

autism network

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ACTION FOR AUTISM



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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.

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YOUR CONTRIBUTIONS

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

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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'.

Cover Illustration

A scene from the book '**Evil Under the Sun**' by Prakriti Ghosh, studying in the 5th Standard, DPS Raj Nagar, New Delhi

WISHLIST !

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PAGE ONE

Winter is on us and another year has slipped by. A year that started with so much promise with the Rights of Persons with Disabilities (RPD) Act in place. We were exultant that finally we had the law that would ensure the rights enshrined in the UN Convention on disabilities. When the Act was passed in December 2016, for me personally it was a moment of deep satisfaction. For over 20 years I had done all I could to bring autism into the main disability legislation and in policies that saw persons with autism also as legitimate citizens of the country.

One of the major battles in this struggle has been to bring autism out from under the umbrella of intellectual impairment. There was a strong unwillingness amongst some to see the two – autism and intellectual impairment - as separate discrete conditions. Autism was confusingly viewed as another form of intellectual disability. There was limited understanding that while there were some individuals with autism who also had accompanying intellectual impairment, as indeed did some of those with cerebral palsy, or even visual impairment or any other conditions; that there were many with autism who had average or above average intelligence; and further that many of the latter lead very challenging lives because they were also 'very autistic'.

Getting the rights for persons with autism has been a long, hard-fought and uphill struggle in this fog of misinformation and confusion.

Once the RPD Act came about, we had presumed that this was one battle that had finally been won. Having served on the drafting committee I believed, naively, that the section of the draft that dealt with the various listed disabilities will be lucid and well-defined.

On reading the text of the Act my heart sank. Was this battle lost?

How is it that Autism has been parked under Intellectual Disability! After the years that we had campaigned to bring Autism into its own! But here we were back with autism under the umbrella of Intellectual Disability. Specific learning disabilities too have found its way under this umbrella. Strange are the ways of policy makers.

Would this exclude persons of average or above average intelligence who have autism – and learning disabilities – but no intellectual disability, from entitlements under the RPDA? Deprive them? Knowing the remarkable ways of officialdom? So while we mark and celebrate one year of the coming of the Rights of Persons with Disabilities Act it is accompanied by a tinge of concern.

While we continue to seek clarity on the law, it is crucial that the autism community strive for greater cohesion within its ranks. Parents in particular are all so busy guarding and nurturing our private trees that, except for the occasional breast beating, none of us want to look at the forest being chopped down around our ears.

When a right is denied, a just entitlement disallowed there are scads of sarcastic posts on facebook, angry discussions over cups of coffee, a flurry of whatsapp messages, but where are the letters to the ministry asking for things to be righted? All it needs is access to a courier service or to email, and of course the will to action. Instead we move swiftly to the next 'cure', hailing parents who are pricking and prodding and endlessly subjecting their children to unspeakable treatments, raising our voices for something 'I' want versus what is urgent for the community as a whole, or guarding our territories. We have time to study a hundred online posts on camels' milk, cranial stimulation, and singing hosannas to those ripping off parents with half-baked so-called treatments; the more expensive the better. Barring a handful, most of us do little to try and understand how policies affect individuals with autism. Not realising that one day it will negatively affect our own!

It will be some years before persons with autism can be their own advocates. Till that time parents and other carers have to play that role. If a core group of parents – the group most invested - takes up advocacy seriously, along with other carers, we can ensure that the few hard-won successes for persons with autism are not slowly eroded. I believe in hope and staying positive. I believe that we will rise and rise together, if we work together, and bring about the changes that are so desperately needed.

Wishing our readers greater awareness, awakening, hope and inclusion in 2018!

Understanding Autism Movement Therapy

Joanne Lara, MA, with Kerry Bowers

The Benefits of a Movement and Music Program

Movement and music make a profound impact on individuals with autism. One of the most exciting discoveries we've made in the 40 plus years of our individual and collective work in autism is how art expression, including movement and dance, profoundly impacts people with autism. Young and old; boys and girls; men and women; verbal and non-verbal, we've watched how participation in the arts improves and builds essential skills in many areas of autism's core deficits of speech and language, social skills and behavioral challenges.

The expressive arts give rise to communication for the voiceless, meaning to the intangible, and comprehension to the mysteries of human interactions. Participation in movement and music provides a literal and metaphoric stage upon which to share the inner being of our souls. Yet movement and music gives opportunity for much more. As the economy dwindles, and the demand for intensive, viable therapies in autism rises, the need for affordable – low cost or free – interventions became imperative. Can you imagine a simple, accessible program in movement and music that could meet many of those needs? Can you imagine having fun while growing and learning in autism?

Science is finally beginning to study the effects of the expressive arts on autism – and it's about time. Steven Kapp, an autism researcher at University of California Los Angeles tells us, "Now that the autism field has begun to intensively study sensory-movement differences, they have become better understood, with potential to spur change" (Kapp, 2013). Research is beginning to support what we've discovered through Autism Movement Therapy (AMT) and other art forms for decades; that an early intervention program that includes the expressive arts is fundamentally productive and the outcomes can (and do) drastically benefit the child's needs. The arts provide powerful, results-based strategies for autistic individuals through solid, well-conceived and structured programs such as Autism Movement Therapy (AMT) that literally *wake up the*

brain! We invite you to come along with us on this journey of exploration and possibilities to see for yourself the rewards in store for you, your child, your students and your clients.

What is Autism Movement Therapy?

When I left my credentialed teaching position in the Los Angeles Unified School District classroom, where I had taught students with moderate/severe disabilities for over ten years in a Special Day Class (SDC) setting, and where I first began incorporating music and movement into the daily classroom schedule, I suspected but did not entirely understand the profound role that music and movement would play in actual speech and language production. It was that teaching experience and the ability to work with hundreds of kids in those early years that lent itself to the development and goals of the AMT method.

Autism Movement Therapy® is a fun, empowering sensory integration tool. The AMT method blends multi-sensory, structured movement and music experiences with Positive Behavior Support (PBS) to connect the left and right hemispheres of the brain. AMT appeals to all people of all ages, and supports strengthening and building a 'whole brain,' cognitive approach – or interhemispheric integration – to significantly increase skills and behaviors through body and brain connection.

Autism Movement Therapy combines patterning, visual movement calculation, audile receptive processing, rhythm and sequencing into 'whole brain' cognitive thinking skills through connections that can significantly impact and improve a wide variety of autism's deficits. AMT is a natural strategy for individuals with autism and related disorders, and provides individuals with limited speech and language communication skills in particular, a way to express what words fail to do. AMT allows the non or impaired verbal individual self-expression through music and movement while developing a strong sense of self-determination and independence, undoubtedly one of the most important tools that the student will develop in his skill set.

Big Dreams; Big Goals

The primary goal of Autism Movement Therapy is that after 12 -14 weeks of two or three 12 minute sessions per week (as demonstrated in AMTaut-erobicsDVD), or one 45 minute AMT class over the same time period, the individual will be more compliant when asked to complete on-task activities, will interact with typical general education peers more frequently, and will have better use of the four lobes of the brain for processing. Increased overall self-determination awareness and self-regulation, along with healthier, improved self-esteem that equates to community inclusion and job opportunities is the ultimate goal. We always ask parents where they see their child in 5, 10, 15 years. As parents, this can be a frightening question to ponder. AMT offers a way to track progress and encourage the development of skills that will be necessary to support inclusive futures. With big dreams and big goals, the AMT method helps us to see those possibilities

The wonderful news about Autism Movement Therapy is that while we typically need to intervene early with traditional therapies, studies indicate that sensory integration therapies can be effective with autistic individuals past the toddler stage offering new hope to older children and even adults (Woo & Leon, 2013). Autism Movement Therapy is that the method offers new hope to parents of older children and even adults. While we typically intervene with traditional therapies such as OT, ABA and Speech and Language as soon as a child receives an autism diagnosis, studies indicate (Woo & Leon, 2013) that sensory integration therapies can also be effective with individuals who are past the toddler stage.

AMT is based on the concept of neuroplasticity, the belief that the brain, opposed to being fixed, can change. Change brought about



through a movement and music program often has a profound effect on the speech and language processing areas of the brain. We have seen tremendous progress in the Wernicke's area of the brain, located at the posterior end of the temporal lobe that is responsible for the pragmatics of ideas of language, as well as the Broca area, which lives in the frontal lobe and controls

speech articulation. Both the Broca and the Wernicke's reside in the left hemisphere of the brain.

With hundreds of anecdotal, real-life stories of how Autism Movement Therapy has benefitted the autistic kids and adults we've worked with, it's a simple brush stroke to share how, for example, twenty year old student, Neal, willingly relinquished his headphones to 'tolerate' the music and boisterous interactions of an afternoon session at a week-long AMT Spring class. The immediate benefits to Neal were apparent. Neal's sensory integration issues (sound,) social and spatial awareness (proximity to others in a group,) and communication skills (improved ability to convey his needs during our sessions) increased. The pleasurable and fluid nature of AMT movement and music, by its nature, puts kids at ease, relaxing their minds and bodies. Neal is one example of this.

Movement and Music Helps Develop Essential Core Skills

In addition to simple, fun exercise and social interaction, Autism Movement Therapy helps to develop essential skills and positively affects autism's challenges, including:

- Speech, language and communication
- Gross and fine motor skills/planning
- Proprioception; balance and spatial orientation
- Sensory processing and integration
- Social and life skills
- Physical health and wellness
- Self-esteem, self-awareness and self-determination
- Lowers anxiety and depression

It is typical for children to start out in AMT classes with behavioral challenges, anxiety, and body balance/coordination deficits. For example, at eight years old, Emma was unsure – or unaware – of where her body was situated in relationship to the environment and people around her (poor body-to-environment challenge). In class, she was significantly challenged by the movements and routines of AMT. Carol Kranowitz tells us in her book *The Out-of-Sync Child* that oftentimes perceptual motor therapy, or integrated movement experiences that remediate the gross-motor, fine-motor, and visual discrimination problems stimulate alternate routes to the memory and sequencing for children who do not respond to the methods taught in the conventional classroom (2005, p. 224).

For years, Emma had participated in intensive Occupational Therapy (OT). OT had helped with many

of her challenges, but in this new environment, Emma was unable to move her body as a unit through space in the class. Whether attempting to imitate the instructions of “arms in the air”; “feet apart”; “feet together”, or just executing simple slides across the room, Emma struggled to move her body parts in unison. Her head, like many kids with autism, preceded her body as she crossed the floor, her legs behind her. Her brain was not wired (yet) to send the proper and necessary signals to her body for her to follow the routines. *Note: we say “yet”, because the very idea of changing or altering brain connectivity after a certain age, remains controversial amongst experts. But we believe in the concept of neuroplasticity, which supports the idea that the brain can indeed form new connections that improve both physical and mental abilities.*

The initial expectations for Emma when she began taking the AMT class in the winter of 2008 were two-fold: A) to help her to become comfortable in the environment; and B) to introduce her to the AMT movement patterns and sequences. She also needed time to adjust to yet another new and unfamiliar teacher in her life. After several weeks, and as Emma’s trust in the environment grew, she began to bond with the class peers and become more comfortable in her new surroundings. It was exciting to see whole body movements begin to emerge. Over time, Emma developed more confidence and enjoyment in the sessions. She did not become comfortable with becoming a leader for at least a year... but wanting all kids to be leaders, it happened. Not all kids are ready in the beginning, but all kids will flourish when being the leader. They will let us know when they are ready.

Say Cheese!

Looking at old film footage of Emma is one way we can see her improvement over time. It is useful to use video and film to document dance, drama, music, and art sessions so that you can create a realistic visual and auditory baseline of the child’s present level of performance. Over time, you and the parents can document growth and development just like you would in a classroom setting. The parents appreciate this as well. ‘Seeing’ is generally better than ‘telling’ and ‘asking’ always trumps telling. When we ask, we stimulate the higher level thinking skills whereby ‘waking up the brain.’ Case in point, if you tell your student to “go put his backpack away in the cubby,” you have not required the brain to do any ‘work,’ but if you

ask, “where do you need to put your backpack?” then you have asked the brain to engage. To formulate a question requires a thought process for an answer. This very act of the student thinking, “where do I need to put my backpack?” activates lobes in the brain and stimulates neurons.

Videotaping a child is also a highly useful and effective tool to use in helping your child to ‘see’ themselves. When they see for themselves how they present themselves to the world; what their body, their movements and facial expressions look like, new discussions and learning can unfold. Keri used to film and photograph her son, Taylor when he was a young boy. Taylor is now twenty seven years old and lives independently through state and federal funding in a small town in southern California. From the time he was one year old and couldn’t crawl or talk, Keri would show him video footage or photograph and ask: “What does Taylor see?” or “Is Taylor happy or sad?” Because he could not speak outside of unintelligible babbles – it would be years before he would speak – she would talk to him as if he understood her. Keri’s intuition and her heart told her he would understand her words if she acted as if he could. This is what we mean by raising the bar.

Keri would add opinions to her questions such as, “It looks to me like Taylor feels sad. Is Taylor sad?” Then she would frown to help model the expression of ‘sad.’ Over time, in the years and language that ultimately followed, Taylor emerged as reasonably sensitive to the emotions and feelings of self and others. He was self-aware, and able to look outside of his previously isolated world. Was this an accident or simply normal development? Considering autism, I don’t think so. It was hard work, creativity and dedication that brought this inward, isolated child out into the light.

The Ease and Naturally Enjoyable Aspects of AMT

Whether verbal or non-verbal, students new to the AMT methods often start the classes overwhelmed and over-stimulated. Kids who are bombarded by a barrage of daily and/or weekly therapies are often emotionally and physically over-saturated by interventions beyond school-time activities. Though highly valuable, Applied Behavior Analysis (ABA), speech and language, OT, and other more rigid interventions overload our children. That is partly why the organically fun nature of AMT can be a welcome relief over traditional therapies. Of course there is structure and expectations that students must follow, but those expectations are ‘hidden’ within

the framework of this more relaxed, ‘recreational’ activity. In more intense interventions, obedience determines the reward. In AMT just being a part of the expressive movement and music is the reward – and the skills gained are the benefits.



The ease and naturally enjoyable aspects of movement and music are key factors in seeing a group of kids – who

start out as Neal and Emma did with core anxiety and behavioral issues – transform, flourish and eagerly perform in sync with one another. When our core AMT group in Los Angeles performs in live stage productions, it is a brilliant phenomenon to witness the bright faces and fierce determination of the participants to perform their roles. When the lights go up, curtains draw and the show begins, tears begin flowing from family members; moms and dads who were initially leery that *their child* could actually perform live on a stage. This happens every time! We make contingencies for those kids who might elope or get stage fright, but we never have to use those contingencies because the reward is in the movement and music, and kids are inspired to ‘show up’ for the show.

Brain Matter: What the Heck is Neuroplasticity?

The premise and underlying foundation of *Waking up the Brain! Autism Movement Therapy® Method* begins with the brain which is a vastly complex and baffling organ.

Despite its mysteries, our brains have an amazing natural capacity to compensate for injury or disease throughout our lives. The ability to reorganize and form new connections, synapsis (chemical or electrical connection points between brain cells); or create neural pathways in our nervous systems is called neuroplasticity. Though controversial, the science of neuroplasticity is based on the idea that the adult brain is capable of improving cognition and/or restoring lost mental abilities and function through regular, continuous physical and mental activities.

While scientists once believed the brain was a static (fixed or unchangeable) organ, research is changing that position by exploring how - and in which ways - the brain changes throughout life. In *The Brain That*

Changes Itself, author Norman Doidge illuminates case histories and research that indicate that the brain is far more malleable than we once thought. His work supports the idea that learning a new skill actually changes the structure and function of the brain – even into old age. Together and individually, our anecdotal experience with AMT and other programs in the arts agrees. We have seen first-hand, literally hundreds of children over two decades restore lost or under-developed skills well into their teens and adulthood (Doidge, 2007).

It is with those successes which our own eyes have witnessed, that we have developed a firm respect and belief in the science of neuroplasticity. With that in mind, the AMT method shows how the use of repetitive patterns and sequencing via movement and music literally wakes up the parts of the brain in individuals with autism - and related disorders - that are dormant or not receiving neural stimulation.

Our Brains are Like Computers

Like a computer, our brains are an information processing wonder. This mysterious wonder retrieves, decodes, processes and stores information in either long-term or short-term areas of our brain. When we need a particular piece or pieces of information, we retrieve it via a pathway called white brain matter in the mapping area (gray matter) of the brain.

So how do our brains process the ‘variables’ in our environments? What exactly is the ‘job’ each of the four lobes in our brain? And how do sensory enrichment therapies increase cognitive abilities while at the same time decrease common autistic behaviors? Brain mapping is beginning to give us these answers.

Brain mapping is an interesting and complex process. Scientists have used imaging to map and watch the brain working on various tasks. While this complex super computer remains in large part a mystery, research is making great strides in better understanding how the brain works. We know that there is a part of the brain whose function is vision, and another whose function is primarily sound. Brain mapping is helping us to look deeper into the vision section to see if there is differentiation within the brain that is responsible for detecting say for instance the color red, or another that detects green, or does the same area in the brain detect both red and green? Brain mapping or cognitive redirection as it is also known, looks from the outside in and seeks to understand how the environment effects the brain and how in turn the brain changes because of the environmental stimuli.

In a nutshell, it's like this. Say you move into a new home in a new neighborhood. You don't know where to find the grocery store, the dry cleaner, your bank or any other neighborhood establishments you need on a daily basis. But soon, after you've located these places, you no longer have to think about the specific directions to get to any of them. Your brain has 'mapped' these locations, so you are able to get into your car and drive right to the spot, almost as though you're on 'automatic pilot.' Every day we map hundreds of pieces of information by placing them in a file in our brain. Without even having to think about it, when we need certain information we retrieve the file by going straight to it, via cognitive maps or highway pathways.

Individuals with autism have difficulty accessing and retrieving information in both long and/or short term memory banks. Either the pathway does not exist or the transmitters are impaired. In both cases, the cognitive maps are not working efficiently, if at all. This makes learning especially difficult for them. The analogy is that our kid's brains function like a library where none of the information is stored in any organized, categorized way. Think of the confusion this would cause! The good news is that scientists now know we can often jumpstart impaired informational pathways or even create new pathways through cognitive redirection or, as discussed earlier, neuroplasticity (Lara, 2009).

The Corpus Callosum: Understanding the Left and Right Brain Hemispheres

The corpus callosum is a thick band of nerve fibers that divides the brain into left and right hemispheres. The job of the corpus callosum is to transfer motor, sensory, and cognitive information between the left and right brain centers. This communication helps maintain balance, regulate eye movement, uphold an equilibrium between arousal and attention, and to assist with tactile discrimination from the outside environment.

In a typical brain, information from the environment is received and travels across the corpus callosum, much like a bridge, to support this communication. For many individuals with autism, however, the left and right brain hemispheres have difficulty communicating. Research points to the fact that kids with autism have a smaller corpus callosum and studies seem to indicate that this inability of the left and right hemispheres to communicate is one of the underlying core challenges for individuals with autism.

Einstein had an extremely thick corpus callosum. According to the journal *Brain*, Einstein's corpus

callosum at the time of his death was a veritable superhighway of connectivity, "thicker in the vast majority of subregions' than the corpus collosi of 15 elderly healthy males and thicker at five key crossings than those of 52 young, healthy males who served as a comparison group" (Healy, 2013).

We all tend to be either left or right hemisphere dominant, but individuals with autism tend to be more dominant on one side of the brain over the other. The left (analytic) or logical hemisphere of the brain is: verbal, responds to word meaning, is sequential, processes information linearly, responds to logic and plans ahead, recalls people's names, speaks with few gestures, is punctual, prefers formal study design, prefers bright lights while studying. The right (global) or artistic hemisphere is: visual, responds to tone of voice, is random and processes information in varied order, responds to emotion, is impulsive, recalls people's faces, gestures when speaking, is less punctual, prefers sound or music in the background while studying and prefers frequent mobility while studying. In order for the brain to function as a 'whole brain', the left and right hemispheres must be exchanging information, talking with one another.

The Cerebral Cortex: Informational Highway

Information in our environment is received via the cerebral cortex which is a vital layer of tissue that coats the surface of the brain, roughly the thickness of two or three dimes stacked. The word Cortex comes from the Latin word bark- perhaps so named for its wrinkly appearance. The cortex is a huge communication system, playing a key role in basic functions like memory, attention, perceptual awareness, planning movements, and making sense of information from our eyes and ears. It is also responsible for more advanced functions like language and abstract thought.

Variations in the structure of the cortex might explain why a neurotypical person and an autistic person who receive the same sensory information interpret or experience the information in completely different ways. Whether you are a parent or a professional, surely you will find the following 'mis-association' interpretation example familiar. A child with autism goes to the park with his father. He sees a dog and as he leans down to pet it. Simultaneously, his father looks up at the sky and says, "What a lovely blue sky." A month later, the boy sees a dog at a friend's home. He immediately rushes over and as he lovingly pets the dog he says, 'blue sky' - the words he cognitively mapped

and stored in his memory bank during his trip to the park. The boy is re-experiencing the same activity, one that he enjoyed, so his brain retrieves the words (speech - frontal & parietal lobes) he heard from his father (receptive audio information - temporal lobe) that were stored along with the picture of the dog (visual - occipital lobe) and the action of petting the dog (gross motor - cerebellum). When the child says “blue sky,” adults then misinterpret and misunderstand the child as thinking the name of the dog is ‘Blue Sky.’ In actuality, the image of the dog was the visual trigger for the retrieval of the stored information in the boy’s brain.

Each of us processes information in this same manner. The difference between processing the correct information and/or misinformation, as in the above example, is dependent on the negative or positive interpretation of the information. We process through audio, visual and natural cues, which in turn become triggers. In other words, we can see it or hear it, or both see it and hear it together in order to establish a trigger. In the example of your cat meowing to let you know he wants to be fed, you can see the cat near his bowl, or you can hear the cat from another room, or you can see and hear the cat in order to trigger you to go to the cabinet and pull on a can of cat food. Autism Movement Therapy utilizes these different forms of information processing and triggers in remapping the brain. It requires that the individual use receptive language to hear the music, visual processing to see the physical image and gross motor skills to reproduce what they see.

Evidence of Success

More and more, researchers are collecting data that supports empirical evidence of the very real therapeutic values of music and movement in autism. In 2001 at the University of Miami School of Medicine, Kristin Hartshorn and her team conducted a study on thirty-eight children with autism who were given movement therapy in small groups led by a trained movement therapist. After two months of biweekly sessions, the children spent less time wandering, more time showing on-task behavior, less time showing negative responses to being touched, and less time resisting the teacher than those in the control group. (Hartshorn, et al., 2001).

In 2013 a study performed at University of California (UC) Irvine, comprised of two groups of children with autism, revealed stunning results. The control group consisted of 15 autistic children who were given standard conventional treatment for autism (ABA, OT,

speech and PT), while the study group ranging in age from 3-12 years, were provided a variety of sensory enrichment therapies. In a six month period of time, the authors reported a 5 point increase on the Childhood Autism Rating Scale (CARS) as well as an IQ increase of 10 points (Woo & Leon, 2013) in the sensory enrichment group. These are not only significant findings, they are profound.

CARS is a diagnostic assessment method that rates children on a scale from one to four for various criteria, ranging from normal to severe, and then yields a composite score ranging from non-autistic to mildly autistic, moderately autistic, or severely autistic. The scale is used to observe and subjectively rate fifteen items: relationship to people, imitation, emotional response, body, object use, adaptation to change, visual response, listening response, taste-smell-touch response, fear and nervousness, verbal communication, non-verbal communication, activity level, level and consistency of intellectual response and general impressions. A five point increase on the CARS can literally move a child from autistic to non-autistic in one fell swoop.

As the UC Irvine study group reported, and as the AMT method has anecdotally demonstrated over and over again, the more information that travels across the corpus callosum - that wide flat bundle of nerve fibers beneath the cortex - and the more access to stimulation in the left and right hemispheres, the more chance that visual, audio and gross motor processing growth can occur. The benefits, however, are not only seen in processing functions, but in the storing and retrieving of information in a more efficient and effective manner.

How can this be possible?

Think of it like a laundry room. You buy a new home with a guest house in the back yard. No one has ever lived in the guest house, and the back yard grass is green, lovely and covers the entire yard. Your friend or relative moves into the guest house, and they use your laundry room, located at the back of your house. After a while, inevitably a pathway forms from the guest house to the laundry room. This is how we make new pathways in the brain, by having the information travel back and forth, over and over again, along the same white brain matter transmitters until the brain establishes that the traveled route is the preferred pathway to the stored information. Doesn’t sound so impossible after all, right?

The Dalai Lama, the Brain and Meditation

When the Dalai Lama teamed up with Wall Street Journalist and author of *Train your Mind, Change Your Brain*, Sharon Begley, to speak at the annual meeting of the Society for Neuroscience, the world's largest gathering of brain scientists, in 2005, the Dalai Lama asked the attendees to ponder this key idea: "In addition to the brain giving rise to thoughts and hopes and beliefs and emotions that add up to this thing we call the mind, maybe the mind also acts back on the brain to cause physical changes in the very matter that created it. If so, then pure thought would change the brain's activity, its circuits or even its structure." Sharon Begley went on to say, "Recent pioneering experiments in neuroplasticity, a new science that investigates whether and how the brain can undergo wholesale change, reveal that the brain is capable not only of altering its structure but also of generating new neurons, even into old age. The brain can adapt, heal, renew itself after trauma, and compensate for disability (Begley, 2007). Following his lecture the Dalai Lama later arranged for Tibetan monks to travel to American universities for MRI brain scans to measure the changes that meditation brought about in the brain. Imagine that! Combining music and movement with meditation to heal the brain's neurological dysfunctions.

Notwithstanding the encouraging results of relatively limited research and longitudinal studies into autism, the arts, music and movement, currently we see that music therapy currently has the largest body of evidence to support its efficacy for students in special education - especially those with autism. Scientists hypothesize that music engages the mirror neuron system in the human brain, which supports development in sensory-motor integration, speech and social skills. The AMT method simply adds movement to the science of music 'therapy' to increase the developmental and educational benefits to those engaging in the processes.

We encourage - and one day fully expect to see - evidence based research on the arts, substantially qualifying them as viable, scientific interventions in autism. And one day, we envision the arts will also become 'Best Practices' in autism therapies.

- **Joanne Lara, MA**, founder/Executive Director of Autism Movement Therapy, and Autism Works Now. AMT/AWN is the recipient of three Autism Speaks grants, Lara was the autism expert on the FoxTV show *Touch*, and is core adjunct faculty at National University in Los Angeles. Lara produced the documentary

Generation A: Portraits of Autism & the Arts, and is co-author of *Teaching Pre-Employment Skills to 14-17 Year Old's: The Autism Works Now Method*, Jessica Kingsley Publishers, London and *Autism Movement Therapy: Waking up the Brain!* with Keri Bowers. For AMT Certification and licensing, visit: www.autismmovementtherapy.org & www.autismworksnow.org

- **Keri Bowers** is the co-founder of The Art of Autism (www.the-art-of-autism.com) and owner of Normal Films (www.normalfilms.com). Her films, *Normal People Scare Me*, *Normal People Scare Me Too*, *The Sandwich Kid*, and *ARTS*, embody possibilities, disabilities, and the arts. Keri is a consultant on the "art" of transitions and skills development.

ACTION FOR AUTISM

Invites applications for

Direct Support Staff for Ananda Group Home

Ananda is located in a pollution-free rural community 40 minutes from the Sikandarpur Metro Station, Gurgaon, and is home to residents with autism and other developmental conditions.

We have openings for Direct Care Staff who:

- Have a background in Special Needs Education
- May not have a background in Special Needs but are excited about the opportunity

We will provide:

- A POSITIVE and FUN work environment
- Accommodation

If you:

- Enjoy *learning skills on the job!*
- Can provide *hands-on support* to residents in their *daily life activities* - getting ready for the day, doing chores around the house, vocational work, leisure time
 - Have the sensitivity to be a MENTOR and BUDDY to the residents
 - Have the ability to work well in a calm, supportive, and encouraging manner

Then do write to us:

~ **Email at:** positions.afa@gmail.com

~ **Or snail mail at:** Action For Autism, Pocket 7 & 8 JasolaVihar, New Delhi 110025; Tel: 40540991/2

No More Airport Blues For Us

Mona Rai

When I heard about the recent sensitisation program conducted by Action For Autism (AFA) for the CISF staff of the Delhi airport, it really helped me smooth my nerves. In a fortnight's time, I was to take a flight with Tanmay, my 17 year old son with autism, and Bhanu, my husband would not be with us on that flight. While Tanmay is an airplane travel fan, anyone travelling with a person with autism knows that the crowds, security checks, the wait, is often very challenging for them. And when you mention that you are travelling with a person with autism, you usually get a blank stare. Most parents have learnt to be a bit more demanding and request for special help to jump the queue, but the security check aspect is still a nightmare. We make 'Airport travel' stories for Tanmay and start preparing him for the trip in advance and if there is a meltdown at the airport, then we helplessly look the other way, waiting to reach the destination somehow.



Tanmay with Limainba

But this time there were 'No airport blues' for us. Since AFA had done the training for the CISF staff, I was absolutely assured that it will work well for us. I called the CISF number* provided by AFA, a day in advance and was told "Maam, we will be here to help you, just call us when you reach the airport". These words were like music to my ears. We were met by the CISF staff at the Indigo check in counter at

the Delhi Airport, Terminal. Thereafter Tanmay was escorted with utmost care by the CISF staff, who seamlessly helped with luggage drop, smooth security and communication with Indigo Airlines. A special thanks to Limainba (who is in this pic with Tanmay), who says "I am doing my duty".

The sensitisation program done by Action for Autism was visible right through. We felt so much at ease. And as parents, when you are at ease you can enjoy the little

moments. Tanmay walked confidently through security, with direction and assistance (as I was in the ladies' queue) and when he showed some signs of getting a bit disturbed, he was prompted to take a chair at the other end. How cool was that!

The next challenge was to visit the washrooms – who would take him to the 'Men's' and where would he wait for me, while I freshened up? The CISF staff member again came to my rescue and waited with Tanmay. By the time we had to board the bus, Tanmay was walking way ahead, jumped in to take a seat. He was all set to enjoy his inflight experience. I learnt so much about handling persons with autism with dignity and respect and what impact it has on their frame of mind and confidence level.

So those of you travelling with a person with autism via Delhi airports, please do connect the CISF.* Hopefully other airports will follow soon.

Flying Easy with Autistic Co Travellers

Families traveling with PwA, requiring assistance at the Delhi airport may contact :
Shift i/c T3: 9871175747*
Terminal 1: 9871135863*

Please get in touch at least 24 hours prior to travel time and carry the respective disability (especially autism) certificate.

This is the first step by CISF following the sensitisation talk by AFA at New Delhi. AFA has conducted a sensitisation programme with the CISF in eastern region of India- Kolkata, Bhubaneswar, the north east and is planning to do the same in other parts of the country.

Similar programmes are also planned for the CISF in Mumbai and Bangalore.

Happy travels :)

For feedback email: igi-apsu@cisf.gov.in

आगम/वृद्धि करने वाला संचार

“निकलस की पहले से ही 22 चित्रों की शब्दावली है”

हिल्डी डे क्लेरक (Hilde De Clerq)

अनुवाद – पूजा खन्ना

Continued from Autism Network December 2017

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संचार के कार्य, संचार क्यों करना है, का संचार की शक्ति में अनुवाद हो सकता है। सामान्य बच्चे बड़े सहज तरीके से यह ढूँढ लेते हैं कि वो अपने संचार से अपने वातावरण में हेर फेर कर सकते हैं। कुछ हफ्तों का बच्चा जब ही उसे कुछ चाहिए होता है तो वो रोता है: और माँ उसके अलग अलग तरीके से रोने के समझ लेती है। कब वो भूखा है, कब उसे उठाना है, कब उसे दर्द है। सामान्य रूप से विकसित होने वाले बच्चे में बोलने से पहले ही बहुत सारे संचार के कार्यों का विकास हो जाता है, हमारे बच्चे हमेशा इस संचार की शक्ति को सहज रूप से नहीं खोज पाते। इसको उन्हें यह सिखाना हम पर है।

इसलिये संचार के क्या कार्य हैं को समझना बहुत जरूरी है। यह सिखाना कि असली संचार खुद को मारने से, चीजों के फेंकने से, गुस्सा करने आदि से ज्यादा प्रभावी है। ऑटिज्म की इस मूल परेशानी को समझना यह हम पर है। हमें यह कोशिश करके उन्हें यह सिखाना है कि आपको लोगों से कुछ मिल सकता है और आप अपने माहोल में संचार द्वारा हेर-फेर कर सकते हैं।

संचार के कार्य: सबसे प्रमुख कार्य है:

कुछ माँगना: जैसे टॉफी एक वस्तु चित्रकारी, या लिखे शब्द के इस्तेमाल से।

टिप्पणी करने के लिये: सामान्य रूप से विकसित होने वाले बच्चे सबसे पहले ‘यहाँ और अभी’ के बारे में बात करते हैं, वो उन वस्तुओं के बारे में बात करते हैं जो वो देखते हैं, वो चीजों का नाम बताते हैं। यह संचार का एक ऐसा कार्य है जो कुछ मामलों में ऑटिज्म वाले मौखिक बच्चों में बहुत उच्च रूप से विकसित होता है। अपने स्कूल के बड़े भाग में उन्हें चीजों का नाम देना सिखाया जाता है, एक केला, एक सेब, एक बिस्कुट। दुर्भाग्य से जब मेज पर बैठते हैं और उन्हें ‘केला’ चाहिये वो इस शब्द को संचार के लिये केला माँगने के लिये इस्तेमाल नहीं करते हैं। वस्तु पर टिप्पणी करना/ नाम लेना और उस वस्तु को माँगना दोनो में एक बहुत बड़ा फर्क है।

जानकारी देने के लिये: सामान्य रूप से विकसित बच्चे धीरे-धीरे ‘वहा’ और ‘तब’ वर्तमान और भूतकाल चीजें जो तुरन्त दिखती और प्रस्तुत नहीं रहती के बारे में बात करना शुरू करते हैं। उदाहरण जॉन कहता है: “कल मैं ग्रैन्डमा के साथ था और उन्होंने मेरे लिये पैनकेक बनाये थे”। यह जाहिर है कि इस तरीके का संवाद (जो अदृश्य और ज्यादा निराकार) ऑटिज्म वाले व्यक्ति के लिये और मुश्किल है।

मना करने के लिये: ऑटिज्म वाले कुछ लोगों कि यह त्रासदी है कि ज्यादातर उन्हें सब कुछ सिखाना पड़ता है यहाँ तक कि बालिका योगर्ट मीठे के रूप में हर दिन खाती थी। उसकी माँ ने बताया कि उन्हें खुद योगर्ट इतना पसन्द है इसलिये उन्होंने अपने बच्चों को भी दे दिया। जब मैरी को तस्वीरों द्वारा संवाद स्थापित करना सिखाया गया, तो सबसे पहली चीज उसने जो कि वो

थी योगर्ट की तस्वीर को लेकर जितनी दूर वो फेंक सकती थी फेंका शायद मना न कर पाना बहुत बुरा होगा।

हेल्प/मदद माँगना

सामाजिक नियमित कार्यक्रम के लिये: जैसे 'बाई' थैंक्यू, हैलो, कहना।

अपनी भावनाओं का संवाद स्थापित करना: अपने भावों की अभिव्यक्ति और उनके बारे में संवाद स्थापित करना दोनो में बहुत बड़ा फर्क है।

रिक्स के प्रयोग को याद करें। यह साफ और जाहिर है कि ऑटिज्म वाले लोगों की सामान्य लोगों जैसे ही भावनायें होती हैं। परन्तु उनकी अभिव्यक्ति अलग तरीके से करते हैं। मैथ्यू का एक ऑपरेशन होना था। उसके माता पिता अत्यन्त चिन्तित थे। परन्तु डॉक्टर ने उन्हें आश्वासन दिलाया कि सब ठीक है और मैथ्यू बिस्तर में गाना गा रहा है। माँ और पिता ने तुरन्त पूछा कि वह किस प्रकार का गाना गा रहा था। डॉक्टर के हिसाब से यह बड़ा ही अजीब सवाल था। दुर्भाग्य से मैथ्यू "हैपी बर्थडे" गा रहा था और इसका मतलब था कि इसे बहुत दर्द था।

अगर एक बच्चा गिरता है और रोता है वो अपने दर्द/पीड़ा के भाव व्यक्त करता है। पर इसका मतलब यह नहीं कि वो अपने भाव के बारे में किसी और को बता/समझा सकता है क्योंकि यह ऑटिज्म का एक अत्यन्त मुश्किल कार्य है। अपने आप को किस के सामने ले जाना यह बतलाने के लिये कि आप अन्दर से कैसा महसूस कर रहे हैं। कोई भी चीज भावों से ज्यादा निराकार और अदृश्य नहीं होती है। क्या आप मुझे गुस्सा, डर, प्यार जलन दिखा सकते हैं? नामुमकिन! टॉप मुझे एक ईर्ष्या करते हुए बालक का चित्र दिखा सकता है, परन्तु इसका मतलब यह नहीं है कि आप ईर्ष्या की 'धारना' को समझते है। इसका यह मतलब नहीं है कि आप भावनाओं को पहचानते और समझते है, दूसरे व्यक्ति अथवा स्वयं की भावनायें और अगर आप समझते भी है, उनके बारे में संवाद स्थापित करना फिर से एक नया

कदम है। मेरी इस किताब ऑटिज्म में विस्तार सोच, "माँ यह इन्सान है या जानवर"? मैंने इन मुश्किलों को ऑटिज्म वाले व्यक्तियों के नजरिये से उदहारण देकर स्पष्ट किया है। और इस विस्तार से सोच की संज्ञानात्मक शैली हमें संचार के तीसरे आयाम की ओर ले जाती है।

प्रसंग/संदर्भ- संचार के : कहाँ, किसके साथ और किन परिस्थितियों में बच्चा संवाद स्थापित करता है? क्योंकि हमारे बच्चों की बजाय धारणाओं और पूर्ण अर्थ विस्तार पर केंद्रित होने की प्रवृत्ति होती है उन्हें व्यक्तिकरण में बहुत अधिक परेशानी होती है। उन्हें एक कौशल को किसी एक विस्तार, एक व्यक्ति के साथ एक जगह से एक परिस्थिति के साथ जोड़ने की आदत होती है। अन्य शब्दों में एक विशिष्ट संदर्भ में। यह उनके संवाद स्थापित करने के कौशल के लिये भी सत्य है। औलिवर सिर्फ अपनी माँ और भाई के साथ ही बात करता है, वो स्कूल में कभी बात नहीं करता है। डेविड को अपने स्पीच थैरेपिस्ट के साथ संचार कार्ड का इस्तेमाल करना आता है परन्तु अपने टीचर के साथ नहीं। थामस, हमारे साथ स्पेन छुट्टियां मनाने गया था, उसने कभी फ्रिज़ से कुछ सामान नहीं निकाला, मुझसे कभी कुछ पीने को नहीं माँगा। जब मैंने उससे कहा कि उसमें बहुत पेय जल है, उसने बड़े ही आश्चर्यजनक से जवाब दिया। "ओह माँ, मुझे नहीं पता था कि यह हम स्पेन में भी कर सकते है।"

इन सब उदाहरणों में कहीं भी करने की अनिच्छा नहीं है, परन्तु यह मुश्किलें उनकी संचार के व्यापकीकरण की है। थामस की एक दिन उँगलिया स्कूल में दरवाजे के बीच पिचक गयी। सारे नाखुन चपट कर निकल गये। टीचर जो उसे अच्छे से जानती थी, उसे इतनी पीड़ा में देखकर कहा, "पर थामस जब आपको इतनी पीड़ा हो तो आप रो सकते हो"। और थामस ने जवाब दिया "नहीं मैं सिर्फ अपनी मम्मी के साथ रो सकता हूँ, और कभी-कभी अपनी बहन के साथ"। संदर्भ उदाहरण देकर स्पष्ट करते हैं कि लोग जो बच्चे के साथ काम करते हैं और रहते हैं उनके बीच सहयोग कितना जरूरी है अन्यथा उन्हें सिर्फ खंडित और टुकड़ों में सीखने को मिलेगा।

अर्थ श्रेणियाँ : संचार के इस पहलू में बच्चा क्या संवाद कर सकता है हम उस पर ध्यान देते हैं। अर्थ का तर्क मतलब से है। 'कुत्ता आदमी को काटता है' और "आदमी कुत्ते को काटता है" दोनों के बीच बहुत बड़ा फर्क है। जब थामस बच्चा था तो वह अभिव्यक्ति हर उस सवाल के लिये करता था जिसका जवाब उसे नहीं पता था। वो 'कल' शब्द हर उस चीज के लिये करता था जो भूतकाल में हुई थी। तो अभी भी 'पर्याप्त' शब्द का इस्तेमाल करता है जब वो यह कहना चाहता है कि उसने बढ़ा-चढ़ा कर नहीं किया "बहुत अधिक" का विपरीत "अगर मैं उसे कहूँगी कि उसने बहुत ज्यादा कॉफी ली है वो जवाब देगा" मेरे पास पर्याप्त कॉफी है। उसके लिये इसका मतलब कि काफी "बहुत अधिक" नहीं अगर हम ऑटिज्म वाले व्यक्तियों में इन चार आयामों में जैसे रूपों का अवलोकन, कार्य, अर्थ श्रेणियाँ अलग-अलग संदर्भ में स्वाभाविक संचार देखे तो हमें उनके असली या सही संचार कौशल का उद्देश्य विचार मिलेगा। यहाँ उद्देश्य बहुत खास है क्योंकि हमें यह समझने में समय लगता है कि हमारे बच्चे संवाद स्थापित कर रहे हैं। जबकि असलियत में ऐसा नहीं है, क्योंकि उनको इसकी जरूरत ही नहीं है, क्योंकि हम उनके सामने हर समय सब हाजिर कर देते हैं। "यह सेवा बहुत अच्छी है" यह एक ऑटिज्म परिवेश में कॉफी सुनी हुई अभिव्यक्ति है। हम उन्हें इतना प्यार करते हैं कि हम उन्हें जो हमें लगता है उन्हें जरूरत है हर समय देते हैं और इसलिये अनुभव नहीं करते कि हम उन्हें संवाद स्थापित करने के अवसर ही नहीं दे रहे हैं। तो वो क्यों संवाद स्थापित करें? उनके नजरिये से वो सही है। संवाद स्थापित करने की कोई आवश्यकता नहीं है अगर पूरे समय आपकी सेवा हो रही हो।

एक संचार के लक्ष्य को विकसित करते समय जो लक्ष्य ध्येय पर आधारित है यह जरूरी है कि हम सबसे प्रेशित संदर्भ से शुरुआत करें (उदाहरण-निकलास की स्नैक वाली परिस्थिति) और सबसे प्रेरित शब्द से शुरुआत (उदाहरण बिस्कुट)। निश्चयीकरण बहुत जरूरी है - हर एक खास व्यक्ति के सीखने के वास्तविक स्तर पर काम करना। निकलास के लिये जैसे कि हम खास प्रकार का बिस्कुट चुने क्योंकि वो उसके पसन्दीदा है निकलास तस्वीर समझता है, परंतु सिर्फ अपने खास बिस्कुट के।

इसलिये जब हमें निकलास के लिये संचार का तरीका चुनना हो तो इन सब बातों का ध्यान रखना होगा। हमें हमेशा ऐसा तरीका चुनना है जो बच्चा समझ सके, और वो तरीका जिसका मतलब हो। बच्चे की मेज कुर्सी पर बहुत सारा प्रारंभिक कार्य पहले से ही किया जा सकता है छटाई अभ्यास, वस्तुओं को उनके समरूपी तस्वीरों के साथ रखना श्रेणियों का अभ्यास इत्यादि आदि।

हम संदर्भ को सरल बनाने की कोशिश करते हैं। एक आदर्श स्थिति में हम सिर्फ एक बच्चे और दो प्रोफेशनल्स के साथ काम करते हैं। निकलास कुर्सी मेज पर बैठता है, एक प्रोफेशनल बिस्कुट लेकर उसके सामने। दूसरा प्रोफेशनल निकलास के पीछे खड़ा होता है उसको बिस्कुट तस्वीर द्वारा कैसे माँगना है सिखाने के लिये। इस संचार की प्रक्रिया कुछ ऐसी है जिसे हमें सिखाना है। अगर हम केवल बिस्कुट की तस्वीर बच्चे के सामने रखते हैं तो इसका मतलब यह नहीं है कि वो इसके साथ संचार करेगा। शुरु में निकलास को समझ नहीं आया वो खड़ा हो कर भाग गया। या उसने बिस्कुट देखा और उसे लेने की कोशिश की। दूसरे प्रोफेशनल ने उसे बिठाया और तस्वीर इसके हाथ में रखी और शारीरिक मदद से सामने वाले व्यक्ति को दी। बहुत अभ्यास के बाद, अचानक निकलास ने संचार की शक्ति को समझ लिया। धीरे-धीरे हम शारीरिक मदद को क्षीण कर सकते हैं और निकलास आखिर में स्वतन्त्र रूप से माँग सकता है। यह जरूरी है कि हमें ध्यान रखना है कि किसी भी प्रकार की मदद व्यक्तिगत होनी चाहिये।

निकलास को शारीरिक मदद चाहिये थी कुछ ऑटिज्म वाले बच्चों को प्रदर्शन, मौखिक मदद या संकेत की जरूरत हो सकती है।

जब हम संचार पर काम करते हैं तो हम एक समय में एक ही पहलू बदलने का कोशिश करते हैं। निकलास के लिये दूसरे कदम घर पर बिस्कुट माँगना था। कार्य (माँगना) और तरीका (तस्वीर) दोनों वही रहे परंतु संदर्भ का आयाम बदल गया (स्कूल के बदले घर) अलग कदम शब्दों के आकड़ों का विस्तार, और जैसा कि आपको पहले से पता है, "निकलास के पास पहले से 23 तस्वीरों की शब्दावली है" अब।

Cure for Autism - Chasing the Mirage: Try Hunting for the Oasis Instead

Swaminathan Rajan

The Autism fraternity is polarized in many ways. There are many sects and sub-sects, bio-medical vs conventional therapies; Verbal vs Non Verbal; Aspies vs HFAs vs Rest; homeschooling vs special schools vs integrated schools, to name a few.

One of the interesting polarizations are a sect of parents who try for a 'recovery/cure or at least improvement' for autism with *every* trick in the book (and a few outside it). Another fairly recent sect who feel that autism is not a disability at all and there should be no attempt towards a cure/recovery or even attempt towards improvement for the same and advocate 'let them be as they are'; though surprisingly this sect also pursues conventional therapies and/or miracle cures with as much or even more vigour. It is a real oxymoron.

However, perhaps in no other condition is there such a plethora of 'magic cures'. Recently some Hindi daily proclaimed camel's milk as a cure, and manywhatsapp groups went into overdrive. In 13 years, I have heard of a profusion of these; from 'Secretin' to 'Stem Cell' and all of them, at this moment seem to be just shots in the dark.

I'm part of a whatsapp mainstream group. Every once in a while when there is a post for stem cell or HBOT, or any such magic cure, the group resembles a beehive on steroids. And it goes on for a while, until there is a dampener by a few parents coming out with the confessional that it was as useful as a comb to a bald man after a few lacs down the drain. The euphoria dies down (only to resurface a bit later on another reference to any of these mirage magic cures). I think autism is the fastest growing start up in India, right from therapies to miracle cures.

Science has not understood the human brain and the wiring (else there might have been a cure for all intellectual disabilities). Thus given the fact that science has not even discovered what causes autism, we are still some time away from a cure. The chances of a famed 'eureka' moment in the billion dollar research done by many seem remote.

What adds fuel to the fire is a number of stories of children claimed to be cured of autism that appear in the media every now and then. From what I found on the net, US Based Data puts it at 13% (children cured of or recovered from autism).

While this 13% figure in itself is questionable, most of us (including most advocates of- celebrate autism as a gift) try to make them 'recover' in our own ways, with a truckload of therapies, special education and at times medication and bio-med. We are trying to fix them, at times with the 'quickfix' of the mirage of miracle cures. And I feel many think that there is an Einstein or a Newton or a Mozart waiting to be unboxed after all the therapies and wonderful treatments. The tinge of sarcasm is given the fact, that a number of awareness campaigns show these great persons as poster boys of autism, leading not only to self delusion, but also to glamourizing autism, at times with vested interests. Am sure in the near future Bill Gates and Steve Jobs can be prospective poster boys of autism, given the delusional levels and the superiority complex that some of parents of children with autism seem to have.

My own theory of this 13% recovered from autism is three possible eventualities:

1. *Mis-diagnosis in the first place*: This to me is highly possible and probable. Considering there are no blood or diagnostic tests, and it is just based on behaviors (and that too of 2-3 year old kids), there would always be a possibility more so in the borderline case
2. *Autocorrect*: This is my term to a theory by Stephen Shore that I heard in one of the workshops where he spoke. He said that his turning point was when he realized that something was wrong with him, during his teens. And then he started on his auto correct. And he seems to have done very well (much better than the mobile companies), if his books and talks are anything to go by.
3. *Percentile*: ASD is widely recognized as a spectrum.

So mathematically there would be a percentile in the population of people with autism. I think the disability would be barely noticeable in the say 99 percentile and beyond, who will be like the IIM grads of the fraternity.

Point No 3 is my own theory, but one look at persons on the upper end of the spectrum will tell its own story.

And the sad part is that the autism movement has been hijacked by the top ten percentile folks, as it makes a good, glamorous story

There is one more thing I have noticed about autism. The challenges that a person faces, seems to be dictated much more by the severity of autism, rather than IQ levels. And the social impediments are the key differentiator, and that is why the employment rate is abysmal among the Aspies as well.

In the midst of all this confusion, the one thing stands out clearly is that as of today, is that there is no miracle cure despite many canards.

In my view, we try to harness the potential of the kid to the optimal, while keeping our targets realistic which to me, is making my child an all-rounder and as independent as possible after our demise.

With a lot of love, acceptance, compassion, hard work, help from therapists/teachers/extended family, and a bit of luck, and of course the capabilities of the child, there can be substantial improvements in the child and maybe, in some cases pretty close to a complete recovery.

I'd say, let us not chase the mirage of magic cures, let us try to find the oasis of acceptance. And to me acceptance is accepting our children with all their limitations (and strengths), and trying to love them as unconditionally as they love us, rather than wallow in self-pity and angst.

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HELPLINE



Q My daughter, S is 3 years and 5 months old. Recently she was diagnosed as mildly autistic. I was given a treatment plan for 3 to 4 months, but no insights to what exactly are the issues relating to her and how best can I help her. I refuse to believe that I as a mother cannot help her in any way. I need to understand how I can help her make friends. She has problems in majorly two areas: she is not making friends yet and she is not that verbal. She IS speaking; just not framing sentences on her own yet. I understand she has a social interaction disorder. I need help to know what the next step is for me. She is in nursery class; she is a bright child and has no major issue academically. About her autism, all I was told is that her CARS score is 35 and I don't know what that means. The internet is also very vague in this matter. Please help me help my child. If there is any way I can get help in understanding her specific situation better, and help her make friends. I know she wants to, she always wants to be around children, she is just not sure yet of how to join them.

A Thank you for writing to us. S sounds like a delightful little girl and it is wonderful to know that you are looking at ways to understand her specific situation better. You've raised some pertinent points and it is a pleasure to try and address some of the concerns you have expressed. Receiving a diagnosis for autism for one's child is a difficult time and especially so if you don't fully understand the condition. Understanding autism and how it affects your child is the first step. Without that knowledge a parent is vulnerable in not being able to assess the quality of advice that is received. An understanding of autism places you in a position of strength where you can question and assess any treatment plan that is suggested for S.

You are quite right when you say that "I refuse to believe that I as a mother cannot help her in any way" because no one knows S as well as you do. AFA is a parent run organization and our children progress because of the dedication and hard work that mothers and often fathers too, put in.

You have noted that S is not making friends and is not sufficiently verbal. As you are perhaps aware, autism comes with challenges in the development of communication and social interaction. People on the autism spectrum find it hard to interact with others and

make friends. Many want to make friends but are unable to do so because they do not understand 'how' to make friends. They find it difficult to understand the social norms and rules around such situations. However, with focused intervention children on the spectrum can learn ways to interact with other children appropriately. The key is to keep the interaction motivating, fun and free from demands as much as possible.

There is much that you can do for this. One would be for you to play a game like catch and throw with S, but without the other children, so that she learns the rules of interaction and what is expected of her. Then introduce a child into this scenario, all the while helping S by facilitating the social interaction. Initially it may be hard for her to make connections on her own so adult facilitation will have to be continued for a length of time. Since she likes being around other children, you can also take her to the park where they play and facilitate interaction but without placing demands on her.

It's great that she is using words to some extent for communication and we understand that you would want to further work on her speech. Autism is a neurological condition in which one of the areas that is most affected is the ability to communicate, which includes both understanding of language and using language to express oneself. It would be a good idea to think of the language from S' perspective and be 'her voice' when trying to communicate. For example, when she wants water you can say very clearly "I want water" and immediately give her water so that she understands that saying "I want water" will get her water without fail. You can also try giving her more vocabulary during play time, for example every time you are throwing the ball you can say "throw ball" and so on. All this while not putting any pressure on her to perform would ensure that her motivation to speak does not go down.

Social and communication challenges are at the core of autism. S will have to be helped to learn the power of communication as well as the social rules that guide our communication and interaction with the world and enables us to make friends.

For you to know where to start, it is helpful to have an assessment of S' strengths and challenges. The CARS score in itself will only tell you the 'degree' of autism but

a full report would certainly highlight the areas that you want to focus on when helping S learn. It would also help in getting an Assessment of Functional Skills to help you to understand current strengths and needs, specific to your child.

As a mother it would really help to learn as much as you can about autism. Equipped with this knowledge will lead to the confidence to help S learn in a manner that will be most beneficial for her. There are numerous books and journals you can find online.

In addition AFA runs foundational trainings and courses for parents. You will find more information on these on our website: www.autism-india.org

Hope this helps. Do write in if you have any further queries.

LETTERS

After so many years in corporate life, circumstances had forced me to give up my cushy job and explore other options in life. I took this opportunity to make a paradigm shift in my work focus from a research oriented management function to try my hand at something which may be useful to the society; my way of giving back to society.

At this juncture of my life, I was fortunate to come in contact with Action for Autism (AFA) which has completely transformed my idea of autism. Before this, I was vaguely aware of the term autism and knew that people who had autism were part of the variety of specially-abled people present around us.

My first meeting with Merry Barua was an eye opener. Her infectious zest for life, her positive outlook and welcoming nature, immediately made me feel I have reached the right place that I had been seeking. I immediately joined as a volunteer and started spending time at AFA.

I realized that Merry was a parent herself of an autistic child and as she was bringing up her child, she realized that there was very little understanding of Autism in India. She along with a few likeminded parents spearheaded the setting up the centre specific for Autism that we now know as Action for Autism (AFA). We are grateful that she looked beyond her personal

circumstances and utilized her experiences to help other people in similar situations.

AFA taught me to celebrate autism. Their approach to Autism and handling of autistic children was an eye opener to me. They are doing such excellent work for autistic people by trying to build an inclusive environment where it is clearly understood that each child is unique, whether autistic or typical, and need individualistic handling. As a volunteer, I attended a session of their 12 week Parent Child Training Program (PCTP) where parents are provided support in understanding their child better and improve their bonding with the child. The parents are provided with tools which help them to educate their children more effectively and within this period, I saw such transformation in both the children and their mothers, that I was left spell bound! The details of each activity, so carefully planned by the teachers, the daily discussions, feedback to the parents and their passion towards their work where each child is treated as if one's own, ensures success of each session which is held 2-3 times a year and has helped people all over India and its neighboring countries. The objective of the AFA team is to enable these parents to take back their learning and spread the message and share the techniques learnt at the workshop to their surroundings so that there is a ripple effect which can benefit wider circle of people. This kind of totally selfless attitude is truly remarkable.

Many of the teachers working in AFA are mothers of autistic children and have an excellent understanding of Autism. The positive atmosphere at AFA where everyone greets you with a smile and enthusiasm is very enabling. The basic principle followed in AFA in all their interactions are the 4Es – Energy, Enthusiasm, Excitement and Energy which is displayed in bold letters across the building, as a reminder to each and everyone associated with AFA. Hats off to the dedicated people involved in the running of AFA and its different programs for their efforts which help children with ASD to reach their full potential and live a productive life.

I would like to thank the AFA team who has taught me so much in such a short span of time. Looking at their smiling faces and their enthusiastic attitude for life, I wonder why we are always so unhappy with such little problems in our supposedly normal lives. I have also learnt that the methods of education and bonding that they teach are equally relevant for typical children.

<UPCOMING WORKSHOPS>

VENUE:

THE NATIONAL CENTRE FOR AUTISM, NEW DEHI

Empowering the Child with Autism

30 January - 1 February 2018

Kick starting our year with another exciting workshop for you to understand the world of autism. A workshop for parents, teachers, shadows and other professionals in the field to learn and understand autism beyond theoretical explanations.



A Talk by Dr Wenn Lawson

March 2018

A talk by Dr Lawson, hailing all the way from Australia. Dr Lawson is a psychologist, researcher, author and himself a parent on the spectrum.



Three-day Workshop
for Parents and Professionals

July 2018

A workshop for parents and professionals to experience world from their child's perspective & explore approaches to enjoyable learning. The workshop will explore the different & fascinating learning styles of children with autism.



Know Me, Teach Me

AFA's Annual Training Workshop

September 2018

One of the most awaited workshops, AFA's Annual Training Workshop gives you an opportunity to meet participants from across India & overseas.

'Know Me, Teach Me' will help those who want to get started – in the real sense of the word, as well as those who want to go deep into understanding and help child with autism reach his fullest potential.

Please stay in touch to get regular updates and let us know if you wish to be added to our mailing list for updated information about AFA and our events.

For more information contact by phone <+91 9833885899; +91 11 40540991> or email<anvay.trainings@gmail.com>

AUTI SPEAK

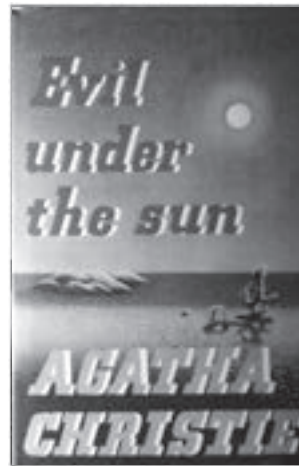
So here's something a bit different in Auti Speak.....a book review by Prakriti Ghosh

BOOK REVIEW

'Evil Under The Sun'

By Parkriti Ghosh

Author: Agatha Christie



I like this book very much, so I want to share my review about it. This book, set in Leathercombe Bay, is about the murder of Arlena Marshall.

The famous Belgian detective, Hercule Poirot comes and solves the case. The main characters are:- Hercule Poirot, Miss Brewster and the Gardeners.

PS: The cover illustration of this issue is a scene from this very novel, too.

- Publisher: Harper Collins • Year of publishing: 2001
- First published : 1941

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AFA MEMBERSHIP FORM

Action For Autism(AFA) is a parent organization that strives to create an environment where individuals with autism and their families can live as fully participating members of the community.

To support AFA to further its mission, please complete the form below and return to: Action For Autism, The National Centre for Autism, Sector 7 & 8 JasolaVihar, New Delhi 110025.

Please complete in BLOCK letters and mail to Action For Autism

Name _____

Address _____

City _____ State _____

Country _____ Pin/Zip _____

Phone _____ Email _____

I am a: (Check all that apply)

Mother Father Other (please specify) _____

Professional: Name of Organisation _____

For Parent of a person with autism ONLY:

Child's Name _____

Gender: Female Male Date of Birth _____
 dd mm yr

Diagnosis _____

Diagnosis received from _____

I wish to become a member of AFA. Enclosed is a contribution
 (Check as applicable)

Via: Cash Online Demand Draft
 (in favour of Action for Autism, payable at New Delhi)

Online Transaction/Draft No _____ Dated _____

Drawn on _____

Amount in Words _____

Annual Membership Charges:

Parent: Rs. 500 Professionals: Rs. 1000 Institutional: Rs. 3000

Online bank transfer may be made to:

Beneficiary: Action For Autism

Bank: Vijaya Bank, Defence Colony, New Delhi, India

SWIFT No: VIJBINBBDCD IFSC Code: VIJB0006005

MICR Code: 110029007

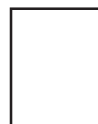
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Oversees Registrations: 600501550010210

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

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