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WISHLIST !

FOR THE STUDENTS o Sensory toys o Trampoline o Plastic slide, Plastic seesaw, swings o Sewing Machine o Franking Machine o Music CDs & Cassettes

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FOR THE NATIONAL CENTRE

o Cleaning Materials

<u>BUILDING</u> To house a residence for youngsters with autism

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PAGE ONE

Sunnu ate his meals off a ceramic plate. He was a mostly unfussy eater if he got his dry roti and dahi. During tea time he ate cake, cookies and other favoured items off a mauve plastic plate. One Sunday his aunt came to visit. Helping Sunnu's mother in the kitchen she offered to lay out Sunnu's lunch. She took his favoured roti and dahi in his mauve plate and laid it out for Sunnu to eat. Sunnu had a major tantrum. Flustered the aunt tried to figure out what she might have said or done that could have triggered the tantrum. But Sunnu's mother coming into the dining room knew instantly what the problem was. Sunnu's mauve plastic plate communicated to him that he would get some cookies and cake to eat. Instead he was given roti and dahi. Sunnu felt confused and cheated and did the only thing he could to express his confusion: he threw a tantrum.

I began to truly appreciate the complexity of human communication only after I was gifted with a son with autism. It was actually several years after he received his diagnosis that this perception began to dawn on me. Till then communication for me was this effortless way of connecting with people. Something that came as naturally as breathing. It did not matter whether you could use speech or not. Communication was as easy as the water that flowed out of our taps.

For a long time after the diagnosis I thought Neeraj's 'lack' of communication had to do with his lack of speech. I believed that my son had only to speak for things to get sorted out. How deluded I was. How complex is communication. And how difficult to convey to those with an 'outsiders' perspective on autism the baffling ways that communication can be impaired in an individual with autism.

Families want their children to talk. "If only he can start speaking he will be alright". So they make a lot of effort showing an object or a picture of an object and trying to make their child repeat the label for the object. But since vocalizing alone is no guarantee that the child will communicate the child often ends up with a lot of labels but still no communication.

Most children with Autism Spectrum Disorders (ASD) learn differently from other children. Therefore teaching

strategies that are effective with other children often do not work with children with ASD.

We tend to believe that the primary mode of communication should be the spoken word, because that is what we are used to. But many people with autism who do not speak, communicate eloquently through the printed word, writing by hand or on the computer. We are increasingly realizing the importance of alternative and augmentative communication in enabling persons with autism towards independence. Persons with autism have difficulties with the abstract and the transient. Communication must therefore be adapted to the individualized level of abstraction using signs, gestures, picture-cards, photo-cards, wordcards, and objects, in addition to spoken words.

In this issue, Theo Peeters introduces us to the language of objects, to an understanding that objects serve a communicative function for persons with autism. Peeters is a gifted professional. The sensitivity of his understanding of autism, coloured by the viewpoints of the individuals with Autism Spectrum Disorders he has known and whose development he has followed from childhood into adulthood, permeates his writing. It is an understanding that escapes many of us who have followed a either a limited spectrum, or over a limited period of time, or in limited numbers.

(cont on page 4...)

ANNOUNCEMENT!

Workshop on Relationship Development Intervention

The Developmental Program for Social and Emotional Growth developed by Steven E Gutstein that has stirred up enormous interest and excitement...

For information See Page 16...

The Language of Objects

...continued from Autism Network April 2006

Theo Peeters

Augmentative communication and augmentative education

There was a time when non-verbal children were pushed and pushed towards speech. If speech did not come, then the child could not be helped. Later the insight grew that, after all, speech is just one form of communication (the most abstract, invisible, temporal form). After all, children with difficulties in developing language could learn to communicate if language was supported with concrete and visible forms of communication: pictures, objects. The expression augmentative communication reflects a new insight into the learning of those with space and time, and the injection of feelings of success through independent tasks. Elsewhere (Peeters 1997; Peeters and Gillberg 1999) I have explained the basic principles, so I will only summarise the main points here.

The creation of predictability in space: the language of objects

In a pre-symbolic world there is little or no independence Or self-esteem. Persons with very young developmental ages have to learn that this world is one of meaning, that there are meaningful connections

autism and in this sense perhaps offers a message of hope. Similarly, there was a time when children with autism were considered as ineducable. Afterwards the insight grew that children with autism were only ineducable if they were asked to adapt to a type of education that did not, in fact address their very real learning needs (was not 'autism specific').

AWARD

Dr RP Roy receives National BioScience Award for Career Development

Dr Roy is Staff Scientist at the National Institute of Immunology and is father to young Amartya who is on the spectrum. Dr Roy has donated his Award money to social causes

and one of the donees is Action For Autism.

Congratulations Dr Roy and a big Thank You!

between objects and activities or situations. Since these persons seem to have pervasive difficulties in developing flexible thinking and seem .to be better talented at making concrete associations teachers will exploit their strengths. I will illustrate what I mean by concrete associations through a few anecdotes.

ONE child had experienced that after having watched TV

AS soon as educationists began to understand that children with autism treated information differently and to propose an education adapted to this different brain functioning it became clear that these children are able to learn more than we ever thought. For some children verbal teaching was supported by two-dimensional symbols (pictures, photos), while for others verbal teaching was supported by objects. In short, teaching became more concrete, visible, spatial. Also, the expression augmentative education reflects this new insight, it is a message full of hope.

WE will now further develop this theme of augmentative communication and augmentative education at an object level. Especially, if we think of students with autism at a very young developmental age, the basis of an education consists of two elements: the creation of predictability in it was time for supper. He made a concrete association: TV - then eating. One evening after having watched his programme, father was not home yet. There he was; the whole house was full of information about eating, the table was set, he smelled food, TV was over, but nobody started eating. He felt cheated and developed a temper tantrum. He had done his very best to understand a little about this complicated life, and people did not respect his understanding.

ANOTHER boy smiled very happily when he came downstairs from his bedroom. Mother wondered why. He liked his breakfast, yes, he also liked going to school, but she could not understand why he looked so extraordinarily happy. Then, when the school bus came his smile disappeared, in fact it was a struggle to get him on the bus. Was he a 'bad boy' or did he simply understand things differently? As a good detective his mother tried to find the reason for his happiness that changed so suddenly into unhappiness. Then she saw that she had left the folding chair in the corridor, The yellow folding chair that they had taken to the beach last weekend. Now everything became clear. Her boy had made a concrete association between the yellow folding chair and the beach. He had tried to understand the world his own way instead of the way we want.

IT is this natural tendency to try to understand the world through making concrete associations that we as carers will use to organise the classroom or the group home, so that the world becomes more predictable. We need to teach our pupils with autism that there is a predictable relationship between spaces and activities and behaviours. We need to make explicit: this is the activity corner: this is where you do school activities, where a learning behaviour is expected, always here, but only here. This is the free time corner: this is where you can let yourself go, no learning or concentration here. This is the domestic area: this is where you eat with the other students and where self-help skills are being taught.

IF all these behaviours and activities can be associated with predictable places then life for the pupils is a little bit more under control, then they have gained a bit of power and independence, this may be the beginning of a good feeling about themselves, the first injection of success. My suggestion here is that this success may be generated by our use of the language of objects. For example, the answer to the question 'where do I do things' is given in a concrete visible spatial way.

The creation of predictability in time: the language of objects

One does not see time directly. Time has to be analysed. If we can accept that dealing with abstract, invisible, temporal information may be particularly difficult for children with autism, then clearly dealing with time must be particularly onerous. Time is very abstract, it is invisible and has a transient quality. Persons with autism are often described by carers as seemingly lost in time.

IN order to be able to organise our own lives better we make time concrete, visible in space with our watches and our calendars. This, of course, enables us to impose some sense of control over our lives. My argument is that persons with autism have the same basic needs as we do and therefore we have to develop what we may call 'autism-watches'. We need to give them concrete, visible, spatial answers to the very abstract question 'When?'

THE answers need to be individualised at three different levels (Peeters and Gillberg 1999) the form of the symbol; the length; how the symbol is used.

The form

An ordinary child first understands words, then uses them expressively for communication. For a child who will eventually learn to communicate with objects, it is important also that he starts with the receptive side, that he learns that there is a meaning beyond the object. For example, each time when he goes to the free time area he is given a ball, when he goes to snack he is given a cup, when he goes to lunch he is given a plate, etc. This way he is being helped to make concrete associations between an object and an activity. It may, of course, be very threatening to parents who still hope their child will soon speak that a professional proposes the use of objects as the start of a communication program.

WHAT can be useful in diminishing any threat is that parents have watched the assessment that has been made of their child. So they have seen that their child did not react to verbal instructions, did not imitate words, was not able to match pictures with objects, maybe did not even react to the sound items. All this seems to suggest that speech (the most abstract form of communication) will not be ideal for the immediate future.

IN my own practice I tend to explain the advantage of using objects as a starting point by employing the image that in ordinary development speech is like an island that at once appears in an ocean of non-verbal communication. The biggest problem in autism is not speech but communication in general, also non-verbal forms of communication. In ordinary development children have developed so many functions of communication already before the first words appear (Watson et al. 1989; Layton and Watson 1995). Only a few days after giving birth mothers recognise: 'now she cries because she is hungry', 'now she cries differently because she needs attention' and so on. Before nine months the child looks at the mother/ father and directs their attention towards something she finds interesting in the environment. In other words she is already making comments in a non-verbal way. Ordinary babies have had so many experiences that they understand well the power of communication when they discover an even more powerful form: speech.

IT seems logical that children with severe communication problems learn to communicate in easy concrete ways, as with an object. It is important to know that forms are not necessarily permanent. A child learns to recognise the meaning of objects, and is then learning to see the relationship between objects and pictures before he uses pictures for receptive (and later expressive) communication. In the beginning the first objects may be very concrete and will be used in the next activity (e.g. the cup for snack, the platefor lunch). Later the objects may be of a more abstract nature (e.g. the cup will be checked in, but not used any more: on the snack table there will be another cup, the screw as a symbol for a work session.

FOR some students the implication of important details in the objects is necessary, e.g. the use of objects of a certain texture for .a student who still gets a lot of information from touching things. Other students will attach too much importance to colours and will not see that a red cup may have the same 'meaning' as a green cup. Due to this 'overselective thinking' it is important that the educational approach for such students is very well coordinated and that all carers use exactly the same symbols (in terms of size, colour, texture etc.) with the students who sill have not learned very well to generalise (Van Dalen 1995; De Clercq 1999; Verpoorten 1997)

Length

Usually persons concerned with offering predictability in time talk about timetables, day schedules, etc. Activities are then announced for a whole day or for half a day. Sometimes only three or two activities are announced, and often in the beginning only one (this may be all the student can understand in the near future - the sequence of tWo activities in a row may still be too difficult). Learning the meaning of objects may be seen as learning a new and very difficult language, so teachers need to recognise that pupils will be able to respond better if they do not start with too many 'words' at once. Building up a whole vocabulary of objects will be for later. Using the term 'vocabulary' also for objects is helpful for parents. It reminds me of a particular father. Each time I asked him how his son was doing, he answered sadly, 'He still does not speak.' And then months later when his son was in a classroom which specialised in autism, he said, 'He has a vocabulary of 50 photos.' So the term vocabulary should also be used when dealing with pictures or objects. But before the pupil can use his/her vocabulary expressively he/ she has to understand its meaning first.

Tbe use of the symbols

Some students with autism may be able to use a classroom agenda just like ordinary students. For students with autism and with the capacity to abstract meaning only at an object level, however, this is not an option. The first use of the symbol is probably when the teacher puts the object in the student's hands and guides him with the object to the corresponding place (e.g. ball to free time corner). This will probably need to be done several times before he is able to make the concrete association ball means free time. If the distance between the place where the symbol is given and the place of destination is too wide (and the student has a very young developmental age), it might be an advantage if the teacher first leads the student to the destination and shows him the object just before the activity (e.g. giving the plate not 20 metres before the entrance of the lunch area, but just before he sits down at the table and starts eating).

LATER the distance between the moment the symbol is given and place/ activity it stands for will grow. Afterwards new object-words will have to be added to his vocabulary but they all will be used in a similar way. In fact the teacher still continues to give the object to the student. Still later the student will make use of a real object-schedule. In a cupboard with different compartments each object from top to bottom will represent an activity or time-slot (e.g. cassette for music in the free time area, then box for work, the cassette again for free time, then glass for snack, then shoe for walking etc.). Until he sees and finds his bag at the bottom of the schedule. This bag means going home again. A very important step in the use of such an object-schedule is that the student himself becomes much more active and independent. If he is going to take the objects himself instead of being dependent upon the teacher's assistance, that also means that he is going to be able to situate himself in time in a more detailed and understanding way. He will not only understand what comes next but will also have some idea about the sequence of activities.

ONE could say that such a schedule really functions like an object-watch: the more objects that have been taken away from the schedule the fewer there are still to be seen. So the pupil directly sees time go by (perceptual synthesis versus conceptual analysis; time does not have to be analysed, it is perceived directly, the open analysis is replaced with information almost speaking for itself. Students who have reached this level of object-use very often also are able to handle a transition card that tells them to go and find the next symbol for the next activity (like saying in a non-verbal way, 'go and consult your agenda'). The transition card could be a card with the student's name or any card of a certain colour or form (sometimes the same for all students in one classroom).

A few teachers have told me about a difficulty they experience with a few exceptional students. These particular students seem to understand the duration concept when making use of an object-schedule, but seem to be too much fascinated by one or other (often favourite) activity on the schedule. Waiting for this activity to come seems impossible for them. Help in such a case always needs to be individualised, but often teachers then had to cover the later compartments of the object-schedule. Only the compartment for the next activity was left open. This way the student still had an idea of time to come without having the detailed information about the specific activities.

An augmentative educational approach: an illustration

I will now try to summarise some of the above issues by discussing a non-verbal child with autism and the parents' wish to develop his communication.

BRYAN was a five-year-old non-verbal child with lots of behaviour problems. An evaluation showed that he had an overall two-year developmental level, with peak skills in eye-hand communication, but no emerging skills at all in the area of verbal communication. Also he was not able to see the relationship between a picture and an object. In fact Bryan was still at a 'precommunication' level, he had not yet entered the symbolic world. His top performances in communication were' that he put himself at the table when he wanted to eat something and at other times he pulled his mother or father by the arm towards the fridge. And there were lots and lots of problem behaviours: many of them being desperate attempts at communicating something for which he had no words or pictures or objects. His parents accepted that it would be a good idea to start with object-communication.

BUT the transition from understanding to expressive communication may be much more difficult. From now on 'the service will be less perfect' and Bryan will need to experience that the initiative will have to come from him. When Bryan's mother thought he was hungry she would put the plate in front of him and ask with an open gesture: 'What do *you* want?' If he did not react she would point to the plate: 'What do *you* want?' She would push him close to the plate: 'What do *you* want?' and if he still did not take the initiative then his father would guide him physically and show him how to take the plate and give it to his mother. With the extra help of his father success was guaranteed. In the course of the following weeks the whole procedure was repeated and the levels of help decreased wherever possible from physical help, to pointing, to asking with an open gesture: 'What do *you* want?'

THE teacher and teacher assistant also taught Bryan to communicate with objects as a first step and slowly the vocabulary of receptive and expressive communication increased. In the meanwhile Bryan's teachers were preparing all types of exercises at school to prepare him for another level of communication: with pictures. At school the teachers were also aware of the fact that Bryan needed a very concrete teaching style: even though he had a developmental age of two, verbal language as teaching approach may respond to our dream but not to reality. The verbal language had to be supported at an object level. Bryan, like all children with autism, needed an 'augmentative education'. Also, to make our expectations (e.g. teaching objectives in self-help skills, domestic skills etc.) more concrete we make use of objects. So we use object-communication at three different levels: (1) receptively (to make his life predictable); (2) expressively (to teach him to communicate his needs); (3) an augmentative teaching style.

I have explained this augmentative teaching style elsewhere (Peeters and Gillberg 1999). In this text I will only give one example. It is known that ordinary children in a certain developmental phase will speak aloud and that this language helps them to organise their play. Later on this 'external language' becomes 'internalised'. Inner language (a repertoire of concepts) helps us to get our behaviour organised. If someone asks me to 'clean the room' I understand the different detailed substeps included in this one word 'cleaning' (my 'inner language' or my 'brain script' helps me then to get my cleaning behaviour organised). Persons with autism, it seems, have less inner language than we often suppose and when we ask them to 'clean' the room, their inner language does not tell them how to carry out the different substeps involved. They may seem stubborn then, or lazy, but the real problem seems to be of a cognitive nature. It is not therefore a matter of 'bad boy' but rather of a lack of inner language. So written language, or pictures, or

objects may serve as a compensation for the lack of inner language.

A certain person with autism may not 'know' what cleaning means, but when he 'sees' the pictures and follows them, then he gets his cleaning behaviour organised more easily. For persons who still have not reached the picture-level, object information may show them what to do: 'external communication' to compensate the lack of 'inner language'. So in the teaching of work skills, leisure skills, social skills, selfhelp skills and domestic skills the verbal teaching style is supported by more concrete information: pictures, objects.

IN my view then an autism specific approach, an augmentative education, is the best possible treatment, based on the prevention of problem behaviour. It is important to understand that the problem behaviour is a symptom, just as the tip of the iceberg is the symptom of the iceberg (Schopler 1995). The most important part of the iceberg, however, is hidden under the water. The causes of the problem behaviours in autism are .hidden, are invisible. It is important to understand these invisible causes and develop a treatment based on causes and therefore on prevention (Peeters and Jordan 1998). Persons who have autism in combination with a very young developmental age may have many 'problem behaviours' because we do not understand their way of thinking enough. In the following example of Charles you will see that objects communicate many things to him. If the carers around him do not understand the communication value of these objects, then they will react to the symptoms, not to the causes. Then the approach will be very disappointing, for them and of course for Charles. The key question is: is he 'a bad boy' or does he think differently?

AT the end of one week practical training we always have a discussion on the 'problem behaviour' of the week (I will not go into details about the whole analysis). Charles was selected as he had been hitting himself very often during the week. Charles was an almost entirely non-verbal six-year-old child with autism with a very young developmental age. In fact the only word he said was 'mama'. He used it for every possible frustration or need. His fascination consisted of looking at cars. His parents admitted that they had a very difficult time at home. He would only sleep in a car, eat in a car and look at cars in his free time. His parents said that they simply had to give in often if they wanted to have a 'relaxed' time themselves, or have a night's sleep. We had started to teach Charles the use of symbols: .a beaker was given before he had snack, a bib before he had lunch, a diaper before taking him to the toilet, a ball announced free time, a box to announce that he had activities, to do at his desk, a bag became the symbol to return home. So. Charles slowly learned to understand that there was a meaning beyond the perception.

THERE were problem behaviours at his desk. One time the participants had prepared a new task for him: taking balls from one box and putting them in another box. This was a terrible mistake since the ball had become the symbol for free time. When Charles saw the balls he wanted to go to free time. The participants made it clear he had to stay. Charles started hitting himself. Then he accepted and started doing the task. Unfortunately for Charles they had also forgotten to 'close' the second box, so that Charles continued to see the balls. Seeing these balls 'told' him: the task is not finished yet, I have to do everything all over again and he put them in the first box, then in the second and so on. He really did his best to understand what the participants had prepared for him. But the participants started talking to him: 'Charles, dat moet je niet doen. Als je de blokken in de doos gelegd heb, moet je ze laten liggen...' Not that they spoke Flemish. I put the comment in Flemish to give you an idea about the effect of speech on Charles. A combination of hearing the difficult speech with the balls he continued to see meant that he started hitting himself.

DURING our communication snack children have to ask for themselves in order to have the drinks and food in front of them. In such a 'sabotaged' situation, participants see how helpless some children are if they are not being helpless all the time. In fact they may have words but not understand the real power (or the 'functions') of communication. Also our non-verbal Charles did not seem to understand yet that giving a plate to an adult to ask for eating might be more powerful than hitting himself. So during this snack Charles did not ask, even with his favourite biscuits in front of him. The conclusion of some of the participants was that he simply was not hungry; otherwise he would have asked for his favourite biscuits. Yet, when his group taught him how to ask for bread by giving a plate to an adult, he rather quickly understood the principle: 'I have to take the initiative and give something and in exchange I get something interesting back.' During that teaching session Charles went on asking with his plate till he had finished all of the bread!

So, it was not a question of not being hungry, but Charles still needed to discover the real power of communication with objects: when you're hungry you show a plate, it is that simple! Charles had discovered that day a very important step in the development of independence and self-esteem.

REFERENCES

• De Clercq, H. (1999) *Mama, Is This an Animal or a Human Being? About Autism.* Antwerpen: Houtekiet.

• Gazzaniga, M. S. (1970) *The Bisected Brain*. New York: Appleton.

• Happe, F. (1995) 'The role of age and verbal ability in the theory of mind task performance of subjects with autism', *Child Development* 66, 843.

• Jordan, R. R. (1996) 'Teaching communication to individuals within the autistic spectrum', *REACH. Journal of Special Needs Education in Ireland* **9**, 95.

• Layton, T. and Watson, 1. (1995) 'Enhancing communication in nonverbal children with autism', in Quill, K. (ed.) *Teaching Children with Autism*. New York: Delmar Publishing. '

• Peeters, T. (1997) *Autism: From Theoretical Understanding to Educational Intervention.* London: Whurr Publishers.

• Peeters, T. and Gillberg, C. (1999) *Autism: Educational and Medical Aspects*. London: Whurr Publishers.

• Peeters, T. and Jordan, R. R. (1998) 'The importance of training in the prevention of violence and abuse against people with autism', in Autism Europe (ed.) *Code of Good Practice on Prevention of Violence Against Persons with Autism.* Brussels: Autism Europe.

• Schopler, E. (1995) *Parents' Survival Manual*. New York: Plenum Press.

• Sinclair, J. (1992) 'Bridging the gaps: an inside-out approach of autism', in Schopler, E. and Mesibov, G. (eds) *High Functioning Individuals with Autism*. New York: Plenum Press.

• Van Dalen, J. G. T. (1995) *Autisme: Weinig Keus?* (Autism: Not Too Much Choice). Engagement Special, NVA (Nederlandse Vereniging Autisme, Dutch parental society), P.O. Box 1367, Bussum, N ,1400 BG, Netherlands ,

• Verpoorten, R. (1997) *Kwalitatieve Stoornissen in de Waarneming* (Qualitative impairments in Perception). Antwerpen: In-service Opleidingscentrum Autisme.

• Watson,L., Lord, c., Schaffer, B. and Schopler, E. (1989) *Teaching Spontaneous Communication to Autistic and Developmentally Handicapped Children*. Austin: Pro-Ed.



Our 30- year old daughter Sanchari is autistic with additional handicap of profound deafness and muteness. Her behaviour problems are perhaps due to her severe lack of communication. After years of training she is now partially independent though she will need lifelong supervision and custodial care. She has learnt writing, stiching, knitting and other activities. She does lots of other chores under supervision. She communicates very little though she understands and follows Sign-Language. Her eye contact is very good. Her worst problem is her bad tantrums and occasional explosive rage. A time-out cools her after a while. She is under medication for many years.

There must be many parents who have autistic children. Young parents with autistic children might not foresee the hard future. In my younger days I too had nursed a hope that some closest kin of Sanchari will take her over when we will be gone. We got settled accordingly. Soon it proved to be a disaster. The sooner we shed such absurd ideas the better for us. Who can guarantee an abiding commitment of the closet kin. Even their sincerest plan may go adrift.

A proper Home for the Autistic Adult is the only answer. We the concerned parents must unite and build a proper Home for the Adults for their life-time rehabilitation. A Home away from Home. A better Home where with like minded friends they may live together. Such a Home shall be our best gift to them. There they shall lead a free life and continue to grow to their full potential under expert guidance.

Dear brothers and sisters, let us make a Home for our children.

Banashri Bhattacharya KANPUR 208002

My son was diagnosed at NIMHANS. We live in Hyderabad and have been receiving Autism Network for seven years. It is so useful and I wait to receive every copy. We get many tips to work with my son. I have all the copies and I read them sometimes and feel stronger.

AN CHENNAI

Signing for Babies

Wendy Jensen

Wendy Jensen teaches American Sign Language to graduate students and is a certified interpreter for the Deaf. She is the author of "Sign Language for Babies and Beyond: How to promote early communication and language development in your child."

Less than a year old, little Jaiden climbed onto my lap — her blond hair pulled into a tiny little pony-tail on top of her head. She turned her big blue eyes to look at me purposely and lifted up her chubby little hand to squeeze it open and shut. She wasn't just playing a game, she was communicating with me through sign language! Through this simple little sign, she was telling me that she wanted some milk. As I responded to her needs and asked, "Would you like some milk?" she broke into a beautiful tooth-less smile of approval. It was our little miracle!

BENJAMIN Franklin said: "Tell me and I forget, teach me and I remember, involve me and I learn!"

WHEN we teach our children sign language, we "involve" them in the entire learning process. This is one of the reasons that sign language is so successful with helping our children learn to communicate. By pairing signs with speech, we utilize all styles of learning – auditory (we hear the word spoken), visual (we see the word signed), and kinesthetic (we form the sign ourselves). When we use a variety of learning styles or techniques in order to learn new concepts, we have a greater capacity to retain that information. When we "involve" our children – they learn!!

SIGN Language is beneficial for both typical children, and those children with special needs. Some of these special needs may include children who have Autism or Downs Syndrome, or those who are Hearing-Impaired (just to name a few).

HERE are some of the benefits of signing with your child:

• Learning sign language at an early age helps develop the brain in the critical early years of language development.

• Sign Language allows your baby/toddler to communicate much earlier with you than they would be able to otherwise.

• Babies who can sign have shown less frustration and

tantrums overall since they can usually communicate their needs better.

• Studies have shown that babies who learned sign as infants had a higher IQ overall than babies who didn't learn sign.

• Children who have learned sign have been shown to have more advanced language skills than children who have not learned sign.

• Signing with your child provides a unique bonding experience between you and your child.

• Signing helps promote self-esteem in children.

ONE of my friends wrote this about her experience using sign language with her niece:

'When my niece was about 10 months old she would get very frustrated and yell and cry a lot. I taught her how to sign 3 signs "please" "more" and "eat". She stopped yelling and throwing tantrums in a matter of 20 minutes!'

I had similar experiences teaching my own children sign language. Wendy is the mother of six children. When our son was 18 months old he had trouble saying words. We started teaching him signs and he was thrilled to be able to finally communicate with us! He communicated quite well in signs for an entire year before the flood-gates opened with a rush of completely articulate words, sentences, and phrases! He is now in the second grade and reads two years above his grade level and is in the top of his class in math.

TWO researchers, Betsy Gibbs and Ann Springer (Gibbs and Springer 1995) wanted to learn whether sign language (along with speech) could help infants and toddlers who had verbal-language delays, communicate with others. THEY conducted various research projects with children who were able to hear but who were experiencing expressive language delays. They published the results of their research in a video-tape and booklet entitled Early Use of TOTAL Communication: An Introductory Guide for Parents.

TOTAL Communication in this context is used to refer to speaking and signing simultaneously. In their booklet, they state: "According to the research literature, many young children who have significant delays in language development can benefit from the use of a total communication approach. The method has been particularly useful with children with Downs syndrome, autism, apraxia, and other conditions that can cause significant expressive language delays."

THE authors point out that Sign Language is helpful for children with special needs since many of these children are delayed in their ability to express themselves through speech, even though their comprehension is not lacking. They give some explanations for why these speech delays may occur and explain how signing can help:

"Ear infections and fluid in the ears can cause temporary hearing problems that interfere with language development; low muscle tone (hypotonicity) may affect not only the large muscles but also the muscles in and around the mouth and tongue, leading to difficulties in coordinating the muscles needed to speak clearly; and some children may have auditory processing difficulties – difficulties making sense of spoken words and sounds.

THE early use of total communication can also help circumvent these potential interferences with language development by providing a visual language that is understandable to children who have auditory-processing or hearing difficulties and by allowing the child with oral motor difficulties to communicate using his or her hands."

THEIR findings show a positive result with both parents and children when sign language was employed. Sign Language stimulates language development and gives you a chance to see how much your child really understands. Infants and toddlers are able to learn sign with greater ease and usually at a quicker pace than they can learn speech, thus promoting communication and speech development. It is also an incredible bonding experience when you and your child understand each other!

NOW my daughter Jaiden is a little older and can speak lots of words. However, she still uses lots of signs, and often speaks and signs at the same time. She comes up to me and says: "Mama!" and taps her little hand on her chin in the sign for "Mother" and my heart melts!

REFERENCES

• Gibbs, B. and Springer, A, (1995) *Early Use of TOTAL Communication: An Introductory Guide for Parents*. Paul H. Brookes Publishing Co.

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खेल और संवेदिक एकिकरण (एक सिक्के के दो पहलू)

डा० अन्जली जोशी (अनुवाद : ऐक्शन फॉर ऑटिज़म)

खेल एक बढ़ते बच्चे के विकास का अनिवार्य हिस्सा है। पिछले चालीस वर्षों में बच्चों के साथ और उनके लिये काम करने वाले लोगों ने विस्तृत अनुसंधान किया है। इनमें बाल मनोवैज्ञानिक, बाल चिकित्सिक, शिक्षक, ऑक्युपेश्नल थैरेपिस्ट इत्यादि हैं। उनके अनुसंधान के फलस्वरूप बच्चों के लिये "ऑक्यूपेश्न" की अनेक धारणाओं एवं विधियों का विकास हुआ है।

आज के युग में जहाँ टैलिविज़न और कम्प्यूटर जैसे इलैक्ट्रोनिक साधन उपलब्ध हैं, तो ऐसा लगता है मानो बच्चे के मनोरंजन की कोई कमी नहीं। परन्तु प्रोफेश्नल लोग जो बच्चों के साथ जुड़े हैं उनके विचार कुछ अलग ही हैं। वह इस विषय पर विवाद कर रहे हैं कि "खेल का अभाव" या "खेल न मिलना" बच्चे के विकास पर क्या असर करेगा।

यह सही में एक गम्भीर विचारण हैं और इस पर ध्यान देना होगा। खेल की महत्वता और बच्चे की वृद्धि एवं विकास में गहरा संबन्ध है। बच्चे के शैक्षिक विकास में भी किस तरह खेल प्रभाव डाल सकता है, इसे समझना होगा।

इस अंक में हम विशेष ध्यान "खेल के महत्व"े और संवेदिक दुशक्रिया पर दिया जायेगा। खेल और संवेदिक एकिकरण की महत्वता केवल किसी प्रकार के स्पेश्ल बच्चों में ही नहीं, प्रत्येक बच्चे के विकास में होती है। इसके लिये आवश्यक है कि पहले हम "खेल" को एक प्रत्यय या विचार (कॉन्सेप्ट) के रूप में समझें।

शेरिडॉन द्वारा 'खेल' की परिभाषा इस प्रकार है

"खेल एक उत्सुक लगन है, जिसके द्वारा व्यक्ति किसी मनोहरीय या आनंददायक शारीरिक अथवा मानसिक प्रयत्न कर, अपने लिये भावुक संतोष प्राप्त करता है"।

खेल किसी भी प्रकार में क्यो न हो, वह निश्चित रूप से हमारे मस्तिष्क और बुद्धि को विकसित और तैयार करता है। यदि माता पिता या शिक्षक चाहते हैं कि उनके सामान्य या विशेष बच्चे (सामान्य और स्पेशल) अपने सामाजिक और शैक्षिक कौशल प्राप्त करने की ओर बडें, तो हमें ' खेल ' द्वारा उनके सामने चुनौती रखनी पडेगी , ऐसी चुनौतियॉ जिनका वह खेल द्वारा सामना करे और अपने स्किल्स या कौशल का विकास करे ।

कुछ बहुत ही सरल परन्तु अनिवार्य तरह के खेल है जो कि बच्चों के विकास को प्रभावित करते है। इनमे है – साकेतिक या प्रतीकात्मक खेल (सिम्बोलिक प्ले), रंग भरना, गाना इत्यादि। ऐसे खेलों की सबसे रम्य बात है कि माता पिता को महंगे खिलौने लेने की जरूरत नहीं होती । बैट्री से चलने वाले महॅगे खिलौने बच्चो की काल्पनिक शक्ति को विकसित नही कर पाते, उनमे रचनात्मक गुणों को विकसित करने में विशेष योगदान नहीं दे पाते । इस प्रकार शैक्षिक और चिकित्सीय दृष्टिकोण से यह लाभदायक नहीं है। यह केवल बच्चों को आनन्द प्रदान करते हैं ।

क्या आवश्यक है :– 1. एक विशेष खेल–स्थान। यह घर का कोई हिस्सा हो सकता है। एक छोटा सा कोना कोई पुराना टी वी या अन्य कार्डबोर्ड का बक्सा (बॉक्स भी चल सकता है)

2. निश्चित समय जिसमें बच्चा स्वंय समझे कि अब वह खेल सकता है ।

3. कुछ ऐसे पदार्थ या वस्तुऐं जो बच्चों को अन्य कियाओं (ऐक्टिविटीज) से इस सांकेतिक एवं काल्पनिक खेल में पारगमन या परिर्वतन लेने में मदद करें । यह आम वस्तुऐं जैसे लकडी के ब्लॉक्स, बोतल के ढक्कन, जूस पीने वाले स्ट्रौ, कले (या पानी व तेल में गुन्दा हुआ मैदा) इत्यादि हो सकते है ।

और सबसे अधिक महत्वपूर्ण :-4. एक ऐसा वातावरण जिसमें लोग बच्चे का प्रोत्साहन बढ़ाते है और उन्हें समय देते है ऐसा गुणात्मक समय जिसमे वह बच्चे के खेल का हिस्सा बन सके । उदाहरण – बच्चा यदि किसी गुडिया की या काल्पनिक '' प्रीतिभेज '' (पार्टी) खेल रहे है तो माता पिता या घर के अन्य सदस्यों को समय निकालकर इस नाटकीय खेल में किसी पात्र की भूमिका निभानी चाहिये । यह तो निशिचित रूप से माना जाता है कि जो आन्नद बच्चे को मित्रों के साथ या अकेले किसी बगीचे में या अन्य व्यायाम सहित खेल द्वारा मिल सकता है उसका स्थान और किसी भी प्रकार का खेल नहीं ले सकता । कभी भी माता पिता बच्चे के साथ उसके स्तर की पुस्तकें लेकर बैठ सकते है । इनमें से कहानी सुनाना, गाने या बाल गीत बनाकर सुनाना अत्यन्त लाभदायक होगा । बच्चे की काल्पनिक रचनात्मक, मनोयोग (अटेन्शन) और सामाजिक बन्धन और लगाव बनाने में यह मदद करेगा ।

प्रारंभिक खेल ''निःसंग'' या ''अकेले'' होता है और फिर ''सहयोगशील'' या दूसरे बच्चों के साथ ''मिलकर'' होता है । माता पिता को बच्चों को ऐसे अवसर और प्रोत्साहन प्रदान करने होगें ।

आज हमारे देश में भी, विशेषतर शहरों में छोटे/एकल परिवार (न्यूक्लियर या सिंगल फैमली) पाये जाते है , जिन में सब कुछ बच्चे पर केन्द्रित रहता है । इस से बच्चे को कुछ योज्ञताएं सीखने के अवसर नहीं मिलते। जैसे की साझेदारी (शेयरिंग), समन्वयता (ऐडजस्टमेट) औ सम्बद्धता (रिलेटिंग) । यह सारे गुण आज के बच्चे को " कल का व्यसक" बनाने के लिए अनिवार्य है , विशेष रूप से उसके भावात्मक विकास के लिए। इसलिए बार–बार माता पिता के योगदान की ओर हम ध्यान दे रहें हैं। स्वांग रचाना (प्रिटेन्ड प्ले), सांप–सीढी या लूडो जैसी लेनल किया (टर्न टेकिंग), इत्यादि बच्चे के बच्चपन का हिस्सा होने चाहिए।

कुछ अन्य कियायें भी खेल के रूप में प्रस्तुत की जा सकती है। मोती पिरोना, फिंगर पेंटिंग, रंग भरना, रेत में खेलना, जल कियाऐं, झूला इत्यादि कुछ ऐसे खेल हैं जिनके द्वारा बच्चे का शारीरिक विकास तो होता ही है, परन्तु साथ ही उसके अन्य कौशल जैसे अटेंश्न (ध्यान) और एकाग्रता भी विकसित होते हैं। आगे चलकर यही सारे कौशल उसके शैक्षणिक, सामाजिक और आत्मनिर्भरता के विकास में मदद करते हैं।

इस प्रकार कहा जा सकता है:--

खेल चाहे जैसा भी हो , वह एक ऐसा इमारती तत्व है जिसके द्वारा शारीरिक, दार्शिक बोध, सामाजिकरण स्वाभिमान, आत्म–ज्ञान और सम्पन्नता जैसे कौशल विकसित होते हैं।

संवेदिक संघटन और खेल-

हम अपने आस–पास के संसार को अपनी इन्द्रियों द्वारा खोजते हैं और समझते हैं। हमारी इन्द्रियाँ हमें एहसास दिलाती हैं– स्पर्श, गीत, आत्म–बोध, दृष्टि, ध्वनि ''हमारे मस्तिष्क की वह सम्पूर्ण किया जो संसार से प्राप्त सूचना का संसाधन कर उसका बोध दिलाती हैं, उसे संवेदिक संघटन या संवेदिक एकीकरण (सेंसरी इन्टिग्रेशन) कहते हैं। (डॉ. आयरस)

डॉ. आर्यस संयुक्त राष्ट्र अमरीका की एक माननीय आक्यूपेश्नल थैरेपिस्ट है जिन्होंने संवेदिक संघटन के सिद्धान्त (थ्योरी) को जन्म दिया। पिछले पचास वर्षों में उनके इस अध्ययन पर अनुसंधान हुआ है। आज इस बात को खोज द्वारा माना गया है कि जो बच्चे लर्निंग डिसेबिलिटी से प्रभावित हैं, उनमें संवेदिक एकीकरण का आभाव रहता है। हमारे स्पेशल बच्चों में एक ऐसी ट्रेनिंग प्रणाली लाभप्रदायक हो सकती है, जो कि उनमें संवेदिक दुशकिया में सुधार लाने पर केन्द्रित हो।

यह ट्रेनिंग एक ऐसा व्यवसायी व्यक्ति दे सकता है जिसने इस क्षेत्र में स्वयं ट्रेनिंग ली हो। ऐसा व्यक्ति (ऑक्यूपेशनल थैरेपिस्ट) जो बच्चे को केवल खेल ही नहीं करवाये परन्तु उसमें ज्ञान प्राप्त करने की क्षमताओं का विकास करे।

संवेदिक द्शकिया क्या है ?

यह कोई चिकित्सा रोग या बीमारी नहीं है जिसे आसानी से अलग किया जा सके। केवल एक प्रशिक्षणीय या ट्रेन्ड आक्यूपेशनल थैरेपिस्ट व्यवहार देखकर समझ सकता है कि वह एक कमजोर या प्रभावशाली संवेदिक एकीकरण (सेन्सरी इन्टीग्रेशन) के फलस्वरूप है। कभी कभी साधारण या सही रूप से विकासशील बच्चों में ऐसे व्यवहार दिखते हैं। केवल जब ऐसे बहुत से व्यवहार सामूहिक रूप से लगातार या प्रायः दिखें, तब ही मेडिकल हस्तक्षेप (इन्टरवेन्शन) की आवश्यकता होती है।

संवेदिक एकीकरण का खेल पर क्या प्रभाव है ?

बचपन और किशोरावस्था में खेल द्वारा संवेदिक अनुभव प्राप्त होते हैं। इन अनुभवों से व्यक्ति के नरवस सिस्टम और मस्तिष्क परिपक्व (पक्के, मैचोर) होते हैं। इसलिए जिन बच्चों में ऐसी संवेदिक सूचनाओं की प्रक्रिया करने में असमर्थता हो, उनके खेल में विघटन होत है। उदाहरण– स्पर्श बचपन का प्रथम साधन होता है, जिसके द्वारा वह अपने वातावरण को खेजने या ऐक्सप्लोर करने की कोशिश करता है। यदि बच्चे को स्पर्श द्वारा अनुभव प्राप्त करने में संवेदिक दुशकिया है तो वह बहुत से खेल और बहुत सी ऐक्टिविटीज में बेआरामी महसूस करेगा। जैसे की बालू में खेलना, क्रयौन (मोमी रंग) या फिंगर पेन्टस से खेलने में बेआरामी। या इन सब वस्तुओं और अन्य खिलौने को अटपटे ढंग से छूना या मुंह में डालना।

ध्वनि भी खेल का सामूहिक भाग है, खास तौर से शिशुओं और बच्चों में। सांगीतिक वाद्य (बाजे, इत्यादि), इलेक्ट्रिोनिक खिलौने, चहकने वाले खिलौने इत्यादि में संगीत का तत्व होता है। जो शिशु और बच्चे इन आवाजों को सह नहीं पाते (श्रवण संबंधी दुशकिया या ऑडिटरी डिस्फंक्शन) वह इन खिलौनों से दूर रहने का व्यवहार दिखायेंगे। जन्मदिन की पार्टी या अन्य सामूहिक खेलों में भाग नहीं ले पायेंगे।

एक और ऐसा तत्व है जिसे हम खेल में स्वीकृत रूप से देखते हैं, वह है ''गीत'' अथवा ''मूवमेन्ट'' किसी भी खेल की कल्पना बिना 'गीत' के नहीं की जा सकती। वैसे तो अपने वातावरण के साथ कोई भी सम्पर्क या पारस्परिक किया गति के बिना नहीं होती।

कुछ बच्चों में गति सम्बन्धित दुश्किया होती है जिसके कारण वह मूवमेन्ट या गति सम्बन्धित ऐक्टिविटीज से डरते है (ग्रेविटेशनट या गुरूत्वाकर्षण असुरक्षा) ऐसे बच्चे किसी भी किया में जिसमें सर की स्थिति बदलनी हो या पैरों को जमीन से उठाना हो, चिन्तित और व्यथित हो जाते हैं। वह निश्चित रूप से किसी भी प्रकार के सामूहिक खेल पारस्परिक किया या खोजबीन खेल (ऐक्सप्लोरेट्री) में भाग लेते समय परेशानी में दिखेंगे। झूले, फिसल पट्टी, जंगल जिम या उद्धम वाले खेल में बच्चों को कठिनाई होती है। नतीजा यह होता है कि बच्चे के शारीरिक बढ़ौती और विकास में ऐसी गति संबंधित दुश्किया बाधा डालती है।

ऑटेस्टिक बच्चों में खेल व्यवहार बहुत ही अटपटा रहता है। रूढ़बद्ध या घिसी पिटी कियाएं और प्रतीकात्मक कौशल की कमी (लिमिट का सिम्बोलिल खेल) ऑटिस्टिक बच्चे में नम्यता की कमी के कारण होती है। इसके कारण बच्चा अपने खेल को आयोजित और व्यवस्थित नहीं कर पाता। वह रचनात्मक या स्वांग रचाने वाले खेलों को नहीं खेल पाता।

आरम्भ से ही, बच्चा नकल या अनुकरण द्वारा दोस्ती की भाषा समझता है। आटिस्टिक बच्चों में अनुकरण करने की कमी रहती है और इसी कारण मित्र बनाने में या सामूहिक किया में उनके सीमित गुण दिखते हैं। उन्हें या तो देखी गई क्रियाओं को याद रखना कठिन लगता है या वह देखी गई क्रियाओं को अपनी शारीरिक क्रियाओं में बदली करने में असमर्थ होते हैं।

खेल को बच्चे के ट्रेनिंग का साधन कैसे बना सकते है? खेल में विस्तार लाकर हम ऑटिस्टिक बच्चों को सहयोग दे सकते है, जिस से वह अपने वातावरण में पूर्ण रूप से कार्यशील हो सकते है। खेल द्वारा बच्चे को बहुत सी व्यवहारिक कलाएं और गुण सिखाये जा सकते हैं। बच्चे में ध्यान (अटेन्श्न), घनिष्ठता (इन्टिमेसी), आभिव्यक्ति, ध्यान से देखना और प्रतिक्रिया देना, सामजिक रिश्तों का विकास और तर्ककिक विचारण (लौजिकल विचारण) जैसे गुणों में खेल द्वारा सुधार लाया जा सकता है।

<u>खेल वृद्धि के लिये कुछ विशेष नीतियाँ व योजनाऐं:-</u> एक सुरक्षित संवेदिक वातावरण इसकी कुन्जी है। निम्नलिखित बातों का पालन करें:--

 बच्चे के व्यवहारों पर ध्यान दें और देखें कि उनमें कम्यूनिकेशन या संचारण के संकेत हैं या नहीं।

 यदि बच्चा किसी व्यवहार द्वारा अपनी बात समझा रहा है या कोई व्यवहार कम्यूनिकेटिव है तो उसका प्रेक्षण करें और सही प्रतिक्रिया दें।

3. बच्चे के पास सुरक्षित दूरी पर रहें।

- 4. आँख से सम्पर्क करने को प्रोत्साहित करें।
- 5. बच्चे के साथ अनुप्राणित रहे और खेलें।
- 6. बच्चे को दूसरों के साथ पारस्परिक क्रिया बनाने में प्रोत्साहित करें।
- 7. एक आकर्षक वातावरण को तैयार करें।
- 8. संगीत का प्रयोग करें।
- 9. सहयोग दें।

10. लेनल क्रिया या बारी लेने वाले खेल करें (लूडो, साँप-सीढ़ी)।

 बच्चे के खेल या क्रियाओं की नकल करें और उसे भी नकल करने को प्रोत्साहित करें।

12. बच्चे के रूढ़ीवादी खेल में सोच समझकर, खेल खेल में रूकावट डालें और नये रचनात्मक खेल को प्रोत्साहित करें।

उदाहरण –

यदी बच्चा गाड़ियेां की पंक्तियाँ बार—बार बना रहा हो, तो उसके रास्ते में फर्नीचर या तकियों द्वारा रूकावट डालें,जब बच्चा विवलता से आँख मिलाता है तो रचनात्मक खेल में डालें। खेल में नियमित रूप से नवीनता लाएें। खेल का मुख्य आधार बच्चे की जानी पहचानी हर दिन की घटनाएें और क्रियाएें हों। इस प्रकार एक संवेदिक खेल वातावरण प्रदान करें। कुछ स्पर्श, गीत और शारिरिक क्रियाओं को खेल में पेश करें।

खेल में परिवार की भूमिका

यह समझना जरूरी है कि परिवार में असमान्य बच्चे के होने पर भी वह सबसे पहले एक परिवार है और अन्य दूसरे परिवारों की तरह ही इस परिवार के भी कुछ उत्तरदायित्व हैं। क्योंकि ऐसे परिवार में स्पेश्ल बच्चा है, तो कुछ जिम्मेवारियाँ बढ़ जाती है। यदि परिवार के सदस्य बच्चे के साथ खेल और मनोरंजन से पूर्ण ऐक्टिविटिज में भाग लेते हैं, तो उनपर जो तनाव रहते है वह कम हो जाते हैं और स्थित का सामना करना सरल हो जाता है। साथ बच्चा अन्य गणों को विकसित करता है जैसे ज्ञानात्मक गुण जिनमें सामाजिक व्यवहार में सुधार होता हो।

अगले अंक में हम इस लेख का अन्तिम भाग देंगे जिसमें कुछ और खेल और मनोरंजन प्रदान करने वाली ऐक्टीविटीज का वर्णन होगा।

HELPLINE

 \mathcal{Q} My friend has a younger sister, 14 years who always seemed odd to me. I have known her since she was born and see her as if she were my own sister. Lately another family friend of ours has been dating a doctor, and as soon as he met my friend's sister he noticed that she suffered from a very mild form of Autism. So far no one has told her parents or anyone in her family, because they would never accept something like this. They would also never speak to whoever told them for the rest of their lives. We are currently trying to find a way to break it to them.

I just wanted to ask if there is any advice about telling parents their child is autistic. Also until someone finally tells the family, is there anything that can be done to help her without the family's knowledge?

 \mathcal{A} There are two things I understand you want to address: how to tell the family and how to help the girl. It may not be possible or appropriate to tell the family their girl has autism without a formal diagnosis. And since the family is not willing to go for a diagnosis this is obviously ruled out. An option might be to leave information on the noticeable symptoms particularly of persons with high functioning autism, in their home, for the family to come across and come to their own conclusion.

Regarding helping the young girl it depends on what specific and evident issues she requires help on. Particularly given that she appears functionally quite able we would need inputs on specific areas where she requires support.

 \mathcal{Q} The Doctor has advised us to give resperidon to our son. I have a confused notion about medication. Please help me.

Your son's doctor must have explained to you why he has prescribed the resperidon. From what I recall your son has significant sensory issues and a certain amount of over stimulation and over activity. Providing activities for sensory integration, as well as specialized teaching, will of course help. However, due to the stresses of parenting a child with autism a family ACTION FOR AUTISM

sometimes finds it difficult to handle a child's behaviour by training alone. A doctor might then prescribe a drug like resperidon to enable the family start teaching the child. Once the child 'learns to learn', the drug may be slowly tapered off and stopped. Of course this must be done under the physician's supervision.

 \mathcal{Q} My baby is not yet signing but I've started trying to introduce a few signs. I do have a question though and am wondering if you have any advice. My wife speaks Hindi and is trying to teach it to our son. She speaks only Hindi and I speak English to him. But I am wondering how to fit signs into this. Whether I just use the signs with the English words or also with the equivalent words in Hindi as well?

I had a thought that if I was to teach the sign for the word in English and then in Hindi, it might be too confusing and our son might be at the risk of using neither languages and just signing.

 \mathcal{A} Good question! Research has shown that Sign Language actually helps children learn more than one language simultaneously. I would suggest using the signs along with both the English words AND with the equivalent words in Hindi – this way the signs will help bridge the gap between the two languages and your baby will learn that signs and words are symbols for objects and concepts.

One parent in a bilingual family, could show their child a ball while at the same time showing the sign for "ball" and then another family member could sign "ball" while saying the word in the other language. Seeing the same sign while hearing different words, helps children understand the meaning of the concepts behind the words and the signs. Using sign language in this way has also been helpful for families who speak two or more languages or for families who have adopted children from another country who speak a different language.

Sometimes children who learn two different languages will mix up the words from both languages at first, simply because they don't yet know enough words to separate the languages. But it won't be long before these children will learn to code-switch, or separate their languages and use each one appropriately in the correct setting.

 ${\cal Q}$ My son RM is 18 and currently studying in a special school. He was a caesarian baby and his milestones were normal except for a big forehead which was noticed by doctors when he was about nine months old. Immediately various tests were carried out and he was examined by a group of neuro-surgeons and neuro specialists. AIIMS advised that he has mentally subnormal and referred him to the child guidance. We visited the child guidance units for nearly three years after which they advised to send our son to an intergrated school. We put him in an integrated school when he was four years and initially he learned to read, write, both English and Hindi and some basic math. After a few years the school stopped giving much care to the unit for special children beyond the usual repetitive reading and writing. At this time RM began to love and worship Lord Hanuman and regularly began singing the Hanuman chalisa, Amritavani etc. He picks up tunes of devotional songs and film tunes with remarkable accuracy. We shifted him to a new school and for the last two years RM is in the school hostel. But there is not much progress.

RM has poor eye to eye contact, poor response. He is always in his own world and unconcerned about others around, and not willing to play. He gets irritated and beats crying children. He is not violent but if he does not get his wish then he becomes moody and aloof. He operates the radio and TV and watches mostly religious channels. He can operate the computer and sometimes play on it or listens to music. But his writing is odd and not sensible. He repeats the words and speaks unfamiliar language but obeys commands and understands what we say to him. His IQ level reported is 54%.

 \mathcal{A} RM may be having difficulty in expressing himself in an appropriate manner. When hitting children who are crying , he maybe actually communicating that the crying bothers him. It could be sensitivity to the sound or an inappropriate emotional response. He needs to learn an alternative way of coping with the situation. He can be trained to cover ears or move away when a child cries. He also needs to know that sometimes people cry and that it is okay.

Making and sustaining eye contact is often very painful for people on the spectrum. Rather than forcing him to look, reinforce his looking with praise or attention. Interact with RM at his level. This means do things he likes, let him take lead in the interaction. It could be through singing/ chanting/ puja. You can ask him to help you by putting the computer or the music system on for you. Acknowledge and praise his compliance.

RM's difficulty in engaging in play with others is typical of people with autism: they find it difficult to interact with their peers. Games are difficult because they involve social skills like turn taking, waiting, reciprocity, understanding rules of the games. Playing within a small group, of two or three persons, maybe easier. At the start the games chosen too will have to be simple like ludo or snakes and ladders.

RM seems to have a good rote memory and has therefore learnt Mantras and Chants by rote. At present he is around 18 years and many of his behaviors like being aloof and moody maybe a result of his age: many typical boys also behave the same way at this age. RM will need sensitivity and acceptance to weather this stage in his life. At the same time given his age, priorities have to be set with a focus on functional and pre vocational skills. We do not have information of any place in Delhi that has a residential set up for people with autism or Mental Retardation. However, there are residential places in Una in HP, Dehradun and in Bhopal.

 \mathcal{Q} My daughter always touches every one in the house and also some times people at her school. She sometimes bites at home, pinches, repeats utterances, and makes faces. Also she does not know how to react with her peers. She likes to talk like someone a lot older than her.

A We would suggest that you start with just one or two difficulties that you would like to target as a priority. Perhaps you might like to work on those behaviours that are either causing injury to your child or other people, or that are coming in the way of your child's direct learning time. For eg.if pinching or biting other children at school is your primary concern, you could try behaviour modification techniques. This would be finding out through observation why the pinching is taking place, for e.g., is it a sensory need or is it to get attention of other people, to access an activity or object, or to escape from the situation?

Accordingly deal with the behaviour. e.g., if you feel it is to get attention, do not pay undue attention to the behaviour, and rather pay attention to the child who has been pinched. Keep yourself neutral and comfortable within the situation and do not talk about what happened and do not say 'no' or 'don't' etc. Instead, when your child is behaving appropriately, praise and acknowledge that behaviour.

At another time (when the behaviour is not occurring) you can facilitate social interaction with another child by taking your child's hand and helping her say hello, take turns on a game, and so on. All this while you may need to remain focussed to ensure no inappropriate behaviours happen during this time. If the behaviour is a sensory need, fulfil that need during another time by structuring it into her daily routine or schedule.

You could also try preparing your child with visual cues about what is going to happen in school or at the park and talk about the situation. However, make sure you do not use words like 'we must say hello' and so on. Instead, keep language positive and use language like 'we can try to stay smart', etc. Social Stories are another technique you could try if your child is ready for them. Going through all the steps of a social story is beyond the scope of this column but a book like 'Social Stories' by Carol Gray would help. You could also see 'Social Stories' in previous issues ofAutism Network

Finally, behaviours like making faces and repeating are all a part of the difficulty in social understanding and inflexibility in thought and behaviour associated with having a diagnosis of Autism. It may be useful to focus on what your child is already doing well, and use her strengths to teach her more skills. For example if she repeats words or sentences, put it in context for her and make it meaningful. You can also model appropriate language for her to copy in a social situation.

 \mathcal{Q} I am a 28 year old lady with Aspergers Disorder. I am established in my job and highly educated but cannot get my life partner and get settled due to lack pf proper communication skill. I want your help to overcome my problem.

 \mathcal{A} As you have found yourself, getting a life partner requires rather complex communication and social skills which can be an issue with people on the spectrum. While we would like to help you, we work out of Delhi and it would be difficult for us to have regular discussions on your needs. If it is at all possible for you to travel to Kolkata from Midnapore then you could contact the Autism Society West Bengal: <autismsocietywb@hotmail.com> for support.

Annual Training Workshop for Parents & Professionals

INDIAN SOCIAL INSTITUTE, LODI INSTITUTIONAL AREA, NEW DELHI

23, 24, 25, 26 September 2006

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

Individual consultations on the last day of the workshop, will be available at no extra charge to those families who book in advance.

Childcare will be available during workshop hours for families who find it difficult to leave their children at home. Childcare is open to children with special needs as well as their siblings. Please register in advance. Information about your child's special needs will have to be given at the time of booking so that adequate arrangements can be made. *Last date for availing childcare 10 September. Childcare will not be available to on-the-spot registrants.*

Accommodation

Limited number of rooms from noon of 22 September to noon of 26 September at the Indian Social Institute at Rs 1500/- per bed (twin sharing) and Rs 3000/-(double room) for a *four night stay with breakfast. Last date for booking accommodation 5 September 2006.*

Daycare charges: Rs 200/- per child, per day

Registration Costs

• *Parents:* Rs1750/- per parent attendee (Rs 1400/- for life members & full annual members)

• Rs 3000/- per parent couple (Rs 2500/- for life members & full annual members)

• Non parents: Rs 2500/- per non-parent attendee

(Rs 2200/- for life members & full annual members)

• Rs 2300/- for each attendee from an organization that has taken membership if more than one person attends

• All registrations received after 31 August 2006: Parents 2000/- each and Non-Parent Rs 3000/- each.

| PRE-REGISTRATION FORM | | | | |
|---|--|--|--|--|
| Do 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 | (<i>Tick relevant box</i>) Parent Professional | | | |
| | | | | |
| Tel | Email: | | | |
| If parent, name of child | Child's DOB | | | |
| If professional, name of organisation | | | | |
| Please find enclosed a Demand Draft No | | | | |
| dated | drawn onBank | | | |
| Do you require accommodation YES/ NO | Do you require childcare YES/ NO | | | |

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