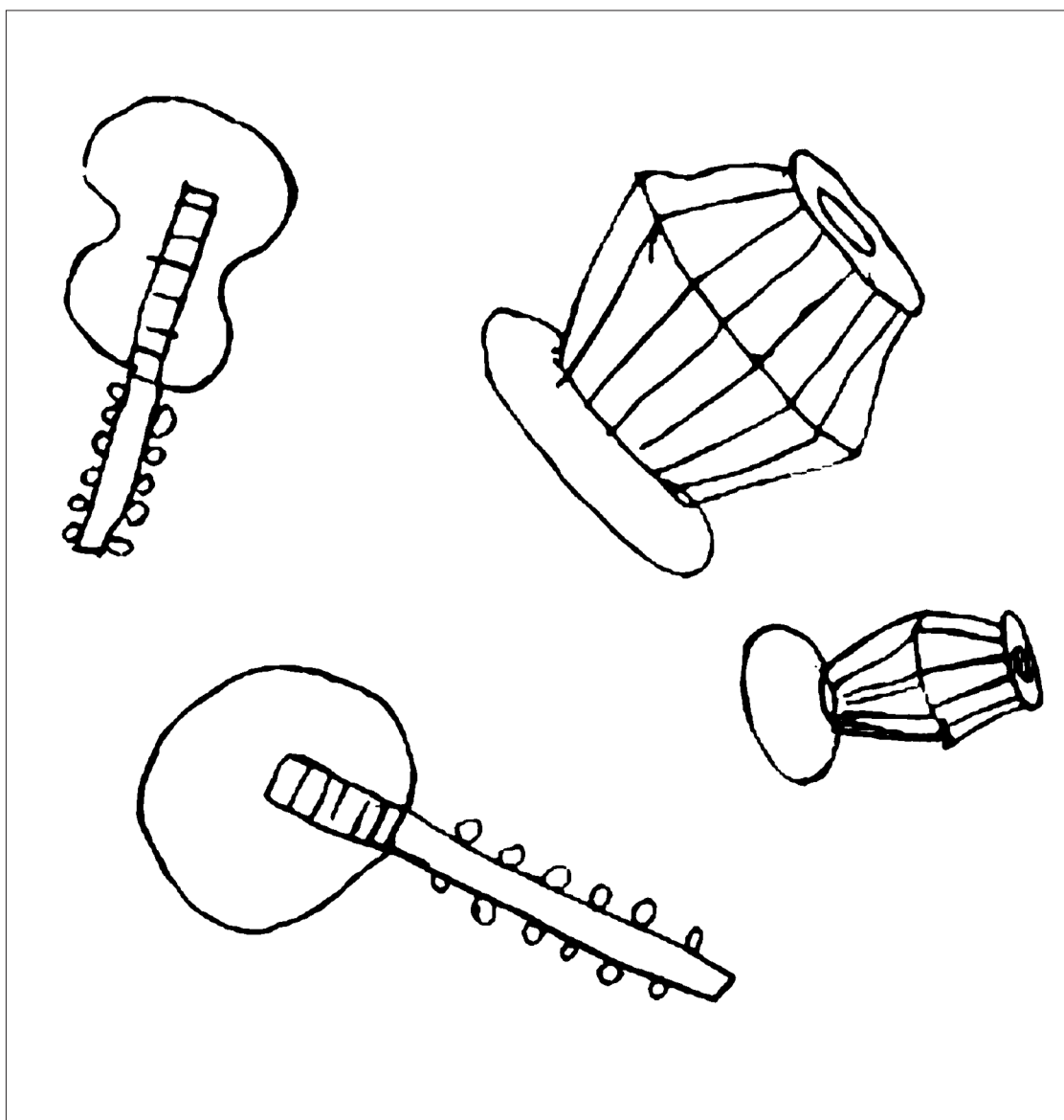


autism network

AUGUST 2011 VOL.6 ISSUE 2



ACTION FOR AUTISM



autism network

AUGUST 2011

VOL 6 ISSUE 2

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.

Autism Network is a forum for expressing diverse opinions. Action For Autism does not hold itself responsible for opinions expressed by individual writers. Publication of any information does not mean support of Action For Autism.

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INFORMATION

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Sector 8, SFS Flats, New Delhi - 110025. Tel: 40540991/2

YOUR CONTRIBUTIONS

Do you have any comments, suggestions to offer? Information and experience to share? We look forward to our readers' participation. Send letters, articles, illustrations to:
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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'.

Website: <http://www.autism-india.org>

Helpline Email: helpline.afa@gmail.com

Cover Illustration

'Musical Instruments'

by Saubhik Bhattacharya, 16 years, Student
Indigo Class, Open Door

WISHLIST !

- Apartment/ House/ Residence for people with autism
- Microwave for cooking skills
- Washing Machine for independent skills training unit
- Computers that can support graphics
- Digital Video Camera to record children's progress
- Laptop & LCD projector for trainings
- Trampoline
- Cross trainer
- Light & sound making toys
- Lego: large & small blocks

Stationery:

- Cobra/ Box files for student records
- Fevicol Jars
- Paper & plastic file covers
- Markers, pencils, pens, coloured sheets, chart paper
- Reusable/ fresh A4 paper
- Handmade paper sheets for artwork
- Glossy magazines
- Sticky back Velcro
- Reusable visiting cards
- Empty shoe boxes
- Acrylic paints

Volunteers :

For yoga, art & craft , music, Respite care
If you want to help, write to AFA or call:

- AFA: 40540991/2 • Reeta: 9811103702

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PAGE ONE

As the sweltering days come to a close, this issue brings a breath of freshness in Fazli Azim, a wonderful young man from Karachi we were privileged to welcome to the South Asian Regional Conference that Action For Autism held in Delhi in 2008 – the second in a series initiated by Rukhsana Shah of Pakistan. Fazli is very comfortable about his autism diagnosis which he received in adulthood. Interestingly, his family does not raise any objections to his openly speaking about his autism. This, in South Asia, is rare. In India persons with autism who communicate their experiences are mostly those who do so with support of their parents; independent communicators like Fazli are rare.

It was Temple Grandin's autobiographical *Emergence*: Labelled Autistic that opened up the possibility of persons with ASD communicating: speaking and writing, about themselves and their autistic reality. While there are not many who can or do advocate for the autistic community as a whole, a significant number of persons with Aspergers Syndrome (AS) and High Functioning Autism (HFA) are effective self-advocates. I remember listening to Gunilla Gerland and Ros Blackburn, way back in 2000 and being struck, especially by Ros, revealing matter-of-factly and with humour, aspects of her life that most families in India would react to with embarrassment and shame. This acceptance of the autistic experience as valid, is something we are still very far from achieving.

It is pertinent to look at the reasons for this; and there are several. One is that there are few identified adults with AS or HFA since they would have had to receive a diagnosis around 15 years ago; and it is only in recent times that this population have begun to receive a diagnosis in India. Most adults continue to remain undiagnosed. Secondly, of those who have a diagnosis many do not want to 'come out' so to speak because of the 'double' stigma attached to a diagnosis of any disability that is non-physical in nature. Where families or schools or other environments hold on to judging autism as bad and shameful, those beliefs get picked up by the person with autism too, so much so that many cannot accept that they have autism.

Some individuals have had such traumatic experiences all their lives, and particularly at school, that though they are

comfortable with their diagnosis they, quite expectedly, still prefer not to speak about it openly for fear of a repeat of those experiences. And then there are those individuals whose diagnosis have not been revealed to them by their families. Sharing their diagnosis with the individual with autism is surprisingly rare in India. For families who wonder if there is any point in doing so, it is worth quoting Gunilla Gerland: "Eventually I ... was diagnosed. That is one of the best things that happened. The diagnosis also put me in contact with several people with diagnosis within the autistic spectrum and some of them have become my friends."

Given society's perceptions of disability, the desire to pretend that there is no special need, is very strong. Especially where like autism, the condition is 'invisible' and acceptance is harder to come by, and using the 'we should not label' stand is tempting.

BREAKING NEWS!

Action For Autism is the 2011 recipient
of the International
Naturally Autistic People Award

What makes the award precious is that
it is given by ANCA, an organisation of
Persons with Autism Spectrum Disorders

A friend who has mobility impairment and uses what he calls a 'walker' once joked: "Yeah don't label me. My 'walker' is invisible haha!"

He elaborates: "My 'walker' stares you in the face. You don't need a label to see that I have a disability. You can see I need help

with latches and switches. Someone holds the door open for me if the door switch does not work. But I really think it's stupid to not label Neeraj's autism. How else will people know that he needs a visual: to help him wait; or to know what is expected of him so that he does not have a meltdown."

How indeed?!

And that is what I enjoy about Fazli's view of autism. It's all out there, with no ifs and buts. Take me as I am, label and all. On a further subcontinental note, Bangladesh recently held a conference at the initiative of the PM's daughter Saima Hossain, with support from Autism Speaks, the WHO, the Bangladesh Government, and the Centre for Neurodevelopment and Autism in Dhaka. Saima pulled out all stops, inviting first ladies and government officials from nine south Asian states and with Mrs Sonia Gandhi as Chief Guest. With the resultant media blitz, civilian interest, and the awareness generated, Saima achieved in two days what it has taken AFA more than 15 years of dogged struggle to achieve. More power to the Saimas of the world!

Message from Fazli Azeem of Planet Earth

Fazli Azeem

International Self Advocate for Aspergers Syndrome

Hello to everyone, the special educators, the parents, doctors, friends, the network of people around the world, who are reading this right now. I met some of you during January 2008 at Delhi, when I presented a paper on my life and living with Asperger's Syndrome, at the 2nd South Asian Conference on Autism, which was hosted by Action For Autism. If you have not seen my video interviews on my YouTube channel www.youtube.com/qfazeem or read about me on my websites www.fazliazeem.com and www.autismpakistan.org or gone through the thousands of pages of free advice on www.autism.meeup.com/77, then I encourage you to do so, after you have read this article.

I live in South Asia, speak the same languages as most of you, eat the same food as you (and don't get sick) and watch the same movies that you do. I have photographic episodic memory, the same as described by Dr Temple Grandin in her book 'Animals in Translation'. This means that I remember things well, and use every experience, conversation, book, every video or TV program I have seen, to help me understand the world better. The more I help others, the more I understand myself.

I never lost speech, but had echolalia, I repeated sentences to get things, e.g. I would say 'do you want water' to people, they used to think I am being polite, but this was what I heard others say to me before I got water, hence I repeated it to be able to get water, not understanding what this sentence actually meant. The most painful thing I can remember is the sound of a child crying. I only have a sister, nine years elder to me, hence my house did not have other small children, and this gave me a quiet environment to play, and emulate and copy what I saw. I used to see my sister read; both comics and books, and I tried doing the same, when she was at school. This led to 'hyperlexia', I was partially making



sense of comics and understanding pictures before I could speak.

My parents saw me attempting to read comics and rewarded me with toys and picture books, and hence started a cycle of positive re-inforcement. Whenever I was praised or got attention, I did that thing even more. I look back and seem to understand how I overcame most of my sensory issues. I had lack of eye contact with others, and was shy, often hiding underneath the bed when strangers came in the house. I understood more about empathy, relationships and conversation by studying the behavior of my cat for over a decade, than from any person.

MY food was high in spices, not the packaged kind but the fresh powdered or home prepared version, with a high dose of citrus fruits and Vitamin C in everyday food. Vitamin C has been medically proven a natural chelation agent, used in cleansing the body of harmful substances. My mother followed a family tradition which has been done for hundreds of years, to soak seven almonds in water overnight and eat them before breakfast the next day, without their peel. Almonds are a natural source of Vitamin B12, some children in the west are given injections of it under the supervision of doctors, and B12 is the only known preventive and remedy for Alzheimer's and Dementia, with no documented side effect, aside from almond allergy in rare cases.

I remember three things that really bothered me for a long time, cutting nails, cutting hair and taking a bath, for which my family had to chase and catch me. With nail cutting, clipping too close to the finger caused the sensitive part of the skin to be exposed, and that sensation caused over stimulation for days, so one way I fixed that was learning to cut nails myself, leaving some space and nail far from the fingers. With hair cutting, the sound and feel of the metal scissor was irritating, and that was fixed when the barber switched to plastic scissors on my insistence. With taking a bath, the water had to be

slightly warm, not cool and not mild, and I used to sit in the bath for hours, just as I used to play with clay for hours and this through osmosis, removed water from my skin, made it all wrinkly. I read in 2006 that this is the safest biological way to remove metals from the body, to play with clay or sit in water for hours, so that some water leaves the body and the skin turns wrinkly. I also used to swim in shallow water pools at the local club, and all the people swimming and making noise there bothered me, so I started doing underwater swimming, using goggles and ear plugs. This helped me in exercising as well as adjusting ear pressure changes. The same ear pressure changes happen when I travelled in a lift or in an aircraft, was quite painful, yawning, as well as closing nose and blowing, as well as menthol nasal medicine helped cope with it. Later, I started removing all hair on and near the ears using hair removing cream, this helped in temperature and sound sensitivity, as well as skin sensitivity (when I used hair removing cream to remove hair on arms and body, due to the heat of the summer). Getting the whole head shaved at least once around age 8-10 is also recommended, the hair grow back fast and the body adjusts to temperature and sensitivity changes.

I was never good at social conversation with other children, so neutral activities like playing with Lego, or making jigsaw puzzles, drawing, making small toys with clay, these became social group activities with other children in which we did not talk, but participated at our own pace, making something and showing it to one another, competing, learning and sharing creations with parents and other children. I noticed that when I concentrated on the words and read books, my hearing stopped, hence I kept comics and books with me, in social situations, I started reading and hence did not require a quiet room to calm myself down. I noticed my heart beat increased and I started sweating when around too many random noisy people, this was due to adrenaline being released due to hyper stimulated large amygdala, a part of the brain related to fight and flight response, a common feature in children with autism, and this was one of the reasons for not making eye contact: it was over stimulating and alarming, a simple conversational glance in someone eyes felt like a long aggressive stare, perhaps due to the resonance effect. Nikola Tesla, one of the greatest inventors in human history, and the inventor of most electrical equipment used today, used this concept in his work commonly. Resonance is an electrical phenomenon, and is the basis for the transistor, working on the concept of feedback and overflow of current. The human brain works on a 5

volt electric circuit, the myelin sheaths of neurons are sometimes weak, and a synapse firing may trigger other parts of the body. In my case, a pin prick to one hand gives a signal to my brain that the other hand is being pricked, i.e. the wiring is sometimes crossed and confused. When a person with autism sees another person's eyes, a visual image is recorded, and on prolonged conversation with variable volume indicating urgency or importance of a topic, the snapshot of the eyes in memory coupled with increase in volume of the speech and repeated fixed gaze, overloads the visual brain, causes the adrenaline to enter the blood, causes a fear or panic situation, where the conversation must be broken and a quiet environment is needed to reset the senses, hence the sensory neutral environment or room. I was able to reset my hearing and block it by focusing on text, hence I could only talk to people if I had a book or comic in my hands which I could look at again and again, to reset myself.

I had issues with remembering phone numbers, names of people, which I fixed using associative sound based memory. If I wanted to learn someone's name, I remembered another person or city or object which had a similar sounding name, associated the image of both of these people or objects, remembering one linked with the other allowed me to remember names. With phone numbers, I had to say out the phone number, and remember it as a sound recording, not as numbers themselves.

I never went through the hand flapping or 'stim' phase, by that time I had discovered cracking knuckles and pulling fingers, it used to calm me down in overloaded sensory unfriendly environments. In 2006 I studied this phenomenon, and contacted people with Asperger's all over the world, through the internet. I asked them about this and it confirmed my findings, which to my knowledge are still un-documented. This forms the base of physiotherapy and is the same biological concept. Human joints and bones are surrounded by a liquid called synovial fluid. When you pull a joint or a finger, or even exercise or stretch, the pulled or stretched joint leaved space in the synovial cavity of the joint, causes a temporary vacuum to form, hence the popping sound. As soon as the vacuum is created, carbon dioxide bubbles are pulled out from the synovial fluid and into the vacuum, signalling to the body that some carbon dioxide has left the body, increasing the concentration of water and oxygen in the synovial cavity. This automatically makes the brain release dopamine neurotransmitter as a result of rewarding this 'temporary removal' of carbon

dioxide. By the time the finger or limb goes back to normal position, the dopamine has already been released into the bloodstream, and acts as cigarettes do, i.e. it calms a person down instantly, reducing the sensitivity of all the major senses in the body. Dr. Arvid Carlsson of the University of Gothenburg was awarded the 2000 Nobel Prize in Physiology of Medicine for his discovery in the 1950s that dopamine is a neurotransmitter in the brain and that it has a role in movement control. Dr. Carlsson's work laid the foundations for use of levodopa as a treatment for Parkinson's disease. What this means is that for a person on the spectrum, with the obvious motor and grip control problem (symptomatic of dyspraxia), the dopamine neurotransmitter not only acts to calm them down, but to also act as motivation, intercommunication between the two brains hemispheres as well as a way to balance movement, and fine motor control. Hence hand flapping or jumping or even rolling on the floor is the body's unconscious attempt to release dopamine, perhaps due to secondary addiction to, but primarily as a natural response to environmental sensory stimulation. Hence if a child is told to control and 'de-stim' using the cracking of knuckles, it's certainly a better alternative to hand flapping. This has implications for using Parkinson medication to manage some forms of Autism, the research on which is going on across the world.

MY later awareness of Autism in 2006, when I was 25 years old, made me understand and work with the world in a very different way. Before 2006, I had not the words to describe what I went through, since I thought everyone went through this every day. When I read that Wikipedia article on Asperger's Syndrome, I thought they were describing my life, it was so similar. I find that lack of awareness around the world leads to late diagnosis of Asperger's Syndrome, since the language areas are not majorly affected, and hence less of an immediate concern for parents, they mistake social confusion for shyness. Since 2006, I reached out to the world, emailing world experts in Autism, Savant Syndrome, Genetics, Advocates, Doctors, Special Educators and parents abroad. Since I was looking for my own diagnosis as well as explaining myself better, managing my own issues, this became an obsession, most of my free time was spent in online interaction, learning, sharing and understanding myself through others, watching documentaries, reading articles and current research. My ability to remember most of it helped me to meet these people online and in real life again and again, since the autism community is not very large, there are few experts who know each other on a first name basis.

The first person I had emailed was the expert on savant syndrome, Dr Darrold Treffert of the University of Wisconsin USA, I kept running into him online, as well as Adam Feinstein who I had met online during his first 2006 Autism Online Research conference at awares.org, and I met him for the first time in person during January 2008 at the 2th South Asian Conference on Autism as Delhi. He interviewed me there for his book "A History of Autism: Conversations with the pioneers". It was at Delhi that I also met fellow Asperger, Dr Stephen Shore, a director at the Autism Society of America, and the ASA website allowed me to get latest updates, which included attending the UNESCO disability conference at Qatar in 2008, meeting Bob and Suzanne Wright, the founders of Autism Speaks USA, who were the main guests there of Shieikha Mozah, the Queen of Qatar. I represented my country as speaker at the Bangladesh 3rd South Asian Conference on Autism in 2009, expanding my contacts, training people in Chittagong later in 2009. I followed Dr Darrold Treffert's work closely, since I suspected some of my abilities may be related to savant syndrome, since I had not yet heard of other people on the spectrum matching them, except for Dr Temple Grandin. Dr Treffert wrote the introduction of the *Artism: The Art of Autism* book by Debrah Hosseini, I applied for it in 2007 for its second volume, which was just published a few months ago in USA and can be read about on www.artismtoday.com.

I see advocacy and fundraising as well as recreation have been combined well with the international movement to promote awareness of Autism through Art, and this is something that we can do much about, in this part of the world. I had been trained in sculpture and drawing at a young age due to my work with clay, and my current career as a graphic designer and computer graphics teacher allowed me to create both digital and conventional art, which was displayed at local and international art galleries, and featured in the 'Artism' book. The work of all the artists in the book has recently been displayed at the Soho Gallery for Digital Art in New York 7-27 July 2011, selling prints of original art to support a non-profit special school in New York for children with Autism.

NEVER forget that we are a single community. We all have contacts, resources, ideas, the same objectives and needs. Across the world, parents and families of children with autism are working together, sharing resources, using the media positively to spread awareness as well as provide and promote opportunities for fundraising. The Internet forms a central part of this, it's very easy to be

an armchair activist, changing the world a little every night through the internet, posting articles, videos on forums, emailing experts, guiding those who need it and networking online. With Google+ as the new social media network after 'Facebook', up to 10 people can video chat at the same time, using any laptop with a built-in camera and microphone. This has implications on group learning, where an expert does not have to be invited if there are restricted funds, you could train and educate online, and get paid online for the number of hours taught, all without leaving your room. There are websites like freelancer.com, odesk.com and elance.com where you can work from your home and still take care of your children whenever you need to. My video interviews and their recordings were put on YouTube where they act as 24 hour awareness, I even put subtitles in English on the local language ones, the awareness goes on even as I sleep and do other work.

IT's very important to contribute and teach others after you have learned something and applied it well, since you never know what the person seeing your video or reading your article can share and teach you. You are not alone, you never have been. I taught myself to use the computer, and I failed consistently for over 5 years, breaking the computer or crashing it every few weeks, but I was adamant and kept at it, learning from mistakes. I teach at universities, with over 8,000 highly qualified professionals trained in the last decade. It's important that we use technology to enable our lives, to help us multi task, to help us network. The world is filled with millions of parents and special educators and doctors just like you. Come forward, we are one people with the same future, a shared future, a brighter future. Today is the first day of the rest of your life. I have done it, I have trained thousands, changed their lives, and I know you can do it too. You are pioneers, each and every one of you, the more you share and teach others, the more your name will live on. Humanity will look back on this time as an age when people overthrew these mental and self-imposed limitations, and embraced their international identities, and became true citizens of the global village. You are an international community, so email someone you don't know today, some will write back, some will share, some will learn, but we all will benefit from your initiatives.

GOOD luck, this is only the beginning. We do this for the future, we do this for the children, we do this for the human race.

Contact Fazli Azeem: www.fazliazeem.com
www.autismpakistan.org, <http://autism.meetup.com>

Morning and Night

Tapati Ghosh

Am I always wrong and you are right?
 Are we as different as Morning and Night?

'No' and 'Don't', so often you say –
 To anything I do or come in your way.

I am confused - I wish I knew
 What have I done to confuse you?

You think that I am odd to the core.
 Your social rules unsettle me more.

Over my head I see these fly -
 I am relieved, I do not lie.

The street lights make me blink my eye
 I cover my ears when the taxi goes by.
 I climb up the stairs and can't get down.
 You laugh at me and call me a clown?

Does it hurt you if I flap my hand?
 Or, play with a string - on toes I stand?
 Makes me wonder, then why you should
 Stop me, when I feel so good?

Look, I am okay and not perplexed,
 When I get to know what is next.
 With the sameness I feel safe,
 Changes make me 'lost like a waif'.

You said something? Did I defy?
 Come again slowly, I'll comply.
 Something in me strikes a chord.

Peep into my world once for a change,
 Maybe you'll find it not so strange.
 Maybe you'll enjoy what you see,
 And then won't wish for a different ME.

No harm to have our different ways,
 We - 'Morning and Night' will bring...
 HAPPY DAYS!!

Strategies to Enhance Social Understanding, Leisure, and Play Skills

A central feature of Autism Spectrum Conditions (ASC) is a different social understanding and social functioning. It is usually difficult for the individual with ASC to develop and maintain meaningful and fulfilling personal relationships. The earlier perception of individuals with ASC was that they were 'loners,' because they do not want to interact with people. But now is accepted that people with ASC want social interaction, but lack the necessary skills to interact effectively. So the child who pushes his peers away in the playground may actually be doing so because he wants to initiate social interaction. The anxiety of not knowing what to do in a social situation is what often leads the individual with ASC to avoid social situations, thus creating greater isolation.

WHEN we begin to encourage social interaction in the very young child, we have to begin by first building connections with the child, by helping the child understand that interacting with others can be fun and non-threatening. We do not demand interaction, but rather let the child lead the interaction and respond with a great deal of enthusiasm and energy. We give the child things he likes – hugs, tickles, a favoured toy, etc, without expecting anything in return, teaching the child that proximity of people is fun.

WE can try and create an interest in others by joining him in his solitary play. So when the child is playing on his own we play on our own in a manner similar to the child's – again and most important, making no demands - using a lot of exaggerated energy and encourage any connection that is created. Playing games with anticipation like tickling games and 'peek a boo' games can also be tried here.

WE can then move to slowly joining the child in parallel play so that a teacher / peer and the child are both playing with similar materials in the same physical space, but there is no sharing of materials. For example, both the child and the partner are fixing their individual jigsaw puzzles whilst sitting on the same 'dari'.

FOR the older or more socially adept child, there could then be sharing of materials with a partner in cooperative

play for instance, both the child and the partner make individual structures with blocks, but both selecting blocks from a common box. Others can play simple turn taking games where the child needs to take turns with a partner or partners.

IN all of this it would be helpful to have a very clear visual structure to the game, so that the child can understand the 'rules' of the game clearly, predict exactly when he is going to get his turn, when is it his turn to wait, how many turns he is going to get and when the game will get over. We can start with simple customized games as shown below:.



Examples of simple adapted turn taking games

For instance, each of the two players has a set of dice. One child puts a dice in the central box. The partner has to place a matching dice in the box. The turns continue until all the dice are over. Here the children know what has to be done from the way the game is laid out; how much they will have to play ie whenever the dice are all in the central container; and when it is over ie whenever their trays are empty. This visual clarity helps the child with autism stay focused on the game and participate without frustration or confusion. Such customized games can then help the child move on to board games like 'tic tac toe', 'snakes and ladders', 'checkers' and 'ludo'.

ALONGSIDE, we can also introduce basic pretend play, where we can have simple scripts that we can help the child to follow. It is essential to keep small variations in the 'script' daily so that the child does not 'memorise' the game. For example, we can have a game with dolls about going to the shop and buying things. So on one day, the doll can go to shop 'A' and buy tomatoes, on another day she can go to shop 'B' to buy 'Kurkure'. If

the same game is played each time without a variation, then the child with autism will tend to memorise the game and replicate it every time without understanding the 'play' aspect of the game. We can include situations in the game that will help the child learn to understand other peoples' minds and other peoples' behaviours (Theory of Mind), which people with autism have difficulty with. So, in the shopping with doll's game we can pretend that the doll is buying his most favourite ice-cream, and we can ask the child how he thinks the doll feels. On another day, the doll could buy an ice cream, trip and knock against something making the ice cream drop to the floor, and we could again ask the child how he thinks the doll feels in this situation.

WE know that most children with autism do not learn by watching and imitating others in quite the same way that most of us do. Hence they have to 'learn' a lot of things that other children pick up spontaneously. Sometimes we need to contrive social situations and social events to teach appropriate social skills to the child with autism. This may include even the very basic socially 'polite' overtures like responding to greetings, greeting others on one's own, waiting, asking for help, going to a friend's house etc. Of all the skills that we might want to teach, it is a good idea to target one skill at a time. Break each skill into smaller components and keep the time that the child spends in the social situation short to begin with and then slowly increase the time. Use of predictable structure and visuals will allow the child be successful in his efforts.

LET us take a scenario where the child finishes his class work and then tends to roam around instead of waiting in his seat while the other children are still completing their work. We want the child to learn to wait quietly in place once he has finished his work. Telling the child "No" when he is roaming does not help him understand what he is supposed to do. Instead we can tell the child what he has to do. So the child could have a favoured book or a toy and he could be taught that once he finishes his work he can look at his book or play with his toy. A brief schedule on his table saying: 'Work then toy' could also help. Likewise, a visual timer that tells him till what time he has to stay in his seat or in other words when the class will get over will also help the child learn to wait.

WE can also teach the child appropriate behaviour on an outing whether to a shop or a park or a friend's house, by clearly telling the child exactly what is going to happen. Visiting a friend, the child goes in, greets his friend and his mother, plays a simple turn taking game (one that is

of high interest to both the children and has been mastered by the child with autism), eats a snack, says bye to his friend and leaves. It is good to keep such situations brief at first. The entire interaction could take just ten minutes. This way the probability of the child's success and our being able to praise that success is going to be extremely high. Once the child is successful consistently in this pattern, we can increase the expectations for the child, as well as the time spent on the outing.

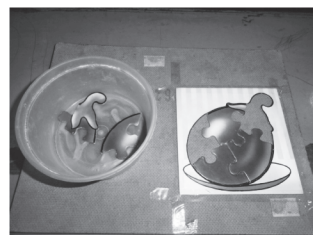
Teaching social skills at appropriate social situations, instead of teaching it at a one on one work situation will make it easier for the child with autism understand the relevance of the skill and also help him be able to generalize it.

LEISURE activities are very important for a child with autism. They can practice social skills, get enjoyment and satisfaction out of the activity, and gain some self-confidence all while being part of the community. Whilst choosing a leisure activity for the child it is important to keep his interests in mind. If he likes listening to music, we can use that as a leisure activity, if he likes water, we could try swimming and so on. Many children with autism have interest in bus timetables, the railways, the different models of cars or airplanes, or the armed forces. Leisure activities can be structured around these interests: creating scrapbooks and gathering information on these as well as building friendships with non-autistic youngsters with similar esoteric interests. We would teach leisure activities in the way we teach every other skill, with the use of clear visuals, appropriate prompts and... REINFORCE every effort made by the child.

Examples of simple leisure activities



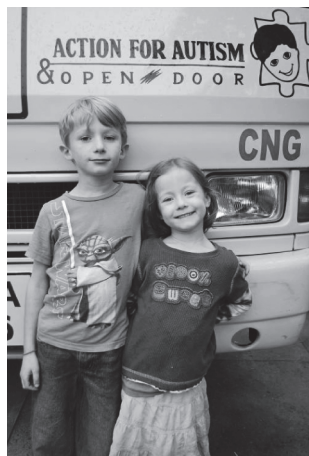
Adapted books for matching



Adapted puzzle



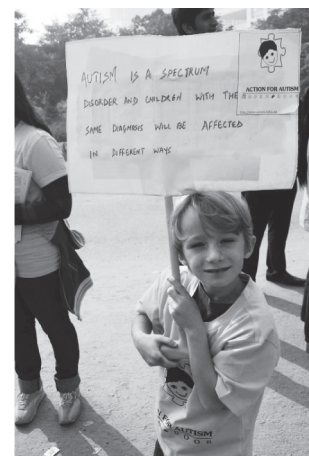
Picture matching



Volunteering: Starting Young

Tamara Daley

During six months of 2010, Tamara and Matt Daley were living in New Delhi with their children, Lucas (7) and Nora (5). Tamara has been a long-time volunteer with AFA and she approached AFA about the possibility of Lucas and Nora to volunteer.



This was an experiment on both sides: the kids had no experience being around people with autism, and AFA had never had such young foreign volunteers in the classroom! We decided to place them in the Violet class, where they would be particularly useful because they were close in age to the children in that group.

How it started

Tamara's turn: In 1995 and 1996, I spent a year meeting families and visiting schools in Kolkata, Bangalore, Chennai, Hyderabad and Delhi while doing research on autism in India. I loved the experience, but I had no idea at the time how much that year would impact my life. Fast forward 15 years: those years in India not only influenced my work for my PhD, but career as well. When I found myself with an opportunity through my job to spend six months in New Delhi, with my family in tow, I jumped! We spent from June through December of 2010 in Delhi. It turned out to be a very busy period for me at work, and I had barely any free time. But my husband and two children were looking for things to do, and it occurred to me that maybe they could volunteer at AFA. It seemed like a perfect opportunity: it is important to me that my kids are comfortable around people with all types of disabilities. But, unfortunately, the opportunity just doesn't arise very often. Their exposure, until India, was limited to a one-time meeting with the son of an acquaintance of mine, a 10 year old with autism.

Matt's turn: I was excited even just to have them volunteering, because I think that's a good thing to do. So, I was happy to have them have

the opportunity to contribute to something. And I liked that they would get to understand a little of the work Tamara does. I was a little nervous, though, because of the double layer of difference—not only a different culture, but also being around people with autism. Particularly with Nora—I was worried how she would manage that. I was also really concerned that our kids not be a burden on the teacher or at the school. As much as I figured that our kids would benefit from the experience, this was not *their* school and I didn't want their presence to distract anyone. I was interested to see how it would turn out.

Preparation and implementation

Sudhanshu's* turn: We discussed this idea of Lucas and Nora joining a class one day a week during our daily meeting, and talked about what it might be like. We knew it was important to prep the kids, so before Lucas and

Nora came, the children in Violet class were told that two children would be joining their classes. The children were shown photographs of Nora and Lucas. Also, on the calendar, the days when Nora and Lucas were to come were marked. This was followed by a discussion on what friends are, what are the different things that can be done with friends, and how friends can be fun.



Tamara's turn: I talked to them a lot before we went. We had already spent time with Neeraj [Merry Barua's son] and Abhimanyu [the son of another Delhi family], so the kids had met adults with autism. But still, we definitely tried to prepare them for things to seem weird or different at first, and that it would be OK if they felt uncomfortable. Matt stayed close by the first part, but the teachers did such a great job of getting them involved right away that they got over their hesitance.

Matt's turn: There were some touchy moments—literally. Some of the kids were especially interested in the kids' hair, and I thought for sure there would be an issue when one little boy grabbed Lucas and yanked—but he really seemed to understand not to react, and he actually giggled. Nora, on the other hand, is much more sensitive, and I think it was hard for her to understand that kids weren't physical with her to be mean. We had to do more preparation with her before going back the next time, since she was a bit nervous. But we made a plan and stuck to it, and that let her feel more in control. It was important for us to be consistent in our schedule, too, so that we weren't disrupting the class plans by not showing up.

**Sudhanshu's turn:* We saw very clearly how typical kids can be used as models. Nora and Lucas turned out to be good role models for children in the violet class. Children in this class have excellent imitative skills. When the teachers asked Nora and Lucas to demonstrate, the students then copied them: in the class, on the playground, in the play area and during tiffin time. The children were more willing to copy from the board, do art and craft activities, stand in the line for assembly when they were imitating their new "classmates." Also when Nora and Lucas told the children to do something the children were more willing to listen to them.

In conclusion...

Matt's turn: It seems like Lucas and Nora have a general awareness of disability and difference now, and certainly comfort around people who are different. I notice that they seem really attuned when we see someone with a disability in public, but certainly not in a fearful way—they seem to feel a connection. In the end, the experience at AFA might be what they remember best of India.

Between their time at AFA and our social time with the people Tamara knows in Delhi, who all have adults with autism, they certainly got so much more comfortable. We sometimes joke that the kids might have ended up

with the impression that all Indians have children with autism, and that autism is much more common in India than the US!

Tamara's turn: It was so terrific to have been able to work with AFA to make this experience happen. I had looked for an opportunity to do something like this last year, in the US, but there weren't any options to pursue it where the interaction would seem natural. Also, I wanted the kids to develop actual friendships by seeing the same kids every week, which is what they were able to do by the end of their volunteer stint. Despite the language barrier, Lucas definitely felt a connection with several of the kids he met with AFA, and still talks about them. Matt is right—when we see people with disabilities now, he is curious in an open and comfortable way that I think comes from being able to transcend the differences he initially felt.

Sudhanshu's turn: It seems like with the right planning, we were able to make this work for all the kids involved. We were sorry to say goodbye!

Lucas and Nora's turn



What do you remember when you first went to AFA?

Nora: I was a little bit scared. *How come?* I was afraid they might hurt me.

Lucas: I felt excited.

Excited? Really?

Lucas: To be there with kids with autism. I thought it would be cool to help them.

What kinds of things did you do while you were at AFA?

Lucas: We did everything that the other kids did. There would be a table, with lots of stuff on the table. Everybody had a turn to go up and take two of the things

that were a match and put them together. Like toothpaste and a toothbrush. We also did a game where we said who was there—there was a chart where they wrote down everybody who was there, and they would draw an X in the square if the person wasn't there.

Nora: We drew pictures!

Lucas: There was snack time, where you brought your snack and you could share. You could ask for something and trade with another kid. There was also a beginning snack time where you had to ask for the snack.

What do you think that was for?

Lucas: To try to get the kids to talk.

What was your favourite part?

Lucas: My dad worked in the Mother Child place, and I liked to go in there and be with the kids in there.

How come in there?

Lucas: Because it was fun! We just played around. There was this kid I really liked, who would laugh a lot if I pretended to fall off the wall. But if he got too excited, he would pull my hair. And also, once, one of the kids pulled me around holding my hand.

Was that nice?

Lucas: Yes, that was good for her because she was interacting with me. And I liked it too.

Nora: My favourite part was the snack time!

What did you learn about autism?

Lucas: Before I went to India, I hardly knew a thing about autism. And then when I was there I spent half the day with kids with autism at the school. And sometimes we played at parks, too. So you could say that I learned a LOT. I learned that there's not just one group, like not everyone is at the same level of autism. There are a lot of different levels of autism. I learned how you can help kids with autism. You help them by letting them talk to you and ask for stuff and share stuff and play with them. One of the older kids always shared food with us. We shared with him, but he didn't like our granola bars.

Nora: I know how to help kids. If there are grownups, it's just like "whatever." When we were there, it's like they were kids and we were kids and then they knew that they could do it because we could do it.

How do you think going to AFA changed you? Or what effect did it have on you?

Lucas: Well, it changed my thinking about autism. I never really thought about autism very much before. It made me not so nervous to talk to new people. I used to be nervous to talk to new people. But I was talking to lots of people I didn't know there.

Anything else?

Lucas: I like being with kids with autism. It feels nice.

Can you think of why it feels nice?

Lucas: It feels nice to help them. I'd like to be around them more here!

————— * Sudhanshu Grover is the Coordinator Educational Services at Action for Autism —————

Grant of Concession in Rail Fares to the 'visually impaired' and 'mentally challenged persons' in Rajdhani and Shatabdi trains

Commercial circular no. 32 of 2011: No.TCII/2196/11/Policy, dated 22-6-2011, signed by DR Monica Agnihotri (Director Passenger Marketing, Railway Board) states that a grant of 25% concession will be provided to orthopedically handicapped persons in Rajdhani/Shatabdi trains.

It also mentions that a 25 % concession in 3-AC and AC chair car of Rajdhani and Shatabdi trains will be extended to:

- (i) Completely blind persons and
- (ii) Mentally retarded persons.

The same concession will also be admissible to one escort accompanying such persons.

The concession will be effective on tickets purchased on or after 01-07-2011. In case of tickets already issued for travel on & after 01-07-2011 refund of difference of fares will not be admissible.

HELPLINE



Q I have a 10-year-old autistic boy, L. I do apologise for not having more input and communication with you and the 'autism' world. I guess (like most parents of autistic kids) I haven't got a lot of spare time. But I would really appreciate your help with some of my queries.

First and foremost, what do you think causes autism, and do you think they will find a cure?

And something that really has me at my wit's end: over the past couple of months, L has been having meltdowns - at least one every three days. Can you please advice of any strategies of what to do when L goes into a melt- down? At the moment, I 'put' him in the bath with a running tap (coldish water). The cause of his meltdowns we think may be due to pain (possibly internal - we are treating him for blockages in stomach) or frustration of being unable to talk and being 'different' (he is quite intelligent, though totally non- verbal) or something else we haven't thought of. I'm recovering from a meltdown and a big day with L. I'm searching for answers and I'm at my wit's end....

A Your situation is similar to families across the world; dealing with complex situations and without sufficient support. The cause for autism is yet unknown though there is a great deal of research underway in different parts of the world. Current findings lean towards a combination of factors and there being a genetic component, though the exact genes or combinations of genes is yet unknown. Given this, there is as of now no cure for the core difficulties in autism and it is extremely difficult to predict, despite frequent hype in the media, whether there will be a breakthrough with regard to finding the cause and hence a cure for autism in the next 50 years!

As you rightly note, behaviours have a reason though the reason may not always be apparent to us. Every behaviour serves a function: it gets the person something he wants: something to eat, drink, do - such as get to go out etc, gets him attention, gets him out of a situation or activity that he does not want or finds unpleasant, gives him some sensory input, and so on.

Further, a behaviour may not always be for the same reason; reasons can change. Let's take the example of a friend sitting in a cafeteria and fanning her hands vigorously in front of her face. We would react very

differently depending completely on why she was doing what she was doing, isn't it? For instance, if it was a particularly warm day and she was trying to cool herself off, we'd probably switch a fan on or increase the speed of the fan in the cafeteria. On the other hand if she has eaten something very sharp, we may want to offer her something sweet to ease her discomfort. But if she was just getting rid of a fly that had been buzzing in front of her face, we may do nothing.

So you are absolutely right when you say that there could be many variables leading to L's meltdowns. It is entirely possible that his meltdowns happen at different times for different reasons. It would therefore be extremely important to try to understand the reason behind each time he has a meltdown, because the strategies that one would use would vary based on the reason.

You have mentioned that you put L in a bath of running water. Is it that he enjoys the bath and that you feel that it may help ease the pain that you think he is having; or is it a punishment? If it is the former, I do understand the need for us as parents to want to ease our children's discomfort. However, we may want to consider here that, if L really enjoys a running bath, given the fact that he may not be able to ask for it, his meltdowns at times may be his way of communicating that he wants a running bath and not because he is in pain. He may have learnt from past repeated experiences that when he has a meltdown he gets a running bath, just like a child who can say "I want a bath" learns by repeated previous experiences that by saying these words he can get a bath. If on the other hand you are using this as a punishment, the thing to consider is whether the behaviour that was being punished has reduced. If not, then perhaps this punishment is best discontinued.

To get an understanding of why your son has his meltdowns, it might be a good idea to try and keep a record of each meltdown for a period of ten days to two weeks. This would be a bit of extra work, but would be worthwhile. You would want to keep track of the following:

1. Anything that you feel might be triggering the behaviour. Here you would note what took place before the meltdown: when and where did the meltdown occur;

who were the people present during the situation, what did the people around say or do before the meltdown happened; is there any other meltdown that usually happens before he has a meltdown? Does the meltdown happen more with any person? Less with any person? Does it happen more when you are out/at home/at school/ during bedtime/etc.

2. The meltdown itself: what exactly did the child do or say? How many time, viz: how many time did he shout / throw himself on the floor/ scratch / throw things. How long did each episode last: one minute /five minutes/ half hour / etc.,

3. What happens after the meltdown takes place. So for eg, if he throws himself on the ground, what happens then? Does anyone say something? Do something? Is he given something? A chocolate/ an outing / a meal / a bath / anything?

Once you have this information to refer to, you may have a clearer picture on why L is having the meltdowns and accordingly take some pre-emptive measures as well have an idea on actions to take when the meltdown occurs. Of course it will also be essential to give L appropriate alternative outlets for his behaviour. For instance, if you see that L seems to be calm when you are playing with him or interacting with him, but when you are busy doing your chores, he goes into meltdowns, which result in you coming to him to calm him down or to see what the matter is, hence giving him the attention that he may be seeking. In this case, we could take some pre-emptive measures to give him the attention well before he 'asks' for it through a meltdown. So, say you are in the kitchen doing the dishes, you could try to have L in the vicinity and strike a 'conversation' with him, with a lot of fun, excitement and energy. For example, you could draw his attention to the pot that you cooked in and talk about all that you ate for the meal or the vegetables that went into that dish. Or you could draw his attention to the soapy water, and maybe blow some bubbles with same. You could also try to involve him at times in whatever it is you are doing, like teaching L to put away the cutlery in the right places.

Further the appropriate alternative to this particular instance, would be to teach L to ask for attention appropriately, by either tapping you on the hand or using any other mode of communication that are mentioned below. Alongside, we could also build up on L's leisure skills, so that he has something of interest to do for some of the time that you are busy. However, in this particular circumstance, if L does have a meltdown whilst you are otherwise occupied, it may be a good idea to not react in

any way during the meltdown and just make sure that the physical environment is so structured that he cannot hurt himself.

You have said that L is completely non-verbal. Does he have an alternative mode of communication (AAC)? If not, you probably want to introduce some form of AAC like signs, picture exchanges, a communication board, amongst others, to help L express himself in a more appropriate manner. Not being able to express wants and needs is often a primary cause of challenging behaviour. One can completely appreciate how overwhelmed you must feel particularly since autism can appear to be such a confusing condition. There are times that it seems to be difficult to understand the condition and what our children may be experiencing, but this is probably the crux of the matter: understanding autism, understanding the unique ways in which our children think and learn, accepting their autism as a vital, vibrant part of their being and then approaching the intervention, the teaching of skills, and / or changing of behaviours, from that paradigm of understanding and acceptance. The wonderful part is that all people with autism can learn and show progress, irrespective of their age or the degree of their support needs.

I hope that you find this information of some help and wish you the best in your journey with L.

प्रश्न – कुछ महीने पहले मेरी दोस्त की बेटी जो विशेष स्कूल में जाती है, ने अपनी मां से कहा कि एक लड़का जो उसका सहपाठी है, स्कूल के टॉयलेट में उसके निजी भागों को महसूस कर रहा था। जब मेरी दोस्त ने यह बात स्कूल के अधिकारियों के सामने लाई, उससे कहा गया कि इस लड़के के बारे में यह पहली शिकायत नहीं थी और वे सफलता के बिना कोशिश कर रहे थे लड़के के व्यवहार में परिवर्तन लाने के लिए। मेरी दोस्त को अपनी बेटी को इस तरह के शोषण के खिलाफ सुरक्षित रखने की सलाह दी गई, जो वह करने की प्रयास कर रही है। स्कूल और वह इस मामले में क्या कर सकते हैं ?

उत्तर – धन्यवाद आपने अपने दोस्त की चिंता हमारे साथ बांटने के लिए। हालांकि लड़की को कुरुपयोग के खिलाफ शिक्षण देना जरूरी है, पर इसके अलावा अन्य कदम हैं जो

उपयोगी हैं। उदाहरण यह अत्यन्त महत्वपूर्ण है कि लड़के का व्यवहार बदले। न केवल इस सवाल में यह जवान लड़की के लिए हानिकारक व्यवहार है, बल्कि यह खुद लड़के के लिए एक संभावित खतरनाक स्थिति हो सकती है। इसके लिए निम्नलिखित रणनीतियों को लागू किया जा सकता है :

1. स्कूल को ऐसी स्थिति में लड़कों और लड़कियों का शौचालय अलग और स्पष्ट दृश्यों से संकेत देना चाहिए।

2. स्थिति का विश्लेषण और लड़के के व्यवहार को समझने की कोशिश करने की राह पर पहुँचो। इस लड़के को बताना चाहिए कि वह अपने शरीर के निजी भागों को छू सकता है न कि दूसरों के। उस समय लड़के को समझाना चाहिए कि केवल वो स्वयं या शायद एक या दो प्राथमिक देखरेख करने वाले (माँ/पिता) विशिष्ट परिस्थितियों के तहत उसके निजी भागों को छू सकते हैं, जैसे स्नान के समय। इस स्थिति के लिए एक सामाजिक कहानी भी उपयोगी हो सकती है।

3. वातावरण में परिवर्तन लाना चाहिए सुनिश्चित करने के लिए की दोबारा से यह घटना होने का मौका ना हो। एक चीज जो कर सकते हैं यह है कि लड़के का शौचालय जाने का समय अच्छी तरह हमेशा संरचित हो। लड़के के शौचालय जाने के समय के लिए एक 'वर्क सिस्टम' का पालन करना सिखा सकते हैं जिससे रीति अनुसार उसे बता दिया जाए कि उसे सटीक कदम पर क्या करना है।

उदाहरण : शौचालय जाओ, पेशाब घर का उपयोग करो; हाथ धो; वापस क्लास में जाओ; अगली क्रिया। 'वर्क सिस्टम' लड़के के क्रिया पद्धति पर आधारित होना चाहिए। शुरू में 'वर्क सिस्टम' का पालन करने के लिए लड़के की मदद करनी होगी जब तक वो पक्का व्यवहार न बन जाए। इसके अलावा ये भी देखना चाहिए कि वो लड़का आपके दोस्त की बेटी के साथ कोई भी संपर्क बड़ों के बिना नहीं रखना चाहिए। इस अनुचित व्यवहार को तोड़ने के लिए ये जरूरी है।

4. लड़के को सिखाओ कि लड़कियों के साथ उचित बातचीत कैसे करते हैं, खेल-खेल में एक दूसरे की बारी-बारी खेल,

कैसे करते हैं, वीडियो देखना या संगीत एक साथ सुनना, थोड़ा अनौपचारिक वार्तालाप कैसे करना चाहिए। उपयुक्त बातचीत के लिए लड़के को बहुत प्रशंसा देनी चाहिए। संपर्क का समय छोटा होना चाहिए शुरू में और फिर बाद में इसे सकल बनाने के लिए धीरे-धीरे बढ़ाना चाहिए। इसके अलावा और भी सामाजिक निपुणता सिखा सकते हैं जैसे अलग-अलग लोगों के साथ बातचीत के समय सही दूरी रखना और अलग लोगों के साथ उचित शारीरिक संपर्क कैसे रखते हैं।

5. अंत में लड़के को सिखाना चाहिए कि अपने यौन जरूरतों को कैसे संभालना चाहिए।

यह बहुत अच्छी बात है कि आपकी दोस्त की बेटी के पास इतनी संचार करने की कुशलता है कि वो अपने मां को बता सके कि क्या चल रहा था। यह बहुत ही जरूरी है कि हम अपने बच्चों को संचार सिखाएं, उसके उपलब्धियों के साथ। भाषा समझने के अलावा हमें अपने बच्चों को ये भी सिखाना चाहिए कि अपने जरूरतों को कैसे व्यक्त करना चाहिए। एक और क्षेत्र जिसमें ध्यान देना चाहिए यह है कि बच्चों को सूचित करना सिखाना चाहिए, जैसे इस परिस्थिति में हुआ था। ये अन्य तरीकों से हो सकता है।

उदाहरण : घर पे संकेत देने से शुरू कर सकते हैं। जैसे, जब पिता ऑफिस से घर आते हैं तो वो बच्चे से पूछ सकते हैं कि दोपहर में क्या खाया था, और मां उसे जवाब देने में मदद कर सकती है। एक 'डायरी' भी रख सकते हैं जो स्कूल और घर के बीच में हो और जिसमें दोनों वातावरण के मुख्य लक्षण हों, जहाँ शिक्षक बच्चे से पूछ सके कि घर पर क्या हुआ और शिक्षक तुरन्त बच्चे की मदद कर पायेंगे अगर जरूरत पड़े और इसी तरह से घर में भी। यह कहने की जरूरत नहीं है कि हमारे बच्चों के लिए अत्यन्त महत्वपूर्ण है कि इस संचार के लिए एक औपचारिक साधन का प्रयोग करें, वह चाहे वाणीयुक्त हों या किसी और प्रकार के संवर्धी और वैकल्पिक साधन।

हमारे बच्चों में विशेष रूप से दुरुपयोग की संभावना बनी रहती है। अतः इन्हें यह सिखाना होगा कि अपनी सुरक्षा कैसे करें,

संबंधों के बारे में, यह कि किस प्रकार विभिन्न लोगों से कैसा व्यवहार करना है जो उनके जीवन में विभिन्न भूमिकाएं निभाते हैं दूसरों के किस प्रकार के व्यवहारों को बर्दाश्त करना चाहिए, विभिन्न परिस्थितियों में किस प्रकार की शारीरिक समीपता बनानी चाहिए, अलग-अलग परिस्थितियों में किसके पास जा सकते हैं। यह समुचित रूप में सामाजिक व्यवहार एवं उनकी सुरक्षा दोनों के लिए महत्वपूर्ण है। निम्नलिखित कुछ विशेषताओं का विस्तृत रूप से वर्णन किया गया है।

हमें अपने बच्चों को दूसरों से उचित भौतिक/शारीरिक दूरी रखना, सिखाना जरूरी है। अन्य रणनीतियों के साथ/बीच हम एक हाथ की दूरी रखने की संकल्पना सिखा सकते हैं। यह हम अपने बच्चों को दूसरों के साथ बातचीत करते वक्त वास्तव से एक हाथ की दूरी पर खड़े रखकर, सिखा सकते हैं।

यह रिश्ते सीमाओं की संकल्पना 'सकील प्रोग्राम' लेस्सी वाकर हिर्स और मारिलिन पी शैम्पेन) के विचारों से लेकर भी सिखा सकते हैं। यह समझाने के लिए कि किसके साथ किसी तरह का व्यवहार/शारीरिक विकटता उपयुक्त/उचित है।

इसमें एक बड़े कागज के बीच में एक बिन्दु बनाया जाता है, और उसके सब ओर एक के बाद एक चक्र बनाया जाता है।

अन्य लोगों के चित्र और/या नाम हर एक चक्र में डाले जाते हैं जो व्यक्ति और इन लोगों के बीच के संबंध के मुताबिक है। आप इसे अपने बच्चे के कमरे में टांग सकते हैं और लोगों के चित्र या नाम जोड़ सकते हैं जो आपके बच्चे और उनके बीच के संबंध के आधार पर हों।

इसका उपयोग करके हम अपने बच्चे को उसके क्रिया पद्धति के मुताबिक समझा सकते हैं। किस तरह का व्यवहार शारीरिक नजदीकी के संदर्भ में बातचीत या कोई और उपयुक्त मुद्दा चक्र में उपस्थित लोग के साथ ठीक होगा। जब भी वो नए लोगों से मिलेगा, हम उन्हें इस चित्र में जोड़ देंगे।

सेंटर से शुरू होने वाले अलग चक्रों का वर्णन है :-

– **किसी चक्र/नजदीक अलिंगन चक्र** : बिन्दु के सबसे पास का चक्र उन लोगों का वर्णन करता है जो बच्चे के बहुत करीब हो, जैसे की करीब परिवार के सदस्य।

– **अलिंगन चक्र** : इस चक्र में विस्तारित परिवार और करीबी दोस्त हैं।

– **दूर का अलिंगन चक्र** : वो लोग जो दोस्त हैं लेकिन परिवार या करीबी दोस्त जितने नजदीक नहीं।

– **हाथ मिलने का चक्र** : इसमें वो लोग होंगे जिन्हें बच्चा स्कूल में देखता है या वो लोग जिनके साथ वो काम करता है। (जब हम एक एडल्ट जिसे ऑटिज़्म है उसकी बात करें)।

– **लहर चक्र** : इसमें वो लोग होंगे जिनके आगे से आपका बच्चा हर रोज पड़ोस की सड़क से गुजरता है, लेकिन युद्ध नहीं जानता।

– **गैर चक्र** : ये वो लोग हैं जिन्हें एक व्यक्ति अनदेखा करता है या नमस्कार नहीं करता क्योंकि वह उन्हें जानता नहीं है।

1. यह अच्छा सुझाव होगा हमारे नौजवानों के लिए कि वो अनुपयुक्त आलिंगन या चुम्बन ना करे जब वो अपनी युवावस्था में प्रवेश करे। कंधे को हलके से दबाना अब आलिंगन हो सकता है बजाय कि पूरे शरीर का अलिंगन।

2. हमारे बच्चों के लिए ये सीखना जरूरी है कि अनुपयुक्त शरीर के संपर्क के तरफ क्या प्रतिक्रिया दिखानी है। और तरीकों की तरह हम एक बनावटी स्थिति बनायेंगे। बच्चे को इन कदमों का अभ्यास करवाईये जब तक वो यह गुण सीख ना जाय। इसके लिए एक सुकारक बच्चे के पीछे होगा जो आवश्यक प्रतिक्रिया के लिए प्रारम्भ करेगा। और एक छेड़नहार होगा जो व्यक्ति को शरीर के अनुपयुक्त पद पर छूएगा और

सुकारक तुरन्त बच्चे को छोड़नहार के हाथ को जोर से धक्का देने के लिए प्रारम्भ करेगा और ऊंचे स्वर में 'नहीं' बोलेगा जो कि अगर बच्चा 'वांचिका' है उसे यह दोहराना सिखाया जा सकता है। धीरे-धीरे सुकारक प्रारम्भ को हलका कर सकता है जब तक बच्चा ये स्वतंत्र रूप से कर सके।

प्रश्न : एक पुरुष चिकित्सक जिसने एक छोटा, अपरिचित संस्थान से, छः महीने का प्रशिक्षण कार्यक्रम किया है। वो माता-पिता से उनके किशोर ए.एस.डी. लड़के की ज़रूरतों के बारे में बातचीत कर रहा है। चिकित्सक माता-पिता को बता रहा है कि अपने बच्चे के लिए उससे हमउम्र से बड़े बड़ड़ी की कितनी ज़रूरत है। जिससे वह करीब हो सकता है और अपने डर और चिन्ताओं को बांट सकता है। चिकित्सक एक शर्त पर बड़ड़ी बनना चाहता है कि माता-पिता उसे बच्चे के साथ एक बंद कमरे में बातचीत करने दें। उसका दावा है कि यह तरीका उसका अपना है और यह तरीका युवा बच्चों में व्यवहारिक और क्रोध के मुद्दों को कम करने के लिए जाना जाता है। जब यह बात मेरे ध्यान में लाई गई एक मनोवैज्ञानिक होने के तौर पर मैं चिन्तित हो गई। हम इस तरह के अभ्यास जो दुरुपयोग करने के लिए नेतृत्व कर सकते हैं को कैसे रोके ?

माता-पिता को ऐसे दावों का जवाब देते समय क्या करना चाहिए जिससे उनके बच्चे सुरक्षित रहे।

उत्तर : यह सही है कि नौजवान जिन्हें ऑटिज़्म है, उनको सामान्य लोगों के बड़ड़ी बनने से लाभ होता है। ऑटिज़्म के लिए बड़ड़ी का प्रयोग स्कूल कार्यक्रमों में और घर के वातावरण में बढ़ता जा रहा है। बड़ड़ी एक दोस्त है जिसके साथ एक व्यक्ति समय बिता सकता है और ऐसा कुछ कर सकता है जो दोनों को पसन्द हो। वो एक ऐसा साथी है जिसके साथ बातचीत कर सकते हैं, सैर पर जा सकते हैं, बाहर जा सकते हैं, इन्टरनेट पर काम कर सकते हैं, गाने सुन सकते हैं या बस ऐसे ही समय बिता सकते हैं। और हां, buddy के साथ अपने डर और चिन्ताओं को भी बांट सकते हैं।

ये बात भी सच है कि ऐसे चिकित्सक/स्कूल/हस्तक्षेप केन्द्र (Intervention Centre) है जिनकी नीति है कि माता-पिता या अन्य देखभाल करने वालों को सेशन देखने की अनुमति नहीं है, यहाँ काम बच्चों के साथ अकेले में किया जाता है। इसका कारण स्पष्ट नहीं है, क्योंकि ज्यादातर हस्तक्षेप केन्द्र इस बात से सहमत है कि व्यक्ति जिन्हें ऑटिज़्म है, सबसे अच्छा/बेहतर सीखते या प्रगति करते हैं जब सभी वातावरणों में एक ही कार्यनीति प्रयोग की जाये और लगातार की जाये। सभी लोग जो उस व्यक्ति जिसे ऑटिज़्म है उसके साथ कार्य करते हैं – स्कूल, स्पेशल एजुकएटर, आक्यूपेशनल चिकित्सक, स्पीच चिकित्सक, buddies, या कोई और, और कभी-कभी माता-पिता सब एक साथ एक टीम में काम करते हैं। सबको सामान्य तरीकों का प्रयोग करना होता है। माता-पिता के लिए अपने बच्चे को कोई गुण कैसे सिखाना है, ये सीखने के लिए एक अच्छा तरीका किसी अनुभवी व्यवसायी को देखकर और उस सिखाने के तरीके को दोहराना है, खासकर किसी नैचुरल वातावरण में। अवश्य है कि कुछ ऐसे व्यक्ति भी होंगे जिन्हें ऑटिज़्म है जो दूसरों के उपस्थिति में अच्छे से काम नहीं कर पायेंगे। ऐसे में बच्चे के साथ अकेले में काम करने की फैसला बच्चे से साथ समय बिताने के बाद लिया जायेगा, पहले नहीं। परन्तु यहाँ एक जवान आदमी buddy बनना चाह रहा है। यह साफ नहीं है कि ऐसा एक बन्द कमरे में, दरवाजे के पीछे हि क्यों। Buddy परिवार में सबके साथ टी. वी. देख सकता है, कुछ खा सकता है, वरान्डे में बैठकर दुनिया के बारे में बातचीत कर सकता है, या बाहर जाकर बॉल के साथ खेल सकता है।

किशोर ए.एस.डी. व्यक्ति को उस buddy का लाभ होता है जो उन्हें उनके जोश को घर के बाहर खेले जाने वाले खेल में लगाने में मदद करता है।

हम जवान आदमी कि नीयत पर शक नहीं करना चाहते जो शायद वाकई में नौजवानों के साथ बन्द कमरे में समय बिताने के लाभ में यकीन रखता है। परन्तु स्पेशल एजुकेशन के नियमों के संबंध में ये उचित प्रक्रिया नहीं है। शायद यह

जवान आदमी इससे सचेत नहीं है और यह नए तरीके सीखने में रुचि दिखा सकता है। और अगर वो एकान्तता चाहता है तो एक कमरा जिसमें पर्दा बन्द हो सके वो सही रहेगा।

आपने यह पूछा है कि हम किस प्रकार से ऐसी प्रथाओं को रोक सकते हैं जिसके कारण उनका दुरुपयोग न हो। ऐसे क्या तरीके हैं जिनका माता-पिता लाभ उठा सकते हैं ऐसे दावों को स्वीकारने से पहले कि उनके बच्चे सुरक्षित हाथों में हों। मैं समझता हूँ कि इसका एक ही तरीका है कि हम एक कदम पीछे लें और अपने आप से पूछें “क्यों?” एक चिकित्सक बंद दरवाजों के पीछे क्यों काम करना चाहता है? क्या इसके लिए कोई प्रमाणिकता है? अगर हम अपने बच्चे की जगह होते, वेदनीय होते और बोलचाल करने का कौशल भी नहीं होता, यह बताने के लिए कि बंद दरवाजे के पीछे क्या हुआ तो क्या हम अपने बच्चे की जगह में होना चाहते?

मैं जानता हूँ कि माता-पिता होने के नाते हम अक्सर सेवाओं को लेकर आशाहीन रहते हैं। परन्तु मैं नहीं समझता कि हम ऐसी स्थिति में हैं “भिखारियों को चुनने का हक नहीं है”। हमें वह हमारे लिए निर्णय लेना होगा कि वो क्या है जो हम अपने बच्चों के लिए चाहते हैं। हमें यह तय करना होगा कि क्या हम अपने बच्चे की सुरक्षा के बदले चमत्कारी सुधार होने के दावों (अक्सर : अफवाह) पर यकीन करना चाहते हैं।

एक बार माता-पिता इन सवालों के जवाब जान लें, तब शायद उनके लिए यह तय करना आसान हो जाएगा कि उनके बच्चे के लिए कौन सी प्रक्रिया सबसे बेहतर है।

मनोवैज्ञानिक होने के नाते परिवारों को सलाह देते समय आपको यह स्पष्ट करना होगा कि युवा व्यक्ति की मांग स्वीकार्य नहीं हो सकती। मैं यह कल्पना कर रही हूँ कि आपको इस संबंध में कुछ चिंताएं होंगी और इसी वजह से आपने हमें लिखने का सोचा। कृपया माता-पिता को इस बात से अवगत कराइए कि लड़के भी दुरुपयोग की ओर उतने ही कोमल हैं जितना कि लड़कियां। कृपया परिवारों को समझाइए कि जबकि बहुत अच्छा होगा कि उनके बेटों के *buddies* हों,

परन्तु उन्हें उन स्थितियों जिनमें पहचाने की क्षमता है उनके विरुद्ध सुरक्षा करनी होगी।

युवा लोग जिन्हें आटिज़्म है, उनको जरूरत ही नहीं बल्कि वो तरस्ते हैं *buddies* के लिए। पहले की धारणा से विपरीत जहां लोग यह मानते थे कि आटिस्टिक लोग सामाजिक संपर्क पसंद नहीं करते, हम अब यह जानते हैं कि ज्यादातर आटिस्टिक लोग दोस्त बनाना चाहते हैं, वह बस यह नहीं जानते कि यह कैसे करना है। तो यह बहुत प्रशंसनीय होगा कि हम अपने युवाओं के लिए कोई सुरक्षित तरीका खोज पाएं *buddies* बनाने का। वास्तव में ऐक्शन फौर आटिज़्म कोशिश कर रहा है बेस्ट बडीज इन्टरनैशनल (*Best Buddies International*) के साथ जुड़ने की जिससे हम ऐसा कार्यक्रम भारत में ला सकें जिसे यह काम सरल बन जायेगा।

प्रश्न : मेरी बेटी का स्पेशल स्कूल एक बड़े सामान्य स्कूल का भाग है। कुछ समय पहले जब मैं अपनी बेटी को स्कूल छोड़कर आई तो सामान्य स्कूल के एक चपरासी ने उसके साथ छेड़खानी की। स्कूल के कैंपस गार्ड ने इस घटना को रोका और बाद में मुझे सूचित किया। परन्तु जब मैंने स्कूल संचालन से इस बार में बात की तो उन्होंने कहा कि मुख्य स्कूल के संचालन और कर्मचारियों पर उनका किसी तरह का कोई अधिकार नहीं है। मैं अपने आपको असहाय महसूस करती हूँ और अपनी बच्ची की सुरक्षा को लेकर चिंतित हूँ। कृपया सहायता करें।

उत्तर : बच्चों के साथ छेड़खानी अभिभावकों के लिए हमेशा ही चिन्ता का विषय रहा है, चाहे बच्चा सामान्य हो या स्पेशल। यह एक ऐसा विषय है कि जब यह घटना होती है तो अभिभावक इससे बचने या रोकने में अपने आप को असहास पाते हैं। एक अभिभावक होने के नाते आपके लिए यह अवस्था से निबटना आवश्यक है। मेरी आपसे यही विनती है कि एक अभिभावक होते हुए आपको ना सिर्फ अपनी बच्ची की सुरक्षा के लिए बल्कि बाकी सब बच्चों के लिए इस प्रकार के हालात से समझौता नहीं करना चाहिए।

आपकी बच्ची का स्कूल किसी भी हालत में अपनी जवाबदेही से पीछे नहीं हट सकता चाहे मुख्य स्कूल के संचालन स्पेशल स्कूल के चलने में कुछ कह सकता है या नहीं। इन हालात में उनका पूरा अधिकार बनता है दखल देने का। अपने विद्यार्थियों की शारीरिक और भावनात्मक हर प्रकार की सुरक्षा की जिम्मेदारी उनकी है। इस प्रकार की घटना से पल्ला झाड़ना एक तरह से ऐसी घटना में उनका सहयोग करना और बढ़ावा देना ही माना जायेगा। सीखने की क्षमता एवं अपनी योग्यता की चरम सीमा तक पहुंचना स्कूल जाने का एक आवश्यक भाग है जिसके भरोसे अभिभावक अपने बच्चे को निश्चित होकर स्कूल भेज पाते हैं।

आपकी अपनी ओर से मुख्य स्कूल के प्रधानाचार्य से बात कर सकते हैं। हो सकता है वह एक सहानुभूतिशील व्यक्ति हों और

आपकी समस्या को सही प्रकार से समझ कर सही कदम उठाएँ। उन्हें यह भी बताना ठीक रहेगा कि अगर अपराधी चपरासी को अभी दण्डित नहीं किया गया तो वह यही नहीं रुकेगा। ना सिर्फ आगे जाके आपकी बच्ची के साथ यह घटना दोहरा सकता है, बल्कि सारे विद्यार्थियों की सुरक्षा खतरे में है।

यह सब कार्यवाही के अतिरिक्त आगे से जब आप अपनी बच्ची को स्कूल छोड़ने जायें हमेशा उसे अध्यापिका के पास ही छोड़कर आयें।

आपकी बच्ची की सुरक्षा आपका अधिकार है और आप इसकी मांग कर सकते हैं। इसके अतिरिक्त अपनी बेटी को आपको इस तरह के यौन उत्पीड़न से बचने के उपाय सिखाने होंगे जो अगले प्रश्न में बताये गए हैं।

Upcoming Workshops at a Glance

The Child with Autism in the Mainstream Classroom

Autism is an 'invisible' condition; hence making accommodations for them in mainstream classrooms does not come easy to most teachers. However, once the teacher understands the fine nuances of the difficulties that the child with ASD faces in the classroom, the teacher is better able to implement strategies that would help the child learn.

While the child with autism makes an effort to learn neurotypical rules, the classroom has to evolve to accommodate the specific needs of the child if mainstreaming has to succeed.

The workshop can be attended by teachers from mainstream and specific needs classrooms; OTs, SLPs, vocational trainers, psychologists and anyone involved in helping individuals with autism receive education in an inclusive setup.

Dates and details about the workshop will soon be available on our website: www.autism-india.org.

Know Me Teach Me

Dates: 27 - 30 September, 2011

The workshop will target teaching of cognitive and daily living skills that are a priority both in classroom situations, as well as at home, and situations that must be addressed to facilitate their entry into mainstream classrooms; and will be based on a practical understanding of Autism Spectrum Conditions.

The workshop is *for both the newbie as well as a refresher for experienced hands* and can be attended by all those who work closely with children with autism on a daily basis: professionals of every discipline related to ASD, as well as parents interested in learning how to teach their children life skills.

Registration forms for the workshop will be up on our website shortly

*For more information add
'WORKSHOPS' in the subject line and write to:
anvay.trainings@gmail.com*

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To continue to receive 'Autism Network' please complete the revised 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/- *Overseas Member* : \$ 30

Professionals: *Associate Member* – Annual: Rs 150/- *Full Member* – Annual: Rs 1000/- *Institutional Member* – Annual: Rs 2000/- *Overseas Member*: \$ 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.

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I am a: (tick all that apply)

☐ Parent ☐ Relative _____

☐ Professional: Name of Org. _____

☐ Other _____

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

Child's name _____ Sex _____

Date of birth _____ dd _____ mm _____ yr _____

Diagnosis (if known) _____

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

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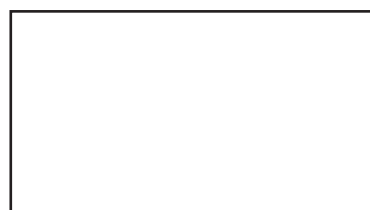
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