

autism

N E T W O R K

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INFORMATION

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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:

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

Editor: Merry Barua
Editorial Board: Ann Varavukala, Indu Chaswal
Design & Production: Bindu Badshah, Sudhir Pillai

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Cover Illustration

"Colour" by Pranshu Singh,
a student at Open Door, New Delhi

WISHLIST !

FOR THE JUNIOR SECTION

- o Paper to recycle for children's worksheets:
 - A4 sheets of paper that have been used on one side
 - Used computer paper
- o Glossy Newspapers: Sunday & Saturday supplements for craftwork
- o Battery-operated toys
 - o Batteries
 - o Children's tricycles
- o Slides, swings, seesaws that can be kept indoors

FOR ALL STUDENTS

- o One air cooled or airconditioned room for 1 hour, twice a week, for children to do yoga and allied activities
 - o Large Dhurries
 - o Two small music systems
 - o Plastic chairs & stools

If you want to help, write to AFA or call:

- Action For Autism Tel: 641 6469/70
 - Indu Chaswal Tel: 609 4410
 - Merry Barua Tel: 6566584

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PAGE ONE

Autism Network, and Open Door are both back in business after the summer break. Its hot, its humid, the classrooms are sticky, but our children and the teachers are having fun. If we're really lucky, once a week, we get to jump into a nearby pool to wipe off some of the sweat and grime. The air-conditioned classrooms that you see mentioned in advertisements and billboards seem to be from some other land, not the one we inhabit. We like it this way in Chiragh Dilli village – for the children to be in touch with a reality consisting of a crowded, cramped cul de sac, with motor mechanic grease and cow dung and cows for company. The brightly coloured clothes of the college students down the road do break the dullness a bit.

On a more serious note, its been a long break from the regular school curriculum, but there's no getting away from the basic issues we are faced with, on the issue of teaching children with autism. Who are the people best equipped to teach children with autism? Can expertise in one area of 'special children' be a plus, or can it end up being a minus, in this context.

There is no better idea of what we're up against, than to quote this recent gem from the Health Minister of Delhi, in response to a reporter's question about MMR vaccinations and autism, "Autism, wo kya hota hai?"

This issue continues the series on developing play skills with a contribution from a professional from the UK. It also carries some heartwarming contributions from parents and carers.

AFA is always grateful for the opportunity to share experiences with other organisations through training workshops and interactive discussion groups. This year such events took us to Jaipur, Mumbai, Kolkata, Pune, Chennai and Bangalore, among other places. In Kolkata Dr Sharda Fatehpuria, Director of Monovikas Kendra and my colleague on the Board of the National Trust, has taken the wonderful initiative towards a small unit to help children with autism at her school. A therapist trained at AFA, a creative and committed individual, is the resource person who has set up the unit and provides training. The Bangalore visit provided a long awaited opportunity to touch base with KPAMRC (Karnataka Parents' Association of Mentally Retarded Children). Apart from AFA, theirs is the only other organisation conducting a training course on teaching children with autism. It was also an occasion to meet with Jayshree Ramesh, and visit

her lovely school Asha, which along with Open Door, has been one of the first schools that specialized in working with children with autism. In Chennai we had the opportunity to visit Dr Vasudha P Natarajan a dedicated and generous soul who has lately done her training in the Miller Method (MM) and has the equipment set up at the center she has recently started. Vasudha introduced us to another way of looking at children with autism – as system ordered or system disordered.

We asked her why the MM, which has been around for nearly 40 years is used merely by a handful of schools and families. Unlike TEACCH, or ABA, or OPTIONS, among others, which are used at hundreds of sites across the world. Dr Natarajan attributes this to the high and continuing expense involved. She also opined that though some of the activities can be used with benefit, the MM was not effective beyond a point. She confessed quite candidly that the Miller Method is not really suited to India and "though it sounds unprofessional I don't advocate it". I cannot help but second her opinion having explored the Miller Method over ten years ago when I was desperately looking for a therapy that would help my son and others like him. I had come to much the same conclusion.

However, knowing how things work in India I foresee schools happily investing the few lakhs in setting up the large colourful wooden structures that the method incorporates. And if the staff does not really understand autism how does it matter? Any school that sets one of these up will have a line of applicants and a bevy of admirers. Why? Because parents, being as human as any of us, are attracted to pills, medications, equipment. They are so concrete! The established primary methods of working with kids with autism involve trained personnel whose prime equipment is the knowledge and training in structured behavioural methods which is in their heads, and the willingness and dedication to work with this most complex segment of disabled children which is in their hearts. How visually exciting can such abstractions be?

In Chennai, we met with Professor Jeyachandran who expressed an interest in how persons who complete the Special Education Course in Autism at Action For Autism were faring. Earlier at a meeting convened by the RCI both Mr Jeyachandran and the Mr JP Singh had assured Mrs

(...cont. on back page 18)

Teaching Thinking Skills through Play and Drama to Children with Autism

Dave Sherratt

Dave Sherratt is a teacher from the UK and has specialised in teaching children with autism to play. He has presented papers on play and affective cognition.

Developing early thinking skills should be considered a priority for children with autism, as these skills open opportunities for better understanding and open doors to further learning. Children with autism have particular difficulties in learning about their social worlds and have impairments in communication, social skills and thought flexibility. Early thinking skills include predicting and anticipating which lead towards planning and problem solving. These are areas of difficulty for most children with autism. In order for children to develop these skills they must re-organise their capacity for memory to more effectively link objects, events and experiences with their concept of self. Children with autism need to develop an understanding of cause, intent and effect. Children with autism particularly need to learn how to think creatively and imaginatively through play and active exploration and by so doing, make and apply new connections and ideas. This article will describe an approach to teaching thinking skills through play and drama that is designed for children with autism. Both practical ideas for differentiated group work and work with individual children are described in terms of their use for teaching thinking skills to children with autism.

TEACHING thinking skills to children with autism presents particular problems. Children with autism are impaired in their ability to reflect on meanings and intentions in themselves and others. Although many of these children show impressive skills in relatively concrete and factual information, they find great difficulty in understanding or even recognising that people's behaviour is guided by their thoughts. Faced with people that may well be thinking about things in a different way and seeing things from their own perspective, children with autism can become easily confused and frustrated by the apparent anomalies in the behaviour of others.

CHILDREN with autism also have difficulties in communicating their thoughts and intentions to others. Children with autism are often impaired in their attention to other people and in sharing an interest in an object or an event with other people.

ONE of the core difficulties that are universally shared by all children with autism is an inflexibility of thinking processes. This leads to fragmented memory patterns and an atypical and often impoverished cognitive architecture. The obsessive, repetitive and stereotyped behaviour patterns of children with autism result from this. Difficulties in understanding others, communication and thought inflexibility often produces consequent social withdrawal or inappropriacy, an emotional detachment from everyday matters and a tendency to "work on one's own agenda". Imaginative and interactive play has often been thought too difficult for children with autism, yet a remarkable paradox has been shown by some of these children.

CHILDREN with autism can be shown how to play and many of these children are then able to extend this using imagination and creative pretence (Sherratt 1999). Some of these children have also been able to use drama to extend their play (Sherratt and Peter 2002). These achievements are all the more remarkable when for most of these children play and imagination have been severely impaired or absent throughout their development.

THE techniques used to enable children with autism to use this hidden potential are based upon two tenets.

THE first of these is that children with autism need a structure. The second tenet is that play should be meaningful. Play becomes meaningful for children with autism when it has an inherent interest value for

the individual or when its value is enhanced through the exaggerated enthusiasm of other players.

MEANINGFUL play has an emotional value to the child. It is probable that the triggering of emotional centres in the brain is causally connected to subsequent changes in neural organisation.

THROUGH repeated engagement in pretence and learning how to construct narrative structures, most children with autism become not only more capable and skilled at play, but additionally develop greater fluidity and flexibility in thinking. Sherratt and Peter suggest that neurological changes in the developing brains of young children with autism may result from extensive engagement in pretence that uses narratives with a high affective content.

THROUGH play and drama it is possible to teach a range of important thinking skills that are often absent, delayed or need elicitation in children with autism. Creativity and imagination are of course central to this. Other skills include imitation, turn-taking, communication about items of interest and labelling abstract mental states such as attitudes and intentions. It is also important to construct pretence by scanning possibilities from memory and one's environment and then modifying these to form a coherent narrative. The process of make-believe involves holding symbols in mind that only make sense by taking an attitude towards pretence. In so doing, children with autism are able to gain an insight into the possibility that people's behaviour is guided by their thoughts and thoughts are guided by attitudes.

IN developing thinking skills through a play and drama approach, children with autism need to be guided through several stages of understanding increasingly abstract mental states in self and others. Initially children may need to be taught how to hold their attention onto objects or events that are new or different. At a later stage this may be adapted so that children are encouraged to develop a shared attention with others. As children progress they learn that having a different perspective on an object or event may result in different understanding and different behaviour. Recognising that people are also affected by their desires is a step closer to understanding intentionality. The stage after this has proved difficult for many children with autism to achieve and relies

on an understanding of belief as an explanatory reason for more sophisticated behaviour.

USING play structures that are designed to develop flexibility for each stage, children with autism can make progress in developing their thinking skills beyond the here and now and beyond the concrete behavioural forms that are commonly seen. Play structures are used to form a narrative that structures the sequence of events within the make-believe. This framework allows children with autism to hang ideas together with greater coherence and to communicate this to others. It also helps children with autism to generate novel ideas within pretence, as there is a clear reason to think of ideas that will fit into spaces intentionally left in the scaffold.

EXAMPLES of suitable play structures are outlined below. These are based around a play/drama lesson using the story of the Three Little Pigs. This is differentiated for children who are able to understand the story at the different stages described above. In these structures, the teacher steers the action around the moments of tension so that these can be understood in terms of the thoughts, feelings and beliefs of the main characters.

- **Play Structure 1: Attention**

Prepare the child for this by showing them a photograph of the puppets before they are introduced. Read the story of the "Three little pigs" from a picture book as a preliminary script for the drama. Attempt to share the story with the child by making it sound special. Model what the affective behaviour of the main characters (e.g. the pigs go "squeak, squeak, squeak", the wolf says "Rahhh" when he growls). Act out the story of the three little pigs using lots of eye-catching gestures, a continuous variety of stimulating objects and events and engender a sense of excitement through dramatic tension.

- **Play Structure 2: Shared Attention**

Introduce pig and wolf puppets by bringing them in a magic box. When the lid of the magic box is removed appear highly animated and full of excitement. The teacher using exaggerated gestures and voice, draws the attention of the children to the most salient features of the action. The teacher looks for and points to props as they are positioned around the room and shows a joy in discovering things together. The teacher shares

(...cont. overleaf on pg. 4)

A Special Learning

Chaity Ghosh

When I first heard the term “Childhood Autism” from a Psychologist, I thought that when my son Sanket grows up he would be cured, that he would leave his autism behind in his childhood. Gradually, I learnt the terrible truth, that autism will be part of my son for the rest of his life.

FROM then on, I was determined to find out more about this disorder. Where ever, I went and who ever I went to, the attitude I encountered was always negative. In their opinion my son’s future was bleak and frightening. Then I heard of an organisation called Action for Autism (AFA) in Delhi. I contacted Merry and she invited us – Alina and myself and our sons Pablo and Sanket – to do a Three-Month Training Programme. Those three months were the most valuable and special in my life.

AT AFA I discovered that the positive approach and the method of teaching autistic children that was used were completely different from what I have known before. Their 1:1 sessions with the students are so enjoyable and so much fun along with learning many things. Not only that, I also realised that this approach was very appropriate to children with autism.

(cont. from previous pg. 3...)

a moment of excitement in features of the story that the children find interesting. Other strategies to achieve this might include the following. Hide a pig puppet under the chair of one of the children; send out the wolf to find it. Put a wind-up toy pig in a clear plastic jar and point and say, “Look, look at the pig”; allow one of the children to give you the jar to re-activate it. Give the three little pig puppets to three children and tell them to run back to their chairs each time the wolf (teacher) growls at them.

• Play Structure 3: Perspective

For children who are capable of using shared attention the following strategies can be used to develop an understanding of perspective taking. Play a game of “What is going to come out of the magic box next?” Will it be a pig or a wolf ? Alternatively, the teacher can place a blindfold over the child’s eyes and ask them to guess which puppet they are feeling. During

WHAT I learnt at AFA helped me to feel close to Sanket. I now understood him better. I learnt why there are temper tantrums; why Sanket is afraid when there is no apparent reason, but shows no fear when he has a reason to be afraid. I learnt about Sensory Defensiveness, why he does not want to eat food which is soggy, why he will not set foot on a wet floor. I learnt why hitting a screaming child does not work.

I learnt to deal with a whole lot of ‘problem’ behaviours which I could not deal with before. I realised what a bright and intelligent child Sanket actually was. Earlier I did not know how to get him to use his intelligence. But now I knew how.

BUT AFA is not just about teaching methods. It’s about selflessness, cooperation, punctuality, dedication and love. After returning to Calcutta all that I gained at AFA has helped me work with Sanket and he is improving. I use every opportunity to teach him.

I want AFA to grow and I hope there will be other organisations like AFA that will help the countless mentally challenged children in our country.

the story of the “Three little pigs” the teacher draws the children’s attention to the following points. The three little pigs make a hot fire to boil a pot of water, but does the wolf see the fire or hear the water boiling ? Ask the children to look at the puppets. Can the wolf see the fire, when he drops tail first down the chimney ? Look at the pig puppets, what can they see ? Can they see the fire ? Can they see the wolf’s tail ? Hide a pig puppet under the chair of one of the children (as in play structure 2), send out the wolf to find. Next time ask a child to hide it for you and show that the wolf puppet cannot see where it is being hidden.

References

- Sherratt, D. (1999) ‘The importance of play.’ *Good Autism Practice* Vol.1, 2, 23-31.
- Sherratt, D. and Peter, M. (2002) *Developing Play and Drama in Children with Autistic Spectrum Disorders*. David Fulton Publishers. London. <http://www.unhchr.ch/html/menu3/b/k2crc.htm>

(To be continued in the next issue of Autism Network)

Farewell Interview

Amitava, a young trainee at the Action For Autism vocational unit Aadhar, will have left for Kolkata by the time this appears. Amitava and his family will be missed deeply by everyone at AFA. Below is a farewell interview with Amitava.



Interviewer: How long have you been at Aadhar for?

A: How long have I been in Agra?

Interviewer: No, Aadhar ...
(Handing Amitava a mint candy)

A: It tastes a bit like toothpaste. I've been

here for four years. I'm sorry, the spit fell out of my mouth.

Interviewer: That's O.K.

A: (laughing) I'm sorry.

Interviewer: What activities do you do at Aadhar?

A: I do screen printing, stitching, weaving, and I help Ola with cooking and making tea. I also make envelopes. And do Quality Control.

Interviewer: Which is your favourite activity?

A: I haven't thought about it, but screen printing I like best.

Interviewer: Do you like the atmosphere here?

A: I don't understand the question.

Interviewer: What do you like here?

A: It's a very difficult question. I haven't thought about it. But it's nice. There is no punishment here if I don't do my work, and I can be myself.

Interviewer: Now that you are leaving for Calcutta, do you have any message for all the teachers and children at Open Door and Aadhar?

A: Yes. The balcony should be moved over so that I can have my own private Shatabdi express in the senior section. And also my own bus station and train station should be constructed downstairs. I would operate the telephones. People would phone and ask train times and I would say, "I'm busy having a bath.

Call back later" and put down the phone.
(laughter...)

Interviewer: What will you say to people when you leave?

A: Good-bye AFA.

Interviewer: Anything else?

A: No. That's it. Good-bye AFA.

Interviewer: Will you miss the AFA Centre?

A: Yes, a lot.

Interviewer: What will you miss the most?

A: Everything. Will you miss me?

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The DAN Protocol

Part 1: The Biochemical/ Nutritional Treatment of Autism/ PDD

In 1995, one of the leading researchers into the field of Autism, Dr. Bernard Rimland, brought together a group of experts to brainstorm the nutritional, genetic and chemical factors that might be involved in Autism and PDD conditions. Their sessions, refined over the years, brought about what has been popularly called the DAN Protocol.

DAN (Defeat Autism Now) is an organization which is a leading research group, centered at the Autism Research Institute. Two members of the original group, Dr. Sidney Baker and Dr. Jon Pangborn were selected to write the actual protocol, using the information that had been developed. Then the full group reviewed the protocol and suggested changes before it was finally published.

ONE of the key tenants of the DAN Protocol is returning to a diet that is healthy. To quote Dr. Baker, "The American diet is not fit for human consumption."

Elimination of refined sugars, junk foods, artificial additives, and the other things that are common in the diet of most children in the United States does nothing to promote good health. Instead it loads their system with unnecessary substances some of which have been shown to be harmful.

A Gluten Free/Casein Free diet is also an important step toward implementing the DAN Protocol. This diet has been shown to have beneficial affects in Autistic children and is a key component of the Protocol. These substances often are found in laboratory blood tests that are done on Autistic

children, as well as in urinary peptide tests. The DAN Protocol suggests specific lab testing that should be done, and provides a list of recommended laboratories to do these tests. These labs have been found to provide the best quality information about the test results and help the treating physician determine the priorities that must be addressed in each individual case. It is important to note that each child should be looked at on an individual basis, and there is no "cookie cutter" approach that can be taken for everyone.

DIETARY supplementation is also a key ingredient of this treatment method. Many Autistic/PDD children

have been found to have deficiencies in various vitamins and minerals. The combination of all of the above factors have been shown to have sometimes dramatic effects on Autistic children, but the people at DAN are the first to admit that it is not a "cure all" and that all improvements may not be solely the result of the protocols. Autism is a complex illness, and there are multiple factors that may influence it's course.

As with any treatment, the Dan Protocol should be undertaken with medical supervision. Part Two of this article will give a basic summary of the protocol in list form and Part Three will give a list of physicians who utilize the DAN Protocol in their practice.

Part 2: A Summary of the DAN Protocol

Recently I was asked a question regarding the DAN (Defeat Autism Now) Protocol, which is gaining popularity. Just what is this method of treatment that's attracting so much attention?

FOR YOUR INFORMATION

Following the article by Greta Kertz: 'Autism, Joshua, The Dan Protocol and Immune 26', in Autism Network, December 2001, Vol VIII No 3, we were inundated with calls from readers wanting the DAN Protocol.

While we carry the DAN Protocol in this Issue, due to a lack of space we have had to leave out the very long list of physicians in the US who practice the Protocol.

Readers who want the list can send Rs 20/- and a self addressed stamped envelope to the AFA office requesting a copy:

***Action For Autism, T370F Chiragh Dilli Gaon,
New Delhi 110017***

THE Protocol involves a combination of changes to the diet and implementation of vitamin supplement therapy as a means of producing changes in Autistic behaviors. These changes include the following steps, according to published information.

1. Eliminate dairy products. The introduction of a Casein free diet appears to be primary in the treatment of Autism by means of this Protocol. Instead of cow's milk, substitute rice or soy milk or use Vitamite (chocolate) as a replacement.

2. Eliminate cereal grain products. Gluten has been shown to aggravate the digestive systems of individuals and with the known bowel involvement found in Autistic/PDD children, this action helps to relieve these problems. Instead substitute rice or another product for the Gluten containing wheat.

3. Eliminate junk foods and other food products that contain refined sugars. These are not necessary to good health and in fact have been shown to be harmful, due to their chemical composition and the artificial additives that are included in many of them. A "natural" source of sugar, such as fruit offers a much better alternative.

4. Supplement the diet with the vitamin and mineral therapy. Below is a list of the supplements and their dosages which are recommended:

- **Calcium:** 300 mg twice a day. This can be done in two doses, or once at bedtime to facilitate sleep.
- **Magnesium:** 50 mg twice a day
- **Vitamin C:** 50 mg twice a day
- **Vitamin B5:** (Pantothenic Acid) 500 mg twice a day
- **Vitamin B6:** 100 mg twice a day 1 multiple vitamin daily
- **DMG:** 125 mg twice a day
- **Pycnogenol:** 50 mg twice a day
- **Gaba:** 75 mg twice a day

5. If your child is currently taking any medications especially those such as Prozac or Ritalin, it is recommended that you discontinue use before beginning Secretin infusions.

AS with any treatment, the DAN Protocol should only be undertaken with medical supervision.

WHO AM I

Deepa Rabhavan*

This work was inspired by N. Madhavan, a person with autism, and is on understanding people like him

I'm not indifferent, jus' different
I may not talk, but I DO communicate

I don't look at you to 'see'
But I glance through when you 'blink'

I don't stop 'babbling' to LISTEN
Sometimes even if I'm quiet, I can't HEAR

If I laugh at you, smile back
I may learn to reciprocate your courtesy someday!

When I cry help ONLY if you know the reason
Or just leave me alone, that's much better

I may get up in between, don't shout 'NO'
Perhaps I just want to close the door!

I throw a tantrum, not to avoid the activity
Only to indicate to you, I'm not yet prepared

I know a lot on my own
Don't underestimate me if I didn't say 'I KNOW'

You can set goals that are 'idealistic'
I won't learn if your teaching is unrealistic

Prepare me for ANY change, even the UNEXPECTED
For my behaviour would be much better

I need to 'plan a lot' to follow your commands
Wait a little longer... than your patience level
Before you repeat or scream

Too many prompts make me dependent
Too little prompts lead me nowhere

The more you control, the more I resist
You are BIG, I'm small
It's unfair to take advantage

Let's give and take
If YOU care for MY sake

Listen to me when I don't talk
Be with me even if you can't stand anymore

I would understand your good intentions
Though I may not express it AS YOU DO!!

**Deepa is a young special educator at the
'WE CAN' School for Children with Autism in Chennai.*

Dear Family and Friends...

...This article has been written for the purpose of sending it to relatives and hosts of holiday gatherings who might need a crash course in what to expect from their guest with autism.

Sent by a reader from the FEAT Daily Newsletter

I understand that we will be visiting each other for the holidays this year! Sometimes these visits can be very hard for me, but here is some information that might help our visit to be more successful. As you probably know, I am challenged by a hidden disability called autism or what some people refer to as a Pervasive Developmental Disorder (PDD). Autism/ PDD is a neuro developmental disorder which makes it hard for me to understand the environment around me. I have barriers in my brain that you can't see but which make it difficult for me to adapt to my surroundings.

SOMETIMES I may seem rude and abrupt, but it is only because I have to try so hard to understand people and at the same time, make myself understood. People with autism have different abilities: some may not speak, some write beautiful poetry, others are whizzes in math (Albert Einstein was thought to be autistic), or have difficulty making friends. We are all different and need various degrees of support. Sometimes when I am touched unexpectedly, it might feel painful and make me want to run away. I get easily frustrated, too. Being with lots of other people is like standing next to a moving freight train and trying to decide how and when to jump aboard. I feel frightened and confused a lot of the time, like you would if you landed on an alien planet and didn't understand how the inhabitants communicated. This is why I need to have things the same as much as possible. Once I learn how things happen, I can get by ok. But if something, anything changes, then I have to relearn the situation all over again! It is very hard. When you try to talk to me, I often can't understand what you say because there is a lot of distraction around. I have to concentrate very hard to hear and understand one thing at a time. You might think I am ignoring you – I am not. Rather, I am hearing everything and not knowing what is most important to respond to. Holidays are exceptionally hard because there are so many different people, places and things going on that are out of my ordinary realm. This may be fun and adventurous for most people, but for me, its very hard work and can be extremely stressful.

I often have to get away from all the commotion to calm down. It would be great if you had a private place set up to where I could retreat. If I cannot sit at the meal table, do not think I am misbehaved or that my parents have no control over me. Sitting in one place for even 5 min. is often impossible for me. I feel so antsy and overwhelmed by all the smells, sounds, and people. I just have to get up and move about. Please don't hold up your meal for me – go on without me and my parents will handle the situation the best way they know.

EATING in general is hard for me. If you understand that autism is a sensory processing disorder, it's no wonder eating is a problem! Think of all the senses involved with eating: sight, smell, taste, touch AND all the complicated mechanics that are involved with chewing and swallowing that a lot of people with autism have trouble with. I am not being picky– I literally cannot eat certain foods as my sensory system and/or oral motor coordination are impaired. Don't be disappointed if mommy hasn't dressed me in starch and bows. It's because she knows how much stiff and frilly clothes can drive me buggy! I have to feel comfortable in my clothes or I will just be miserable!

TEMPLE Grandin, a very smart adult with autism, has taught people that when she had to wear stiff petticoats as a child, she felt like her skin was being rubbed with sandpaper. I often feel the same way in dressy clothes.

WHEN I go to someone else's house. I may appear bossy and controlling. In a sense, I am being controlling because that is how I try to fit into the world around me (which is so hard to figure out!) Things have to be done in a way I am familiar with or else I might get confused and frustrated. It doesn't mean you have to change the way you are doing things – just please be patient with me and understanding of how I have to cope...mom and dad

(cont. on pg 9...)

LAST ANNOUNCEMENT FOR AFA's...

Annual Training Workshop

October 3 - 6, 2002

INDIAN SOCIAL INSTITUTE, LODHI INSTITUTIONAL AREA, NEW DELHI

The eagerly anticipated Action For Autism Annual Workshop has something new to offer every year as the team learns and evolves. The workshop is open to anyone who wants to understand Autism, the myriad ways it affects individuals, the methods used to teach them cognitive, self-help and social skills, and most important how these skills can be taught.

LIKE all Action For Autism seminars and workshops, the sessions will be free of jargon, and will be illustrated with practical examples based on hands-on experience and exposure to children with Autism Spectrum Disorders of varying ages and across the spectrum. They will follow a format of lectures, video clips, question-and-answer sessions and discussions.

- **Individual consultation** for families will be provided on the last day of the workshop. The consultations will be available to those families who

make prior bookings – so do book well in advance.

- **Day care** will be provided during workshop hours for those who find it difficult to leave their children at home. Bookings must be made with Action For Autism well ahead of time.

- **Accommodation** can be organised at the ISI for a limited number of attendees on a priority basis.

- **For details and pre-registration forms:**

- See *Autism Network Vol. IX No.1 April 2002*
- Check out our website: www.autism-india.org
- Or write to us with a self addressed, stamped envelope (with stamps worth Rs.5/-) to:

**Action For Autism,
T 370 F Chiragh Dilli, New Delhi –110017.**

(...cont.from page.8)

have no control over how my autism makes me feel inside.

PEOPLE with autism often have little things that they do to help themselves feel more comfortable. The grownups call it “self regulation” or “stimming”. I might rock, flick my fingers in my face, flap my arms or any number of different things. I am not trying to be disruptive or weird. Again, I am doing what I have to do for my brain to adapt to our world. Sometimes I cannot stop myself from talking, singing, or partaking in an activity. The grownups call this “perseverating” which is kind of like self regulation or stimming. I do this only because I have found something to occupy myself that makes me feel comfortable and I don’t want to come out of that comfortable place and join your hard-to-figure-out-world.

PERSEVERATIVE behaviours are good to a certain degree because they help me calm down. Please be respectful to my mom and dad if they let me “stim”

for a while as they know me best and what helps to calm me. Remember that my mom and dad have to watch me much more closely than the average child. This is for my own safety, preservation of your possessions, and to facilitate my integration with you tippies (what we autistics fondly call you neurotypical folk!) It hurts my parents’ feelings to be criticized for being over protective or condemned for not watching me close enough. They are human and have been given an assignment intended for saints. My parents are good people and need your support.

Holidays are filled with sights, Sounds, and smells. The average household is turned into a busy, frantic, festive place. Remember that this may be fun for you tippies but it’s very hard work for me to conform. If I fall apart or act out in a way that you consider socially inappropriate please remember that I don’t possess the neurological system that is required to follow tippy rules. I am a unique person – an interesting person. I will find my place at this celebration that is comfortable for us all as long as you’ll try to view the world through my eyes!

My Brother is Different

Swapna Thampi Nair

Swapna is a parent and a Special Educator, based in Bangalore

"I don't want to celebrate my birthday at home (as long as Raja is around)"

"Mummy throw him out of the house (or better still make him disappear)"

"You don't have time for me, you spend all your time with him".

'He looks so normal, I don't think that he has any problem'

I have heard all these complaints and comments from siblings of autistic children for several years and do so even today. I always feel that as parents we can try to make their lives better even with a severely disabled sibling living with them. When I got my second child after my autistic boy, I wanted to gather more information to prepare my daughter to live with her autistic brother and his autism. I realised that I needed to prepare my boy too, to live with a sibling with 'normal' requirements.

Prepare your autistic child before the siblings arrival

I enquired of my trainer, when I was doing my professional training at Action For Autism, as to ideas regarding preparing my autistic child to receive a sibling. As usual, she showered me with many a wonderful idea and suggestion.

THROUGHOUT my pregnancy my son was aware of the existence of another life inside me which I explained to him in a very concrete and simple way. I showed him pictures of newborn babies, allowed him to listen to recorded cries of babies, and even took him to houses where there were infants. Whenever I took him to such places, I allowed him to touch the new born with his hand in a very gentle way and I told him "baby, very small, touch gently", this way I was conveying to him the way an infant had to be handled. I still had my imaginary fears, but I sought my husband's help to give adequate emotional support and body contact to my son during my hospitalisation days. Well before my trip to the hospital I made him sleep with his father. I feel the autistic child needs a predictable environment before any major change takes place in his life. During my

hospital stay my child used to visit me every day and I used to hug him and explained to him that when amma is back home with the baby we will have a lot of fun together. The preparation helped me to bring up the little one with my affected son. The major problem which I faced was the sound sensitivity which my son had when his sister used to cry out. The only option which I had then was to take the baby out or take my son to another room and to provide him with an alternate sound like music.

Sibling coping

There are different ways with which the siblings cope with their autistic brother or sister. Research suggests that about fifty percent of the siblings have to make some kind of adjustments in their life to cope with a disabled sister or brother throughout their lives or compromise in some substantial way due to the stress associated with the presence of their affected sibling. Again a large number of siblings believe that having a very special brother or sister helps them to develop into better human beings.

How we can prepare a sibling

I always feel as parents, we may often directly or indirectly influence the child to behave like a parent to their autistic sibling. We feel proud that, say, our five year old is like a "mother" to her twelve year old autistic brother. I feel that in the beginning this may go well as the normal child may show more mental maturity than her peers, and also at the same time get into the good books of parents and well wishers. However we need to keep one thing in mind, that in the process of looking after the disabled sibling by the normal child, the latter should not be deprived of it's own childhood. We can definitely include our normal child in our day to day activities and may be we can plan a few activities which the normal child can do with her affected sibling, like play activities, listening to their favourite music, turn taking games, and arranging the table before a meal etc.

I remember one experience of a mother in Bombay and how much her daughter had to struggle to protect her school work from her autistic sibling. If we can make little adjustments like, in this situation keeping

the child's belongings in closed cupboards with proper locks, providing a separate space for her and consistently remind her to keep her things in the designated place, we can prepare her in avoiding such mishaps. Perhaps if the whole family including the sibs of autistic children are a little more organised and consistent we can avoid such incidents.

ANOTHER aspect is the balancing of parental attention and affection between the children. In bringing up a normal child, especially if the child is younger to the autistic child, we need to assure the child that he or she is equally the focus of their parent's attention along with their autistic sibling. Recently one of my student's siblings visited me and I found him very shy and withdrawn. After a couple of visits he opened up and told me as to how much he had to adjust to the needs of his autistic brother and was still making adjustments. He felt that his mother would spend all her time with the affected child. After a few sessions with the mother, I was able to help her

realise as to how much the normal child missed her company. She now makes an effort to spend quality time with him and they have special outings together.

Super achiever sibling

When parents accept the autistic child unconditionally by providing a positive atmosphere all the members in the family are benefited. In such an environment the normal child may show positive adaptations. We can very well encourage this sort of adaptations as long as the typically developing child is not pushed beyond his abilities and limits of tolerance.

FROM my experience both as a teacher and as the mother of a disabled as well as a regular child, I have come to believe that as long as parents are not putting the burden of looking after the affected child on the normal sibling, and if they are positive about the autistic child in general, then the sibling can be helped to lead a normal and an eventful life with their affected sibling.

About Inappropriate Emotional Responses

Geetha Pradeep

“When he laughs it may not always indicate that he is happy. Sometimes such laughing spells could be due to discomfort or distress.”

This, and that person's with autism sometimes have inappropriate emotional responses, was explained to me by M, the therapist attached to the *Mother Child Project* at Action for Autism. My son Ashwin, who is non-verbal sometimes exhibits a boisterous laughing behaviour regarding which I queried the therapist during one of our feedback sessions which we have after a day's programme. I was somehow not convinced about the explanation because, even though I did not know **what** made him happy, I always felt certain that my son feels happy or ticklish as a result of which he laughs.

SIX months later, we had gone out on a Sunday outing and were on our way back home. We stopped en route for a little routine shopping. I went to purchase the items leaving my husband, my daughter, and Ashwin and behind in the car. My daughter thought it was not a bad idea to have some pav-bhaji, as she knew that I would take some time at

the shop. My husband purchased the pav-bhaji for both children and brought it to the car. As he was trying to sit near Ashwin with the plate, the hot pav-bhaji slipped and fell on Ashwin. It was quite hot and Ashwin reacted with a few sounds. My husband immediately cleaned him, and offered him another plate. I returned to the car after completing my purchases when I found all these things were going on. Ashwin was quite excited. and kept laughing away to glory. Once or twice he also pulled at his shirt. Thinking that he may be feeling hot, I told him he could remove his shirt after going home.

ON reaching home I first gave him some cold refreshments. After that when he was allowed to take remove his shirt we were astonished to see burns on his chest and thigh. The hot pav-bhaji had scalded him and there were significant patches of burns at both places. I was numb for a moment. All the way home Ashwin had had one of his laughing spells and I had been wondering why he was so excited and what made him so happy. Suddenly what M had said clicked and made perfect sense to me. The statement proved right!

Update on OPEN DOOR

The year started with some of our students and teachers moving out of Delhi. Amitava, our young philosopher in the senior section, move to Kolkata, and that was quite a serious loss. It is always sad when some of the family move on. Amitava was a special favourite; but such is life! New children have joined in a phased manner. We have some new staff as well. And volunteers – parents, students.

VOLUNTEERS are always welcome. But the lack of space makes it difficult to optimise their skills.

MUCH brainstorming and discussions later, the year brought about changes in the teaching methods as well as the curriculum used with the children, in an effort to make our efforts more appropriate, relevant and interesting.

THE children observed Republic Day and celebrated Holi with gusto. And in April it was time for the Annual Day. The Sanatan Dharam Mandir next to the Centre was the venue. And as usual, the students delighted us with their performance. Mrs Yasho Karan Singh, our gracious chief guest for the occasion, stayed right through the evening's performances and charmed all those present with her warmth and her sensitivity.

THE children have also been learning a lot from a community education component in our programmes. Among the areas covered are attending weddings, eating at restaurants, hospital situations, post office work, travelling by bus and buying tickets etc. All these community interface activities are simulated in our classrooms, ultimately helping them to generalize these skills.

THE Vocational Training Centre gets more exciting each day. The printing unit and the weaving unit are the biggest hits. In addition the seniors take a particular interest in the discussion on current affairs that takes place every day; standing on its head some widely prevalent myths like: "they don't understand anything", "he does not speak", "I don't think he understands what you say"!

AN enormous amount of cooking goes on at the vocational centre. Our children participated in an exhibition during the convocation at the Indira Gandhi National Open University (IGNOU). Greeting cards, woven items and food prepared by the boys sold like hot cakes. And there was coffee to wash it all down.

THE new batch of teacher trainees have started their practical training at Open Door. Two of them have a year's experience each of working with persons with autism at Camphill communities in the UK. The other trainees have all had some previous exposure to persons with autism.

THE Mother Child Program continues to be a favourite with families, and news of its effectiveness has travelled wide. Other than families from Delhi, Haryana, Gurgaon and Faridabad, we welcome families from Chandigarh, Himachal Pradesh, Kolkata, Jamshedpur. Bangladesh, among others.

ENORMOUS fun was had at a dance therapy workshop conducted at the Centre by Tripura Kashyap of Bangalore. Tripura has trained at Kalakshetra Academy, Chennai, and the Hancock Centre of Movement Arts in Wisconsin, USA. The children participated with gusto, and to put things as they were, they just had a ball.

IN the meantime, our in-house Clinical Psychologist, who will be available to families on fixed days and times, joins us. She also observes the workings of the different programmes. We are joined as well by an Occupational Therapist who is available to provide occupational and sensory therapy, on Saturdays.

ALONGSIDE, Open Door is simply bursting at the seams. We have enough trained personnel to help more children and families, volunteers aplenty who want to pitch in and help, but lack the space to accommodate them all. A couple of prefabricated structures on the roof top are under consideration and an application for funding for those, will go in shortly.

IN the meantime we soldier on.

"The Problems I Faced in Implementing a GFCF Diet"

A Parent Shares

The GFCF (Gluten Free Casein Free) diet is very restricted and soon my son became very weak in spite of my efforts to give him a nutritious diet. I was giving him soya milk instead of dairy milk. Then, while reading some well researched articles I found that about 70 per cent of persons on a GFCF diet may have problems with soya also. It is very strange that dairy milk and soya have similar effects! The GFCF diet should be 100 per cent to be effective; sorry 98 per cent does not work. Each molecule of gluten produces 15 opioid molecules. So even a little bit can cause the child to be drugged, being lost, and other similar characteristics.

MY son craved soya milk and that made me become suspicious. I decided to try and remove soya milk.

And to our surprise his health improved further and so did his behavior. In school also the teachers noticed the change. They had fewer complaints.

A major problem that I faced was the atta ground at the commercial chakki. The non-wheat cereals that I got ground was getting mixed with wheat that was being ground in the same chakki. The chakki owners were not willing to clean the chakkis before putting my cereals despite my requests. So the gluten free atta that I was giving him actually contained traces of wheat. I solved the problem by buying a home chakki. Now I was sure that my atta is gluten free.

MY son's health has certainly improved after his diet became 100 per cent GFCF. He is growing strong and the muscle weakness and coordination problem is no

more. I read up about proteins. The amino acid present in milk and non vegetarian foods are essential for children's growth. The vegetarian source was raagi and spirulina. Spirulina is a water plant very rich in proteins and minerals. Just a pinch of it mixed in his food did wonders.

HE no longer looks pale and undernourished. I found the sources of every amino acid. Nuts and seeds are good sources of minerals and proteins. Plenty of fruits and vegetables, pulses, nuts, seeds and non-wheat flours, gur instead of sugars is the best diet for every person. Also it is cholesterol free, has the roughage. Channa, makka, bajra ,raagi etc flours are in no way less nutritious than wheat.

IF the diet can completely change his health, behavior and intelligence I feel a potential way to attack Autism is also through the stomach. I can say this because some of our children were nearly normal till 12-18 months. The onset of autism matches with the time when we introduce dairy milk and wheat in the diet. The abnormal molecule formed from dairy and wheat in the diet is perceived by the brain as opium. Most autistic children also crave for these foods that makes it

even more difficult to remove them from the diet. It all depends on the parent's attitude. I feel that the earlier we start the faster a child will catch up with other kids. I lost a few years of very important language and social development but still it can be taught a little late.

BETTER late than never.

– ANNOUNCEMENT –

VERBAL BEHAVIOUR

AFA will be organizing a talk followed by a discussion on Verbal Behaviour led by a member who has just completed her course with Dr Vince Carborne.

The talk will take place either on 17 August or 24 August 2002, for half a day.

Those wishing to participate please call Annie at the Action For Autism office for details, after 10 August, 2002

Award-winning Girl Scout Project Inspired Creator to Reveal her Autism

Angela Loo

(This article first appeared in the Seattle Times)

Katie Grimes is not your typical college student. The 20-year-old from Federal Way has autism, a disorder she did not openly reveal until three years ago when she started working on a Girl Scout project.

THAT project became the Federal Way Autism Support Group, the community's first support group for parents of autistic children. Grimes organized monthly meetings, scheduled speakers, distributed fliers and designed an autism-information booklet. The group now provides support for more than 90 families in the area. The project has earned Grimes, a sophomore at Washington State University, national recognition from the Girl Scouts. She and nine other women from across the country will be honored in Washington, D.C., next month as this year's Young Women of Distinction. The award recognizes ten young women who have provided an exceptional service to their community and shown great dedication to achievement.

THE honorees will meet several U.S. senators and Supreme Court Justice Sandra Day O'Connor, and participate in career-development training.

Each will receive a \$1,000 scholarship. They'll also get to meet Elizabeth Dole, former president of the American Red Cross; Alma Powell, wife of Secretary of State Colin Powell; designer Vera Wang; and seven other women who have been named National Women of Distinction in honor of the Girl Scouts' 90th anniversary.

MORE than 300 women were nominated by local councils as this year's Young Women of Distinction. To be eligible, nominees must earn the Girl Scout Gold Award, the organization's highest honor. The gold-award project is crafted by the scout who works with an adult volunteer to implement it over one to two years. "I was struck by (Katie's) project because it was so inspiring," said Colleen Ozolitis, manager for young-adult development services for the Girl Scouts' local Totem Council, who nominated Grimes. "She was filling a need for something that didn't exist when she was younger. The fact that this was such a personal thing for her was one of the reasons it succeeded."

AUTISM is a developmental disorder that encompasses a broad spectrum of behaviors and levels of severity. Most people with autism struggle to communicate. In

Grimes, the disorder manifested itself in language-development delays and social awkwardness. Grimes' determination and drive were key factors in her success, said her mother, Lisa Grimes. "She just would never accept that she couldn't do this, that or the other.

THE support-group experience not only helped her realize the extent of her abilities but pushed her to disclose her disorder as well. "Early on in the project, I decided that I

would let others know I have autism," Grimes wrote in her project report. "This took courage; I had in the past felt ashamed of my disability... However, I knew that doing so would help my project and provide a chance for others to know something of who I really am."

A Teacher for Kuwait

A reputed Academic Institute is looking for a teacher with the following requirements:

1. Experience in dealing with autism, behavioral problems & practical solutions.
2. Should be able to set an example to others in time management & preparing IEP etc.
3. Should have minimum 5-7 years of experience in a similar position.

Interested persons can send their C.V. to the following address:

**Kuwait Center for Autism,
P.O. Box: 33425 Al-Rawdha, 73455 Kuwait
Fax: +965-254-0247
E-mail: kwautism@qualitynet.net**



A suggestion for your next workshops: In my work, both with parents and professionals and from personal experience, I find that "burn out" is really common. I think this needs to be addressed. The work requires one to be "positive" all the time and this can be quite energy draining. Perhaps you could include sessions in this area.

It is unfortunate that this field (of Special Education) does not pay well. Therefore, it detracts a lot of good people. We seem to be reluctant to talk money; and work in this field is still viewed with the charity model in mind. Ah well, as they say, if you pay peanuts, you get only monkeys!

I am trying a lot of your suggestions - and some of them have made my work more interesting - I see the results sooner than expected and more importantly, it is real fun to see things work! Apart from all this, your energy and passion is wonderfully infectious - and I think most of us will take a piece of that with us!

Anuradha Shyam, Special Educator
CHENNAI

First of all I would like to thank you AFA very very much for conducting a workshop on autism in Chennai for four days. Myself and my wife Anuradha attended the same and at the end of the four-day workshop, were honestly going back with so much valuable information, that we are very confident that on application of these methods discussed at the workshop, will improve and fetch a lot of results on our five-year-old son.

It gave us so much confidence that we have started to apply immediately. You have gone into quite a depth in actually dealing with various kinds of behaviours and teaching patterns, which all of the educators, earlier workshops, and books have failed to provide us. You successfully applied these methods yourselves before preaching to others and that has helped us.

How I wish I was staying in Delhi at a close proximity to you people to learn and interact more better. Now we have started to prepare a structured environment and education for my son. Also fortunately his special educator has also attended the workshop and feels she is better equipped with knowledge on autism and to handle the children.

We thank Hema Jairam in guiding us and pressurizing us to attend the workshop. Before attending the workshop, we were literally lost in our world. We just did not know what we were

doing and if that was the correct approach. But now we know where we just are. With god's grace and your blessings, we are sure to bring up our son in the best way. It was nice to also meet various other parents of autistic children. I do not want sympathy, but guidance, which you have given.

V Chandrasekhara Rao
CHENNAI

The workshop conducted by AFA at Pune was really very useful and practical. The dedication and perseverance of the AFA team has served as a source of inspiration for all of us. What I particularly liked was your emphasis on respecting the individuality and needs of each child. I do wish more special educators had attended the workshop. God bless you and your families

Evelyn Williams
PUNE

It was a wonderful experience for us. The staff was extremely dedicated and lovable. One day at AFA is more useful than weeks which we had spent at Lucknow Medical Knowledge. For first time since Murtaza got diagnosed as autistic, we realized the reasons for his tantrums and violent behaviours. Now we have learned to control his challenging behaviour up to a large extent thanks to AFA and its talented staff. Previously he was not socializing with other kids, now he interacts a little with his friends.

Iqbal and Nudrat Hasain
LUCKNOW

I have received today your package with "Autism network". Thank you very much for it. I would like us to make a similar journal / magazine in Romania. Autism Network is a very good journal and very inspiring for us.

I have received it at an extremely good moment. These days we are trying to plan our journal and it is very helpful to see the design of another journal of an organization that isn't very different than ours even if you have been working as an organization for more than ten years and have a lot of achievements. We too will try to offer basic and new information on autism and to connect people. Unfortunately, we have not yet a school and center like yours to offer a hope for parents regarding their children's education. Can we use information/ articles from your magazine? Of course we will specify the source. Very good luck in your activity.

Liuba Toader
AUTISM SOCIETY OF ROMANIA

HELPLINE



Q. An Autistic girl of 20 is self-sufficient to a great extent. She shows signs of attraction for the opposite sex, has regular menses. She is beautiful, and plays the violin quite nicely.

1. Is marriage advisable?
2. Is there a possibility of normal sexual behaviour?
3. Will it improve her condition?

A. It is very difficult to respond to your queries one and two with such limited knowledge about the person in question. Many persons with autism develop normally through puberty including developing an attraction for the opposite sex. However, that may not automatically equip them for marriage or 'normal' sexual behaviour. Marriage requires the ability to take responsibility not merely of oneself, but also of ones partner, as well as of possible offspring.

On the other hand, there are persons with autism who are on the very able end of the spectrum who marry and raise a family.

Each individual has his or her own potential and limitations. No one blanket judgment can be applied to all. Each situation has to be seen in its own light. The only question one can answer with confidence is the last: No. Marriage will not 'improve' the condition of a person with autism.

Q. We had the great chance of attending the Action for Autism training workshop at Disha in Jaipur from 5 -7 April. I also went through your book: "Compilation of Reading Material" and the December 2001 issue of "Autism Network" and found them a very good guide for parents like us whose child has been recently diagnosed with Autism.

For my four-and-half-year old son, I would like to go for Megavitamin Therapy, and seek your guidance on the following points:-

1. For Vitamin B6, the daily dose of 17 mg per kg of body weight is advised, at what time of day should this be given, and is it only once a day, or may be given in doses throughout the day?
2. The best pharma company for DMG in India or USA or UK?

A. Thank you for your kind words about our workshop at Jaipur. Regarding Vitamin B6 it can be given at any time in the day. But the times remain the same. So if you give it around eight in the morning after breakfast, try and give it around that time each day.

It can be given in two doses; but not sure if it would be advisable to break it up into too many. I suggest you write to the *Autism Research Institute* directly and query them. Their web address is: <http://www.autism.com/ari/>; and postal address is: **4182 Adams Avenue, San Diego, CA 92116, USA.**

The company in the USA that supplies DMG is: **Kirkman Laboratories, Post Bag No 1009 Wilsonville, OR 97070, USA Tel: 503 694 1600, 503 694 1603, Toll Free 800 245 8282.**

To the best of our knowledge there is no company in India that supplies these food supplements. Send an SASE to the AFA office to receive a sheet of information material on the subject. In addition, you will find an article on the subject in *Autism Network Vol VIII No 3 of December 2001.*

Q. I am writing from Canada for a friend of mine. Her boyfriend has two autistic children and they look for some kind of information on how to teach them to put their shoes correctly on the left and right feet. If you have any kind of written instructions that may help them teach the children it would be very appreciated.

A. Ask your friend to put a sticker on the same foot of each pair. For instance a Mickey Mouse on the right shoe of each pair.

If this does not work then try the following. Take a large sheet of paper and outline her daughter's feet on them. Next to the outline of one foot, say the right foot, place a small sticker of a Mickey Mouse or a red star. Put an identical sticker on all the right shoes of every pair. When she wears her shoe, place this paper

on the floor and have her sit with her feet "matched" to the outline of her feet on the sheet, and then put the shoe on "matching" the stickers. Slowly reduce the size of the sticker and finally remove completely.

Q. I am a mother of a four year old autistic son. Both of us parents work in Guwahati. Our son was diagnosed with autism by a pediatrician in Guwahati, Dr. Sabinah Ahmed, when he was two-and-a-half years old. From the age of three years he is being trained by a psychologist specializing in developmental delays of children. My son is not retarded and in fact is quite smart. Hence we have been able to teach him a few things. He is also very emotional. He does everything possible to keep me from getting annoyed. Therefore he is more than compliant.

Due to the progress made by him in academics we have been able to get him admitted to a regular school. He is quite gentle with other kids and does not hurt them.

The problem is that his odd behaviour and responses to touch etc appear very bizarre to his own peers. He gets over-stimulated by external stimuli, like touch, sound and sight. I do not want him to be shunned by his classmates and hence I need to modify his odd behaviours with more appropriate behaviours. If we can help him manage his over sensitivities, I am sure he will improve a whole lot more, especially in social aspects. He likes his classmates, but really does not know how to approach and behave with them and does not realise that his odd responses puts some of his friends off.

Kindly let me know if we can become a member of AFA and how we could benefit.

A. It is wonderful to learn of the progress your son is making. You have indeed taken him very far on his developmental path and helped him cope with a regular school. You refer to some difficulties he is having with his peers at school because of the unusual ways he expresses excitement. You naturally want him to learn more regular ways of doing so and generally learn to control himself. As you are aware, individuals with autism spectrum disorders may have sensory difficulties. As a result they may respond in unusual ways to touch, or sound etc. Your son could benefit from desensitizing exercises. Your letter does

not explain in what way your son responds to over stimulation. Without this information it is difficult to suggest exercises that can help him. Perhaps you could write in with a few specific examples.

In addition you want to teach your son alternative behaviours for when he is excited. For instance if his unusual behaviours are to do with his hands: give him something to do with his hands when he is excited. Teaching the concept of private and public in relation to behaviours can also be helpful. He thereby learns that it is okay to have certain behaviours when he is on his own, and not when he is in company. Try also using social stories to help him learn appropriate behaviours in specific situations (see Autism Network Vol VI No 3 and Vol VII No1). Social stories can be amazingly effective when well written and used.

You might consider discussing with the principal, the possibility of giving a talk to the kids at his school to create awareness about disability and help his classmates see the reasons behind your son's behaviours. Kids can be very unaccepting, but they can be great buddies also if an adult can facilitate them well.

Action For Autism is a parent organisation. Its aim is to create a society that is inclusive of our children. AFA is a movement aimed towards this end, through the creation of awareness, developing teaching methods, imparting training, facilitating the formation of parent support groups, changing legislation, and so on. Every member contributes directly or indirectly to this goal and a brighter future for our children. Should you decide to become a member you will be part of this pioneering movement.

Q. Whenever we do an activity with toys, my son throws them. How to stop this?

A. To get around the throwing of toys when you are trying to do an activity there are a number of things you could try: Prepare him for the activity. Structure the worktable so that he cannot throw. Reduce clutter and keep exactly what you will use on the table. Structure the activity so he knows exactly what is to happen, how much, what will happen, when it will end. If he does manage to chuck something despite all this, do not give the behaviour a reaction. Instead catch him being good. Which means that if you get through an activity without him having thrown anything, then acknowledge, praise, reward.

(cont. from pg. 1...)

Uma Madan, who was representing KPAMRC, and me that there is no objection whatsoever to both KPAMRC and AFA continuing our training of teachers. A big relief for families. We should know. Every day our office is urgently visited by families – from as far apart as Nepal, Assam, Ladakh, Hyderabad- seeking help and training for their children.

At the same time the Rehabilitation Council of India continues to hold that children with autism do not need a specialized training course. So the one year Course in Special Education in Mental Retardation will instead be extended to two years and include a three month module in Autism to equip participants to become competent teachers for children with mental retardation as well as autism. On the one hand the RCI says that the DSE (MR) should be made a two year course on par with other courses. One would assume this is because it believes that the young trainees would require two years to become efficient teachers of children with mental retardation. Ironically, on the other hand the RCI believes that children who have autism – acknowledged to be far more complex, difficult to understand, and more difficult to teach - will do fine with a three-month training course. This not taking account of the fact that the trainees will first spend a good part of the three months unlearning what they have learnt for MR!

Prof. Jeyachandran complained to us about individuals who were charging Rs 1,000 to Rs 2000 per session from families. Will we have more to complain about later? What about the bounty hunters seeking fame, public recognition and the trappings of public life? Instead when will we complain about the dearth of appropriately trained teachers?

Perhaps we need to introspect deeply on what our children really need.

When we talk about these issues to those in charge, we're given what is perceived to be a comforting reassurance – 'we're restructuring curricula and eligibility, things will be okay in a few years'. Years! Ever thought what that means in the life of a child? Or in the lives of all those children and carers in the autistic community?

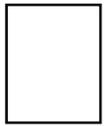
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AFA Mission Statement

To create an environment
where children and adults with autism
and their families
can live as fully participating members
of their community



AFA's own E-mail and Homepage

Action For Autism now has an *e-mail address* and its
own *Homepage* on the Internet.

Our e-mail address and internet access details are:

autism@vsnl.com
http://www.autism-india.org