

# autism

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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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'Dussehra' – before and after  
by Vishu, student at Open Door, New Delhi

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

- AFA : Tel. 55347422, 30964730
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# C O N T E N T S

Page One	1
Member Share	1
Augmentative Communication: "Niklaas has already a vocabulary of 23 photos"	2
Buy-a-Brick Programme	7
Message in a Book	8
Letters	9
Behaviour Change – Part 2 (Hindi)	10
My Story – Inside My World	12
Helpline	14
Workshop on Management of Children with Developmental Disabilities through Behaviour Management	17

## PAGE ONE

Fifteen years ago following 'The Sound of a Miracle' by Annabelle Stehli, AIT practitioners gave out convincing literature on miraculous cures by AIT. Some parents of that generation 'did' them all: AIT, Super Nuthera, DMG. However the 'net bazaar' was still awhile away. Drugs and treatments to 'cure' autism, even the latter day secretin, did not have the kind of 'captive' audience that the net now provides. From diagnosis to treatment options is just a click away. While on the one hand this is a great boon, on the other the information overload can sometimes be confusing.

Unfortunately, painstaking, planned work with the child on a day to day basis, teaching skills, teaching concepts, is tough. As parents, the urge to find something we could 'give' the child that would make him 'not autistic' is strong. Especially when anecdotal accounts of medical 'cures' abound.

That is why when I spoke to Sapna, a young mother a week ago, I was filled with concern. It can be very hard when you are 'hit on' with information about 'cures' from every quarter. "I am so confused" she said. "I no longer know what to do or not." "Where will this end?"

Where indeed! Her son is on every therapy propagated on the net, chelation, GFCE, vitamins, etc. Her concern was that she was so exhausted dragging him from clinic to therapy to clinic that she no longer had time to enjoy her wonderful son in her quest to cure him of his autism.

I had for her the suggestion I have given other mothers before. Keep records. Well before starting a new treatment,

start keeping a record: of your child's behaviours, communication, daily living skills. When we live with our child on a day-to-day basis, we often do not notice the little improvements. But the minute we start a time-and-money-consuming therapy, I am on the lookout for improvements. I will notice every little new thing my child does and credit everything to the therapy. Keeping records ensure I do not miss out improvements either before or after and that can help in not getting psyched into seeing progress. I recall Sapna telling me her son's hand flapping was down since starting chelation. Then I learnt that at the time he had also started sensory therapy. But for Sapna, who had invested enormous time, money, and emotions on chelation, the improvement was only because of that.

During the course of our conversation it also transpired that now her son was jumping a lot. I asked her, "You believe chelation reduced hand flapping. Why do you not attribute the jumping to that as well?" She admitted with surprise that she had not thought of that at all. She was so 'convinced' by the endless barrage of encouraging accounts that there was no room for thinking otherwise. We see what we want to see. We believe what we want to believe.

Autism Network has been carrying information on the DAN Protocol for over eight years. We do believe that there can be benefits from following aspects of the protocol for some of the children. But does that lead to a 'cure'?

We know young people with autism who are completely included. Some married as well. Of course they still have

*(cont on page 13...)*

## Member Share

Of the numerous emails we receive everyday, at least five are requests for help. Some of the responses find their way into our helpline. A few families and professionals have requested that we start a *mail consultation/ discussion/ helpline service*. After some deliberation it has been decided to start this service on a trial basis, but extend the responses to all members through an elist of members of AFA. A select panel will respond to queries that AFA members have on various issues, through the elist. These queries may be of, but not restricted to, therapy issues, teaching methods, medication, legislation, rights, among others. In short anything a member might have queries or concerns

about. Since many of us have similar concerns it would be helpful to share more widely a response given to a specific question.

There will be an effort to: a) maintain a scientific temperament, and b) respect the rights of individuals with autism, in keeping with the philosophy of AFA.

If you are a member of AFA and do not receive emails from us and would like to receive responses to queries, please do send your email address to Action For Autism with the subject '*Discussion/ Helpline.*'

In addition if you have any comments/suggestions on this venture do write to [autism@vsnl.com](mailto:autism@vsnl.com) about it with the subject line '*C/D/H comments.*'

## Augmentative Communication: "Niklaas has already a vocabulary of 23 photos"

Hilde De Clercq

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There is a big difference between 'talking' and 'communicating'. A father of a non-verbal young lady with autism once told me that he still dreams about his daughter "being able to speak one day." This kind of dream is normal, and human and comprehensible, and justified. Unfortunately even if his girl would speak she would still be a person with autism.

VERBAL people with autism may have a big vocabulary of 'spoken words' but do not always use their words in order to communicate. Their language is often characterized by echolalic sentences, they have a tendency to talk about their favourite subjects in long monologues, they remain having difficulties with abstract concepts, their communication and language may be proof of autism-thinking, pragmatics and the social use of language remain difficult etc.

ESPECIALLY in the field of communication and social skills even very intelligent people with autism have to face very many difficulties. Marc Segar, a person with autism and author of 'Coping. A survival guide for people with Asperger Syndrome' gives a very interesting kind of definition about autism: "Autistic persons have to learn scientifically what ordinary people already know intuitively"<sup>1</sup>.

THE communication problems in autism go much further than – in some cases - not having words. The core problem in autism consists of the fact that our children or adults with autism are not sufficiently aware that they can influence the environment by communicating. And communicating does not necessarily have to be with words. Several other *forms* of communication can be used in order to communicate.

A useful instrument to observe spontaneous communication in children with autism is the TEACCH Communication Curriculum<sup>2</sup>. It mentions several

*dimensions* of expressive communication: FORMS, FUNCTIONS, CONTEXTS, and SEMANTIC CATEGORIES.

THE aim of this article on communication is to give the reader an idea of how to observe communication according to these different dimensions and how to develop communication goals starting from objective observation.

**FORMS** - of communications could be seen as the *how* of communication. People with autism very often have private ways of communicating with their environment. All too often parents or siblings seem to be the *translator* for the child. A very interesting experiment in this field is the one of Derek Ricks<sup>3</sup> who put 'normal' children and children with autism together in 4 situations:

1. They could see a balloon (feeling of joy)
2. They could see and smell food (they liked to eat it)
3. The food was taken away (they were frustrated)
4. They saw their mum (they were happy to go home)

RICKS recorded all the vocalizations of all the children in these four situations. He then invited the parents afterwards and had them answer two questions.

THE first question was, "Do you recognize your own child?" The parents of the children with autism could easily recognize the vocalizations of their own child whereas the parents of the ordinary children could not. Ordinary children seem to use a kind of universal, standard way of expressing their emotions. Children with autism have a *specific, individualized, non-universal* way of doing so. This is the reason why it was so difficult for parents of a standard child to recognize their children.

THE second question was, "Do you know in what situation the child is when you hear the vocalization?"

ALL parents could identify the exact situation for the neurotypical children, not only for their own but for the others as well. For the children with autism however, parents could only recognize the situation for their own child. The children with autism seemed to have used a way of communication that was incomprehensible for other people. This private communication means that you only understand what the child feels if you know him very well. Thus, from the very beginning onwards, people with autism seem to communicate in a specific way and not according to universal codes.

VERY often this private way of communication grows with the child. Of course children with autism can be taught to communicate in a universal way, with universally understood symbols such as words or pictures, but because of their specific cognitive style (eg in making associations) they often continue to express emotions in a very specific way.

THIS aspect of their communicative style plays a very important role if we discuss communication. In the TCC it is called 'Pre-Communication'. Pre-Communicative Behaviour is communication that is not universal, but private and idiosyncratic. One has to know the 'manual', or 'the user's guide' of the child in order to understand him. It needs to be interpreted and of course it could be interpreted in many different ways by different people! For this reason it is not a real, not a full form of communication, and above all it is a form that cannot be elaborated on in the future. For example, when Thomas is in the kitchen with grandma he develops stress-behaviour. Grandma does not understand why he is stressed and crying. Elisabeth, his sister, tells grandma that Thomas has been asking for coca cola the whole time. Grandma says that she has not heard anything. And Elisabeth answers: "But grandma, he had his coca cola-look!" And she is right !

THOMAS as a little boy had several 'looks' that we called : 'Coca-cola -look', 'Pizza-look', 'Water-look' This is not a universal way of asking for something, it is very private and in the future it would be impossible to teach him also a 'coffee-with-milk-and-sugar-look' !

BART, a boy with autism and mental retardation, who knows a few words says, "Bravo". The person who tickles him does not understand his 'manual' and continues to tickle him. Result? There is a tantrum! Unfortunately for Bart the word "Bravo" means: "Stop!" Bart's mum knows how to explain this. Bart is in a

classroom where the teacher often says "Bravo" each time when Bart's work is finished. So, for Bart , "Bravo" means "finished", "stop", instead of "you did your work in a perfect way." As in this example we can see that some 'private' expressions in some cases are echolalic.

COMMUNICATING in a pre-communicative way may put the person with autism in difficulties, especially if the environment does not understand this. Sometimes there is a relationship between communication problems and 'problem behaviour'. In many cases problem behaviour is a way to communicate or at least an attempt to communicate with the (only) means the person with autism has at that particular moment.

RACHELLE, an adult woman with autism and severe mental retardation starts to bite her hand each time when she is hungry. We could say that Rachele communicates when she bites herself. Yes and no. Let's call this behaviour 'pre-communicative'. She has never been taught how to communicate for food in another way. Biting is considered to be one of her biggest behaviour problems, yet from her point of view it is an attempt to communicate. It is not a universal way of asking for food. (For example, for Tom, hand-biting means that he has to go to the toilet). It is therefore a confusing situation for professionals and it certainly is not a form that can be expanded. You cannot teach her, for instance, to scratch herself when she is thirsty.

I have emphasized pre-communicative behaviours because it is a form of communication that needs to be *interpreted*, and in observation we have to be *objective*. Though we cannot teach each person with autism to talk, we can teach them to communicate. Our people with autism can be helped by **augmentative communication**: communication with *visual support*.

FORMS of communication should be individualized for each person with autism, the goal being that the person with autism is able to use it to communicate independently. So, it is important *not* to choose the form of communication that is most adapted to our wishes (usually spoken words, the most abstract form) but to choose a form adapted to the level of understanding of the student. This is logical since we know that children first understand the words that they then use later on when they start speaking. Understanding comes first! Likewise, we cannot expect a person with autism to communicate using a form of communication (e.g. photo) that he does not understand. Maybe after a lot of training sessions he

will, but unfortunately in this case we are only conditioning the child and that is not our goal ! Children with autism who have been in a predictable environment and who are used to having visual timetables and other types of visualization adapted to their level of understanding have a good basis to use this visualisation for an expressive communication as well.

PEOPLE with autism can communicate by means of the following:

**Motor Communication.** For example, the child takes a person by the hand and shows him what he wants, or body language viz iconic gestures where the meaning is in the gesture itself and does not have to be derived. Gestures such as “look up there!” or “Come here !” are clear, visual, iconic gestures. On the other hand expressive gestures such as ‘consolation’ - when I take somebody in my arms for instance – is in many cases too difficult for people with autism, because these gestures are too ‘open’, one has to derive meaning. The meaning is not immediately evident in the gesture itself.

**Sign language.** Such as used for people with hearing impairments is only a solution in exceptional cases since this language is as abstract as spoken language. We risk that the child is able to imitate a few signs without understanding the meaning. One difficulty is that sign language is not understood by everyone in society.

**Objects.** This is covered a few paragraphs later.

**Pictures.** Such as photos, drawings, pictograms etc.

**Written and Printed Words.** When verbal children with autism have difficulties in retrieving words it may be helpful to give them a piece of paper and a pencil. It is sometimes easier for them to write down what they want to communicate. Verbal students with autism with the necessary intellectual level of understanding can be helped a lot with a computer. If words are difficult to say or to find, they can express themselves better if they use a computer. Of course this is relevant mostly to high-functioning students who are able to work on a computer independently.

**Spoken Words.** They are a difficult form of communication for many of our children and in some cases words and expressions are echolalic. Echolalia is not typical for children with autism since it also occurs in ordinary development between the ages of 18 months

and 36 months. It is the literal repetition of words that have been heard before. People with autism may use it without fully understanding the real meaning of the words. Echolalia can be delayed or immediate. It may also serve a communicative purpose. For instance, while leaving the swimming pool a boy with autism sees a vending-machine with chocolate. He has been such a good boy that mum puts the coin in the machine. Unfortunately nothing happens. The boy gets very nervous and so does mum. When the child is about to have a tantrum, mum says in a very loud voice, “But the machine doesn’t work!” Right at that moment a bar of chocolate comes out of the machine! Ever since that day, when he wants to have a bar of chocolate the boy cries in the same voice, “But the machine does not work!” In fact this echolalic phrase is communicative, but unfortunately it has to be considered as pre-communication since it is not understood by everyone. But it is okay to use it with mummy of course!

**A mixture of different forms.** These forms are *visual and concrete* and thus adapted to the visual thinking style of persons with autism. Since they are visual they are *spatial* as well, and our students do not have to search for them somewhere in their brains; the information stays there all the time.

THE fact that communication is also a *social* activity between two or more persons is an extra difficulty for people with autism. People with autism do not always direct themselves towards the person they communicate with. By using ‘Augmentative Communication’ (eg. a child giving a cup to an adult in order to get milk) we obtain a kind of ‘visualisation’ of the communicative act. In other words ‘the *process* and the *effect* of communication’ can be seen. There is a real interaction between two persons: the child gives the communicative aid and gets something back. You see the *reciprocity* and you see the result immediately.

COMMUNICATION with objects and pictures is universally understood and can easily be elaborated. If a child is able to communicate with a cup in order to get a drink, we can teach him to give a plate in order to ask for food, or to give his shoes in order to ask to go for a walk. If someone with autism communicates with a photo, one can elaborate the quantity of photos in the future. In this sense we talk about the *vocabulary* of the child. Instead of having to say that the child doesn’t speak yet, Niklaas’ father told us that he was so happy since *his son already had a vocabulary of 23 photos*. By

the way, almost all the vocabulary was about 'biscuits', since they were the most motivating thing for Niklaas. Communication is so difficult for our children, so we start with their biggest motivation, with the *most motivating word*.

THE biggest concern of parents as well of professionals often is that the child would lose his words or that he might not develop spoken language anymore if 'augmentative communication' were used. In our experience with augmentative communication we experience the opposite. If a child has the potential to speak, the chance that he will use the verbal communication is much higher if his communication is supported. David, a young man with autism, would come to the classroom after his jogging circuit, breathless, thirsty, uttering the words, "I want....I want....", but he never found the word 'water' that was somewhere in his brain. His teacher started to teach him to communicate with photos. David has all his photos in a small 'album'. After jogging, he now enters the classroom, takes his album and says (while turning the pages and looking for the picture of the bottle of water), "I want...water". He feels less frustrated thanks to his visual help. Here we witness that visual help does not take away the possibility to speak, it rather stimulates the child to use his capacity. Also verbal and normal intelligent people with autism are helped by this way of communication. Thomas, being very upset when he got teased during recess, used a 'help' card he could give to the professional in the playground. The fact that he had this card also gave him a lot of emotional support: in case he was so stressed that he had difficulties finding his words, he still had the card ! Only one big sorrow, "Mum, what am I going to do if I lose my help-card?"

SOMETIMES even when children with autism have words, they do not always *direct* themselves towards the person they want to communicate with. Here again visual help is very useful. Mary can be in her room for hours saying "fruit juice", fruit juice." Unfortunately her mum is downstairs and cannot hear her. This problem was solved when pictures were introduced. Mary now goes downstairs and when she sees her mum, she gives the picture to her while saying: "Fruit juice." This is real communication.

THE functions, the *why* of communication, can be translated into the *power* of communication. Communication is much more than talking. Ordinary babies discover in an intuitive way that they can

manipulate their environment by communicating. A few-weeks-old baby cries when he wants something; and mum can easily understand the different types of crying: he is hungry, he wants to be picked up, he has pain. The normally developing baby has already developed many functions of communication before he is able to speak! Our children do not always discover this *power* of communication in an intuitive way. It is up to us to teach this to them! This is the reason why understanding the functions of communication is very important; teaching the child that real communication is much more effective than hitting yourself, throwing objects, having tantrums and so on. It is up to us to understand this basic problem in autism. We have to try to teach them that you can get something from people, that you can *manipulate the environment by communicating*.

**FUNCTIONS** - of communication. The most important functions are:

**To ask for something.** Example to ask for a candy by using an object, a drawing, a written word.

**To comment.** In typical development children are first able to talk about 'here and now', they talk about things they see, they name things. This is a function of communication that is in some cases highly developed in verbal children with autism. During a big part of their school years they have been taught to name things: a banana, an apple, a biscuit. Unfortunately when they are at the table and they want a banana, they do not use the word in order to communicate, in order to ask. There is a big difference between naming (comment) and asking for...

**To give information.** In ordinary development children gradually start to talk about the 'there and then', about present and past, about things that are not immediately visible and present, e.g. John says : "Yesterday, I was with my grandma and she prepared pancakes for me". It is obvious that this function of communication is more difficult (since invisible and more abstract) for people with autism.

**To refuse.** The tragedy of some persons with autism is that we often have to teach them everything, even the function of 'refusing'. Mary, a girl with autism used to eat yoghurt as a desert, each and every day. Her mum told me that she herself likes yoghurt so much, so she gave it to her child as well. When Mary had been taught to communicate by means of photos, the first thing she

did was taking the yoghurt-photo and throwing it as far as she could....not being able to refuse must be terrible!

**To ask for help.**

**For Social routines.** Such as saying bye, thank you, hello.

**To communicate emotions.** There is a big difference between expressing emotions and communicating about them. Remember the experiment of Ricks<sup>3</sup>. It is clear and obvious that people with autism have the same emotions as neurotypical people, but the expression is different. Matthew had to undergo an operation. His parents were very worried but the doctor reassured them that everything was okay, Matthew was singing in his bed. Mum and dad immediately asked what kind of a song he sang. What a strange question according to the doctor. Unfortunately little Matthew was singing 'happy birthday' and this meant that he was in great pain.

IF a child falls down and then cries he expresses the emotions that he has pain. This does not mean that the child is able to communicate about his emotions because this is one of the most difficult functions in autism; addressing yourself to a person in order to tell him how you feel inside! Nothing is more abstract and invisible as emotions. Can you show me anger, fear, love, jealousy? Impossible! You can try to show me a picture of a jealous boy, but this does not mean that you understand the 'concept' of jealousy. This does not mean that you recognize and understand the feeling, the feeling in another person or in yourself....and even if you do, communicating about it is again another step.

IN my book on detail thinking in autism, 'Mum, is this a human being or an animal?'<sup>4</sup> I try to illustrate these difficulties from the point of view of people with autism. And this cognitive style of thinking in details leads us to the third dimension of communication.

**CONTEXTS** - of communication: **where, with whom,** and **in what circumstances** does the child communicate?

BECAUSE our children have a tendency to focus on details rather than on concepts and full meanings, they have a lot of problems of generalisation. They have a tendency to associate a skill with a detail, with a person, with a place, with a situation...in other words with a specific context. This is also true for their communication skills. Oliver is only able to talk with his mum and

brother, he never talks at school. David knows how to use his communication card with the speech therapist but not with his teacher. Thomas, being with us in a holiday house in Spain, never took something out of the fridge, never asked me for something to drink. When I told him that there were drinks and that he could take them or ask for them, he answered in a very surprised way: "Oh mum, I didn't know you could also do that in Spain!"

ALL these examples have nothing to do with a feeling of unwillingness, but with the difficulties they have with generalisation of communication skills. Thomas one day had smashed his fingers between a door at school. The nails were all flattened and fell out. The teacher who knew him very well saw him in such pain and said, "But Thomas you can cry when you have so much pain!" And Thomas answered, "No, I can only cry with my mummy, and from time to time with my sister." Context problems illustrate the importance of collaboration between all the people who work and live with the child as they may otherwise only learn in a fragmented way.

**SEMANTIC CATEGORIES** - In this dimension of communication one observes *about what* the child is able to communicate. Semantics logically have to do with meaning. There is a big difference between 'dog bites man' and 'man bites dog'. When Thomas was a child he used the expression 'I think twelve' for each question that he could not answer. He used the word 'yesterday' for everything that happened in the past. He still uses the word 'enough' if he wants to say that he did not exaggerate - the opposite of 'too much.' If I tell him that he took too much coffee he answers "I have coffee enough." For him this means that it was not 'too much'.

IF we try to observe spontaneous communication in people with autism using the four dimensions i.e. observation of **forms, functions, semantic categories, in different contexts**, we get an objective idea about their real communication skills. The word *objective* is very important here because from time to time we think that our children communicate when in fact they do not, because they do not have to, because we serve them all the time! "The service is too good" is an often heard expression in autism-environments. We love them so much that, we give them what we think they need to have all the time, and thereby without realizing, we do not create opportunities for them to communicate. So, why should they communicate? From their point of view they are right! There is no need to communicate if you are served the whole time!

IN developing a communication goal based on objective observation it is important to start from the most *motivating* context (eg the snack situation for Niklaas) and to start with the most motivating word (eg biscuit). *Individualisation* is very important: work on the real level of understanding of each specific person. For Niklaas for instance we chose specific type of biscuits because they were his favourite. Niklaas understood photos, but only if they were of the specific biscuit. So, when choosing the form of communication for Niklaas these have all to be kept in mind. We always have to choose the form that is *understood* by the child, the form that has *meaning*. A lot of preparatory work can already be done at the work table of the child: sorting exercises, putting objects together with the corresponding photo, putting the photo together with the corresponding object, categorization exercises, and so on.

WE try to simplify the context. In an ideal situation we work only with one child and two professionals. Niklaas sits at the table, one professional with the biscuits in front of him. The second professional stands behind Niklaas to teach him how to ask for the biscuit by means of the photo. This communication process is something that has to be taught. If one simply puts a photo of the biscuit in front of the child that does not mean he will communicate with it. In the beginning Niklaas did not understand, he stood up and ran away. Or he saw the biscuit and tried to take it away. The second professional made him sit down and put the photo in his hand and helped him physically to give it to the person in front of

him. After many exercises, Niklaas all of a sudden discovered the power of communication. Gradually one could fade off the physical help and Niklaas was able to ask independently at the end. It is important to also note that the kind of help or prompt should be individualized: Niklaas needed physical help, other children with autism may need a demonstration, verbal help, a hint.

WHEN we work on communication we try to change only one dimension at a time. The next step for Niklaas was to ask for the biscuit at home. The *function* (to ask for) and the *form* (photo) remained the same, but the dimension *context* changed (viz school versus home). The next step was to broaden the quantity of words, and as you already know, "Niklaas has already a vocabulary of 23 photos" now.

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## Message in a Book

‘Born on the Wrong Planet’ by Erika Hammerschmidt

*Reviewed by Mona Rai*



Erika Hammerschmidt's 'Born on the Wrong Planet' is a must read for all stakeholders involved in one way or the other with special children. The author, provides an insiders' view into the complex minds of people affected with Pervasive Developmental Disorders and associated conditions. Her book does justice to the community of

people and families affected by such disorders, while making us question the environment that we are creating for them. In her own words, "Planet Earth doesn't always feel like home to souls who are labeled Asperger's Syndrome, Tourette's syndrome, OCD, ADD, ADHD, or all of the above".

ERICA has exceptional skills as a wordsmith. She speaks several languages and has an extraordinary mind for her 21 years. Through powerful use of instances from her life during her growing up years, as she moved from childhood through angst ridden adolescence, to adulthood, she compels us to redefine our social codes to accommodate those who are perceived as misfits on this planet.

EVERY parent blessed with a child with a special need would want to respond to Erika Hammerschmidt's passionate appeal. Her story brings out her anguish at the way society has fenced itself within a narrow range of socially acceptable behaviours that does not tolerate anyone who does not comply with these.

SHE scoffs at the rigidity that leads to social reprimand for those who are challenged mentally, emotionally and behaviourally. Even as the latter is clueless at what triggers social disapproval, they are quick to find faults within their own selves. This in turn fuels a sense of self inadequacy and dissociation, resulting in special children and adults becoming uncommunicative and often indulging in so called strange behaviours.

HAMMERSCHMIDT'S account challenges and mocks the readers' psyche, making us think and review our take on relationships. The 123 pages of 'Born on the Wrong Planet' is an achingly honest insiders' view into the mind of someone with a special need and holds an important message to all the constituencies that engage with them at a daily level.

ERICA looks at emotions from the eyes of a special child and lends it a different meaning. It is this different perspective that should open a whole new outlook for specialists who struggle to understand the reasons for some of the behavioural issues of individuals on the spectrum. Erica's story is a celebration of joys of a special child who has conquered social issues and emerged as a successful orator. Her powerful narration of instances like how she imagined herself to be in love; her dynamics with her close friends, and her mother's role in protecting her individuality, is both interesting and insightful. Erica's feisty response to life's challenges is a reflection of her mother's reaction to the challenges her daughter faces. When the school complains about Erica's behaviour her mother says: "They think you're a problem child. They think every problem child should be treated exactly the same way: yell at her, send a note home, make the parents have a long talk with her... You are not some teacher's cookie-cutter model of a bad kid. You're you. Don't worry, I'll find the right school for you, even if I have to look all over the city." As much as Erica's personal journey, Mrs Hammerschmidt's respect of Erica's individuality too makes this book an interesting read for all parents, teachers, and neighbours.

THE publisher captures the real message in the book 'Born on the Wrong Planet' – 'It displays how disorders need not paralyse anyone, or keep them from achieving a potential that is, possibly, quite a bit higher than that of some so-called normal people!' All we need to do is not see them through coloured eyes.

- *Mona Rai is a Marketing Consultant with a global consultancy and mother to a six-year old bundle of energy Tanmay, who has autism.*



In reference to your write-up (Page One of April 2005 Vol XII No 1) regarding the Hindi film 'Black', I wish to inform you that I have written a similar article for 'Mansi' the newsletter of the Society for Welfare of Mentally Handicapped, Ahmedabad.

Hindi films have always been unscientific and thoughtless. I had written a similar letter to the Chairperson of the National Trust and the Director of NIMH regarding 'Koi Mil Gaya' as it shows a magical cure of developmental disability using 'jadu'. My letter was forwarded to the Disability Commissioner. I think this is a right move as the Disability Commissioner has enormous powers and can even teach a lesson to film producers. You can also approach the Disability Commissioner and demand a ban on 'Black'. I am sure like-minded parents and professionals will support you in this matter

Dr SR Apte, Occupational Therapist  
AHMEDABAD

I am thankful for the service you provide. Your training coordinator had given suggestions to us for our child which has proved valuable. She had also advised us to enrol Aakash in a regular local school in our hometown. My baby has changed from being 'antisocial' to being 'social' within a few months. He also likes his school very much. Your journal is excellent with teaching techniques. I read the journal for knowledge enhancement. It's quality work! Thanks!

A Kulkarni  
AURANGABAD

My son Sathwik has unique abilities which are amazing, though he also has deficits which are clear and palpable like lack of speech etc. At five and a half years he can understand The Ramayan, Mahabharat, John Milton, Mark Twain, the Upanishads, and RK Laxman stories. My wife reads him a passage from any of these or a prose of the 12th standard. She then prepares 12 or 14 answer strips which she makes

him read. He does this with very little focus and but 10 times faster than the time we take to read. But Sathwik is not hyperlexic since he can comprehend almost anything. After his silent reading, we ask him questions orally and he picks the correct answer from the 12 to 14 answer strips. The answers are spot on and accurate 95 per cent of the time.

He also does mathematics upto square root level. No teaching is required. An explanation of a minute or two would suffice. Using the analogy of  $a+b$  whole square he expanded  $p+q$  whole square at four and half years. The only drawback is that he does this only when his mother is sitting next to him. He is doing all these things since the last one year.

He is becoming independent in writing, but his mother must sit in front of him. Similarly he types on the computer, but his mother has to sit behind him for him to respond properly. But his mother does not prompt him with touching either for computer typing or for writing. Except for the occasional word he speaks no intelligible language.

At four-and-half years we took him to a swimming pool and put him in the baby pool for three hours, and on the fourth day we put him into 12 feet of water. He not only swam to safety but also stroked his hands and legs like a true professional. He swims independently under water without being taught and without any fear. His gross motor skills are excellent. He skates with terrific speed and balance, without helmet and without getting injured. He bicycles on the road with excellent skills at swerving. However, he does not understand the concept of competition.

We are sending him to a regular school for an hour in the day to learn socialisation skills. My wife works with him for at least ten hours a day since the day he was diagnosed. His speech area or centre is badly damaged and we are skeptical about him getting his speech back again. He had a vocabulary of 150 words up until 32 to 34 months before he regressed. He used those words meaningfully even though he did not do so with communicative intent.

I want my son to be independent so that he is able to lead an independent life after we are gone. This is our first goal.

Srinivas Rao  
MYSORE, KARNATAKA

## व्यवहार परिवर्तन (भाग – 2)

एक्शन फॉर ऑटिज़म

हमने अपने नेटवर्क के अगस्त अंक में व्यवहार परिवर्तन सम्बन्धित कुछ सुझाव और नियम बताये थे। इस दिसम्बर अंक में हम इसी विषय को आगे बढ़ाएंगे। सबसे पहले हम फिर से कुछ ऐसे व्यवहार का वर्णन करेंगे जिन्हें बच्चे का सामाजिक वातावरण (उसके घर, स्कूल या हर रोज के जीवन में उसके निकट रहने वाले लोग) स्वयं पुष्ट करता है।

उदाहरण –

1. पूजा पाँच वर्ष की बच्ची है, जिसे ऑटिज़म है। वह रात को जब सोने को जाती है, तो बहुत रोती है। उसकी माता अपना सब काम छोड़कर पूजा के पास बैठ जाती है। पूजा कुछ समय के लिए चुप हो जाती है परन्तु बाद में और अधिक रोना आरम्भ करती है। इस स्थिति में बिल्कुल साफ है कि पूजा अपनी माँ का ध्यान अपनी ओर करने के लिए रोती है और क्योंकि उसकी माँ रोने पर पूजा को ध्यान देती है, यह रोने का व्यवहार बढ़ता जाएगा।

अब इस व्यवहार को हम इस तरह से देखें :-

1) व्यवहार की पूर्ववर्ती :-  
पूजा का बिस्तर पर अकेले लेटना।

2) व्यवहार:-  
पूजा का रोना और चिल्लाना

3) व्यवहार का परिणाम  
पूजा की माता का आना और उसके साथ रहना और पूजा की ओर ध्यान केन्द्रित करना। इस उदाहरण में हम स्पष्ट रूप से देखते हैं कि पूजा के रोने के फलस्वरूप परिणाम के कारण वह इसी परिणाम की इच्छा के लिए रोयेगी। इस प्रकार पूजा की माँ का पूजा के रोने पर उसे ध्यान देना, पूजा के रोने का “संबलन” है। हम देखते हैं कि प्रायः हम बिना अनुभूति बच्चों के गलत व्यवहार को और पुष्ट करते हैं। रोने पर चॉकलेट या पेप्सी दिलाना एक आम उदाहरण है।

ऑटिज़म से प्रभावित बच्चों को सही तरह से दूसरों का ध्यान लेना नहीं आता। अक्सर वह सामाजिक दृष्टि से अनुचित व्यवहार द्वारा ऐसा करते हैं भाग जाना, सर पटकना, हाथ काटना, बाल खींचना, हँसना, चिल्लाना भी ध्यान आकर्षित करने के उद्देश्य से बच्चे कर सकते हैं। यदि ऐसे में उनके अनुचित व्यवहार को अधिक ध्यान दिया गया तो वह व्यवहार और भी पुष्ट होगा।

कुछ व्यवहार ऐसे भी होते हैं जो बच्चे किसी प्रकार के “पलायन” (एस्कैप, किसी काम या स्थिति से भागना/छुटकारा पाना) के लिए करते हैं। यदि ऐसे में उनका उद्देश्य पूरा होता है तो भविष्य में भी वह व्यवहार होगा।

उदाहरण –

पूजा कक्षा में बैठना नहीं चाहती। जब भी अध्यापिका उसे कुछ काम करवाने के लिए बैठाती है, तो पूजा किताब फेंक देती है और टेबल को उलटाने लगती है। कभी कभी दूसरे बच्चों को धक्का देती है। अध्यापिका पूजा को बाहर ले जाकर झूले पर बिठा देती है।

इस व्यवहार का हम मूल्यांकन करें –

अध्यापिका का पूजा को काम देना।

व्यवहार–

पूजा का किताबें फेंकना, मेज गिराना, बच्चों को धकेलना।

व्यवहार का परिणाम –

पूजा का काम से छुटकारा ! पूजा का झूले पर बैठना !

इस प्रकार हम देखते हैं कि इस ‘पलायन’ व्यवहार के फलस्वरूप पूजा को कक्षा कार्य से छुटकारा मिला। भविष्य में भी काम से छुटकारा पाने के लिए पूजा ऐसा व्यवहार दिखायेगी। वह जानती है कि फसाद करने पर उसे कक्षा से बाहर झूले पर बैठाया जायेगा।

इस प्रकार हम बच्चों के एस्कैप बिहेवियर या पलायन व्यवहार को बढ़ावा देकर पुष्ट करते हैं।

कुछ व्यवहार स्वाभाविक रूप से बच्चा संवेदिक परेशानियों की वजह से दिखाता है।

उदाहरण –

धवनी, सुगन्ध, दृष्टि, स्पर्श, स्वाद, शारीरिक संतुलन इत्यादि संवेदनाओं के प्रति अधिक या अल्प संवेदनशीलता के कारण हो सकते हैं। जैसे– शरीर को लगातार हिलाना, स्वयं को चोट पहुंचाना जैसे– सर पटकना या हाथों को काटना या कानों में उंगलियां डालकर चिल्लाना। दांतों पर वस्तुओं को ठोकना, लार (सलाइवा या थूक) से खेलना भी ऐसे व्यवहार हैं। इनका समाधान सेन्सरी इन्टीग्रेशन थेरेपी द्वारा हो सकता है। ऐसा विशेषज्ञ (ऑक्यूपेशनल थैरेपिस्ट) जिसे ऑटिज़म की भी जानकारी हो।

“दण्ड”

व्यवहारिक परेशानियाँ क्या “दण्ड” या “सजा” से सुधारी जा सकती है ?

यह एक कठिन प्रश्न है। इसका उत्तर हम तब ही दे सकते हैं जब हम “दण्ड” शब्द या “दण्ड” नियम को सही रूप से समझें। दण्ड का अर्थ है— “ किसी व्यवहार के फलस्वरूप कुछ ऐसा होना कि वह व्यवहार कमजोर या उसकी रोकथाम हो और भविष्य में ने उसके होने की संभावना ना हो।

इस परिभाषा से स्पष्ट होता है कि दण्ड तब ही सफल या प्रभावी होगा, जब उसके फलस्वरूप व्यवहार भविष्य में नहीं होगा। अधिकतर हमने देखा है कि डांटना, चिल्लाना, मारना इत्यादि एक स्थिति में व्यवहार को कम कर भी लें, पर इसकी कोई गारन्टी नहीं है कि भविष्य में नहीं होगी। दण्ड का प्रभावी होना निम्नलिखित उपकरणों पर आधारित है –

1. दण्ड विशेष व्यवहार होने पर ही दें। एक ही दण्ड केवल एक ही व्यवहार के लिए होना चाहिए।
2. दण्ड तीव्रता से दें, हल्का दण्ड कोई महत्व नहीं रखता।
3. ध्यान रखें कि आपके द्वारा दण्डनीय प्रतिक्रिया बच्चे के लिए अनुकरणीय क्रिया बन सकती है। वह स्वयं भी ऐसा कर सकता है।
4. दण्ड बच्चे को मानसिक और मनोबैज्ञानिक क्षति पहुंचा सकता है।
5. दण्ड से जुड़े कई कानूनी और जातीय सवाल उठते हैं।

दण्ड के प्रकार –

अक्सर मार, डांट, खाना न मिलना इत्यादि को ही दण्ड माना जाता है परन्तु ऑटिज़म से प्रभावित बच्चों को ‘दण्ड’के अन्य प्रकार से व्यवहार परिवर्तन और व्यवहार प्रबंध कार्यक्रम से लाभ हो सकता है—

(अ) प्रत्यर्पण (रिस्ट्रिक्शन) :

इस का अर्थ है, जो बच्चा बिगाड़ता है, उसे ही सही करना होता है। उदाहारण –

यदि बच्चा कुछ गिरा देता है, तो उसे स्वयं उठाना पड़ता है।

प्रत्यर्पण का एक और प्रकार “ओवर करेक्शन” या “अति सुधार” है। इसमें यदि बच्चा कुछ बिगाड़ता है तो उस से अधिक सुधार लाना होता है।

उदाहारण –

यदि बच्चे ने कुछ गिराया, तो उसे सब उठाना तो है, पर बाकी फर्श भी साफ करना होगा।

(ब) टाईम आऊट :

इस दण्ड प्रणाली का अर्थ है व्यक्ति को अधिक प्रबलन या संबलन वाली स्थिति से कम प्रबलन या संबलन स्थिति में डालना।

उदाहारण –

यदि बच्चा किसी समूह क्रिया के काल में शोर डाले या किसी प्रकार से अस्तव्यस्त स्थिति करे, तो उसे बिल्कुल अलग एक ऐसे स्थान पर छोड़ें (जैसे बन्द कमरा) जहां उसे किसी प्रकार का प्रबलन या रिएन्फोर्समेन्ट न मिले।

टाईम आऊट का समय बिल्कुल कम से कम होना चाहिए

(2 मिनट)/ऑटिस्टिक व्यक्ति का टाईम आऊट से व्यवहार परिवर्तन आसान नहीं है क्योंकि प्रायः वह अकेले रहना पसन्त करते हैं। ऐसे में टाइम आऊट का कोई मूल्य नहीं है।

(स) नकारात्मक दण्ड (नेगेटिव दण्ड) :

यह एक प्रकार का सौदा होता है, इच्छाओं का। व्यक्ति को बताया जाता है कि किसी विशेष काम न करने के फलस्वरूप उसे किसी अन्य वस्तु या क्रिया से अवगत किया जायेगा। जैसे— यदि स्नान न करे तो खेलने को पार्क में नहीं जा सकेगा।

(ड) अनुकृत मूल्य (रिस्पोन्स कॉस्ट) :

इस तरह की दण्ड प्रणाली में व्यक्ति को किसी ऐसी चीज की कटौती या घटने का अनुभव दिया जाता है जो उसके लिए लाभदायक हो।

उदाहारण –

बच्चे को प्रत्याशी व्यवहार के लिए किसी प्रकार का प्रतीक— स्टार या सितारे, अंक इत्यादि या पैसे मिलते हों तब प्रत्याशी व्यवहार के विरुद्ध व्यवहार दिखाने पर इनाम के प्रतीक या पैसे को वापस लिया जाये, ऐसी दण्ड को अनुकृत मूल्य या रिस्पोन्स कॉस्ट कहते हैं।

इस प्रकार हम देखते हैं कि संबलन (रिएन्फोर्समेन्ट) और दण्ड (पनिश्मेन्ट) विधि परिवर्तन के मूल्य आधार हैं। यह सर्व स्वीकृत सत्य है जो कि व्यवहार एक संबलन या प्रतिफल प्रदान करें वह भविष्य में दोहराये नहीं जायेंगे।

हम अगले अंक में चर्चा करेंगे “ऐक्सटिशन” या “विलोपन” के बारे में अथवा व्यवहार समस्याओं को निपटने के कुछ व्यवहारिक सुझाव।

परन्तु एक बात जो हमेशा याद रखने की है – रिएन्फोर्समेन्ट (संबलन ही सबसे उचित व्यवहार परिवर्तन नियम था। दण्ड का प्रयोग कम से कम या सही तरीके से करें।

## My Story - Inside My World

Emma Thomson

*Emma Thomson is a young English girl  
with Aspergers Syndrome*

**M**y name is Emma Thomson. I'm 18 years old. Currently I am learning to dive; I have been for about a year now. I passed my theory test on my second attempt. Not done my practical test yet though. When I was younger I had epilepsy. I was treated by Dr Holton. It was later found that he prescribed the wrong drugs to a lot of children and there was a lot of lives destroyed. I live in Leicestershire with my parents where there isn't a lot of help for Autism/ Aspergers Syndrome and related conditions. I was diagnosed with Aspergers Syndrome when I was 16 by Birmingham Forensic Team in Solihull. All my life I'm going to have this thing that makes me odd and different from others.

I love music most of all. I love songs by Jem, Tatu and others down that line. I also like some oldies but that's a secret that I don't like to admit to. I sing a lot in my bedroom. I wish I had the confidence to sing in real life but I don't, so my voice is unheard by many. I can sing on the karaoke with other people as long as my voice isn't standing out.

MY school days were a total mess. In primary school, I got behind and struggled with the work, especially Maths, though they never refused the right for me to have an education. Secondary school was a terrible disaster that I still hate to talk about today. I was bullied there too as well as getting in trouble. I wrote a lot of times to two teachers there. It ended with police getting involved (because of my excessive letter writing to the teachers) and now I'm not allowed anywhere near that school. Neither am I allowed near the members of staff that work there. Next was High school where I got bullied even worse. To name but a few incidents I suffered there was a boy who tried to strangle me with bulldog wires in science class and prodded me with a stool leg as well. I felt isolated there and never learnt a thing. I didn't have a Statement of Special Needs so I didn't get the help I needed when the Leicestershire funding for education was dropped. Because I couldn't do the work I played up, I skipped classes, and wouldn't go to classes when I was told to. Eventually I got excluded and put on work-sent-home study; in other words distance/ open learning.

THEN I went to college in September 2004. I settled down there quite well, more than I have done anywhere else. But then I slipped into my old Aspie habits again (of excessive letter writing and making phone calls). I've been searching for a best friend older than me who is genuine for a very long time. I got to know a tutor whom I trusted and really wanted as a friend. She was probably twice my age. I didn't know how to (behave with her) so I panicked and just said anything and did anything. I sent emails, letters, made phone calls (to her because) I couldn't get the confidence to talk (to her). The sneaking around I did (to get information about her) behind her back was just my way of trying hard to be accepted. All that happened during the summer.

I was supposed to move on to another course this year. (But because of my behaviour) the college authorities excluded me and I've not been to college since. They are trying to organise a package of distance learning for me. The reason they gave in their letter was that the programme I was on before wasn't suitable for me (though actually the college will not have me back because of my behaviour). Just two days earlier I was doing fine and was talking and getting on well with them all, and two day later (the programme) I was on before wasn't suitable for me!

WHAT they are planning to put in place is stupid. Honestly, sometimes I feel like I'm being treated like a disease. I feel like no one wants me. I can't get used to anywhere because they chuck me out. They are damaging me; I can literally feel the stress and frustration physically. All I ask for is a normal life. I don't want all this stress that I can't take much more of. All I want is a best friend of my choice I can tell things to and a normal college course. I'm sorry for what happened but I can't reverse it although I'd really love to. Every day the college keeps me at home I feel like I'm rotting away. I meant NO one ANY harm by doing any of what I did. I only write because I can't talk confidently to people so I used a strength of mine.

I am a very caring person underneath my Aspergers (and) I don't deserve this. What hurts me the most is that my ex tutor hasn't stood up for me one little bit. When I had opened up to her about my past she promised me last year that this would never happen to me again. Well that was obviously a very false promise.

PEOPLE can be so shallow; they don't care how much they ruin your life or hurt you. All that matters to them is the money they earn for putting up with you at their

workplace. This whole situation has made me very depressed. I hate to think what programme they're going to put me on. I have an idea what it is though and to me that is discrimination because even those with more complex special needs than Aspergers get to go to college.

I believe that it is good to be different though in this world. I would hate to be normal completely even though I get fed up of being an Asperger. Sometimes I wish I could run away from it. But however far I run it's still right beside me. I'm sick of losing people who I liked and trusted because of it.

ONE lesson is to be learnt from all this though. The world won't accept all the odd people in society. Especially the way Autism/Aspergers Syndrome affects you. Everyone with it has different things they do that aren't acceptable. With mine it's not very much but it gets treated very seriously. I don't set out to hurt people or upset or even scare them. I set out to get on with them, have a friendship with them, look after them etc. I can confirm that Aspergers do have feelings that hurt just like every Neuro Typical person. Right now I'm hurting so much but people think just because you have special needs you can't feel anything emotionally. Well that is entirely untrue because I know I feel emotions. Emotions are caring about people, wanting to protect them, being glad that they are there so you know that they are ok. That is emotions so that means we can feel them. When you lose someone you feel like you've lost something that matters to you, you miss talking to them, there's times you wish they were there to cheer you up when things are dark. Now let people say we don't feel emotions. I feel like that about my ex tutor. She taught me to make eye contact with people and I was relaxed with her. I saw her as a valuable friend that I need in my life very much. Her leaving me has hurt me very much.

BUT failure only makes you stronger and that's what I do. Something goes wrong; you build everything back up and try again, eventually something good will come out of it. Yes this girl has her down points but she's a fighter with a strong spirit who will always get through anything. If you ever wonder what happened to me lets just say it's not been easy. Inside I have grown as a person. I feel more alive now and like I can touch everything in the world instead of looking from the outside in. At college last year I felt I was part of something for the first time in my life and I felt so glad to feel that way because I never thought I would. (That is why) I will (try to) sort things out with the college because it's important not to lose

somewhere you have finally settled for the first time in your life. You never know (I) might end up taking up a job there one day and becoming part of the place permanently.

*(Written on 17 October 2005)*

*(...cont from page one)*

issues with complex social constructs, with sensory overload. But they get by fine. More importantly, they are happy being who they are. We know children who started out non-verbal with complex behaviours who are now in mainstream schools. All this happened with appropriate education and a great deal of respect for the child.

Let us not lose our ability to think clearly. Let us evaluate the benefits from various treatments before we start making our children guinea pigs. Many of the medical interventions being propagated may have long term effects that no one knows about at present. Simply because they have not been around long enough.

In India it has taken very little time for 'experts' to propagate biochemical interventions. We have received angry letters from some for daring to suggest on our website that autism has a genetic basis. Yet Dr Jaquelyn McCandless who supports biochemical intervention admits: "There appears to be a genetic factor operating shown by high incidence of affected siblings, high frequency of autoimmune disorders in the mothers and other close relatives, and patterns (but not invariably) of genetic markers in research studies." Interestingly, Dr John Martin who believes that autism is a virus induced disease, referring to the "economic welfare and status of supposedly autism experts", says, "It is easier for them to grasp and communicate mercury contamination, biochemical pathways or gastrointestinal problems than to discuss atypical viruses. There is also a business aspect with vendors and clinicians struggling to make a living out of autism."

We demand that our children be included in mainstream schools and in mainstream society, yet we ourselves are intolerant of their diversity. Perhaps we need to pause and think where we are going. We need to overcome this frenzy of 'finding a cure.' We are sometimes so blinded by our expectations of what we want our children to be that we are in danger of losing sight of who they are. In pursuit of our own happiness are we losing sight of what makes our children happy? Autism is not the enemy. Autism is not worse than death. Autism is not tragic. Autism is my child and your child and our children. And until we learn to respect them for who they are we will not learn how to help them in the best way possible.

# HELP LINE



**Q** My 11 years old son goes to a regular school. He finds the comprehension lessons done in his class extremely difficult. Also, if any day to day question starts with “Why...”, he is at a loss. But if we help him in replying with a, “Because....so and so reason” then he repeats that answer for any other question starting with “Why...” We have tried different ways to solve this but have not been successful and need help.

**A** The issue you have raised is one of the commonest and most neglected, and mostly affecting those children who have better communication skills. Usually when a more able child who has good communication skills begins to attend mainstream school we feel that things will now be fine. But the reality is that even when our children start attending a mainstream school we cannot take it for granted that they will learn simply by being around other children. Children with an autism spectrum disorder, even high functioning ones, may not learn through imitation and observation, and may have very different learning styles. Their often good rote skills deceive us into believing that they are doing fine. In fact they do often do rather well in the junior classes where rote learning works very well.

It is crucial to be aware of and focus on this in the early years. This would enable more of our children to continue in mainstream placements, instead of having to drop out, or start falling behind, around grade four or five, as often happens.

The commonest manifestations of this aspect are in their language classes and in problem sums. Of course these deficits can be changed with appropriate teaching. A good programme targeting these aspects would help your son learn and progress in these areas but would require a visit and face to face interaction.

**Q** My son is three and half years old and has a diagnosis of autism. He has little eye contact, and does not respond to his name. He is able to speak only a few words, otherwise he is a little hyperactive. He listens to music and likes to play with his elder brother sometimes.

We are in Coonoor. It would be of great help if you could send me the books on how to train, and if you could keep me informed of the latest developments, and suggest how to train our child at home.

**A** You want to start your son off with the best possible intervention, as an early intervention programme can show

very good results. An appropriate program for the child would be the one that addresses his specific needs and it can be best planned after doing a detailed Functional Assessment of the child. Nevertheless, we can suggest reading material that will help you to be more aware of his present needs. At this stage it will be beneficial for you to focus on his communication, activities of daily living (toilet training, dressing, eating etc.) and play skills. Many families work successfully with their children at home due to a dearth of services and you too are perhaps doing the same. What you will need support on will be the ‘how to teach’ which is the crucial element versus the ‘what to teach’. For this visit a suitable special education center nearest you for an ongoing program. If you do not have access to any services whatsoever, then we could provide the programme. You will have to visit us for an initial programme following which we could correspond over the mail.

As a start have a lot of fun with your son. Join him in things he likes to do. This will help in bonding with him. You will want to go with his interest versus forcing him to take an interest in what we think is important so that he begins to find you, the person, a reinforcing entity. Therefore, in the beginning play and interact with him using his own likes and strengths and slowly put simple demands on him. Reinforce every little compliance that he shows by giving him things he really likes, so that he gradually learns that doing things on other people’s request is followed by nice consequences.

For example, we can ask him to put an item – a block or a bead – in a container by modelling it for him and saying ‘do this’. The moment he does it we give him whatever he likes most – a favourite food, toy, any other favoured item. If he does not follow the request we can gently assist him by holding his hand and helping him to pick the bead and put it in the container and then give him the reinforcer and let him enjoy it. The child will soon learn that when he imitates your simple actions on the verbal command ‘do this’, it is followed by something nice. It would be great if you can observe such sessions of work taking place with other children in any project that you visit.

Some books that you can benefit from are:

- *The Me Book* - O Ivar Lovaas
- *Behavioral Intervention for Children with Autism* - Catherine Maurice
- *Pre School Activities* - Toni Flowers
- *Teaching Activities to Children with Autism* - Division TEACCH

- *Autism: Explaining the Enigma* - Uta Frith
- *A Compilation of Reading Material* - Action for Autism

The first four books will help in planning an individualized program for the child. The fifth book deals with understanding autism and the last one on the list is our own compilation of useful reading material for understanding and teaching persons with autism spectrum disorders. You could also visit our site at [www.autism-india.org](http://www.autism-india.org) for information on training and current developments.

**Q** At the onset, let me congratulate you on the construction of the National Centre. I am a parent from Goa and presently I am the secretary of the parent support group, Jyot. We are now managing a child care centre (other than the one at Sangath) and have two classrooms integrated in two mainstream schools. There is a proposal of a **vocational centre** (which will not be charity based, but will work on requirements of jobs which are need based in the society) for which we need your advice and guidance. Please let us know the logistics regarding: Scope, Estimates, Resources - Human (staff) and Materials, Location, Funding

**A** It is good to know of the services coming up for persons with Autism in Goa. A Vocational Training Program that lays focus on inclusion into mainstream of society is a brilliant concept.

Our experience at Action for Autism and what we have seen in India and abroad suggests that a team of parents and trained staff can together develop a good Vocational Program. An assessment of the individuals with autism that is based on a sound checklist can provide us with a baseline to train a person on work skills. The AAPEP (Adolescent and Adult Psycho-educational Profile) from Division TEACCH, University of North Carolina, is a very reliable and useful tool for this.

A short-term training for the trainers in order to enable them to get a better understanding of autism, and the needs of the individual should be considered. Some vocational skills in which training could be imparted could be as follows.

**Office Skills:** These could be filing, mailing, and fieldwork like carrying important correspondence/depositing bills and cheques, entering data in the computer, photocopying, typing

**Cooking:** Preparing squashes, jam, breads, cookies, cakes

**Work with a repetitive aspect:** Packaging, assembling, sorting, sticking labels

**Other activities:** Such as weaving, screen printing, block printing

**Self employment:** Running a shop that has a narrow range of items such as Video lending library, stationery shop, milk booth, bakery, news paper distribution, magazine and book renting etc.

The vocational unit should also have recreational areas and work towards enhancing social skills. In whatever the person is doing interpersonal skills will play a very important role. Group discussions including sharing of experiences, current affairs, reinforcing of money and time concepts, may also be an integral part of vocational training.

Of course the use of visual strategies will be important. Even the most able persons with autism can work better in an environment that is predictable and has instructions, expectations and rules laid down clearly and very simply.

**Q** I want to appreciate the good work your organisation is doing to answer all the queries related to autism. This is particularly so since in India people still have limited knowledge about this condition.

I have two cousins in Canada, both boys, aged 22 and 21 years of age who both have autism. The government there is very pro-active and they get a lot of educational help in the form of special teachers etc. Now that they are adults, their perception of the opposite sex seems to be something very traumatic that they are going through. I wanted your advice here.

My uncle is of the view that the elder boy should now be married to someone who will be fully supported by them financially. This boy speaks very little, but is not destructive or loud in his behaviour. In fact he even works a couple of days. Personally I feel we will be doing an injustice to the girl even though she will be fully informed about his condition. How can they relate to each other? On the other hand from the son's point of view he might be a changed person if he gets a partner who understands him.

I would be grateful if you can advice me as to how to handle this situation. Does ayurveda or homeopathy have any possible cures for Autism?

**A** Your cousins are indeed in a place where the state takes a pro-active interest in the welfare of its citizens with disability. You refer to your uncles views on marriage for your cousin because of the 'perception of the opposite sex (which) seems to be something very traumatic that they are going through'. Perhaps you could explain the situation a little as that might give us a clearer idea of how it should be tackled. However, getting your cousin married does not mean it will automatically take care of any sexual issues that he might be experiencing right now.

Looking at marriage per se one needs to be aware of what marriage is all about. You know your cousin and in that light you could ask yourself the following questions: Does your cousin understand what marriage is about? Taking the traditional view where it was all about procreation, is your cousin capable of having children? Of then bringing up those children? And perhaps children with autism, which is a possibility?

In a more current sense marriage is about companionship. Will your cousin provide the companionship that his wife will want? If the girl he marries is someone who is keen to marry him despite his autism this discussion would not be required. But if the girl marries him because she is from a poor family and has no say in the matter but is forced to marry him by her parents, that would in modern terms be a human rights violation.

Finally, marriage is about responsibility. If the marriage is merely about providing someone to look after your cousin, that in Canada is a responsibility that perhaps the state will take on.

There is a strong belief among us Indians that all mental disabilities disappear with marriage. Truth is it does not.

No, there is no cure for autism. I respond to this as a professional as well as a parent. My son is 25 and has autism. He has a general idea of marriage, parenting, etc, but does not understand the intricacies of marriage, homemaking, or parenthood. If a girl comes along and says she wants to marry him despite everything that would be a different matter. But as a woman myself, I would find it hard to justify getting him married to a woman who will end up having a rather difficult life. Hope this helps.

*(Merry Barua - responder to this mail)*

**Q** A rubs himself on the bed, lies on my back and tries to rub. He touches his mother's breast and that of other female relatives. He is hyper active, always trying to play with a string or a rope

**A** Even Neuro Typical i.e. regular eight-year-olds may have such behaviours like rubbing themselves against surfaces; but they are careful of doing so in such a manner that nobody comes to know. In the case of A he lacks the social awareness of doing it in private. Merely stopping him whenever he indulges in such behaviour may not be an effective strategy. Instead if too much 'attention' is given to the behaviour it may actually become an attention getting behaviour and will be more likely to increase. A may start enjoying the attention the behaviour gets for him. Instead, whenever he exhibits the behaviour we gently but firmly move him to another room and let him know that he can

only do so when alone. He may get bored of having to be alone.

A will simultaneously have to be introduced to the concepts of 'private' and 'public' so that he learns that there are certain behaviours that are acceptable in public and some only in private.

At the same time we have to keep A occupied and/ or teach A ways of keeping himself occupied. One reason for A's behaviours could be because he lacks more appropriate ways of occupying himself. As A is taught playskills or he has a definite schedule (routines) to follow during the day, his need to keep himself occupied by rubbing himself may decrease.

Touching parts of bodies of females may have a sensory cause. A may have started doing it just to enjoy the feel of the soft touch. He perhaps still likes it for the same reason. What may have put the behaviour on increase could be that when he touches them, ladies give a high response by screaming, scolding, making faces, laughing, looking shocked etc. This kind of a reaction can be very interesting for a child with autism. Therefore reactions like these can actually increase the behaviour.

The way to deal with it would be to first provide him alternative sensory experiences. Provide him with soft textures like cushion balls to hold in his hands. Next the ladies will need to be focused and the moment his hands move towards them they can hold his hands (very casually without paying any attention to where the hands were directed and without saying anything) and move back.

Playing with soft balls, rolling on a therapy ball, jumping, swinging and getting a massage would help not only in dealing with sensory issues but also in bringing his 'hyperactivity' down. When A plays appropriately with the cushion balls or the other activities, remember to pay him a lot of attention. However, also remember to never provide A with these items and activities when he touches someone. Provide the sensory input mentioned above at other times.

We do not want A to learn that touching a lady gets him cushion balls or fun activities. He has a sensory need and we want to provide the input at other times to decrease the need for it by touching etc. You can also visit our website at [www.autism-india.org](http://www.autism-india.org) and access reading material on sensory defensiveness.

Playing with a string is fine if it does not interfere with his daily routines and his learning. If the string is something that he really loves, you can actually use it as a reward for doing what you want him to do. You can also provide him with a string at particular times in the day.

# Workshop on Management of Children with Developmental Disabilities through Behaviour Modification

**4 February 2006**

Behaviour modification is used in the management of children with various developmental disabilities. The difficulties faced by individuals on the autistic spectrum in particular often manifest as complex and challenging behaviours. Behaviour modification with the reinforcing of wanted behaviours is the cornerstone of management of autism: in changing behaviours as well as in teaching skills. Behaviour modification is used in teaching children to 'attend', control 'temper tantrums', and for teaching the child to behave in a more appropriate and socially accepted manner.

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

The workshop will incorporate question answer sessions where participants will be encouraged to problem solve.

The workshop is open to anyone who works with children with developmental disabilities on a day to day basis.

**Timing:** 10:00 am to 4:00 pm.

**Childcare:**

At this point no childcare has been planned. However, parents who want to attend and may wish to have childcare, should contact Saumya at the AFA office latest by 15 January 2006.

**Registration Costs**

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

----- CUT HERE -----

## REGISTRATION FORM - BM

Please fill this form in BLOCK LETTERS and mail, with a self-addressed stamped envelope to:

**Action For Autism, Sector 5 Jasola Vihar, Behind Sai Niketan, New Delhi 110025**

Name \_\_\_\_\_ (Tick relevant box) Parent  Professional

Address \_\_\_\_\_

Tel \_\_\_\_\_ Email: \_\_\_\_\_

If parent, name of child \_\_\_\_\_ Child's DOB \_\_\_\_\_

If professional, name of organisation \_\_\_\_\_

Please find enclosed a Demand Draft No \_\_\_\_\_

dated \_\_\_\_\_ drawn on \_\_\_\_\_ Bank

in favour of **Action for Autism**

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

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

Child's name \_\_\_\_\_ Sex \_\_\_\_\_

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Contributions are tax exempt under Section 80 G of Income Tax Act.

## BOOK POST



**If undelivered please return to:**

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Sector 5, Jasola Vihar, Behind Sai Niketan,  
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### Do visit us at The National Centre For Autism!

Action for Autism has moved to its own premises:  
The National Centre for Autism at Jasola.

Our new telephone numbers: 55347422, 30964730.  
Look forward to seeing you at the new Centre!

Email: [autism@vsnl.com](mailto:autism@vsnl.com)  
AFA Homepage: <http://www.autism-india.org>