

autism network

APRIL 2011

VOL 6 ISSUE 1

Action For Autism is a registered, non-profit, national parent organisation. Autism Network is published by Action For Autism to provide information on education, therapy, care, and to provide interaction for families and professionals across the country.

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

Autism Network does not accept advertisements. Expenses are met through memberships, donations and sponsorships, from our readers, friends and well wishers. This journal is for free distribution.

INFORMATION

For information on receiving the Autism Network write to:
Sector 5, Jasola Vihar, Behind Sai Niketan, Opp. Gate 6
Sector 8, SFS Flats, New Delhi - 110025. Tel: 40540991/2

YOUR CONTRIBUTIONS

Do you have any comments, suggestions to offer? Information and experience to share? We look forward to our readers' participation. Send letters, articles, illustrations to:
The Editor, Autism Network at the above given address or
E-mail: actionforautism@gmail.com

Editor: Merry Barua

Editorial Board: Indrani Basu, Shikha Bhardwaj, Indu Chaswal, Nidhi Singhal, Ann Varavakula,

Design & Production: Bindu Badshah, Sudhir Pillai

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

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

Helpline Email: helpline.afa@gmail.com

Cover Illustration

A Happy Lion
by Srikar CV, 4 years, Bangalore

WISHLIST !

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

Stationery:

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

Volunteers :

For yoga, art & craft , music, respite care

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

- AFA: 40540991/2 • Reeta: 9811103702

C O N T E N T S

Page One	1
The World of Clinical Music Therapy	2
A Nation of Autism	6
Autism Spectrum Disorder Fellowship, UK	7
Deaf Persons in India to get	
Driving Licence	7
Review: 'Tasks Galore Series'	8
Upcoming Workshops at a Glance	9
To Tell or Not To Tell (H)	10
A Cherished Moment (H)	14
Helpline	15
WAAD Celebrations in India	
and the Sub Continent	17

PAGE ONE

As we enter the second decade of the century, it is clear that disability has made significant inroads into public consciousness. This is evident in policy, popular culture, and to an extent the social environment as well. In addition the ratification by our country of the UN Convention for the Rights of Persons with Disabilities has put pressure on the government to bring about much needed change; and that is leading to measures – excruciatingly slow at times – to factor disability into policy issues. So the decade also begins with the drafting of a new law on disability that would be in harmony with the CRPD and that will address the rights of all persons with all disabilities.

However, in all this, as often happens, developmental disabilities willy nilly take a back seat. Portrayal of disability in popular media tends to play to the gallery. Hence it is all about: *disability hai magar tez hai; intelligent mind in a disobedient body; disabled yet top of the class*; and so on. Like shown in the otherwise lovely film *Tare Zameen Par*, for people to accept one's disability one has to excel in something. Or else be super intelligent and come out top in everything: what we call the Stephen Hawkins syndrome. And we in the disability sector inadvertently contribute to this representation. In addition, one has to 'look' disabled, be visibly disabled, to really receive accommodations. If you have an invisible condition no matter how complex and severely affecting functioning – and what better fits that description than autism – then it's a different matter altogether. It is presumed that if one does not 'look' sufficiently disabled, one's needs cannot be that intense. Any attempt at forefronting this marginalisation is labelled 'divisive'.

In this populist discourse on disability the community has to be vigilant in ensuring a rightful place for persons with combined intellectual and functional impairments. There is a deep dichotomy here. On the one hand we state that everyone has value. On the other you have to be outstanding in some sphere – preferably with intellectual capacity - in order to be considered to really have value. A teenager who has significant intellectual impairment and functions at the level of a two year old, and who struggles to learn and cope and live, is seen as a problem who messes up the popular projection of how well all persons with disability can function in society, how easily they can be placed in open employment, with what felicity each can be placed in an inclusive classroom – with a support who does a little bit of orientation and goes off satisfied into the wild blue yonder to orient other schools. These people are

a bit of a nuisance who are best spoken of only at certain restricted platforms. After all, the world loves a winner; so the world must see the disabled as better if not equal performers at everything.

Thereby creating in society an insidious, easy-recall image of disability that excludes those with intellectual as well as functional impairments.

We all agree that nothing must happen for persons with disabilities without them. "Nothing for us without us". But what about those who cannot articulate what is 'for us'? Or in this age of political correctness– those who 'need support' to speak for themselves? If policy making bodies must only have persons with disabilities, then who will speak for those with severe intellectual as well as functional impairments? Can those who have the ability to communicate their thoughts, emotions, desires cogently, despite severe physical and sensory impairments really represent the needs of those who cannot? And do so better than parents who live with and support their children every day? Of course one can place a token person with intellectual and functional disability who is not really able to comprehend the complexities of a discussion on a policy making body, to satisfy a quota of 'persons with disability'. But are we then not slipping into a form of reverse discrimination?

There is a disturbing increase in a tendency to simplify disability, to see 'disability' as one homogenous entity, so that everyone fits into neat pat little boxes. This promotes the myth that you just need a little tweaking of resources and all children will learn together in one happy, joyous group; just a little tweaking of workplaces and all persons with disability will be in open employment happily earning a living. If only it were that simple. Everyone wants to make the right noises; and anyone who disturbs this nice order of universally competent, achieving, successful, persons with disability is seen as a bit of a nuisance. We want persons with disability – all disabilities – find their rightful place in the sun. But let's not allow our wants take precedence over wants of the person with disability. And let us remember that the wants of persons of disabilities are as diverse, as disability is heterogeneous.

We are ostensibly creating a better world for persons with disabilities. But do those with severe intellectual as well as functional impairment have a place in this brave new world?

The World of Clinical Music Therapy

Mike Hewitt

Introduction to Music Therapy

As a preamble I feel it is important to write about the modern Art and Science that is Clinical Music Therapy, as opposed to the ancient healing Art of receptive music therapy, which most often comes to mind when people in India hear the words 'music' and 'therapy' together. Every ancient culture has a history of using music for healing, and in the West, Plato, the Greek philosopher, made his students play music when they awoke to prepare them for the day – before breakfast. Surely feeding their soul before their stomachs! In addition he spoke about the different modes (scales) – much in the way that different ragas are seen here in India. Indeed I have found that in India people still seem generally more connected to the wisdom of this ancient understanding of the powers of music which only seems left as an echo in the West. Different ragas have been prescribed for different times of the day or season, very much as different psalms were designated for each week in the Christian calendar. Perhaps music has not only been used to connect people together but also to connect us with the daily, weekly and seasonal rhythms of the world.

CHRISTOPHER Small in his book *'Music, Society and Education'* says that in older, traditional cultures 'music is regarded... as one of the skills of staying alive and well. As Sachs says, "Everything that sounds, be it the cruder forms of frightening noise or the organised patterns of music, bears the brunt of mankind's eternal strife against the forces that threaten his life and welfare." It is in fact a kind of magic... to conquer fear, increase communal feeling and come to terms with the environment... There is no audience to be communicated with, since composer-performer and his listeners are both participants in a rite'.

HOWEVER the modern reincarnation of Clinical Music Therapy is very much grounded in the new scientific understandings of the musical nature of language and social development (as well as the parallels between our physiological structure and those of music itself!), music's connection to the emotions and its neurobiological effects on the brain – more than the aesthetics and esoteric nature of music in itself. Furthermore the training requires an understanding of child psychology and normal human development as

well as an understanding of human pathology so practitioners have a good understanding of the difficulties an individual may have to deal with during their life. Equally, a grounding in psychotherapy training is vital, as the development of therapeutic relationships is crucial to the work. Thus Clinical Music Therapy is truly an Art and a Science!

Introduction to Music and Autism

During my 16 years of work as a Clinical Music Therapist in the UK, Australia and now India, I have regularly been approached by parents, carers and professionals about their autistic charges' responses to music. Whether they have been observed to stop and focus when certain music is played, have an excited or emotional response, or – in rarer remarkable cases – have an ear to be able to reproduce music they have only just heard! I am immediately taken back to the lovely and heart-warming article in 'Autism Network' from August 2010 (Vol 5 issue 2) – 'Moving Forward' relating Divya's great piano-playing talent, and perfect pitch! Whilst I haven't, personally, worked with individuals with prodigious musical talents in my career, I have often found that even the most isolated individuals – needing support with most areas of day-to-day life – are able to 'hold' a tune, responding most harmoniously to the music I play with them. Never has the statement from my professional association "The ability to appreciate and respond to music is an inborn quality in human beings. This ability usually remains unimpaired by handicap, injury or illness, and it is not dependent on musical training" (*Association of Professional Music Therapists*) seemed so true! Equally I feel that this shows that those with autism keep skills within the 'normal' range of the population, if only we are able to give them a platform to let them shine through.

Music as a Language of the Emotions

Music is a *language* for all, and I emphasise language as this additional medium of communication is core to training as a Clinical Music Therapy. Furthermore, for many profoundly isolated individuals I have worked with, the gentle, feelingful relationships I am able to foster through Music Therapy sessions, have been the only activities they were willing to attend regularly, and sometimes the only time in their lives they have spent away from their care/support staff! With other more able

individuals, attending college courses, group Music Therapy has allowed them to develop their social understanding and to express their feelings. This has been crucial for them in coming to terms with becoming more independent as adults in a world that is often baffling and frustrating for those with autism. The ability of music to motivate, allow self expression, and bring individuals together was clear, but equally the psychotherapeutic aspect of the training was vital to help me mediate between the individuals – not forgetting the supportive cognitive and behavioural self help skills taught by the college tutors.

I'M sure we can all relate to the powers of music, whether to give us energy for an active day or to relax us after a stressful day! It is vital in films, helping evoke tears of joy or sadness, driving the action forward or building up our sense of anticipation or expectation. I'm convinced that some of the most moving films written would be a shadow of themselves without music enhancing the drama.

Clinical Music

Many people may think that quiet, relaxing and peaceful music is the best to listen to when we need to de-stress. However this is an important way in which the thinking of Clinical Music Therapists is different from the norm. I still vividly recall having an argument with my sisters, as a teenager, and slamming doors, stomping to my bedroom and listening to heavy metal at full volume, only to come back downstairs 10 minutes later as calm as anything! Sometimes matching the music to our feelings can be more effective for relaxation than music with an intrinsic soothing nature! Of more relevance to the quality of music-making found in Clinical Music Therapy is my experience of improvising on the piano to de-stress myself at the end of the day when working as a Statistician in London – in a previous life! I would often arrive home in the evening feeling very stressed due to the pressures of the work and sit, close my eyes and just play. An hour or so later I would emerge from the music calm and grounded. Now this music wouldn't necessarily be tuneful, aesthetically appealing or calm in itself but was rather a personal and spiritual journey where I would allow the upwelling of my feelings to pour out in the moment. It was for me and of me – and, quite frankly, allowed me to survive, emotionally, such a highly technical and deadline-oriented job! These experiences now put me in mind of the writings of Foucault, the French philosopher.

'WHAT strikes me is the fact that in our society, art has become something which is related only to objects and not

to individuals, or to life. That art is something which is specialised or done by experts who are artists. But couldn't everyone's life become a work of art? Why should the lamp or the house be an art object, but not our own life?' (From Gary Ansdehl, 'Music for Life', 1995)

IT can be argued that Western musical traditions (and I suspect in the Indian culture too) have increasingly widened the gap between performance and the audience, with someone else's music performed by experts in artificial conditions with ritualised audience responses. The Arts' Therapies are one of the few areas of adult culture where art is not the sole province of the professional or skilled amateur, and where people can paint themselves, dance themselves, or play themselves.

THIS line of thought is backed up and extended by English paediatrician, psychiatrist, sociologist and psychoanalyst Donald Winnicott's work, which is particularly relevant to the work of Arts' therapists in general. He emphasised creativity as a primal urge, and the ability to play as crucial to getting a sense of our true selves, expressing ourselves and finding our own solutions to problems.

'If the patient cannot play, then something needs to be done to enable the patient to become able to play, after which psychotherapy may begin. The reason why playing is essential is that it is in playing that the patient is being creative.' (D.W. Winnicott, 'Playing and Reality', 1971)

And further ...

'It is creative apperception [n. psychology/ assimilation into the mind of a new concept. Oxford English Dictionary] more than anything else that makes the individual feel that life is worth living. Contrasted with this is a relationship to external reality which is one of compliance, the world and its detail being recognised but only as something to be fitted in with or demanding adaptation.' (D. W. Winnicott, 'Playing and Reality', 1971)

FRIEDRICH Nietzsche the German philosopher wrote: *'There is no such thing as pessimistic art. Art affirms!'*

I'M not sure if I entirely accept this point of view, as the Arts can be used for either good or bad (though music could be seen as *affirming* the bad as well as the good!). I'm sure we can all understand how music and songs can be used to divide people and for warmongering. I am also particularly concerned in this modern technological age

how new technology has increased the ability of music to infiltrate our daily lives. Music is used by marketing teams at a subconscious level to make us buy more and to eat more, and equally our ability to listen to music at a whim with headphones attached to our iPods can isolate us in our own worlds rather than bring us together. In the West, karaoke is all the rage and this is sometimes the only way people can get up and share singing together. I worry about this as it seems to project something of people's fantasy about being their favourite pop star, rather than a truly personal and shared musical experience. One British comic described karaoke as 'the last refuge of the creatively bereft'! I think this statement carries something of the loss we suffer in modern times of our shared musical roots and the social bonds as human beings, that music was traditionally used to evoke.

NIETZSCHE'S words remind me of some very poignant work I undertook with an 8 year old girl who suffered with an intractable and deteriorating rare epileptic syndrome. Over the two years that I worked with her she lost her (limited) speech and most of her co-ordination, and by the end of our time she became very isolated from the outside world. Her mother found it increasingly hard to reach and interact with her daughter, but the one thing that remained and affirmed her life for both was her remaining memory and pleasure at attending Music Therapy sessions. I'm also put in mind of a recent session at Action For Autism with a generally quiet and unassuming chap who within a few minutes of my starting the music joined in and started singing his heart out with such confidence and assertive expression. Although he quickly readied himself to attend, it took more than 30 minutes to successfully persuade him to leave!

WHAT the Arts' Therapies share is the aim to involve people in creative action. Oliver Sacks (1990) remarks that one of the suggested derivations of the word inert is from '*in-art*', is still visible in the modern English word of '*inarticulate*'. Not to be acting is not to be creating and developing in the world. What is interfering could be as extreme as handicap or chronic illness, or as simple (but no less devastating) as a lack of confidence, or an inability to believe they *can* communicate spontaneously and creatively in music art or dance. (From Gary Ansdell, '*Music for Life*', 1995)

TO reiterate my previous Winnicott quote, if your client isn't able to play or be creative then the task of the therapist is to enable them to do just that!

NOW I hope you can see how music can be such a positive, engaging and motivating medium for those with autism from what I have said, and I hope many of you will have witnessed the many positive benefits for yourselves (and feel free to let me know any stories you may have as I love to hear them!). I would now like to speak a little about some of the research carried out into early communication processes and how musical they are, and consequently how developing a therapeutic musical relationship can be so helpful towards building some of the skills that those with autism can find such a struggle.

Our Musical Dance into the World!

In normal development, experiments with new born babies have shown an in-born tendency to move in synchrony with the rhythms of human speech in any language (Condon 1974, '*New Scientist*'), and to join in a self-regulating rhythm - and harmony - of movement and sound with their care-givers (Condon, 1974; Trevarthen, 1974 - '*New Scientist*'). Condon has also analysed adult interactions, and has found that not only is there an unconscious and complex temporal relationship between a speaker's own words and body movements, but that '*Listeners were observed to move in precise shared synchrony with the speaker's speech*' (Condon, 1975, '*Journal of Autism and Childhood Schizophrenia*'). He continues: '*Communication is thus like a dance, with everyone engaged in intricate and shared movements across many subtle dimensions, yet all strangely oblivious that they are doing so.*' In fact these movements happen so quickly that one could even entertain the idea of some sort of innate mind-reading! I would encourage everyone to read some more about this research as it is a truly amazing wonder of human nature.

Empathy

As a Music Therapist I use improvised music to follow, match and 'play the person' with whom I am working with, attempting to empathise with them in their world. AS Professor Rita Jordan stated at a seminar, empathy is a 2-way process, which makes engaging with those with autism - who have such difficulties in this area - such an exhausting task. Educating autistic children seems to focus on giving the child cognitive means to 'empathise' with us in the non-autistic world through highly structured routines, whereas Music Therapists use music to empathise with the child in their world and build a bridge into the non-autistic world. This seems to me a two-pronged approach attempting a balance to develop this two way process of empathy.

Chaos vs. Order

Another quality of music that I believe can be helpful to those with autism relates to the way we process the world

around us. To make sense of and to thrive in the world we need to do two seemingly contradictory things at once. First, we have to be able to hold onto and recognise structures and patterns, and secondly we have to recognise, tolerate and adapt to changes as circumstances demand. The ability to generalize from one situation to another depends on this, as does creativity and spontaneous human interaction. Zen Buddhism encapsulates this coexistence of stability and change in its image of a river being simultaneously the same as and different from yesterday – we may return again and again to the same river, always to find different waters flowing.

IN early childhood we see this form of processing at work in what Piaget defines as the process of assimilation/ accommodation (Piaget, 1950, '*Psychology of Intelligence*'). A young child takes in information, assimilates it into its present cognitive structures which then 'accommodate' i.e. flexibly restructure themselves in the light of the additional information.

MAINTAINING a secure structure simultaneously with being open to change and modification can be immensely difficult, and throughout life we struggle to find and maintain a balance between comfortable certainties and risks. We see this in the larger context with the reactionary/radical polarisation of both religion and politics. We move towards the comfort of ever more structured ways of being, towards the known, the predictable, the controllable, which inevitably becomes self-limiting, stagnating and stifling of growth. Alternatively, we move towards the other end of the spectrum where we find the creative desire for fresh thought, openness to change and fluidity from moment to moment, culminating in radical revolutionism and anarchy, where anything established or ordered is seen to have no value and chaos ultimately prevails.

ALL of our lives we are involved in this constant struggle for balance – holding firm where needed, but simultaneously bending and changing with each new situation, not least in relation to other people. For any of us this can be difficult, for those with autism it can be impossible!

FINALLY, if we consider these two apparently paradoxical factors in our dealings in the world as crucial to developing our perceptions, understanding and relationships, we find the first of these (i.e. the ability to extract and hold to a firmly constructed and unchanging structure) in the very essence of the musical structures of songs, gazals, bhajans and various forms of folk music

from the various Indian states. Simultaneously, and essential to the nature of the music, we find the second factor in the constant fluidity of process and creativity change. The unknown and unexpected are as vital to music as the adherence to form, and we emphatically find this most truly in musical improvisation. Here indeed is the Zen river!

I hope this article has left you with an understanding of how music can be used as a tool for building relationships and for healing, and also encourages you to think about the esoteric mysteries and powers of music too! India has such a rich and ancient history of music within its culture that once the profession of Clinical Music Therapy is firmly established in India it will surely have a great deal to teach us Music Therapists in the West!

Additional Reference

I would also like to acknowledge my thanks to an article written by the late Music Therapist Sandra Brown in the '*Journal of British Music Therapy* 8 (1) 1994' from which I gained a great deal of my thinking and part of the structure for this article.

Mike Hewitt has worked in the British National Health Service for 16 years as well as Child Development Units, Special and Mainstream Schools and Colleges, Mental Health Day Centres, Elderly Care Homes and for Charities. He is currently seconded to The Music Therapy Trust (India) (www.themusictherapytrust.com) to train students and disseminate Clinical Music Therapy within India and Nepal.

Contact Details:

Email: themusictherapytrust@gmail.com

Phone: +91 98 9998 1864

~~~~~

#### Parent Speak

*As parents, before we put our children  
through unsubstantiated, invalidated,  
experimental strategies to 'cure' autism,  
we need to think  
what we consider more important....  
the autism or our child!*

— Richa Ghosh —  
3 year old Prakriti 's mother

# A Nation Of Autism

*Jene Aviram*

When your child is diagnosed on the autism spectrum, you emigrate to a new country called Autism Nation. You don't need a visa, you don't need a passport. You don't even have time to say goodbye, or prepare or pack. And, although you'd like to choose a different destination, you find you're already en route. You stare blankly out the window as the train rambles through the unfamiliar landscape. "Autism Nation" you think to yourself. "I don't want to go there."

AND then you experience an unexpected delay. You get held up at "Denial Station." "This is a pretty nice place," you muse. "I could stay here for a while." In fact, life feels almost perfect. You discover all your fears and concerns were really just a bad dream. You're beginning to enjoy yourself. Just as the calm begins to settle in, the conductor yanks your arm and forcefully pushes you back on the train. "Time to move on," he declares. "Wait a minute!" you protest. "I'm not ready to leave. I like it here!" Your words trail off along with the puffs of smoke as the train picks up speed again.

SLEEP; blessed sleep might help, but just as you doze off the train jolts to a stop. You step onto the platform, overwhelmed with anger. "How dare they transport me here without my consent? This is not where I want to be!" Overtaken with fury you silently blame the messenger who sent you here, this place that is so dark, gloomy and uninviting. "Where am I?" you cry out in frustration. "This is Angerland," says a passerby as he folds his newspaper and steps onto the train. You stare at him in horror as a voice on an intercom booms, "ALL ABOARD!"

AT the next stop you remain seated, your mind racing, torn in millions of directions. You do your best to ignore the thoughts that plague you, but try as you do to clear your mind, you can't help revisiting the situation over and over again. "Why Autism Nation? Why me? Why did this happen? Is this my fault that I'm here? How do I adjust? How do I cope? What does the future hold? Where do I start?" As the train starts moving again you notice the platform sign: "Thank you for visiting Mull Over Point. Next stop 100 miles."

EMOTIONALLY drained, you slump in your seat and stare out the window. Overtaken by a deep sense of grief,

you read the signs as the train passes each of these destinations: "Joy", "Freedom", "Carefree", "Happiness." One by one they slip into the distance.

THE train slows down and a station appears. A voice announces, "Final stop. Autism Nation." "Must I get off this train?" you inquire. "Can't I just go back home now?" "There's no return," is the answer. You step off the train and are hurriedly shuffled through passport control. You appeal to the authorities. "There's been some terrible mistake," you plead. "I'm not supposed to be here." But you are told there is no mistake. There is no going back, no return to your homeland. "This can't be true," you remark in disbelief. You ask other parents for verification. "Surely this is a short stop?" But they shake their heads in unison. "I'm sorry," they say, "but once you arrive in Autism Nation you're probably here to stay."

A few people whisper stories about people who managed to escape. You listen eagerly, anxious for any tidbit that might change your plight. You become fascinated that changing diet, using vitamins and extensive language training may be your ticket out of this nation. In the meanwhile, you reluctantly settle in. You begin learning the language of Autism Nation. It's called Acronym. In the beginning it's confusing but you soon pick it up and words like ABA, DTT, PDD-NOS, OT, SLP, PT, IDEA, EI, and PTC become part of your everyday vocabulary.

AT first this seems to be a very friendly nation and why not? Abandoned here without choice the people share a common bond. But soon you find it's very political and quite combative. The "Autism is OK – Let's Accept It" political party butts heads with the "Autism is Bad – Let's Cure It" party. Subdivisions like the "Biomedical Party" and the "ABA Party" are equally vocal, equally at odds with each other. You ponder the philosophies of each group and try a few of them out. It takes some time but you eventually pledge your allegiance to the party of your choice.

THERE are days you long to be in the company of your old friends when everything was simple. You call them up on the phone but it's hard to communicate. Autism Nation has a different culture and you have developed some new speech and customs. You try and explain some of these customs but they don't seem to get it at all. While many things are perfectly acceptable in your country, your friends seem

confused and even horrified about some of the behaviors you try and explain. With a sympathetic pep talk they bid you farewell and hang up the phone, severing the connection.

TRUTHFULLY, you're often just as confused about the behaviors and customs, but you've already come to accept it. Autism Nation is not an easy country to live in but the daily struggles have made you stronger, wiser and broadened your perspective.

SO you keep your chin up and move forward. You form strong alliances and friendships in your new country, bonded together through a natural empathy and understanding. The people of Autism Nation have learned to appreciate the small things that bring joy to their lives. In fact, there's a celebration for almost everything! Trying new foods can result in a happy dance. An uneventful haircut is a joyous occasion, and a spontaneous conversation results in gatherings of merriment and delight.

THE people of Autism Nation are proud. Faced with judgment at every turn they stand strong. "You're right," they call out to their neighboring countries. "Our people are not the same as yours. But that doesn't make us wrong or less. It makes us different." Autism Nation is a country filled with different people and different hopes. Whatever today brings, they know how to make the best

of it. People unite, fighting for causes they believe in while relentlessly working to improve conditions for all citizens. They are involved; they care.

ONE day you find yourself thinking, "Autism Nation has become home." And, it's not the horrible place you once thought. It's given you a sense of purpose and passion. You no longer sweat the little annoyances of life and you appreciate everything. Once upon a time you thought life was supposed to follow a predetermined course.

*Now you understand that many walk a different path.  
Now you understand what it means to embrace differences.  
Now you understand that being unique can also be great.*

Most of all, you understand that you can never change what happens, but you can change your attitude. Choosing to view your world in a positive light is not only your power - it's your ticket to freedom.

*This article is property of and copyright © 2003-2009 Jene Aviram of Natural Learning Concepts.*

*Jene Aviram, the President of Natural Learning Concepts (<http://www.nlconcepts.com>) has a son with Aspergers, a nephew with autism and stands in unison with Action For Autism that Parent Empowerment and a Change of Perspective is often the greatest factor in helping children reach their fullest potential.*

## Autism Spectrum Disorder Fellowship in UK

Autistica, a UK charity dedicated to biomedical research in Autism Spectrum Disorders, with the support of Fortis India, has put in place a programme of Mentor-Based Fellowships. The programme will allow young talented pre-doctoral and post doctoral researchers of Indian nationality to undertake training opportunities in the UK in order to nurture and develop their expertise and knowledge in the field of autism and autism research. It is intended that upon the completion of the Fellowship, the Fellows return to embed their expertise within the autism research community in India. The Fellowship provides professional guidance delivered by experienced mentors, coupled with an autism specific education and robust scientific training gained within a UK university research environment.

The start date is schedule for academic year 2011-2012. The fellowship will be up three years for PhD registration and either two or three years for a post-doctoral fellowship. For more information you may log on to the Action For Autism homepage ([www.autism-india.org](http://www.autism-india.org)) or visit Autistica at [www.autistica.org.uk](http://www.autistica.org.uk)

## Deaf Persons in India to get Driving Licence!

The National Association of the Deaf were relieved when the Delhi High Court asked the government to grant driving licences to hearing-impaired persons if they satisfy other necessary criteria under the Motor Vehicles Act which prohibits them from driving.

The Court gave its ruling on a public interest litigation by the National Association of the Deaf (NAD) seeking the court's direction to quash the requirement of 'no hearing impairment' stipulation for issuing a driving licence under the Motor Vehicle Act. The NAD had contended that the deaf are allowed to drive all over the world except in 26 countries, including India.

Chief Justice Dipak Misra and Justice Sanjiv Khanna stated in their ruling, "We are obliged to certify that if an applicant is totally deaf, he has to be called for the test if he applies for a learner's licence without medical certificate and if he passes the test as required under the rule, then he shall be granted the learner's licence as that is the statutory requirement." The Deaf community all over India is rejoicing over this development.

BOOK REVIEW: Sharmila Gopal

## Tasks Galore Series

*Published by Tasks Galore Publishing, Inc., Raleigh, NC*

- **Tasks Galore (Book One)** - Laurie Eckenrode, Pat Fennel, Kathy Hearsey (First Edition, 2003)
- **Tasks Galore for the Real World (Book Two)** - Laurie Eckenrode, Pat Fennel, Kathy Hearsey (First Edition, 2004)
- **Tasks Galore, Making Groups Meaningful (Book Three)** - Laurie Eckenrode, Pat Fennel, Kathy Hearsey (First Edition, 2005)
- **Tasks Galore Let's Play (Book Four)** - Laurie Eckenrode, Pat Fennel, Kathy Hearsey, Beth Reynolds (First Edition, 2009)

Being a parent of a child with autism, as well as a professional in the field, I have always marveled at the effectiveness of the use of Structured Teaching with our folks. Structured Teaching is an intervention philosophy developed by the University of North Carolina, Division TEACCH, keeping the unique features and characteristics associated with the nature of autism in mind. It is probably the only intervention technique that goes beyond the usual list of 'what to teach', to the more basic and important of 'how to teach', helping people with autism 'learn to learn', given the fact that most individuals with autism have very different learning styles. This also makes Structured Teaching one of the, if not the only, intervention method that has a lifespan approach, respecting the culture of autism.

I recently came across this wonderful series of four books called the Tasks Galore series. It is a collection of structured activities for children with autism spectrum disorders and related developmental disabilities. I really loved the way the books are laid out with more than 250 colour photographs. Each book features photographic illustrations of various activities showing how sensory and visual elements can be incorporated into educational tasks.

'TASKS Galore' (Book One) emphasizes on developing tasks based on individualization, structure, organization, clarity, movement, sensory input, through the use of child's strengths and interests. It helps us create tasks that teach fine motor skills, readiness, language arts, math, reasoning, and play. The book also contains forms that

one can use to document the concepts one is currently teaching and also note down any additional ideas that one comes up with. Another great thing about these tasks are that suddenly you will start loving all those cartons and empty containers lying around your house that you so far thought were useless.

'TASKS Galore for the Real World' (Book Two) is designed for older elementary students and the adult learners. In this series, the activities are designed in such a way that older students will learn everyday life skills and then transfer them into functional daily living goals. This is a valuable tool for preparing the older elementary students, adolescents, and adults for independence in the home, school, community, or workplace. The 'Introduction' section describes a process for developing and teaching functional goals and the book has forty-three photographs illustrating task ideas in these categories.

'TASKS Galore, Making Groups Meaningful' (Book three) focuses on setting positive group activities including projects, movement, and music groups. The authors draw on their experiences as teachers and therapists with Division TEACCH to describe procedures and tasks that can make group learning successful. They discuss how aspects of Structured Teaching (physical structure, schedules, work systems, and visual structure) are applicable to groups. They further demonstrate how routines related to turn-taking procedures, task completion, appropriate group behavior, and transitions between classrooms ease students into group participation. Activities targeting circle time, project work, dance, physical education, and music groups give ideas about successful tasks. Many examples show how tasks can be individualized for students within a group setting and how aspects from school groups can then be utilized for successful social events at home like birthday parties and other get togethers. The photographs included help clarify these techniques very well.

'TASKS Galore Let's Play' (Book Four) utilizes play as the program for learning. Play is the basis of much of our

learning and I know from my own experience, how important the teaching of play is to the social and educational development of a child with autism. 'Let's Play' lays it all out there for teachers and parents to be able to understand why play is so important, and how to teach play to a child with autism. There is more and more evidence that direct teaching of play skills can increase symbolic understanding and, thus, have an impact on imitation, language, and social skills.

AS in the earlier books, the photographs depict tasks that the authors have implemented successfully to enhance their students' toy play, flexibility, and social interactions. The copy-friendly visual supports will generalize to multiple learning situations.

Chapters demonstrate how routines, organizational strategies, and visual cues make play more understandable, so students can share enjoyment, use toys appropriately, manage play times, make and end choices, pretend, and play with peers.

THE entire Task Galore series is a valuable resource that, I am certain, we would turn to time and time again. The tasks are not meant to be an end in themselves but rather to help the create juices flow, adapt, and innovate on the ideas given here. These books are a must have tool for any autism classroom, parents, and others working in the field since implementation of the ideas mentioned in the books would most definitely have positive impact on most children with autism.

## Upcoming Workshops at a Glance

| Date                   | Topic                                                                  | Brief Overview                                                                                                                                                                                                                                                                               |
|------------------------|------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 22 July 2011           | I am Not Badly Behaved: Teaching and Addressing Challenging Behaviours | The workshop will cover an understanding of the reasons behind behaviours, assessment, and management procedures. It will address the issue of challenging behaviours: seeing behaviours in the correct perspective and helping children move beyond them so that it enhances their learning |
| 23 July 2011           | Not Just Speech: Teaching Communication                                | The workshop will cover an understanding of the development of communication in typically developing children and in those with autism. It will demonstrate ways to develop speech as well as other modes of communication and the use of assistive and augmentative communication.          |
| 27 - 30 September 2011 | Know Me Teach Me                                                       | This is the much awaited annual training workshop that is for both the newbie as well as a refresher for experienced hands                                                                                                                                                                   |
| 24- 26 November 2011   | Fostering Independence: The Magic of Structure                         | This workshop is on the use of structured teaching which fosters the development of independence as well as the development of enjoyable social interactions and meaningful social relationships which are important priorities                                                              |

- Workshops will incorporate question answer sessions and interactive exercises.
- Workshop are open to professionals both in mainstream and special needs education and anyone else who works with children with developmental disabilities on a day-to-day basis. Parents are welcome at all workshops.
- Forms for all workshops will soon be up on our website: <[www.autism-india.org](http://www.autism-india.org)> .

For more information please write: *WORKSHOPS* in the subject line and mail your queries to:  
[anvaytrainings.afa@gmail.com](mailto:anvaytrainings.afa@gmail.com)

## बताएँ या ना बताएँ

बताएँ या न बताएँ— यह एक सवाल है। क्या हम अपने बच्चों को बता सकते हैं कि उन्हें ऑटिज़्म है ? क्या हम 'ए' शब्द का प्रयोग कर सकते हैं ? ऐसे बहुत से निर्णय होते हैं जो हमारे बच्चों के जीवन को प्रभावित करते हैं जिन पर हम चर्चा और बहस करते हैं। क्या हम उनका सहायक या संबंधी मोड से परिचय कराये बोलने के लिए या बोलना सीखने पर जोर डालें। क्या हम मुख्यधारा वाले स्कूल की ओर जाएँ या ऑटिज़्म विशेष वातावरण की ओर । फिर भी दिलचस्प बात यह है कि प्रकटीकरण की बात पर, क्या हम अपने बच्चे को बताएँ कि उसे ऑटिज़्म है ? असाधारणतः भारत में इस बात पर बहुत कम बहस हुई है। यह एक ऐसा विषय है जिसके बारे में अधिकतर माता-पिता और देखभालकर्ताओं ने ज़्यादा सोचा नहीं है। हमारी एक प्रारम्भिक प्रतिक्रिया होती है, "क्या आपको लगता है कि हमें यह करना चाहिए"? इसके साथ ही मतों का एक रोमांचक मिश्रण आता है। कुछ का यह मानना है कि निश्चित रूप से बच्चों को बताया जाना चाहिए। दूसरों का यह मानना है कि वह बताना चाहते हैं पर जानते नहीं कैसे। और फिर भी दूसरों का यह विश्वास है कि यह एक ऐसा विषय है जिसे टाला जा सके।

वेब पर हमेशा की तरह बहुत सारे विचार दिए गये हैं। इन्टरनेट पर एक लेख "एक अलग दृष्टिकोण" दिया गया है जो "ना बताने" वाली धारणा का एक दिलचस्प कोण दिखाता है। यहाँ हैं बेक्का जो खुद एक माँ है, जिन्हें अल्प मस्तिष्क श्रुति का लेबल दिया गया था, उनका कहना है "हम देखते हैं अगर मैं इसे सही से कह सकती हूँ ... पर एक बच्चा जिसे लेबल दिया गया है, (अल्प मस्तिष्क श्रुति, ऐसा इसे उस समय कहा गया था) जिसने कभी उसे समझने की कोशिश नहीं की और न कभी करेंगे, मैं निश्चित रूप से एक दूसरा दृष्टिकोण प्रस्तुत कर सकती हूँ।

"पहले तो मैं 'एम' के यह जानने से कि वह ऑटिस्टिक है आंशिक रूप से आश्वासक हूँ क्योंकि वो वास्तव में नहीं जानती कि उसका मतलब क्या है। और न वो यह समझ सकती है कि दूसरे लोगों की अंदरूनी प्रतिक्रिया क्या है इसके बारे में। ऑटिज़्म के बारे में परिवार में जो खुलापन आया है वो मेरे दूसरे बच्चों के लिए ज़्यादा लाभदायक है, खुद 'एम' की तुलना में। मैं यह आशा नहीं कर सकती कि भविष्य में वो इस बारे में ज़्यादा जानकार बनेगी पर मैं यह जानती हूँ कि अपने मतभेदों के बारे में जानकर उसे बहुत असुविधा नहीं होगी।

"दूसरा मैं यह कहना चाहती हूँ कि अपने लेबल को जानना एक आत्म संतोषप्रद भविष्यवाणी है। एक व्यक्ति ऑटिस्टिक है या नहीं, यह और अधिक है उससे जो उसे लेबल दिया गया है। परन्तु स्वतः एक ऐसा व्यक्ति होना जिसे लेबल दिया गया है, केवल अपना लेबल जानना मुझे अंदरूनी रूप से सीमाबद्ध कर देता है। आप देखिए मुझे यह सिखाया गया था कि क्योंकि मेरा मस्तिष्क क्षतिग्रस्त है तो मैं कुछ चीज़ें सिद्ध करने में अयोग्य हूँ। जब उस लेबल के साथ कुछ भी अस्थिर था, मुझे साहसहीन करने के लिए किसी की जरूरत नहीं थी, मैं खुद ही अपने आपको सीमित कर लेती थी। उस लेबल ने मुझे ऐसा बना दिया था कि मुझे लगता था कि मैं एक धोखेबाज हूँ। यह मुझे दृढ़ रहने और अपनी क्षमताओं को अधिकतम तक ले जाने से भी रोकता था। इसके अतिरिक्त उसने मेरे अंदर हीनता की ऐसी भावना डाल दी थी जहाँ कुछ शुरू करने से पहले ही मैं जानती थी कि मैं हार गई हूँ। अगर मुझे उन सालों में वापस जाना पड़े, मैं कभी नहीं चाहूँगी कि मुझे मेरा लेबल पता होता और इस बात को साराहती कि मुझसे वो छुपाया गया।"

इसी साइट से जेन ही कहते हैं " हम ना बताने में स्वीकृति रखते हैं"। "वह पहले से ही कम आत्म-सम्मान

के साथ संघर्ष करता है और आखिरी चीज़ जो हमें करने की जरूरत है वह है उसे एक बहाना देने की जिससे कि वह अनुचित व्यवहार कर सके या सिर्फ एक और बहाना अपना कमरा न साफ करने का।”

एक और सामान्य तर्क जो “ना बताने” के दृष्टिकोण के पक्ष में है वह यह है कि ऑटिस्टिक बच्चों को वैसे ही संप्रेषण में क्षति है, और ऊपर से उन पर अधिक जानकारी का बोझ डालने की कोई जरूरत नहीं है जो उसके किसी काम की भी नहीं है। और फिर जो तर्क बेक्का ने पूर्वगत उठाया है : क्या वह उसका मतलब समझते भी हैं ?

स्पेक्ट्रम के दूसरे छोर पर ये दृष्टिकोण है कि हो सकता है कि हमारे बच्चे समझ पाएँ या ना समझ पाएँ कि “ऑटिज़्म” क्या है, परन्तु अपनी कार्य पद्धति के स्तर पर विचार किए बिना, वह किसी न किसी स्तर पर अवश्य पता लगा लेते हैं कि वह “अलग” है। इस क्षेत्र के कई विशेषज्ञों और वह युवक जिन्हें ऑटिज़्म है उनका यही मानना है। इसके अतिरिक्त, विवाद यह भी उठता है कि यदि माता-पिता उनके सामने ऑटिज़्म के बारे में बात न भी करें, बच्चों को उसके बारे में सुनने से रोका नहीं जा सकता। सामान्यतः जब माता-पिता यह समझते हैं कि अपने बच्चों को जीवन के तथ्यों से दूर रखें तो यह उनके बच्चों को लिंग के बारे में सुनने से बाधित नहीं कर पाता। इसकी बजाय वह कहीं न कहीं से टुकड़ों में सीखकर, वह चीज़ों की अस्पष्ट धारणा बना लेते हैं। जब एक माता-पिता या कोई और जिम्मेदार व्यक्ति उन्हें जीवन के तथ्यों के बारे में परिचित कराता है, उससे उनको एक साफ और स्वस्थ वर्णन मिलता है। इसी तरह जिन ऑटिस्टिक बच्चों को उनके ऑटिज़्म के बारे में नहीं बताया जाता, यह अपने बारे में अस्पष्ट बातें सुनते हैं जो ज्यादातर नकारात्मक या अपमानजनक होती है। वह भी फिर ऐसी सोच के साथ बड़े होते हैं कि उन्हें कोई भयानक रोग या दुर्बलता है जिसके कारण वे अक्सर शर्मिन्दा होते हैं और यही कामना करते हैं कि उन्हें ये कभी नहीं होता। इसके अलावा वे अक्सर अलग और अकेला महसूस

करते हैं, यह सोचते हुए कि यह सारी कठिनाइयाँ केवल वे अकेले ही अनुभव कर रहे हैं।

एक ऑटिस्टिक व्यक्ति जो महसूस करता है, वह कहीं न कहीं उसके माता-पिता के व्यवहार को दर्शाता है। प्रारम्भिक वर्षों में जब बच्चे को निदान प्राप्त नहीं था, ज्यादातर माता-पिता सोचते थे कि उनके बच्चे के साथ क्या “गलत” है ? वो जवाब क्यों नहीं देता ? वो बोलता क्यों नहीं ? क्या हमने किसी समय कोई लापरवाही की है जिसके कारण यह समस्या आई है ? अधिकांश माता-पिता इन सवालों के साथ ग्रस्त होने के साथ-साथ घबराहट, अलगाव, क्रोध, हताशा और लाचारी की भावनाओं में घिर जाते हैं। अंततः जब बच्चे को ऑटिज़्म का निदान मिलता है, निदान के आघात के साथ-साथ, उनको राहत का एहसास भी होता है कि कम से कम उन्हें ये तो पता चला कि उनके बच्चे के व्यवहार का कारण क्या था, यह कि वह जान बूझकर अपेक्षापूर्ण अनुशासनहीन बच्चा नहीं था, लेकिन वह बहुत कुछ इसलिए कर रहा था क्योंकि उसे ऑटिज़्म है, और यह जानकर भी कि वह कोई बुरे माता-पिता नहीं थे, पर वह ऑटिज़्म था जिसके कारण उनका बच्चा उनकी बात नहीं मानता था।

उस समय सबसे अधिक शक्ति देने वाली बात माता-पिता के लिए यह है कि वह यह समझें बल्के वो लोग अकेले नहीं हैं जो इस स्थिति में हैं कि उनके जैसे सैकड़ों ऐसे लोग हैं। एक बहुत ही इसी तरह की भावना ऐसे बहुत से युवकों द्वारा गूँजी जाती है जो स्पेक्ट्रम पर होते हैं, विशेषतः उन लोगों द्वारा जिन्हें बड़े होने पर देर से निदान मिला है। अंत में यह राहत मिलना कि वह ऐसे क्यों है जैसे की हैं कि उनके विचित्र होने का कोई कारण था और उन सब कठिनाइयों के लिए जो उन्हें बहुत से क्षेत्रों में उठानी पड़ी। कि वे “अजीब” नहीं थे। उन्हें केवल “ऑटिज़्म स्पेक्ट्रम अवस्था” थी।

प्रकटीकरण अतः की अपनी जगह है। अतः जबकि कुछ माता-पिता और देखभालकर्ता यह मानते हैं कि इससे

केवल समस्याएं उत्पन्न हो सकती हैं, जिनमें से कुछ का वर्णन पहले किया गया है, वहीं कुछ ऐसे भी लोग हैं जो यह मानते हैं कि बच्चे से उसकी स्थिति के बारे में बात करना बहुत महत्वपूर्ण है।

जब हम अपने बच्चों को ऑटिज़्म का लेबल देते हैं, हमें यह अवसर मिलता है कि हम उस शब्द का भाव यह निकालें जो हम चाहते हैं। शायद जो प्रकटीकरण नकारात्मक अनुभव कुछ माता-पिता ने बताए हैं, वह माता-पिता या देखभालकर्ता के ऑटिज़्म के प्रति नकारात्मक भाव पर आधारित है। क्या माता-पिता और देखभालकर्ता ऑटिज़्म को दुखान्त घटना या शर्मिन्दी मानते हैं। क्या यह एक "समस्या" है जिसके कारण उनके "बेचारे" बच्चे को "दुखान्त ज़िन्दगी जीनी होगी? जब माता-पिता या देखभालकर्ता इस स्थिति की ओर नकारात्मक नज़रिया अपनाते हैं, तब सर्वदा बच्चे भी उन भावों को मन में बसा लेते हैं। बिना ये माने की बच्चे को अपने ऑटिज़्म के बारे में पता हो या न पता हो, पर बच्चा अपने बारे में नकारात्मक प्रत्यक्ष विकसित कर लेता है।

जैसा कि कैथी वैदरफोर्ड ने कहा है "आप वही अपने बच्चों को सिखाते हैं जिसमें आप वास्तव में विश्वास रखते हैं।" अतः जब माता-पिता बच्चे से उसके ऑटिज़्म के बारे में बात करते हैं, उनकी व्यक्तिगत मान्यताएं स्वभावतः प्रकटीकरण को रंग देती हैं। बच्चा यह सीख लेता है कि उसे ऑटिज़्म है जो कि बहुत शर्महीन है, अभिशाप है जिसने उसे माता-पिता के जीवन को मुरझा दिया है। अन्यथा बच्चा ये सीखता है कि हम सबमें विभिन्न मतभेद और कठिनाईयाँ हैं, वैसे ही उनमें भी है। और यह कि उनमें भी औरों की तरह क्षमताएँ हैं। तो बच्चे सीखते हैं कि ऑटिज़्म केवल जीने का एक अलग तरीका है। यह ऐसा कुछ नहीं है जिसके लिए उन्हें शर्मिन्दा होना पड़े।

इसके संकलन में ऑटिज़्म कोई 'बहाना' नहीं है। वो एक बहाना बन जाएगा अगर हम उसे बनने दें तो। अतः

अगर बच्चे अपने ऑटिज़्म का इस्तेमाल करें "अपना कमरा साफ न करने के लिए" वो ऑटिज़्म का इस्तेमाल एक बहाने की तरह करते हैं, उसी तरह जैसे हम सब ज़्यादातर कोशिश करते हैं बहाना ढूँढने की उस काम से बचने के लिए जो हम नहीं करना चाहते। हम बहुतों ने पेट दर्द का झूठ बोला है कि जिस दिन हमारी मैथ्स की मुश्किल परीक्षा थी। अगर हमारे माता-पिता हमारी बात मान लें और हमें परीक्षा न देनी पड़े, तो हम 'पेट दर्द' का बहाना दूसरे अवसरों पर भी करते रहेंगे। यदि हमारे माता-पिता ने हमें पकड़ लिया होता, दवाई देकर हमें परीक्षा के लिए भेज दिया होता, तब हमने 'पेट दर्द' का बहाना परीक्षा में बनाना छोड़ दिया होता। अगर हमारे बच्चे अयोग्य व्यवहार करने के लिए ऑटिज़्म का प्रयोग करते हैं, हम वो कर सकते हैं जो हम किसी अयोग्य व्यवहार के साथ डील करने के लिए करेंगे...यह विश्वस्त करें कि वह व्यवहार मजबूत न बने।

### **अपने बच्चों को कब बतायें कि उन्हें ऑटिज़्म है ?**

जो माता-पिता अपने बच्चों से उनके ऑटिज़्म के बारे में बात करना चाहते हैं, उनके लिए अक्सर यह सवाल होता है कि "कब" हम अपने बच्चों को बतायें ? यह निर्णय हर बच्चे, उसके पर्यावरण और व्यक्तिगत परिस्थितियों पर निर्भर करता है। कुछ स्थितियों में हो सकता है, हम अपने बच्चे को उसके ऑटिज़्म के बारे में तब बताना चाहें जब हमें यह महसूस हो कि बच्चा खुद को अलग समझ रहा है। व्यक्तिगत अनुभव से बात करें तो एक लेखिका, इंद्राणी बासु ने अपने बच्चे से उसके ऑटिज़्म के बारे में तब बात की जब वो 7 वर्ष का था। यह एक विशेष घटना का नतीजा था।

*'हम एक दिन पार्क में गए थे। वो झूले पर खेल रहा था जबकि मैं अपने कुछ दोस्तों से बातें कर रही थी। मैंने देखा कि कुछ बच्चे मेरे बेटे की ओर इशारा करके हंस रहे हैं और उसका मज़ाक उड़ा रहे हैं। वो झूले से उतरकर रोता हुआ मेरे पास आया। क्या ये इसलिए था कि उसने यह महसूस किया कि वो अलग है और कि दूसरे बच्चे उसका मज़ाक उड़ा रहे थे ? मुझे नहीं पता*

*परन्तु मैंने यह निर्णय किया कि उसके रोने की वजह कुछ भी हो, पर वक्त आ गया था कि मैं उसको उसके ऑटिज़्म के बारे में बताऊँ और यह कि वो दूसरों से अलग है।'*

अतः इस बात का जवाब "कि हम अपने बच्चों को कब बताएँ कि उन्हें ऑटिज़्म है? आदर्शतः जवाब है "अब! परन्तु एक अतिरिक्त व्यवहारिक रूप से ऑटिज़्म की चर्चा तभी करनी चाहिए जब माता-पिता या देखभालकर्ता स्वयं निदान को लेकर आश्वस्त हों, क्योंकि यही निर्धारित करेगा कि बच्चा अपने ऑटिज़्म को कैसे समझेगा। हम अपने बच्चे को कैसे बतायें कि उसे ऑटिज़्म है? जिस तरीके से जानकारी बच्चे को दी जायेगी, यह बच्चे की कार्य पद्धति और उसके संग्राहक एवं व्यंजक संचारण पर निर्भर करेगा। इसके साथ-साथ, जो भाषा यह बताने के लिए इस्तेमाल की जाएगी वह भी सहज और सरल होनी चाहिए ताकि बच्चा समझ सके।

इसके अतिरिक्त, यह एक शिक्षण सत्र न होकर एक बहुत ही अनौपचारिक ढंग से किया जाना चाहिए, जहाँ दोनों, हम और बच्चे पूरी तरह निश्चित और आराम से हों। यदि हमारे बच्चे किसी और के बहुत करीब हों, जैसे दादा-दादी या मौसी तो वह अच्छे लोग होंगे जिन्हें अपनी बात में शामिल किया जा सकता है। हम शुरू कर सकते हैं, मतभेदों के बारे में बात करने से यह तथ्य कि हर कोई अलग होता है। हम भौतिक गुणों का उल्लेख दे सकते हैं, चाहे फोटो चित्रों का इस्तेमाल करके कि किस तरह हम सब अलग होते हैं। यदि आपके बच्चे को किसी और खास ज़रूरतमंद व्यक्ति का अनुभव है तो यह अच्छा समय है कि आप उसका ध्यान उनकी कठिनाईयों की ओर आकर्षित कर सकते हैं। उदाहरण की तरह हम यह कह सकते हैं कि उनकी माँ को चश्मा पहनना पड़ता है क्योंकि उन्हें देखने में कठिनाई है। दादाजी बिना अपनी छड़ी के नहीं चल सकते, उन्हें चलने में कठिनाई है। कुछ लोग बिलकुल नहीं देख सकते, वह अंधे होते हैं। कुछ लोगों को

नियंत्रण करने में कठिनाई होती है कि उन्हें किस प्रकार चलना है, क्योंकि उन्हें सेरीब्रल पाल्सी है। उसी प्रकार उसे कठिनाई है। लोगों को समझाने में कि उसे क्या चाहिए और कि उसे बोलने में दिक्कत है, और इस तरह क्योंकि उसे ऑटिज़्म है। इस समय हम उसका ध्यान दूसरे लोगों की ओर भी आकर्षित करना चाहेंगे जिन्हें ऑटिज़्म है।

यह बहुत महत्वपूर्ण होगा कि हम उनकी शक्तियों के बारे में भी बात करें। हम उन्हें बताना चाहेंगे कि हम सबमें शक्तियाँ और कठिनाईयाँ होती हैं और उनमें भी ऐसा बहुत कुछ है जिसमें वह अच्छा कर सकते हैं। यदि वह पढ़ सकते हैं, या प्रबल दार्शिक सीखने वाले हैं, यह विशेष प्रकार का मैट्रिक्स नक्शा, अपनी शक्तियों और कठिनाईयों को दिखाने का अच्छा तरीका है।

जो सबसे ज़रूरी बात याद रखने वाली है, वह यह कि प्रकटीकरण को एक सकारात्मक अनुभव बनाया जाए। भाषा की लय को हमेशा सरल, सकारात्मक और स्पष्ट रखा जाए। हम अपने बच्चों को यह नहीं दर्शाना चाहते कि ऑटिज़्म कोई दिक्कत, दुर्घटना या परेशानी है। बल्कि वह एक अलग, अनूठा रहने का नाम है। यह भी जताना मददगार साबित होता है कि ऑटिज़्म होने से उनके माता-पिता की भावनाएँ उनके प्रति बदली नहीं हैं। यह एक सरल तरीके से भी जताया जा सकता है— "मैं तुम्हें प्यार करता/करती हूँ" या किसी अन्य प्रकार से प्रेम भाव को उनके सामने प्रस्तुत करना। कुछ माता-पिता हंसी मज़ाक को जरिया बनाकर उनके बच्चों के साथ कुछ हल्के पल बिताते हैं।

यह बहुत ज़रूरी है याद रखना कि यह एक बार बैठकर एक ही सेशन में सोचना कि "ठीक है" बता दिया। और मामला खत्म, ऐसा नहीं। यह एक निरन्तर क्रिया है। ऐसे बहुत सारे अवसर आएंगे जहाँ आप ऑटिज़्म को एक सकारात्मक रूप से समझा जाएगा। उदाहरण के तौर पर, यदि बच्चे को 3 साल पहले घूमने वाली जगह के बारे में सारी दिशाएँ, रास्ते याद हों, या किसी धुन

के विस्तार से याददाश्त जो कई साल पहले सुनी हो, या फिर कोई ऐसा किस्सा याद हो जो आम तौर पर औरों को याद ना आ पाए तो हम आश्चर्य दिखाते हुए ऑटिज़्म में चीज़ों को याद रखने की इस योग्यता के बारे में बात कर सकते हैं।

दूसरी तरफ ऐसे बड़े मौके भी होंगे जब कोई बच्चे की उपस्थिति में ऐसा कहे – “इसे क्या है” ? ऐसे में अन्य जवाब हो सकते हैं, पर कुछ इस तरह “कुछ भी नहीं, उसे ऑटिज़्म है” और बच्चे की तरफ देखते हुए— “उसे (जो व्यक्ति पूछ रहा है) ऑटिज़्म के बारे में कुछ नहीं पता है।” जिससे कि बच्चे को लगे कि आप उसकी तरफ है।

या कोई कहे “वह असामान्य रूप से हिलता क्यों जा रहा है ?” इसे इस तरह उत्तर दिया जा सकता है “इसे ऑटिज़्म है” और बच्चे को मुस्कुराते हुए कहना – “क्यों है ना। तुम्हें रोक करना अच्छा लगता है”। “और फिर सामने वाले से कहना कि “जिन लोगों को ऑटिज़्म होता है, रोक करना उनके शरीर की आवश्यकता होती है। यही है कि मेरे बच्चों को ऑटिज़्म है। उसे चाहकर भी हम नहीं रोक सकते। वो वही है। हम उन्हें बताएं या ना बतायें यह हमारे ऊपर है। पर एलेक्स नोबल ने कहा – “सर्वोत्तम रास्ता प्रभावी होने का ‘जैसे आप हैं वैसे ही रहें’ हमारे बच्चे अपने अस्तित्व को पहचानेंगे। अगर उन्हें यह नहीं पता होगा कि वह कौन है।

## एक सुनहरा पल

सन् 2004 जब पहली बार मुझे पता चला कि मेरे बेटे को आटिज़्म है, मेरे लिए तो जैसे सारे रास्ते बन्द हो गये और कुछ सूझ ही नहीं रहा था। उस समय सबसे पहला प्रश्न जो मन में आया था वह यही था कि क्या वो कभी बोल पायेगा ? एक वो समय था और एक अभी का समय है। जब उसने पहली बार मेरे साथ कुछ शेयर किया। हर रोज कि तरह एक दिन मैं उसे सेंटर से घर लेकर आ रही थी। रास्ते में मेट्रो स्टेशन पड़ता है जहां से हम ऑटो लेते हैं। मैं और मेरा बेटा दोनों वहां पर खड़े होकर ऑटो की प्रतीक्षा कर रहे थे। तभी मैंने देखा कि मेरा बेटा मुझसे कुछ कहने की कोशिश कर रहा है। वो मेट्रो की तरफ उंगली दिखाते हुए मेरी तरफ देखकर बोला “ट्रेन”। यह एक पल मेरी जिन्दगी का एक ऐसा सुनहरा पल है जिसे मैं कभी भूल नहीं सकती और ना ही इस पल के एहसास को शब्दों में व्यक्त कर सकती हूँ। यह पहली बार था जब उसने मेरी आंखों में देखते हुए और ट्रेन की तरफ इशारा करते हुए कुछ अभिव्यक्त किया था।

इस पल की खुशी को मैं समेटने की कोशिश ही कर रही थी कि अगला दिन फिर एक नयी खुशी दे गया। हर रोज की

तरह मेरा बेटा स्कूल आने के लिए तैयार हो रहा था। वो अब काफी काम खुद से कर लेता है। कभी-कभी थोड़ी मदद की जरूरत पड़ती है। उस दिन उसे मैंने टी-शर्ट की जगह शर्ट दी थी। चूंकि वो पहन लेता है तो मैं उसे देकर वहाँ से चली आयी। परन्तु शायद उस दिन उसने शर्ट की एक बाजू गलत डाल ली इसलिए उससे शर्ट पहनी नहीं जा रही थी। वो अपने कमरे से मुझे आवाज देता हुआ (मम्मी) बोलता हुआ हमारे कमरे में आया, वहाँ पर मैं नहीं थी परन्तु मेरे पति थे, उसने बोला “पापा हेल्प” इसको सुनकर मैं भी किचन से दौड़कर आयी और उसे हग किया। मैं उस दिन इतनी खुश हुई ऐसा लग रहा था जैसे कोई सपना सच हो गया। अब मैं समझ गयी हूँ कि यदि सही तरीके और सकारात्मक सोच से कोई शुरुआत की जाये तो वो कभी भी असफल नहीं रहती। जब मेरे बेटे को diagnosis मिली थी तब मैं कहती थी कि वो “एक disabled बच्चा है” परन्तु अब मैं कहती हूँ कि वो एक differently-able बच्चा है। मैंने पहले कभी नहीं सोचा था कि वो एक दिन कुछ ऐसा करेगा परन्तु अब लगता है कि वो बहुत कुछ कर सकता है और कर रहा है।

# HELPLINE



**Q** I have just visited your website for the first time and found it very informative, making my experience a very exciting and fulfilling one.

I'd request you help with some difficulties that R, my 7 year old son, diagnosed with autism is facing.

He doesn't mingle/ play with others, but he does play a little with his elder brother. When he is free he plays by twisting on floors and hitting at his jaw with objects. R doesn't speak frequently and expresses his need only by questioning like saying "Do you want water?" when he wants water.

After his 5th birthday (last year), much to our surprise and satisfaction, we noticed some special skills in him i.e. with some moral support (by holding his hand at wrist) he can write English, Hindi, Malayalam, Tamil (alphabets, words and even answer the questions we ask), do mathematics (addition, subtraction, multiplication & division) without anybody teaching him these skills before. This was also witnessed by his special school teachers & occupational therapist. But his level of interest is very low on these skills.

**A** It is a pleasure to know that you found our website useful and we do thank you for sharing your thoughts with us. We appreciate the concerns that you have about R and will try to provide some general strategies that may help with some of the issues that you have mentioned.

Autism is a neurological disorder in which the areas that are most affected are: the ability to communicate, which includes both understanding of language and using language to communicate; the ability to understand social rules and interact with others; and differences in thought and behaviour, where our children have a different way of perceiving the world, a different style of learning and difficulties in developing age and socially appropriate play and leisure skills. These areas are often late to develop, but more importantly, they develop in unusual ways. Further there is also a level of unevenness in the development of skills, for instance some children

may have extremely good gross motor and fine motor skills, but their ability to play with others may be at a very nascent stage.

Many children with autism also have different ways of 'sensing' their world. For example, some children may find bright lights very distracting; some may shy away from a gentle touch, but be comfortable when held firmly. Some may like to rock or can spend hours on a swing. Extreme likes or dislikes in diet could also be part of a sensory defensiveness. This difference in 'sensing' the world is often one of the reasons for the 'unusual' behaviours seen in children with autism. For instance, when you mention that R likes to hit himself on the jaw with objects, it is possible that he is actually seeking pressure on that part of his body. Or when he rolls on the floor, he could be finding the rolling motion and the pressure that the rolling provides his body pleasurable or he is seeking the 'feel' of the floor.

Though your occupational therapist will be better equipped to suggest strategies for fulfilling R's specific sensory needs, some of the strategies that you could try are to give R a firm massage all over his body and along the jaw area. You could also teach him to cup his own hands around his jaw and press hard, so that he can replace his behaviour of hitting his jaw with objects with a more socially appropriate behaviour. Asking him to lie down on a blanket and then rolling him tightly in it may also help. He may also like to be placed in between cushions like a 'sandwich'. All this could be done in a fun playful way.

Playing and interacting with peers is a key area of difficulty with our children. This is because playing with peers involves a lot of skills like waiting, turn taking, understanding the rules of interaction and of the games, being ready for quick changes in a game, anticipating what his peers may do, all of which our children have a degree of difficulty with.

His brother may be able to anticipate some of R's needs, just like R may be able to anticipate some of the rules of the games that he plays regularly with his brother, making this interaction easier and more comfortable.

Further given the fact that our children have difficulties in using their imagination in play, play which provides sensory stimulation may be preferable to a lot of our children in the early stages of play.

Teaching our children to play with their peers, to take turns, to share, will have to all be taught in concrete, literal ways through structured games with making the rules of the interaction, the games very clear and predictable to begin with. It is of course very important that we keep the interaction time an exciting and fun time for the child, one that he can look forward to versus being anxious about.

You have also mentioned that R expresses his needs by questioning. What happens in a lot of verbal children with autism is that they process language in chunks and use it in similar situations in exactly the way they have heard in the past. So for instance, in the past it is possible that R has been asked 'Do you want water?' and then has been given water to drink. R has learnt that entire chunk of language and every time he needs water he repeats this entire chunk he has heard in the past when he has wanted water. This is also seen in very young neurotypical children who are just learning to speak, but unlike our children they outgrow this phase and learn to use the language from their perspective.

For our children, it is a good idea to speak from their perspective, as in use exactly those words/ sentences that our child would use in a given situation, if he could speak. So we become our child's 'voice'. So for instance if R wants water, you say "water" or "give water" or "I want water" depending on whether R is at a 'word/ phrase/ sentence level'. If you are sitting down and he pulls on your hand, then you say for him "Papa come" and then get up. Or if he wants you to open something then you say for him "Open" and then open it. If he wants to pass by someone who is standing in the way, you say "Excuse me" for R and then let him pass by. It does not matter whether he repeats or not, we just say what we want our children to say and then over time they may learn to use this chunk of language in similar relevant situations.

It is wonderful that R seems to be picking up writing and math without any formal teaching. This has been noticed in some children with autism. It is a great skill to pick up, though the two things that one would need to keep a focus on is working towards independence and keeping the motivation to write high, especially since, in addition

to helping with academics, writing can also be an excellent mode for our children to communicate and express themselves.

You have mentioned in your mail that R does not find writing very interesting. We could try to find out try to find out what it is about the activity that he doesn't like and work around that particular aspect of the activity.

For instance, say you are working with R on his writing skills and you notice that every time you ask him a question, his motivation levels seem to drop, but he is more inclined to do his math. In that case, maybe for now, you want to stop asking him questions for a few days and just concentrate on the part of the writing activities that he seems to enjoy and praise him and reinforce him for writing. You could reintroduce asking him questions after a few days, starting with just one question that he has to answer. In the beginning you may want to stick to the questions that he finds easy to answer. Once he has answered the question, do remember to reinforce him very well. You could slowly increase the number and complexity of the questions that you ask. But it is a good idea to keep the activity short per se, so that R's motivation and attention levels can remain high and please remember to always reinforce and praise him for his efforts. This is just an example for you to be able to adapt to situation relevant to R. Further, giving R some kind of visual clarity as to exactly what kind of writing work he has to do and how much of it he is supposed to do may also help. So, you could have a mini timetable of sorts which lets R know exactly how many sums in addition or subtraction or how many questions he has to answer and so on.

In addition to the above, it would also be important to reduce the support that you are providing R so that he is able to complete these activities independently which would also contribute towards increasing his motivation levels for the activity. So you could slowly try to reduce the support you are providing R on the wrist and then move the support to his forearm, then to his upper arm, then to his shoulder to the point where he can write independently without any support whether physical or verbal from you. You may need to make the level of the tasks very easy to begin with as you reduce the support at every stage.

You may also want to read an article on 'Handwriting difficulties in children with autism' published in the August 2009 issue of the Autism Network :(<http://www.autism-india.org/aug09.pdf>.)

## WAAD Celebrations in India and the Sub Continent

**On 19 November 2007, the United Nations declared 2nd April as World Autism Awareness Day (WAAD).**

For the past four years, various kinds of awareness raising events have been observed worldwide on this day, in celebration of this unique, and vibrant community. Many organisations, both in India and the subcontinent, join the world on 2nd April to celebrate WAAD every year. The events often spread over the entire month of April, turning April into *Autism Awareness Month*. This year, organisations in South Asia joined the 'Light It Up Blue' (LIUB) initiative pioneered by Autism Speaks in 2010, wherein major monuments and buildings are lit up with blue lights to raise awareness about autism. It is a pleasure to give our readers an update on the 2011 WAAD activities organised in some parts of India and the subcontinent.

IN **Bangladesh**, the Autistic Children Development Foundation Bangladesh arranged an awareness walk, counselling, consultations, painting and sports competitions, and joined the LIUB campaign.

IN **Nepal**, Autism Care Nepal held an awareness camp and also used the day to start a campaign to raise funds for a national centre for autism in Nepal.

ACROSS India, a host of innovative events were organised by organisations. In Chennai, **We CAN** in partnership with city corporates, supported by Rotary Club of Madras Downtown arranged for the screening of short videos on autism during the World Cup cricket match at hotels like The Park, Courtyard by Marriot, Park Sheraton and the Taj Group. We CAN was perhaps the most effective participant in the LIUB campaign, lighting spectacularly the *Ripon Building, Corporation of Chennai, and the Office of the Director General of Police, among others*.

THE **Autism Society West Bengal**, Kolkata organised a Walk for Autism for autism awareness. Also spectacular in the LIUB campaign, they lit up the iconic *Victoria Memorial*, all four *AMRI Hospitals* and the *East Bengal Football Club*. Parent Circle Time Autism Identified also arranged various awareness events in the city.

**Soch** in Jalandhar was another amazing participant in LIUB lighting up the *Clock Tower, Radisson Hotel*,

*Prithvi*, and the *Mission Hospital* in the centre of the city along with a massive hoarding on WAAD, and large posters on autism displayed at the entrance of the buildings.

IN Goa, **Sangath** and the parent group **Towards Inclusion Everywhere in Society** held awareness raising activities with special needs and mainstream schools, and colleges. Several restaurants joined in the awareness campaign. The International Olympic Committee supported an innovative awareness event where Malay Samant, a 9 year old boy with Autism attending the Lourdes Convent School resource room swam across the river Mandovi, along with three students from the general section of his school. *Betim Cross and the Mae de Deus Church in Saligao* joined the LIUB campaign.

IN Hyderabad, **Aarambh** organised an Autism Care Walk, held an awareness camp with professionals and released information on autism in Telegu.

**Ashirwad and Darpan** in Ludhiana participated in WAAD with activities in the community.

**AFA and the National Centre for Autism** organised various events including inclusive art carnival and performances by persons with Autism. Free multidisciplinary consultation camp with a panel of experts consisting of developmental paediatrician, clinical psychologist, dentist, paediatric neurologist, special educators, music therapist; an autism friendly party with music, dancing, rock climbing; presenting the autism rights charter to the Chief Minister of Haryana; and distribution of autism awareness posters in Hindi and in English to 600 organizations across India. AFA had the India International Centre join the LIUB campaign along with the National Centre for Autism. The **Anil Karanjai Memorial Trust** also held a discussion on autism in Delhi.

THE **National Trust** in partnership with **Max Hospitals** created an awareness film on autism- 'Embracing Autism' for larger public viewing.

THERE were of course many more innovative events than those listed here in many parts of India, but not all the information reached us at the time of going to press. There was a successful thrust to get print as well as audio visual media coverage to raise awareness for autism. It was the most eventful Autism Awareness Month and a sign of more effective celebrations of World Autism Awareness Day in the future..

## MEMBERSHIP TO AFA

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

### MEMBERSHIP DETAILS

**Parents:** *Associate Member* – Annual: Rs 150/- *Full Member* – Annual: Rs 500/- *Overseas Member* : \$ 30

**Professionals:** *Associate Member* – Annual: Rs 150/- *Full Member* – Annual: Rs 1000/- *Institutional Member* – Annual: Rs 2000/- *Overseas Member*: \$ 50

*Associate Members* receive copies of Autism Network and information on all upcoming events and activities. Full Members, Life Members, Overseas Members and Institutional Members are in addition, entitled to concessionary rates for AFA events and workshops.

☐ New ☐ Renewal Date \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Pin/Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

I am a: (tick all that apply)

☐ Parent ☐ Relative \_\_\_\_\_

☐ Professional: Name of Org. \_\_\_\_\_

☐ Other \_\_\_\_\_

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

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

Date of birth \_\_\_\_\_ dd \_\_\_\_\_ mm \_\_\_\_\_ yr \_\_\_\_\_

Diagnosis (if known) \_\_\_\_\_

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

☐ Rs 150/- ☐ Rs 500/- ☐ Rs 1000/- ☐ Rs 2000/-

(Send Demand Drafts Only) Draft No: \_\_\_\_\_

Dated \_\_\_\_\_ On Bank \_\_\_\_\_

Amount in words \_\_\_\_\_

• I wish to give a contribution to AFA \_\_\_\_\_

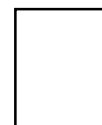
Amount in words \_\_\_\_\_

Mail demand draft payable to:

**Action for Autism, Pocket 7&8, Jasola Vihar,  
Behind Sai Niketan, New Delhi - 110025**

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

## BOOK POST



### If undelivered please return to:

The Editor, Autism Network,  
Pocket 7&8, Jasola Vihar, Behind Sai Niketan,  
Opp. Gate 6, Sector 8, SFS Flats, New Delhi - 110025

Published & printed by Merry Barua  
on behalf of Action for Autism (AFA) from  
Pocket 7&8, Jasola Vihar, New Delhi - 110025

Tel: 91 11 40540991, 91 11 65347422  
Email: actionforautism@gmail.com  
Website: <http://www.autism-india.org>

### Printed at:

Niyogi Offset Private Limited  
D-78 Okhla Industrial Area Phase I,  
New Delhi - 110020  
Tel: 26816301/26813350/51/52 Fax: 26813830

Editor: Merry Barua