autism network

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YOUR CONTRIBUTIONS
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In referring to the child with autism, Autism Network often uses 'he', 'him' and 'his', not as a prejudice against the girl child with autism, but for reasons of simplicity and because the vast majority of children with autism are male. However, many articles also use 'she', 'her', and 'hers'.

Website: *http://www.autism-india.org*
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Cover Illustration

'Old Man' 'Young Man'
by Prosenjit Baral, 10 years, Mother-Child Programme

WISHLIST !

- Apartment/ House Residence for Autistic Children
- Trampoline
- Lego: large & Small blocks
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PAGE ONE

The triad of impairments are considered to be essential markers in the diagnosis of autism. Sensory issues are not considered core to a diagnosis. However, those on the applied side of autism practice know the importance of sensory issues and the role that sensory intervention can play in helping individuals with autism reduce stress in their lives. This issue carries two articles on the subject. One is on the very contentious subject of handwriting. Every mother of a child with autism wants them to 'read and write'. Some do, and many do not. Of the latter, there are many who are in mainstream classrooms, cognitively able, and have difficulty with the process of writing. Forced, and often inappropriately punished, to perform a task that is difficult for them, many develop secondary behaviours to cope with the stress. Yet under the guidance of a good sensory and occupational therapist, many of them can overcome their difficulties and learn to enjoy the process of writing. However, there will be a number of children who will continue to face difficulties with handwriting and their difficulties and differences will be better accommodated with the provision of computers.

Simon Baron Cohen who needs no introduction, raises some very pertinent and disturbing issues relating to media reporting and popular perceptions of disability. Media often reports an event or a comment in a manner such that it totally changes colour and becomes something else. This is often seen in the reportage on every 'discovery' that is made regarding autism and its 'cure'. Baron-Cohen's sensitive article was widely reported in the international media and numerous elists, including Indian ones, with confusing interpretations that were totally out of character with his original article. Some readers of Autism Network wrote to us commenting on what they felt were 'outrageous' comments by Baron-Cohen. As often happens, none had read the original piece. So for all our readers we print here, with permission, the original article by Dr Simon Baron-Cohen. It is a must read for all in helping attain a perspective of respect for individuals who are different.

This is particularly relevant for those of us in India following the controversy that raged about a young woman in a government women's 'shelter' who was expecting a baby as a result of rape by employees. The woman who has some degree of mental retardation, wanted to keep the baby. The lower court in all its wisdom decided she was not fit to keep the baby. Fortunately, the higher courts decided in her favour. What was disturbing were the opinions of people in the disability sector. Here was a woman supposedly in governments care, taken advantage of by those how were supposed to look after her. She takes a decision on the outcome of her mistreatment, and it is considered perfectly alright to overrule her. Wronged once, it is felt acceptable that she be wronged again. Will she be able to take care of the baby and herself? How do we know that she will not! We write her off without a second thought.

As Dr Baron-Cohen says: Some individuals may need more support than others, and it is a mark of a civilized community that we provide such support for those who need it. If we do not, then we have failed.

As children we learnt how we Indians were one people despite our diversity. But we have yet to learn to appreciate the richness of true diversity: of language, of colour, of ability, of religion, of caste, of appearance....

CRE PROGRAMS IN AUTISM

Understanding & Teaching Children with Autism Spectrum Disorders

Duration: 16 – 19 September, 2009
Venue: The National Centre for Autism,
Pocket 7 & 8 Jasola Vihar, New Delhi

The UTCA Workshop is built on an understanding of ASD and works through teaching various cognitive, communication, and daily living skills. This year's workshop is a series of five Continuing Rehabilitation Education topics over the four days.

Day One: Autism: Understanding a Different Way of Being
Day Two: Strategies for Developing Communication
Day Three: Applied Behaviour Analysis: Teaching and Changing Behaviours
Day Four: Parallel Sessions:

- Getting Started with Early Intervention
- Including Children in the Mainstream Classroom.

Registration forms available at Action For Autism or can also be downloaded from the AFA website : <www.autism-india.org>

Last date for registration: Thursday 11 September 2009

Contact: Shikha Bhardwaj, Training Coordinator,
Email: <shikha.afa@gmail.com>, Tel: 011 40540991/2

Sensory Processing Difficulties

Nusrat Hussan

Nusrat has a Masters in Occupational Therapy
and a keen interest in Autism Spectrum Disorders

We explore or learn about the world around us through sensory experiences. These sensory experiences include touch, movement, body awareness or joint sense, sight and sound. The process of the brain organizing and interpreting this information is known as sensory integration.

CHILDREN having sensory processing difficulties may face difficulties in processing information from the seven senses namely tactile, vestibular, proprioceptive, visual, auditory, olfactory, and gustatory; and converting them into purposeful activities. When children have a difficulty in these sensory systems, it means that the particular form or forms of sensory input is confusing, upsetting, or not meaningful to the child. A difficulty with sensory input can interfere with the child's ability to complete important activities successfully

TOGETHER with sensory processing they may also have a dysfunction in sensory modulation, seen as a difficulty in filtering and changing a sensory input into a purposeful activity

SENSORY modulation allows a person to achieve and maintain an optimal range of performance and to adapt to the challenges in life. When a child has sensory modulation impairment, the child may have poor attention and concentration, and be unable to meet external environmental demands, resulting in an inability to sustain engagement with people or in activities

Representation of Sensory Processing and Modulation Dysfunction
Sensory dysfunction can manifest as a sensory deficiency or a sensory overload. Sensory dysfunction appears to affect individuals with Autism Spectrum Disorders (ASD) in particular who tend to use either self-stimulation in order to compensate for restricted sensory input or self-avoidance to restrict or avoid certain inputs, eg covering their ears with their hands to restrict certain sounds.

THE following are some features reported by parents of people on the spectrum that represent various manifestations of sensory dysfunction:

- Differences in auditory processing are one of the more commonly reported sensory processing impairments with a full range of atypical behaviours noted.

- Parents notice signs of auditory hypersensitivity as in the child being troubled or distracted by noise, or not being able to work or focus in the presence of background noise. Hypoactivity to auditory stimuli has been an early diagnostic consideration for autism. eg diminished response to being called by their name, child appears to be deaf, not responding to certain sounds.

- For visual responding, avoidance of eye contact and inefficient use of eye-gaze have been described as an early social feature of autism. Children with ASD also often inspect different objects such as their own flapping hands, other moving objects, in an unusual way with their peripheral vision.

- Children with vestibular hyposensitivity seek vestibular stimulation and are 'on the go'. While those who are hypersensitive to vestibular movement avoid inputs and exhibit gravitational insecurities like avoiding going up and down the stairs or fear of heights. Or they may be constantly trying to provide props to self such as hugging arms and legs to the body whilst sitting or lying down, slouching in the front or sideways while sitting or bending the neck down towards the chest while sitting.

- When exposure to different textures of clothing makes a child extremely anxious, distracted, or fidgety, it may be interpreted as over-responsivity to tactile input. Toe walking, preference for walking bare foot, or avoiding messy activities may also be noticed. On the other hand the child with tactile hyposensitivity seeks out all types of tactile input like touching people and objects.

- Sensitivity to tastes of certain food, excessive mouthing of objects is also seen in children with ASD.

Dealing with Sensory Dysfunction
It has been seen that the tactile, vestibular, and

proprioceptive systems are mainly involved along with other systems. So a change in these sensory inputs may reduce the above mentioned behaviours and increase participation and independence in functional tasks.

THESE sensory inputs can be provided as a balanced **sensory diet** through sensory integration therapy, which uses a planned, controlled sensory input in accordance with the child's specific sensory needs.

THE purpose of a sensory diet is to provide sensory experiences throughout the day in order to help the child maintain a functional level of arousal, which is necessary for learning. The sensory diet must be individualised for each child, based on his needs and responses to sensory inputs.

OUR levels of arousal change frequently throughout the day, usually in response to sensory changes and experiences (eg, feeling sluggish in the afternoon) and we develop strategies to improve our level of alertness which are individualised, based on past experiences (eg, taking a brisk walk or drinking a cup of coffee to counter the feeling of sluggishness).

HOWEVER, children with a sensory dysfunction are unable to self-regulate and sustain an appropriate level of arousal. Further, it is important to remember that, just as our preferences tend to change, so do those of our children.

Components of a Sensory Diet

The sensory diet contains a selection of activities that can be easily implemented throughout the day in a variety of settings. The diet should be thought of as 'nutritional requirement' for actively engaging in daily tasks.

BY incorporating sensory experiences in short tasks throughout the day, the child will be more likely to sustain his level of alertness when it is necessary. The activities recommended in the sensory diet are designed to keep the child engaged and less agitated throughout the day. They are not 'fire-fighting' strategies that are meant to only be used when the child becomes agitated or disengaged.

IN order to design an effective sensory diet, knowledge of types of sensory input is important. Sensory inputs can be categorized into the following seven areas:

1. Tactile (touch)
2. Auditory (hearing)
3. Proprioceptive (heavy muscle work)
4. Vestibular (movement)
5. Visual (sight)
6. Olfactory (smell)
7. Gustatory (taste)

Designing a Sensory Diet

When choosing sensory activities we need to understand that sensory inputs can be of different intensities and may require longer durations and more or less frequent inputs. Also the result of the sensory input on the child has to be monitored in order to determine whether the activity has a calming or alerting effect on the child. Based on the child's responses the activities would need to be changed or modified.

SOME activities that can be considered whilst designing a sensory diet are:

1. Tactile activities

For the child who is tactile hypersensitive (defensive), and avoids touch or being touched:

ACTIVITIES that lets the child support his weight on the hands, feet, and stomach-like wheel barrow walking, walking on all fours, animal crawls . Or the child lies on his stomach on the floor, and a large gymnastic ball is rolled on his back

EXPOSING the child to various textures. The child could walk on a textured mat. Or put his hand in a box which has various objects, and guess what his hand touches.

DIFFERENT kinds of sand and water play.
Finger or foot painting with sand or mud.
Rubbing the child's extremities with hard textures such as a brush or towel.

For the child who is hyposensitive and seeks tactile inputs by touching various objects and people:

CLIMBING up, rolling, jumping, wheel-barrow walking (the child 'walks' on his hands while someone holds his body up by the ankles).

PLAY doh activities as rolling, cutting, making balls out of the play doh.

TRACING designs with fingers on different textures like sandpaper, fur, etc.
Ball pool activities

Obstacle course
Pillow fight

2. Auditory activities

Listening to recordings of environmental sounds such as a cooker whistle, a motorcycle revving (for the hyposensitive).
Using headphones to reduce background noise (for the hypersensitive).

3. Proprioceptive activities

Proprioceptive experiences are those experiences that use the large muscles in the body and are defined as heavy work.

WEARING a heavy weighted vest, carrying weights in a bag, walking with heavy loads.

COCOONING: Wrapping the child in a sheet, or blanket. or towel, like a caterpillar in a cocoon and holding tight.

Animal walks
Jumping activities
Chair or wall push-ups.

4. Vestibular activities involve movement

For the child who is hypersensitive and has gravitational insecurities, and avoids movement:

HAVING fun moving around while experiencing different possibilities of movement
Sitting on a low swing with the feet on the floor and spinning, turning, rolling.
Activities with a large gym ball, such as bouncing whilst sitting on the ball, lying with the stomach on the ball and the hand touching the floor.
Walking through an obstacle course with the complexity of movement gradually increasing.

For the child who is hyposensitive (hyperactive) and seeks movement, the 'on the go' child:

USING the swing in the playground daily.
Spinning, jumping, and running along a designated path, or running between designated start and stop points.
Physical activities and sports to channelise extra energy
Frequent movement breaks.

5. Visual activities

Turning lights off (to calm)
Turning lights on (to alert)
Using flashlights to focus.
Use tracking methods with torch in dark room to improve peripheral and central vision.
Working with children at eye level so they can look directly into the eyes

6. Olfactory and gustatory activities

Providing an oral massage before meals
Providing a 'smell box' with a wide range of smells, from the soothing to the pungent based on the child's preferences
Oral motor exercises including sucking, blowing and chewing

Sensory Diet for Adolescents

Sensory integration suggests that the child's ability to successfully perceive and integrate sensations not only allows him or her to develop skills within the environment, but also promotes socialisation and emotional well being.

THE important thing to remember is that humans are sensory beings and sensations are inherent in all occupations. So children with ASD continuously need sensory inputs across the life span, through early childhood to adolescence, and those needs vary or change as they grow.

IN the pre-teen and adolescent years, children typically have more independence from caregivers and are allowed to make many more independent choices. As teens move into and through this age of freedom, they face the challenge of seeking an effective balance, whereby they may need to adapt their internal drives and desires with the external pressures of socially appropriate norms, personal responsibility, and adult expectations.

IT is possible that the difficulties in sensory processing will add to the tension and mismatch between internal drive and external demand. Sensory integration therapy will help identify distinct sensory needs and develop safe and appropriate strategies for meeting those needs.

TEENS may engage in sensory seeking activities, such as impulsivity and aggression and can benefit from intense sensory therapy.

BOTH parents and professionals dealing with teens and adolescents need to respect their independence and choice, teaching them to meet their own sensory needs,

(cont on page 7...)

Handwriting Difficulties in Autism

Nusrat Hussan

Children with developmental disorders such as autism, learning disabilities, attention deficit hyperactivity disorder, sometimes present with one or more of the following behaviours: over or under sensitivity to touch and / or movement experiences, easy distractibility, clumsiness, difficulties in organizing themselves and their work, emotional reactivity, difficulties in learning new skills, low frustration tolerance and difficulties in making transitions between activities or situations.

THESE behaviours could be because of underlying difficulties in processing sensory inputs that we receive from our senses such as vision, hearing, smell, taste and touch. There are also some internal senses like:

- Position of the different parts of our body (Propioception)

- How our bodies are moving (Kinesthesia)

- Our position in spaces and in relation to gravity (Vestibular)

THE brain processes all the information received by our senses, usually at an unconscious level, organizes them and allows us to respond appropriately such as move efficiently, attend and listen, and learn new skills.

Handwriting

Learning to write, like learning to read or play a musical instrument, is generally a sequential process. Children progress as writers from one phase to the next, with each new set of skills building on skills acquired earlier.

HANDWRITING is an important and essential functional skill for school-aged children. It is required in a variety of daily activities, such as when children compose stories, answer written examinations, copy numbers for calculation, or even as simple as writing messages to friends and family members.

HANDWRITING is a very complex skill that requires many systems to work together viz:

1. Thinking skills
- Visual-perceptual skills
- Planning and organisation
- Memory

2. Biomechanical and motor skills
- Pencil grip and pressure
- Posture
- Use of both hands (Bilateral coordination)
- Handedness
- Muscle tone
- Control and coordination of finger movements

3. Sensory processing
- Sense of touch (Tactile)
- Joint and body awareness (Proprioceptive)
- Movement awareness (Kinaesthesia)

4. Psycho-social
- Confidence
- Motivation
- Behaviours
- Attention

5. Environment
- Learning (expectations, style)
- Physical (seating and table)
- Sensory (noise, light)
- Social

SMOOTH and efficient writing depends on adequate motor planning: namely having an idea of what to do, and then planning and executing that into action, In addition, good handwriting depends upon the ability to visually recognize letters of the alphabet (visual perception), as well as our body awareness (proprioception) and our sense of touch. The 'just right' amount of alertness and focus is also important.

MOTOR planning depends on efficient sensory integration of tactile, vestibular, proprioceptive, olfactory, visual, auditory and gustatory sensations. Adequate motor planning contributes to the child's ease and efficiency in writing.

CHILDREN having problems in any of the sensory systems will show sensory dysfunction and poor motor planning, affecting many functional tasks including handwriting.
Poor writing skills manifest in different children in many different ways:

- Child may have postural weakness in stabilizing muscles of hand, shoulder, neck and trunk

- Poor coordination of hand muscles
- Difficulty in visual perception
- Poor visual memory and/or problem in translating auditory information to motor task of handwriting
- Difficulty focussing and attending to task
- Poor pencil grip
- Poor letter formation, poor spacing
- Frequent reversal in words and letters

- Children with handwriting difficulties may have lowered self-confidence and frustration because they are unable to fully express their knowledge in written form.

Stages of development
To understand how writing may be affected in a child it is important to be aware of the stages of development in children that are relevant to writing, Pre-writing strokes usually develop in specific sequence. However, while there are general developmental milestones for each age, children will individually vary in the amount of time needed to pass through each stage.

Ages 1 and 2:
The child engages in random scribbles. As the child gets closer to age two, the scribble will often develop a very distinct direction, horizontal, diagonal or vertical. The child is imitating or reproducing a form after watching someone else.

Ages 2 and 3:
The child copies vertical and horizontal lines. As the child approaches age three, circles may also be copied.

Age 3 and 4:
The child can imitate and then copy a cross or a plus sign. By the age of four, the child may be able to imitate and then copy a square.

Age 5:
The child can imitate and copy a triangle. Once this is clearly established, children are able to write letters.

Tips to improve handwriting
1. Provide the right ‘sensory diet’ to allow the child to be ‘ready’ to write.

2. It is ideal to address all of the seven sensory areas, but you can select any one activity at a time. This might be as simple as chewing gum, sucking on a sour candy or eating a crunchy snack, playing with Thera-putty or play dough, using a vibrator on joints of fingers, wrists, elbows and shoulders, or cutting activities.

3. Some children work best after intense physical activity such as jumping, bouncing on a gymnastic ball, running, and negotiating an obstacle path.

4. There is a need to notice the times and activities which helps the child to increase attention and concentration.

5. Use a pencil gripper to increase the surface of the writing tool for better pencil grasp and control.

6. Begin with large letters on a vertical chalkboard then decrease the size of letters.

7. Use lined paper and guide the child to write on the line as soon as the child starts to write letters.

8. For ‘Washington movement grasp’ (i.e. when the child moves the entire arm when s/he writes and doesn’t bend the wrist), guide the child to write while lying on the stomach on the floor or write on a vertical surface (slant board, notebook). You can also use sandpaper or a felt buddy (pencil or pen with textured material wrapped around).

9. When the child does not leave spaces between words then practice handwriting by pasting stickers between each word on the first row, and then have child follow the pattern of writing in the following lines. One can also use an inkpad to put a two-fingerprint space between each word.

10. For macrographia (writing large-sized letters) guide the child to write the missing letter between two letters, e.g. c_t for cat, b_t for bat.

11. For children who write with all four fingers extended, a good exercise for stabilising the hand would involve having the child hold a small piece of sponge in the last two fingers while writing.

12. When the child uses too much pressure while writing, use a mechanical pencil. Also use grippers on pens and pencils.

13. When the child uses too little pressure when writing, then have the child use a weighted pencil. Make dots on card board and ask the child to pierce each dot with a pencil. Practice joining dots and targeted worksheets (as rat to cheese, monkey to banana with joining dots).

14. Improper posture needs to be corrected. Proper table height is important. If the child's feet barely touches the floor, you could place a stool under the feet to help 'ground' the child.

15. Keep the amount of writing to a minimum until the child's skills improve.

16. Provide immediate and proper feedback during work time. Involve the child in checking mistakes; checking games can be very motivating. You can also incorporate points or a reward system.

17. Recognition of letters and words is important and should be emphasised during writing sessions.

18. Keep practice sessions fun! Play letter games*, word or spelling list games. Use different colour markers for writing the letters.

**The next issue of Autism Network will carry examples of letter and word games*

(...cont from page 4)

which can be done by providing appropriate equipment and environmental modifications that accommodate their needs.

IN contrast to teens engaging in sensory seeking activities, there may be teens who avoid social situations, limit social participation and withdraw sometimes to the point of isolation. It is possible that these behaviours are related to increased sensitivity to sensations. The teen's nervous system may perceiving typical levels of sensory input as threatening.

SENSORY integrative therapy can teach relaxing and calming activities, gradual desensitisation to stimuli, and coping strategies, that can help the adolescent achieve success in daily activities

BOOK REVIEWS by T.N. Baba

1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorder

By Ellen Notbohm and Veronica Zysk

Publisher: FUTURE HORIZONS Inc Arlington, Texas, USA. (First Edition, 2004)

Ten Things Every Child with Autism Wishes you Knew

By Ellen Notbohm

Publisher: FUTURE HORIZONS, Arlington, Texas, USA. (First Edition, 2005).

Veronica Zysk is an autism professional of long standing who has headed a national autism organization. She is currently the Managing Editor of the Asperger's Digest as well as a book editor with Future Horizons Inc. Ellen Notbohm, on the other hand is a parent, a communication consultant and a freelance writer. Though they live in different parts of the same continent, they came in contact with each other when Ellen submitted an article for Asperger's Digest.

THIS contact grew over a period of exchange of thoughts and ideas, which ultimately culminated in the first book under review: '1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders'; co-authored by a parent who is not a professional and a professional who is not a parent. The book was the winner of Learning Magazine's Teachers Choice Awards 2006.

THE book is organized into seven chapters. The first six deal with the areas of Sensory Integration, Communication and Language, Behaviour, Daily Living Skills, Social Skills, and Teaching and Education. In each of these chapters the topic and underlying challenges are explained in a brief, simple style and then the authors go on to explain different strategies for different situations. Although some of the ideas may not be applicable to the local environment here in our country, many of them are doable or can be adapted to our conditions. They also inspire you to think and come out with your own ideas. Each of us have a creative core, and the ideas in the book provide that little nudge to bring it to the surface.

THE final chapter deals with Special Education Laws in the United States and we can draw from these laws for changing legislation in India. The rights of the special educators enumerated in this chapter is indicative of the value placed on special educators in their society.

THE ideas given in this book have come not only from the authors but also from many teachers, professionals and parents, some of whom have written articles, books or presented papers at different forums. The book is a useful reference and can be used by everyone who comes in contact with the child. The ideas are presented in a very user-friendly language and explained in easy to follow steps. This is a book one would want to keep readily available to read often to understand these ideas and also refer to them when the need arises.

THE second book **Ten Things Every Child with Autism Wishes you Knew** is authored by Notbohm alone, and is the result of her experiences of bringing up two children with autism. There have been many books and articles written by parents and professionals on the subject, but Ellen has been able to present her story in a lucid, crisp style with which many readers will find themselves eminently comfortable. What makes this book unique is that the author presents the everyday challenges encountered by parents who have children with autism from the point of view of the child with autism. Both parents and professionals will easily relate to the situations described and will benefit by the wealth of information on addressing these. The book progresses in a logical fashion, in a series of successive steps presented with a mix of humour and compassion. It reiterates the truism that a child with autism is a child first and a person with autism later. After completing the book the reader will have a better understanding of the child with autism, the child's needs, reasons behind certain behaviors; and this will help immensely with better handling of the challenges associated with raising an autistic child, particularly in the areas of communication, living skills and social interaction. One of the most important chapters in the book deals with 'Meltdowns', which is a common challenge for any parent of an Autistic child. The author explains the use of Functional Behavior Analysis, and Antecedent, Behavior, Consequence (ABC) in simple, easy to understand language. She also logically explains the need to 'Redirect the child to appropriate replacement Behavior'. The emphasis is clearly on fulfilling the underlying need rather than just extinguishing the inappropriate behavior. Quite the most moving chapter in the book is 'Love me unconditionally'.

READING the book and especially this chapter will move one to tears. After the tears are shed, though, we realize that it is time to assimilate the wisdom and gift of understanding the mind and hearts of children living with Autism, the message that is laid out so powerfully in the book. The author ends the book with a 'Foreword' where she narrates her meeting with Laurie, the psychic, and discussions of 'Past Life Regression' something that many readers in India with a familiarity to 'Karma', 'Past Lives' and 'Reincarnation', can relate to.In conclusion, I would emphatically recommend this very useful handbook to parents, professionals and teachers who deal with children with autism.

Research Assistants

Required Immediately

Looking for motivated ***post graduates*** *(preferably in psychology)* interested in research on Autism to join an international project studying the prevalence of Autism in India

The position will be based in Delhi, will run for *one year* and will involve training in and administering of screening and diagnostic tools for 4-7 year old children in various city schools. At the end of first year, there will be an option to continue the position for another two years.

The post is full-time, begins immediately, and will involve travelling within Delhi as well as maintaining a central online database of responses.

Excellent language, communication and computer skills are mandatory. Previous experience with children with autism will be an added advantage.

Remuneration: Between **Rs 9,000/-** to **12,000/-** per month based on qualifications and experience. Increments subject to performance.

For further queries contact:
Dr Nidhi Singhal, +91 98113 32254
Email: positions.afa@gmail.com

वस्तुओं की भाषा

लेखक – थीओ पीटर्ज़

उर्मिला तनेजा

यह तीस साल पहले की बात है और मेरे अनुभव की एक आटिस्टक बच्चे के साथ। डोनलड को आटिज्म के साथ विकासात्मक डिलेय भी था। मैंने उसके बैग के साथ एक सुन्दर क्रिया (एकटीविटी) बनाई। एक्टीविटी के शुरू होने के कुछ देर बार ही डोनलड को बहुत गुस्सा आ गया। मुझे डर था कि उसने मुझे पसन्द नहीं किया पर क्यों ? मुझे बाद में एहसास हुआ कि बैग को उसने घर जाने से सम्बन्धित माना। जब मैं उसे बैग दे रहा था तो उसे लगा कि मैं उसे घर जाने को कह रहा हूं। पर एक मिनट में उसने पाया कि मैं उसे झूठ बोल रहा था। क्योंकि उसे मेरी सुन्दर एक्टीविटी के लिए रूकना था।

मैंने अपनी इस मूर्ख गल्ती से बहुत कुछ सीखा। मैंने जाना कि वस्तु भी बोलती है और अब मुझे ऐसा लगता है कि यह एक अच्छा सबक है, उन सभी के लिए जो आटिज्म में कम्यूनिकेशन की प्रक्रिया से जुड़े हैं।

अभी हाल ही में एक प्रयोगात्मक ट्रेनिंग सैशन के दौरान मैंने देखा कि एक प्रतियोगी भी वहीं गलती दोहरा रहा है। वह दिन का कार्य समाप्त होने के बाद रोनेल्डो को जूते पहनने में मदद कर रहा था। एक व्यक्ति ने उसे जूते पहना कर उसे बताया है कि उसे घर जाना है पर वह अभी भी इंतजान कर रहा है। उसने अपने आप को बहुत जोर से मारना शुरू कर दिया । वह प्रतियोगी भी हैरान था कि रोनेल्डो ने ऐसा व्यवहार क्यों करना शुरू किया। यह एक बहुत जरूरी बात है जो सभी प्रोफेशनल को सीखनी चाहिए कि वस्तु आटिस्टक व्यक्ति के लिए कम्यूनिकेशन का माध्यम हो सकती है। एक और बात सीखने वाली है कि वस्तुओं के इस्तेमाल में भी अलग अलग भाशाएं होती हैं जैसे कि शब्दों को इस्तेमाल में होता है। उदाहरण के लिए वस्तु जिसको हम पीने के लिए इस्तेमाल करते हैं उसके लिए हमारे पास शब्द है 'ग्लास' हमारे पास ग्लास के लिए और शब्द भी है जैसे वेरे, बिच्चारे, पोहर, वासो, बीकर, पोटेरे इत्यादि। लेकिन ग्लासों का डिजाइन, रंग, सुगन्ध अलग हो सकता है और आटिस्टक व्यक्ति के लिए जिसको ग्लास के कानेस्पट की समझ नहीं है उसके लिए बहुत से शब्दों के प्रयोग का फर्क पड़ता है।

जूड़ी ने प्लेट को खाने से जोड़ा। उसे बहुत गर्व और खुशी होती थी अपनी इस समझ पर, यह उसका अर्थों की दुनिया में पहला कदम था। एक दिन जब उसे प्लेट दी गई और वह टेबल पर खाने के लिए बैठी उसने चिल्लाना शुरू कर दिया। एक और व्यावहाकिर समस्या।

जूड़ी की छोटी सी समझ में छूने का (टैक्चर) बहुत महत्व था इस दुनिया को समझने के लिए। उसने सीखा और पहचाना था कि कितना सुखद और अर्थपूर्ण होता है लकड़ी की प्लेट को छूना, खासतौर जब उसके तुरन्त बाद कुछ खाने को मिले। उसके बावजूद उस खास दिन एक नासमझ प्रोफेशनेल ने उसे प्लास्टिक की प्लेट खाने के प्रतीक के रूप में दी। जूडी ने सिर्फ एक ही चीज का मतलब जाना था। उसे लगा कि उसे धोखा दिया जा रहा है और उसने हिंसक रूप ले लिया।

प्रोफेशनल को ट्रेनिंग देते समय सबसे पहले जो चीज सिखानी चाहिए, वह यह है कि व्यावहारिक समस्या कई कारणों से हो सकती है किसी तनाव की वजह से, कुछ कम्यूनिकेशन न कर पाने की वजह से, कुछ बताने के लगातार किये गये प्रयासों से जिसके लिए उनके पास न कोई शब्द है और न ही कोई और माध्यम। हमारा प्रयास हमेशा यह होना चाहिए कि जो व्यवहार व्यक्ति कर रहा है उससे वह हमें क्या बताना चाहता है ? क्या उसका तरीका उसकी सोच से संबंधित है ? उसको क्या अलग समझा आया है ? क्या हम कभी नहीं समझ पायेंगे कि कैसे अपनी इच्छाएं दूसरे तरीके से उसे पहुंचाएं । उस तरीके से जो सिर्फ उसी के लिए ही, चाहे वह लिखे शब्द हो या फिर तस्वीर या फिर कोई वस्तु।

कम या ज्यादा कीमत का प्रतीक, वस्तुओं का इस्तेमाल एक कम्युनिकेशन का माध्यम बनाने में एक अजीब बात है या यह कहे कि यह हमारे दिमाग की अजीब सोच है। अक्सर मैंने यह देखा है कि प्रोफेशनल जब उन लोंगों की मदद करते हैं जो बोल नहीं सकते, अपने आप ही तस्वीर या पिक्चर इस्तेमाल करने की सोच लेते हैं जैसे वस्तुओं की कोई कीमत ही नहीं। मेरा मानना है कि एक कीमत जो आटिस्म से प्रभावित विद्यार्थी को ठीक होने के लिए चुकानी पड़ती है, वह यह है कि हम सभी उसे कम्यूनिकेशन और शिक्षा सिखाने के लिए सबसे ऊंचे प्रतीक वाले स्तर को उद्देश्य बनाते हैं और यह हमारे लिए जरूरी है कि हम उनके लिए सबसे ऊंचा स्वतंत्र उद्देश्य चुनें। अक्सर यह भी देखा गया है कि हम यह मानते हैं कि जिस तरह हम सोचते हैं वही सही तरीका है, और वही एक तरीका है।

यह भी जरूरी है कि हमें यह अहसास होना चाहिए कि वस्तुओं का प्रयोग बातचीत में जितना हम सोचते हैं, उससे कहीं ज्यादा करते हैं। मैंने घड़ी दिखाई जाने का समय है। मैंने ग्लास दिखाया ''चलो कुछ पियें'' मैंने कार की चाबी दिखाई ''हमें जाना है'' इत्यादि। और वस्तुओं का इस्तमेला बातचीत के लिए और भी जरूरी हो जाता है। जब हम बिना किसी परिचय या आरियेंटेशन के एक दूसरे कल्चर (अलग रहन सहन) का सामना करते हैं इसी तरह जिन सिनक्लेर (1992) अपने आटिस्म के अनुभव बयान करते हैं।

आप फ्लेडर में हैं और मैं चार अलग तरीकों से आपसे बातचीत करता हूं। कौन सा बातचीत का माध्यम आपके लिए समझने में सबसे आसान होगा ?

अ बोला हुआ मैसेज – यहां छपा नहीं है क्योंकि बोले हुए शब्द दिखाई नहीं देते।
अ बेला हुआ मैसेज, लिखे हुए मैसेज के साथ
अ विल्ट गी मीट मी मीं कोमेन इटन ?
अ बोला हुआ मैसेज प्लेट की तस्वीर के साथ
अ बोल हुआ मैसेज असली प्लेट के साथ
अ सबने बोला कि जो मेसेज या बातचीत एक वस्तु के साथ बोला जाये वह समझने में आसान होता है।

फिर भी सही समझ न होने के कारण हम आटिस्म से प्रभावित बच्चों को जिनको कम्यूनिकेशन की कमी है वस्तुओं के स्तर को अपनाने नहीं देते। दुनिया के चिन्हों (सिम्बल) को अपनाना मानव दुनिया को अपनाने के बराबर है।

जितना हम ज्यादा कल्पना करने की कोशिश करें एक आटिस्टक और गम्भीर डेवलपमेंट डिलेय व्यक्ति के साथ उतना ज्यादा हमें अपनी कमियों का पता चलेगा। फिलोस्फर ने कहा है कि अर्थों की दुनिया में दाखिल होने का मतलब है मानव विकास की ओर बढ़ना। क्या ऐसा संभव है कि हमारे कुछ लोग अभी भी बिना अर्थ की दुनिया में रहते हैं जहां पर धारणा एक धारणा ही रह जाती है और एक सीमित जानकारी से ज्यादा कुछ नहीं। इस तरह की दुनिया में रहने का अर्थ है कि सभी कुछ संजोग द्वारा कब्जा किया हुआ है जहां पर एक प्राणी बिना कुछ सोचे चीजों को किये जा रहा है। इस तरह की जिन्दगी अपने आसपास के वातावरण पर बिना किसी अधिकार के होगी और यह दूसरे पर मार्गदर्शन और सुरक्षा के लिए आश्रित बना देगी।

साफ तौर पर इस तरह के व्यक्तियों और मेरे ख्याल से कुछ आटिस्म से प्रभावित व्यक्ति अपने आपको इस स्थिति में पाते हैं, इनको हमारे सावधान और जिम्मेवारी की अधिक जरूरत है। यह बात शुरूआत से ही साफ होनी चाहिए कि हमारे शब्दों के अर्थों की शिक्षा दिमाग की कार्यक्षमता के अनुसार होनी चाहिए ताकि हमारी इच्छाओं के अनुसार। मजबूत व्यक्ति को कमजोर के अनुसार सहारा देना चाहिए नाकि कमजोर को मजबूत के अनुकूल होना चाहिए।

यह सबको पता है कि दिमाग के दो हिस्से होते हैं एक ब्रांयाँ और एक दांयाँ और दोनों हिस्से कुछ अलग तरह के काम करने में सक्षम होते हैं। उदाहरण के लिए दिमाग बांया हिस्सा स्पीच (हमीर बोलचाल) उत्पन्न करता है और दांया बाकि के वातावरण को समझाता है। यह भी सबको कम पता है कि दोनों हिस्सों का सूचना को समझने का तरीका अलग होता है। दांया हिस्सा धारणाओं को समझने में माहिर होता है और बांया चीजों को समझने में (कामस्पेट) माहिर होता है।

गजीनीगा (1970) ने इसका अच्छा और सरल उदाहरण दिया है। आपके पास सेब और संतरा है। दिमाग के दांये हिस्से के लिए वह एक जैसे है क्योंकि दोनों गोल है। एक धारणा के आगे नहीं जा सकते तुमने फौरन देखा कि दोनों गोल है। उनकी गोलाई हमें नहीं नापनी। यह सूचना है जो अपने आप बोल रही है। दिमाग के बायें हिस्से के लिए सेब और संतरा एक जैसे हैं क्योंकि दोनों फल है। उनकी फल होना अपने आप नहीं बोल रहा यह हमने विश्लेषण किया है। यह सूचना ज्यादा विस्तृत है। इसके लिए हमें सूचना के लिटरल अर्थ से ऊपर उठना पड़ेगा। बोले हुए शब्दों को समझना और सामाजिक व्यवहार को समझना बांये दिगाम का काम है।

अब ऐसा लग रहा है कि आटिस्म से प्रभावित व्यक्ति को उसके दायें दिमाग की वजह से हम काफी कम्यूनिकेटिव और सामाजिक जानकारी से भरपूर मानते हैं जितना कि उन्हें अपनी विकास की उम्र में होना चाहिए।

कम्यूनिकेटिव और सामाजिक प्रक्रियाओं का असली मतलब समझना उतना आसान नहीं है जितना हम सोचते हे। और खासतौर पर जब आटिस्म से प्रभावित व्यक्ति की सोच धारणाओं और सीमित अर्थों से हावी है। इसीलिए हमें कही हुई बातों का असर ज्यादा देर तक रहता है (लिटरल मीनिंग) उस बात को असली अर्थ के बजाए– हैपे 1995, जोरडलन 1996, पीटर्स 1997, इन सब बातों का कम्यूनिकेशन और शिक्षा पर बहुत गहरा प्रभाव रहता है।

मेरा अनुभव कहता है कि वस्तुओं और कही बातों का सही अर्थ्ज्ञ जानने की क्षमता आटिस्म से प्रभावित व्यक्ति में बहुत कम विकसित होती है जितना उनका वास्तविक विकास होना चाहिए। दो उदाहरण इस बात को साबित करते हैं –

1. मैं छः साल के एक आटिस्टक लड़के को जानता हूँ। उसका नाम टॉम है। उसका विकास दो साल की उम्र का है और उसे स्पीच के निराकार अर्थों का नहीं पता। उसे नहीं समझ आता कि जब मम्मी उसे जूते दिखा रही है तो उसका क्या अर्थ है।
2. मैं किट्टी को जानता हूं। वह एक बड़ी वयस्क आटिस्टक लड़की है। उसका विकास ढाई साल का है। उसे तस्वीर की कोई समझ नहीं है। जब मैं पहली बार उसे मिला उसे समझ नहीं आया कि वह अब खाने जा रही है क्योंकि उसकी आया उसे चम्मच दिखा रही है। वस्तओं का अर्थ समझने की बजाए वह उन वस्तुओं को एक खास मतलब से जोड़ लेती थी। चम्मच, फोर्क और प्लेट को रसोई में रहना चाहिए । उसे कहीं भी चम्मच गिरा मिलता तो वह चिल्लाने लगती है। उसे उस वस्तु से संबंधित सिर्फ एक बात समझ आई थी।

किसी भी वस्तु को दूसरे नजरिये से देखना उसके लिए एक भयानक सपने के समान था। टॉम और किट्टी दोनों को तस्वीर या वस्तुओं के प्रयोग से ऊपर नहीं समझ आता। उनके प्रतीकों को समझना होगा और बाद में उन्हें कम्यूनिकेशन में इस्तेमाल करना सिखाना होगा। अगर हम निराकारात्मक स्तर को नीचा रखने के लिए जागरूक रहेंगे तो हम उनके सामान्य विकास की शिक्षा उपलब्ध करा पायेंगे। जो शिक्षा हम दे रहे हैं वह चाहे हमारी उम्मीदों और इच्छाओं को पूरा कर दे पर वह टॉम और किट्टी की समझ से काफी नीचे है।

मैं अब एक अलग तरीके से इस भाग का नतीजा निकालने की कोशिश करता हूँ । आटिस्म से प्रभावित लोग उन चीजों को समझने में काफी आशक्त होते हैं जो ठोस है और दिखाई देती है। इसके अलावा आटिस्टक लोग उन चीजों में कमजोर होते हैं जो कि दिखाई नहीं दे रही और वक्त के अनुसार बदल रही है। हमारे पुराने शिक्षा के तरीके में हम इसी तरह की चीजों को शामिल करते थे जो कि एब्सट्रेक्ट हो। यह कहने की बजाए टॉम और किट्टी एब्सट्रेक्ट सूचना में कमजोर है और उन्हें वह सीखना चाहिए हम कहेंगे कि टॉम और किट्टी के पास अपनी ताकत है जिसे हम इस्तेमाल करेंगे उन्हें सिखाने के लिए तो हम एक अलग नजरिया विकसित करने की कोशिश करेंगे। आटिस्म से प्रभावित व्यक्तियों को सिखाने के लिए अपने एब्सट्रेक्ट न दिखाई देने वाले और लगातार बदलने वाले चीजों को हम ठोस, दिखाई देने वाले और स्थिर में बदलने की कोशिश करेंगे। यही इन्टीग्रेशन का वास्तविक अर्थ है– जहां ताकतवर और सक्षम कमजोर को अपनाता हैं।

कितना टी.वी. अच्छा टी.वी. होता है ?

एक प्रश्न जो अभिभावक अक्सर पूछते हैं :– मेरा बच्चा टी. वी. देखना बहुत पसन्द करता है; कितनी देर मैं उसे टी.वी. देखने दे सकती हूँ। यह एक कठिन प्रश्न है, जिसका कोई सीधा उत्तर नहीं है।

मता–पिता को स्वयं इस बात का निर्धारण करना होगा कि जो कार्यक्रम उनका बच्चा टी.वी. पर देखता है उसकी महत्वता क्या है। बच्चे टी.वी. के कार्यक्रमों द्वारा बहुत सीख सकते हैं परन्तु हर एक कार्यक्रम के विषय और सारांश बच्चे के लिए लाभदायक नहीं होते।

कुछ बच्चे छः से सात घण्टे टी.वी. देखते **हैं** और माता–पिता इसे अपने ऑटिस्टक बच्चे को व्यस्त रखने का साधन मानते हैं। कम्प्यूटर के साथ भी कुछ ऐसा ही होता है। बच्चे गाना, नाच या कार्टून अधिक देखते हैं। उन्हें ऐसे कार्यक्रम द्वारा रंग, गति और संगीत आकर्षित करते हैं। इन कार्यक्रम द्वारा बच्चा कुछ सीखता नहीं है।

यदि बच्चा टी.वी. देखता है तो ऐसा कार्यक्रम हो जिसके विषय से बच्चा कुछ सीख पाये। विषय प्रेरक होना चाहिए और बच्चे को कुछ सिखा पाये। प्रकशति, वाइल्ड–लाईफ पर आधारित कार्यक्रम बच्चों के लिए आनन्द और ज्ञान दोनों ही प्रदान करते हैं। कुछ बच्चे लगातार समाचार देखते रहते हैं। टी.वी. का समय माता–पिता को ऐसे अवसर दे सकता है जिनमें वह बच्चे के साथ बैठकर कम्यूनिकेशन कर सकते हैं। कम्प्यूटर एक ऐसा माध्यम है जिस पर बच्चा अच्छा नियंत्रण रख सकता है। बच्चे को पूर्वानुमान रहता है कि कम्प्यूटर पर हरकत करने से क्या होगा। इसलिए बहुत से बच्चे इसमें निपुण होते हैं। बच्चे अपने आपको सिखा लेते हैं कि कम्प्यूटर कैसे खोलना और चलाना है। यह वह बिना सिखाये कर लेते हैं।

कम्प्यूटर में बहुत अच्छे शैक्षिक कार्यक्रम प्राप्त हैं। इनका परिसर पर्यावरण से अंकों के ज्ञान, पढ़ना इत्यादि तक होता है। कई बच्चे यह विशय कम्प्यूटर द्वारा अच्छे सीखते हैं। यह आवश्यक है कि कम्प्यूटर का प्रयोग एक बढ़ते रहने वाले कार्यक्रम के रूप

में हो। एक खेल पर प्रवीणता प्राप्त होने पर अगला खेल सिखाना जरूरी होगा अन्यथा पहले खेल को लगातार रूढिबद्ध तरीके से खेलता रहेगा ओर उसके ध्यान को उस खेल से हटाना कठिन है।

क्योंकि कम्प्यूटर बौद्धिक कौशल के विकास में महत्व रखता है। माता–पिता बच्चे को घण्टों कम्प्यूटर पर लगे रहने देते हैं। याद रखें कि एक तरफ कम्प्यूटर हमारे बच्चों को बहुत कुछ सिखा सकते हैं तो दूसरी तरफ वह सामाजिक ज्ञान नहीं दे सकते। इसलिए लोगों के साथ सम्पर्क बनाना और चलाना आवश्यक है और इसके लिए अवसर बनाने चाहिए। घण्टों कम्प्यूटर पर लगे रहने से यह अवसर कम हो जाते हैं तो फिर वही सवाल ''कितना टी.वी. दिखया जाये ? हमें स्वयं निर्णय लेना होगा कि टी.वी./कम्प्यूटर की अवधि क्या होगी घण्टा दो घण्टा जो भी हो हमें दो बातों का ध्यान रखना होगा–

1. जो कार्यक्रम बच्चा देख रहा है उनसे वह कुछ सीखे। वह उसके बुद्धि विकास के लिए प्रेरक हो। यह कोर ऑबसेस न बनें।

2. टी.वी. या कम्प्यूटर पे काम करने से बच्चा सामाजिक आदान–प्रदान से वंचित न रहे। दोनों ही चीजें अच्छी हैं, यदि सही ढंग से प्रयोग करें तो उचित साधन हैं। यह किस प्रकार इस्तेमाल करें यह अभिभावक पर निर्भर हैं।

हेल्प लाईन

मेरे बेटे को ऑटिज्म है। अतः मैं दवा द्वारा आटिज्म के इलाज के बारे में जानना चाहता हूं। यह ज्ञात हुआ है कि थ्त।ग। ऑटिज्म के इजाज के लिए दवा की खोज कर रही है। क्या हम ऑटिज्म के इलाज अथवा ऑटिस्टिक व्यवहार में कुछ कमी की आशा कर सकते हैं ? क्या जीन/ क्रोमोजोमस पर अनुसंधान जारी है, जो हमें कुछ उम्मीद दे सके ?

काफी बड़ी संख्या में अनुसंधान/खोज की जा रही है, और इनमें से कुछ खोज दवा द्वारा ऑटिज्म के इलाज से सम्बंधित है । कुछ अनुसंधान विशिस्ट वैज्ञानिक तरीकों (प्रमाणों के उचित प्रस्तुतीकरण सही ऑकड़ो का संग्रह नियंत्रण समूह, प्लेसबोज आदि) का पालन करते है और कुछ नहीं भी । जीनेटिक्स के क्षेत्र में भी खोज जारी है । हालॉकि समय–समय पर मीडिया में किसी अनुसंधानकर्ता के इलाज खोज लेने की या फिर इलाज के बाजार में कल उपलब्ध होने को इंगित करती एक अदभुत उपलब्धि के बारे में रिपोर्टस् आते हैं, परंतु ये सच्चाई से ज्यादा पब्लिसिटी प्रोमोशन होते हैं। आज तक कई रोचक परीक्षण किए जा चुके हैं, परंतु कोई सीधा परिणाम नहीं मिला है और अब तक ऑटिज्म के इलाज के लिए कोई दवा नहीं है।

हालॉकि कुछ दवाईयाँ ऐसी है जो ऑटिज्म से ग्रसित व्यक्ति को शिक्षण या रोजमर्रा की जिंदगी जीने में बाधा पहूँचा सकनेवाले कुछ संबंधित व्यवहार या दशा जैसे अतिक्रियाशीलता, अत्यधिक ऑब्सेसवि व्यवहार, व्यग्रता आदि में लक्षणों पर आधारित सहायता के लिए दिए जा सकते हैं। यद्यपि कुछ दवाईयाँ काफी सहायक होती है, तथापि उनमें से ज्यादातर के विपरीत साइड इफेक्टस् होते हैं। अतः यह उपयुक्त होगा कि आप अपने डाक्टर या बच्चे के न्युरोलोजिस्ट/साईकिआट्रिस्ट/पिडियाट्रिशयन, जिन्हें ऑटिज्म से ग्रसित व्यक्ति के बारे में र्प्याप्त अनुभव हो, से विचार कर ले ताकि आपको दवाईयों के बारे में स्पष्ट स्थिति पता चल जाए।

हमारा फिर से कहना है कि अब तक कोई भी ऐसी दवा नहीं है जो ऑटिज्म के केन्द्रीय विषमताओं (कोर डिफेसेटिज/ केन्द्रीय कमीयों) का इलाज कर सके। परंतु ऑटिज्म से ग्रस्त सभी व्यक्ति सीखते और प्रगति कर सकते हैं, उनकी उम्र और ऑटिज्म की तीव्रता जैसी भी हो। कमी/क्षति के केन्द्रीय क्षेत्र, अर्थात् कम्युनीकेशन और सामाजिक समझ, को मुख्य रुप से ध्यान में रखते हुए व्यवहारिक सिद्धान्तो पर आधारित शिक्षा, ऑटिस्टीक व्यक्तियों के इलाज का सबसे प्रभावकारी और पूर्ण तरह प्रमाणित विकल्प है। बच्चे के साथ की जाने वाली कोई भी बात इस बात पर केन्द्रित होनी होगी कि वह परस्पर सामाजिक संबंध के कार्य मे रुचि ले सके और सामाजिक नियमों को समझ सके, तथा वह कम्युनिकेशन सीख सके। इसके साथ–साथ दिनचर्या रोजमर्रा के कार्यो/गतिविधियों पर भी ध्यान देना शिक्षा के तरीकों को वास्तविक और मूलभूत रखते हुए शिक्षण में अनुकूलता/स्थिरता/एक समानता और और स्पस्ट ढांचा होना चाहिए।

Autism is not Cancer

Professor Simon Baron-Cohen

Director, Autism Research Centre, Cambridge, UK

Research into the biomedical causes of autism spectrum conditions is moving forward at a tremendous pace, with new genes being associated with autism almost every month, and with a strong drive by scientists to find biological markers, perhaps to improve diagnosis, and to understand causes. On the BBC health website recently, I flagged up the need for the autism community (parents and professionals and those with the diagnosis) to be thinking ahead about how such research might be used, rather than just leaving it to the scientists.

OUR research at the Autism Research Centre (ARC) in Cambridge does focus on understanding possible biological causal factors but is not motivated by a desire to develop a prenatal test for screening. It is simply to increase our knowledge of how autism comes about.

IT is unfortunate that sometimes the popular press seizes on the opportunity to discuss such basic research into causes in terms of its implications for prenatal screening. This happened in the Guardian with our research into foetal testosterone, for example, despite the fact that the research we conducted was not a prenatal screening study and did not study diagnosed autism. (Both were errors in how the research was reported).

HOWEVER, we must realize that as science uncovers possible causes, this information may be picked up by drug companies or other researchers and used in ways that the original team did not envisage. If there was a prenatal test for autism (and there isn't one at present and there may not be one for several years), this could have one clear benefit, which is to bring forward the age at which diagnosis is possible, from the current average age of three years old. Knowing antenatally that your child might develop autism could mean that families could prepare, that proper support could be put in place, and that psychological therapies could be started at an earlier point (even from birth).

IF there was a prenatal test for autism, there might be some disadvantages: There might be eugenic selection against foetuses who might develop autism, and this is a form of discrimination against those who are not neurotypical. Some parents might opt for a termination because they think their child will not have a good quality of life, even though the child may in fact make a good adaptation and/or society could adapt to them. The genes for autism may be linked to the genes for talent (and by talent I don't just mean the musically or artistically or mathematically gifted, but even in those with apparent learning difficulties there may be an excellent memory, or excellent attention to detail and patterns, or an excellent ability to focus attention for long periods, or acute sensory hyper-sensitivity), such that eradicating the genes for autism may also eradicate the genes for these talents.

IF there was a prenatal test for autism, some parents will exercise their parental choice and opt for a termination, and this is within the law, and I support parents' freedom to choose or not choose to have a baby.

MY own view is that I think all foetuses – all people - have a right to life; that the value of a person's life cannot be judged by characteristics such as whether they have good or poor social skills, or whether they are talented or ordinary or have learning disabilities. Every individual is special, and while we are all different, no one is better or worse than any other and no one's right to life is greater or less than anyone else's. Some individuals may need more support than others, and it is a mark of a civilized community that we provide such support for those who need it. Finally, diversity is part of nature, including human beings, and there are many neurological sub-types that make up the spectrum of individual differences.

AUTISM is not like cancer, where there are fewer controversies surrounding whether one should select embryos who will never suffer from cancer. That is because autism is not a disease, and need not lead to suffering, and with enough accommodation by society, people with autism can be free of suffering. Autism itself is a wide spectrum, and many people with autism can make valued contributions. But even those who will remain dependent all their lives are either special to those who love them, or just intrinsically special.

I have a sister, Suzie, who is in her 40's, and has profound learning difficulties and physical disabilities. She is in a wheelchair, needs 24-hour nursing care, cannot feed herself, has almost no language, and probably has a lower level of psychological than a one-year-old. Yet she enjoys people, enjoys simple pleasures, and has a quality of life. She laughs, she cries, she sings, she jokes. My relationship with her is among the richest I enjoy. I am glad that she is alive and that she was not screened out of existence before birth and that my parents did not opt to terminate her life. People don't have to earn their right to life by having the skills to make a contribution. They have a right to life. Period.

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HELPLINE

Q My son, T, is 11 years old and has autism. He has been exhibiting a behaviour which occurs about four to five times a week, for the past four months, where he weeps and closes his ears, and hits and bites anyone who tries to pacify him. The intensity of the behaviour is severe. We are not too sure if this is a sensory problem or a challenging behaviour. We have consulted a paediatric neurologist and he says that there is nothing wrong with T's brain. Also, T has never complained of an ear pain.

A You have mentioned that when T is stressed, he starts weeping slowly and the intensity of his crying increases with time. He closes his ears during this time, starts jumping and asks you to close his ears keeping his hands on the ears. He also hits and bites anyone who tries to approach or pacify him during this time. The hitting and biting is very severe as is the intensity of his crying. When the behaviour is at its peak, you feel it's as if he cannot bear anything further and that unbearable vibrations are coming out of his ears.

You have also mentioned that the triggers to T's behaviour seem to be:
1) In situations that he may not like or want to be in
2) When there is an unexpected change
3) For reasons that you may not be able to understand.

We know that children with autism sense their world differently and may be sensitive to ordinary sounds that people without autism can deal with. So, it is possible that T is hypersensitive to sounds, that he finds some sounds difficult to deal with, especially if he also reacts adversely to loud sounds like that of the mixer grinder, the washing machine, traffic sounds, or any other sounds. If this is the case, we could use some strategies to desensitise him with regards to specific sounds and/ or sounds in general, by exposing him for very short periods to the sounds that he is uncomfortable, so that he can slowly get used to them. We could also teach him to cover his ears with his own hands (initially by physically guiding him to do so) when he hears sounds that he finds aversive.

I would also suggest that you consult an ENT specialist to rule out any ear infection.

However you have also mentioned some other definite triggers that may not be related to only auditory hyper sensitivity or to a medical issue. We may need to deal with these in a slightly different way.

1. For things that he does not want to do, try to find out what it is about that situation he doesn't like. If you can work around that aspect of the situation that he doesn't like, then you could try changing it, to begin with. And then slowly, introduce that 'unwanted' aspect of the situation in very small proportions and praise him a lot when he does it without displaying any difficult behaviours.

For instance, say you are working with T, and every time you introduce a jigsaw puzzle, T gets stressed. Is it because he has been doing jigsaw puzzles repeatedly for a long period of time? Are jigsaw puzzles difficult for him? Is it an activity that is not reinforcing in any way? In that case, to begin with, don't have him do a jigsaw puzzle at all for a few days. Then slowly re introduce a jigsaw puzzle, but start with a very easy one, maybe one with just 3 or 4 pieces, and reinforce and praise him a lot when he completes it. Slowly increase the number of pieces of the puzzle. And remember to always reinforce and praise him for this. This is just an example for you to be able to adapt to a relevant situation with T.

However, once you have introduced the puzzle, he has to complete it. If he starts weeping or hitting himself that should not lead to him escaping from the task as that would increase the occurrence of the behaviour as a means to escape from the task.

2. As we know, people with autism, find it difficult to deal with changes. So when you know that there is going to be a change, big or small, you could try to prepare T for these changes. Use visuals, objects, pictures, written words, whatever T may be comfortable with to help him understand the change better. Also you could use a visual schedule with him. These always help our children to understand and accept changes more easily.

3. When T is crying and closing his ears, I would suggest that you don't try to pacify him or give him any attention just at that point of time. Giving him attention at that

point of time may just reinforce the behaviour and not help reduce it. If he approaches you to close his ears, you could gently help him close his ears with his own hands and then move away from him.

I'd like to point out here, that when T closes his ears, it may be a coping strategy for him to deal with unexpected situations; he may just be trying to shut out all auditory stimuli because that helps him calm down. Or it may be a way of escaping from an activity that he does not want.

I would also suggest that you work intensively on his communication. If T is a verbal child, encourage his vocals. If he is not, you could try to introduce other modes of communication like Picture Exchange Communication System or signs or any other mode of Alternative and Augmentative communication

Q I am a non-resident Indian. Family circumstances have compelled me to initiate an extensive research into the laws governing disabled individuals in India. My particular interest lies in the National Trust Act of 1999. I understand that there is a Board of Trustees formed under the Act with their headquarters in New Delhi, and also local level committees. I would greatly appreciate your assistance in getting the postal address of the Board as well as the local level committee for Mumbai. I also understand that the local committee meets once every three months. Therefore, any advice, suggestions or guidance as to the best time (month) to apply for removal of a guardian would be welcome.

A Contact details of the National Trust:

16-B Bada Bazar Marg, Old Rajendra Nagar,
New Delhi- 110060

Tel: 011 43187878
Email: nationaltrust@nic.in

There will be several LLCs in Mumbai. You could write to the Maharashtra State Nodal Agency for information on the LLCs. Contact details of the Maharashtra State Nodal Agency:

The Research Society for the Care, Treatment, and
Training of Children in need of Special Care,
Sewri Hill, Sewri Road, Op. Abhyuday Nagar, Building
No.12, Near Kalachowki Police Station, Sewri,
Mumbai-400033

Tel: 022 27401231

Regarding removal of a guardian, to the best of our knowledge there is no fixed month for doing this. Action can be initiated at any time. You would be well advised to approach the Maharashtra State Nodal Agency.

Q My brother is 11 years old. He has a diagnosis is PDD-NOS. H seems to be facing some issues related to puberty. He may take off his pants or sometimes he keeps them on and does things that don't look good in front of others. He does this mostly whilst watching T.V and sometimes when he is alone. He has not yet done this in front of everyone but when my family members are not around he does it and when we come he continues doing it .Whenever I see him doing that I tell him to go to the toilet. I am just scared what if he will do this in front of others any day. I keep telling him that one should hide one's private part from others even from me, but he forgets it. I'm looking for an appropriate way to teach him this. Please help.

A Thank you for your mail and sharing your concerns about your brother with us.

As you may be aware, most people with Autism Spectrum Disorders like predictability and routine; dislike, and sometimes, even resist change. Given the overwhelming changes that puberty brings with it, with respect to changes in the body, psychological changes, changes in what the environment now expects from young people with ASD , adolescence can be a rather challenging phase for most people with Autism, perhaps more so than their neurotypical peers.

You have mentioned that there are times that your brother takes of his pants and does things that may not look good in front of people. I assume you mean that he touches and rubs his private parts. Touching and rubbing one's private parts can be a natural urge for adolescents, both amongst neurotypical teenagers, as well as those on the autistic spectrum. So we may need to acknowledge our children's needs, and teach them appropriate ways to fulfilling those needs, just as we do with all their other needs. We can try to accept the fact that this is an inevitable and natural urge, and it may not be possible to stop it by our wishing it away. What we need to teach the child that it is ok to 'touch themselves', but also specify where and when it can be done. We could maybe have a term like 'private time', for it.

Privacy is a rather abstract social concept. People without autism often learn it as a natural part of their growing up.

However, people with autism, given their impairment in the understanding of social norms and rules, may need to be taught 'privacy' in more concrete and specific ways, so that it is easier for them to understand it. The concept of privacy is not only applicable to touching oneself, but also includes other 'private acts' like bathing, going to the toilet and dressing.

Here are some tips on how you may teach the concept of privacy to your brother. This needs to be taught consistently at all times and in all environments.

Children with autism need to learn right from the beginning what private parts are. So when your brother is learning the 'labels' for body parts, those parts of his body could also be labelled as his 'private parts'.

We need to teach them that acts like dressing, being naked, touching one's private parts are all 'private acts' and are to be done 'in private'.

You may need to clearly demarcate where 'in private' is. It could a particular room in the house, your brother's own bedroom if he has one, and the toilet.

Use clear visuals cues. For example you could have the word 'Private' written in bold letters on the doors of the private areas, (both on the front and at the back) or use a particular colour code to denote 'private'.

Whenever your brother is in the toilet, or in his room changing or touching himself, make sure that the door is closed, and whilst you close the door, you could say "Private. Let's close the door"

Let there be only a few specific people who see your brother without clothes on, for instance when helping him to bathe or dress himself.

Every time you see your brother touching himself in any area that is not his private area, gently guide him to his private area, say 'In private' and close the door.

It is extremely important to remain comfortable whilst doing this. Otherwise, what begins as a natural physical urge can turn into an attention seeking behaviour, and dealing with that can turn out to be difficult.

You could also use a social story with your brother that you could read out to him two or three times in the day. Here is an example of a story that you can use:

Sometimes I want to touch myself
That is okay.
I can do it in private.
Private means my room / bathroom
After I have finished I can wash my hands.

Q I am a 26 year old woman. My brother has mild autism. I have a little boy who is two, and does not appear to have autism; however my husband and I would like to have another child. We are worried that with having one child it would be 'pushing it' to try and have another 'normal' child. Am I more likely to have an autistic child because my brother is autistic?
Have there been any studies regarding this? I do know that if you have one child with autism, there is a higher likelihood of having other children with autism, but is this the same with siblings?

A Recent research studies have identified genes as ONE of the causes of autism and multiple genes and chromosomal regions are suspected to be involved.

Having a member of a family with autism implies a genetic predisposition to having a child with autism. According to recent research, the probability is of course greatest amongst monozygotic (identical) twins. The dizygotic (fraternal) twin of a patient, who shares 50% of the genes, has approximately the same probability as a sibling, about 4.5%. Having a relative with autism, decreases the probability further. As yet, however, there are no medical tests available to determine whether or not a to-be-born child will in fact have autism.

The fact that many children with autism have no identified family member with autism or any other psychiatric or neurological condition also points to evidence that inheritance is not the only cause of autism. Role of other factors such as prenatal, postnatal, medication, environment etc is also being researched but no conclusive results have yet been obtained.

Several articles on these subjects have been published in scientific journals across the globe and a lot of these are also available online.

Since you are in the UK it might be useful to contact the National Autistic Society (NAS), UK for more information. You may also want to consult a genetic counsellor available in the genetics department of a hospital in your city. They may suggest genetic tests to rule out some of the genetic causes of autism.

LETTERS

Aryan, our son, is a three year old who has autism. He is a student of the Open Door School. Usually, it needs a patient, systematic and tailor made-approach to get children with autism learn most things, whether it is the alphabet, numbers, self help skills, or so on. The story of how Aryan learnt his alphabet is quite interesting and surprising and in fact we were amazed the day we came to know that Aryan can recognize the alphabet and numbers.

Since his childhood, Aryan was fond of paper and pencil and even today his most favourite leisure activity is scribbling or writing on a paper with a pencil. Initially he used to only scribble on paper, but later on when he learned to say the alphabet and numbers, he started insisting that all family members, whenever available, write the alphabet and numbers on paper. Initially, whenever we wrote a word we would spell out the word for Aryan, and Aryan would repeat what we had spelt. Later , Aryan, would spell out words (the ones that he had heard us spell out earlier) and we would write the letters for him. Aryan grew to like this activity so much that we would be doing this with him many times a day. Our only intention in writing the letters that Aryan spelt out was to keep him occupied and happy. Because we were quite certain that he was just repeating the letters by rote and not because he recognized the alphabet.

One day we went shopping and bought a bottle of Junior Horlicks. We came back and placed the bottle of Junior Horlicks on the kitchen counter and Aryan started reading all the letters one by one as in J, U, N, I, O, R etc. Initially we thought that he was not really recognising the letters but that he had merely learnt the sequence of letters in Junior Horlicks and was repeating that. But later on when we tested him on many different words then we could believe that he is able to recognize the different letters of the alphabet. In the same way by testing we could know that he can recognize numbers also.

Earlier we had been writing only capital letters and so Aryan could recognize only capital letters. He could recognize only those lower case letters which resembles capital letters. Now when he asked us to write, we started writing in small letters and now Aryan is able to recognize both, small and capital letters as well as his numbers.

RAGHVENDRA SHRIVASTAVA
DELHI

Many, many thanks to you and all staff members of 'Autism Network', for publishing our son Abhishek's art and craft on the last two issues (December '08 & April '09). It encourages not only us but also the other parents to explore the hidden talent of their children with autism.

We are also thankful to Ms Indrani Basu, especially for her inspiration and making a nice bridge between us. Our best wishes to all of you.

SOMA & ARUN SARKAR
KOLKATA

I am a senior divisional mechanical engineer posted at Ratlam in MP. My son, aged five and a half years has recently been diagnosed with mild autism. He is currently studying in LKG in a normal school. He is a very calm, co-operative, and active child. He has a special interest in music. Except for his delayed speech, his grasping power and learning ability is almost normal.

I have come to know about your organization Action For Autism (AFA), through the Internet. Myself and my wife attended the three-day extended programme for parents, at AFA, from 16th to 18th March under the guidance of Sudhanshu Grover, Special Educator. This three-day programme was a real eye-opener for us. The organization, reception staff, special educators, infrastructure facilities and library are really excellent. The reading material available in the library is beyond imagination.

Your effort to develop the National Center for Autism is really appreciable since there is so little awareness about autism in India in the medical field. Although I was in regular touch with a family paediatrician, my child could not be diagnosed for autism until I came across the Autism poster in the Outlook magazine.

The National Trust awareness campaign in the Outlook which spoke about the symptoms of autism helped me realize that my child may have autism which was finally confirmed by a clinical psychologist and paediatric neurologist at CHL Apollo, Indore.

It is unfortunate that early detection could not be taken in my case but I want to spend each and every moment for training and development of my son. Although I am a mechanical engineer, I have a great interest in human psychology and behaviour. I intend to enter into the kingdom of an autistic child.

M KUMAR
RATLAM MP

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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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