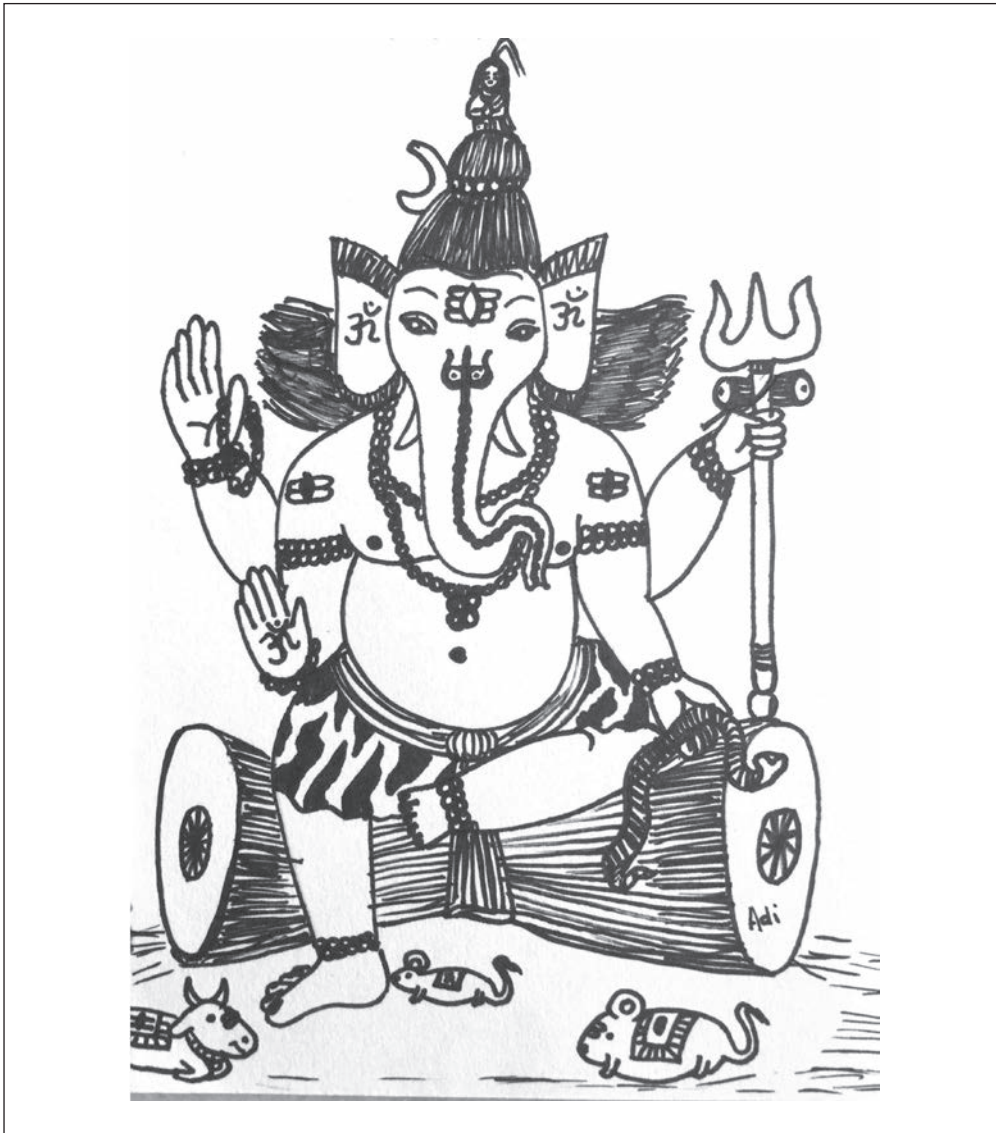
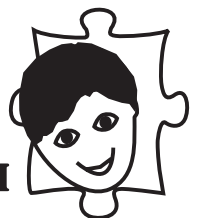


# autism network

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ACTION FOR AUTISM



# autism network

APRIL 2017

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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](mailto: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

### 'Ganpati Bappa Maurya'

Artwork by Adi Swaminathan, 15 years,  
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# PAGE ONE

How society treats its most vulnerable members says a lot about the kind of society we are. When I make this statement I tread nowhere near vulnerabilities of region, caste, religion, age, and so on. I restrict myself to disabilities.

S is a four year old who would be brought for therapy twice a week to a therapist. Sitting across the therapist during the session, S's hand would sometimes start flapping. Each time his hands started to flap S would instantly be met with a spray of chilled water on his face.

P is a 14 year old attending a special needs school. A few times a week she has a session with a particular therapist. During the session she is alone inside the room with the male therapist who closes and locks the door as the 'session' carries on inside.

R meets a man in a store who tells her he knows of a 'cure' for her 11-year-old with autism. She later goes to see him where he concocts for her a large jar of unknown ingredients to take home with instructions to give her son a spoonful for the next year.

Each time D pulls the therapist's hair, the therapist "gives it back to him" by pulling his hair. That's what happens at home too. In addition D is also slapped and pinched every time he tries to leave the table.

M is an adult who has his life posted on social media by his mother: from every outing to each meltdown as well as his moments in the toilet, in the bath, and at the table.

J tracks every new treatment to 'cure autism' and makes sure to put her son through each of them. The latter has been taken to cure doctors for years where he has ingested all manner of substances, has had stem cells injected into his spine, drunk bleach, and continues to be put through invasive procedures; all to applause for J from admirers on social media.

What is common in all these examples, experienced or shared by carers, is the lack of agency on the part of the person with disability. Do they have a say in what happens with their lives? Do we even believe that they have an opinion that matters? What is also common is that they

are all loved by their families. Then how does a loving guardian make the child/adolescent/adult drink bleach or some strange slop from a jar given by a stranger? How can a loving guardian allow a so-called 'therapist' spray chilled-water into a four-year-old's face when the child is already flapping with anxiety? How can a school allow a pubescent 14-year-old spend 45 minutes alone in a locked room with an adult male therapist? How can doting guardians post their wards private moments for the world to see and comment on?

Would any parent / guardian / professional willingly consume an unknown potion from an unknown source?

Would we drink bleach? Would we want private pictures of our unguarded moments posted on social media for all the world to see and discuss? Would a typically developing child allow this? Would I want someone to spray my face with cold water each time I did something they did not like?

Why do otherwise loving guardians allow such unspeakable behaviors inflicted on their wards? Despite the love we bear towards our children with autism, their lives are not worthy enough. The money we spent on them is considered money going down the drain cause there is 'no return on the investment'. Despite the 'love' we bestow on our children we devalue them through our thoughts and actions.

But I pause. And refer anyone interested in exploring this to the lead article in this issue: 'What Really Matters' by Elizabeth 'Betsy' Neville. Special needs schools and homes for persons with disabilities are traditionally at greatest risk of spiraling towards human rights violations. In this light, the principles Betsy discusses take greater urgency.

This issue also carries an article on 'Enhancing Your Child's Communication At Home' by Indrani Basu of Autism Society West Bengal. We are excited to have Basu conduct a workshop on Inclusive Education for AFA at the end of August. AFA has carried out a number of trainings on Work and Employment in Mumbai, Pune and elsewhere. The next one is in September in Delhi. Which will be followed by AFA's signature foundational training workshop in October.

Wishing our readers happy reading and many opportunities to share and learn!

# What Really Matters?

Elizabeth “Betsy” Neuville

What are the questions that are ringing in our hearts and minds when we consider the futures of the people we care deeply for? As advocates and change agents, what are our highest hopes for people with disability in India?

These questions are worth considering, and they require us to think about the needs of vulnerable people, people who experience autism and other disabilities. I believe that how we answer these questions will determine the future in very real ways. However, in my way of thinking, to answer the question, we need to move away from abstraction and center down on individual people we know and care about. I think of a young man named Tim, who carried many labels which included autism, and whose parents were fierce advocates for and alongside him. They fought for every treatment that was available, they advocated for hiring the very best clinicians, using the latest strategies. As Tim grew into a teenager and young adult, they shared their fear and terror when they wondered what would happen when they were no longer living, and unable to provide a home and security for him.

Tim’s parents, and others began to engage in a searching process, trying to thresh out what really mattered in Tim’s life. With the help of a small circle of support, they invited friends and others invested in Tim’s future to think with their family about what really matters to Tim. One of their discoveries was that what was really important to Tim for his future, and his present, were things that looked pretty much like the things most of us strive to have in our lives.... A network of close friends, a sense of connection to our community, a ‘place’ in society, a good reputation, meaningful work to do, self-confidence, and a life that leads somewhere along a path that makes sense based on Tim’s unique identity.

Tim and his family began to think about all the therapies, special strategies, and ‘training’ they had always thought of as his real needs, and reassess them as simply strategies that may (or may not) lead towards

the real goals that matter for Tim to have a good life. This was a sea change for Tim and his support team, and they began to ask questions about their vision for Tim’s life, one that included friends, belonging, connection to places and spaces that are important to Tim, a life of change, transformation and growth, and realized that a razor-sharp, relentless focus on skills development, mitigation of ‘problem behaviors’, compliance training, therapy might actually stand in the way of Tim getting the good stuff.

After all, when does one start actually getting to have a good life, rather than people preparing you to do so? In his mid-twenties, Tim was spending so much time being ‘prepared’ for life that he seemed to be missing out on actually living that life. At about this time, Tim’s family was introduced to the principles of Social Role Valorization, a way of thinking about what *really works* in supporting people with disability or other vulnerabilities to get access to those real genuine components of a full rich meaningful life. A study of social theory tells us that there are certain things in all of our lives that open up the door to the really good stuff. These certain things are the valued social roles that we all take for granted.

For Tim, these were things like being a big brother to his sister Jean, being a member of a faith community, and a member of the chorus at that church. It means being a student in a photography class, and learning to use his photographs for a visual ‘blog’ that he posts. For Tim, it meant taking up his natural interest in the outdoors, and joining a local hiking club that also volunteers at his local park. For Tim, it meant beginning to craft his own life, and developing some friendships with people he met through these activities separate from his family. For Tim, it meant beginning to learn about the local political scene in his home town and becoming an informed voter, as well as a volunteer at the polls on Election Day. As he began to move into some of these powerful and unique roles, those of us who supported him began to see some of those real good things come into his life. For Tim, special strategies

and therapies and training were evaluated in light of how they might help (or hinder) him moving into valued roles. As Tim began to be successful in some roles, new roles were crafted, and he was supported to move into them, often by very natural means and ways that all of us would be familiar with – through role modeling, imitation, immersion in the natural environment.

This process, of envisioning and helping people move into typical valued roles, has great possibility. It is at the heart of Social Role Valorization, an idea base that is newly introduced in India and is generating not only talk and teaching but action. As we help people with autism and other disabilities take their place in Indian society, we must remember that life is now for all of us. That every strategy and method that is employed must have an important question asked and answered. That question is, “For what?” How will this strategy lead to valued role and good lives? At what point do we not only ask people with autism to change in some way, but we expect society to change as well, making space at the community table for all people. People will only learn to be with people with disability by actually being with people with disability. All our training and preparation aside, life starts now. Tim taught me that lesson.

### **What is Social Role Valorization?\***

Over the past year, you may have heard Social Role Valorization mentioned and discussed across the organizations serving and supporting people with autism across India. These provocative and challenging ideas are stirring up those of us who are engaged in supporting people with autism to live good lives and share the good things of life in Indian society. In August of 2016, an intensive 3 day course was provided for a group of 44 professionals, family members, and advocates from 18 states. It was a compelling three days, we the group wrestled with applying the ideas in the lives of Indian citizens with disability. Over the course of the next year, the work towards bringing the ideas alive has been furthered by those initial workshop participants who are teaching and using the ideas across India via a series of workshops. The idea within ‘SRV theory’ are challenging, and they cause us to question the ways to help people move forward in their lives, and also challenge some of the fundamental assumptions that many services and organizations are based on. The idea contained within SRV help us to think and act with high clarity about the realities of life for people with disability and other devalued conditions, and gives us powerful ideas about how to move forward.

Social Role Valorization, developed by Dr. Wolf Wolfensberger an American psychologist and academic committed to understanding and responding to the plight of oppressed and marginalized people, is a high-order framework which helps us understand how people come to be at the ‘bottom of the social ladder’. It further explores what tends to happen to them once they get there, what really works to lift people out of deep devaluation, and how we might work to assist people to have access to the ‘good things of Indian life’.

To understand the profoundness and importance of Social Role Valorization, one must first understand the processes of social devaluation and how they impact all people. Social devaluation happens on an individual level, person to person, where one person sees another person as have less worth than other people. This often happens when a person is seen to have one or more characteristics that are considered to be undesirable. Because the characteristic is seen as undesirable, the person having that particular characteristic also loses their value in the minds of others. This social devaluation also happens on a societal scale, where an entire class or group of people can lose their social value based on a shared characteristic, and when this happens the members of that group are likely to be systematically poorly treated at the hands of that society. This is the kind of devaluation that SRV concerns itself with – the systematic assignment of low value to groups of people, including people autism, mental disorders, people living in poverty, people who are aged, people with impairments in intellect, people of low caste, or of certain devalued ethnic or religious identity, among many others. Once devaluation happens, SRV framework gives us a clear picture of what is likely to come the way of people who are caught in the web of devaluation, unleashing a long list of ways they will be treated and . Understanding this process, which we refer to as ‘wounding’, is a hard pill for many of us to follow, but it rings true for those of us who walk closely with devalued, marginalized people.

Often, people who are judged to have low value in society will begin to lose their individual identity, and their impairment may take over their identity in the minds of others. For a person who experiences autism, he may become thought of ‘an autistic’, first and foremost, and be seen as being much like all other people who share that label or condition. He is likely to be rejected in profound ways, and thrust into devalued roles such as eternal child, alien, divine, innocent, object of ridicule, animal, inhuman object, monster,

object of pity, burden of charity, sick (and in need of all sorts of specialized therapy), and even better off dead. These devalued roles are held powerfully by all of us, we were taught from an early age that devalued people belong in these negative roles leading to all sorts of negative expectancies.

In all likelihood, once a person is cast in one or more of these negative roles, a slew of other negative wounds tend to come their way, some of which are also forms of the hinge wound of rejection. The first is the wound of distancing. Once a person is thrust in a negative role, the response of society, individually and collectively is often to create distance between itself and the person or people they devalue. This often happens quite literally, and devalued people get physically segregated from valued society. They are placed all together, apart and away, often congregated in groups of people who are seen to be 'like them'.

Physical distancing is the most common worldwide way that devalued people are distanced, and the negative consequences of segregating devalued people is well documented, and often deadly. It should also be noted that segregation is often carried out with benevolent intention, but the results can be disastrous in terms of the likelihood of full, rich, contributing lives. Once people are congregated and segregated, it is easy to justify their segregation, and it becomes difficult to imagine how such people could be a part of typical society in any meaningful way.

Once distanced, another wound which flows directly from this is that all sorts of powerful images begin to get attached to devalued people, images which often convey negative messages about the person's citizenship, difference from valued people, and societal worth. This is a particularly insidious wound, as it communicates broadly across the society that 'such people' do indeed have less value, and are in fact in worthless, dangerous, childish, unimportant, animal-like, trivial, or diseased. This process of negative imaging has great power because it relies on symbolic communication, which is a deeply unconscious way of learning. For this reason, people who receive such symbolic communication are unable to decode or analyze the messages and reject them. In this manner, devaluation about certain groups of people is taught broadly across the society, is passed down from generation to generation, and is often unchallenged and unexplicated. Examples abound in marketing materials, fund-raising appeals, and media portrayals of people

with disabilities, or, specifically, people with autism. One need only do a quick internet search of images for autism, and a host of examples will arise. Often these images link directly to the negative roles that devalued people are stuck in, including imagery that reflects the paradigm of 'sickness' and 'treatment', language that refers to people as objects rather than people, threatening or frightening images, images that position people with disabilities as 'broken', suffering, or pitiful, and a host of others in poor treatment. They also drive out room for more positive roles.

Once stigmatized in such a way, the way is paved for profound harm to come to people, and for, at the very least, a restricted and predictable course of life. Unemployment, deep poverty, a lack of freely-given friendships and relationships, vulnerability to violence and abuse, and a lack of opportunity, belonging citizenship and participation in the most meaningful aspects of life are real potential life experiences that lie on that path of life for many people. At the very least, a narrowed course of life in which a person is not fully able to have their gifts and potential recognized and offered to the world is likely. The cost of such lifelong wounding is high to the person directly affected, the entire group of people which they are seen to belong, their families, and Indian society as a whole.

### **Possibilities and Power of Valued Roles**

Many families, professionals, and citizens recognize these difficult and painful life experiences, as they are easily seen in everyday life in India. However, understanding them as universals in the framework of social devaluation makes them especially poignant and painful to contemplate, as they implicate each of us as individual people who of course ourselves devalues people, and a society which is organizing itself in hurtful and harmful ways towards people whom it devalues collectively.

However, once fully understood, a deep and clear understanding of the process of social devaluation provides insight and a pathway towards taking actions which lessen devaluation and its impacts, mitigate the effects of the wounds, and create the potential for profound improvement in the life possibilities for one person, or for an entire group of people. The action implications from such an understanding can drive effective change in individual lives, within families, across communities, and on a societal level.

One adaptive response, at least on an individual and service change level, is to harness what we know actually

works to lift people out of devalued roles and help people gain access to the power of roles. This includes the utility of assisting people with autism and other disabilities to fill valued social roles. As we know from role theory, filling valued roles assists all people to have access to those things that most of us consider to be the 'good things of life', such as belonging, acceptance, relationships, a good reputation, a strong self-image, and many possibilities for person growth and developing ones interests and offering one's talents.

A quick study of the field of role theory tells us that valued roles are an intrinsic and essential part of the lives of all people who have a valued status within their society. An exploration of valued roles shows that they in fact make up the fabric of a desirable human life, bring a great deal of richness, and cause life to be full. Most valued people hold a myriad of valued roles in the spheres of relationships, work, personal growth, civic life, and spiritual life. They are family members, adults sons and daughters, home owners and tenants, club members, voters, exercisers, sports fans, favorite aunts, neighbors, best friends, music lovers, pet owners, needleworkers, woodworkers, facebookers, team members, committee members, poetry lovers, avid readers, tax payers, members of faith communities, just to name a few. These kinds of examples represent only a few, and most valued people weave in and out of such valued roles throughout the days, weeks, and years of their lives, never stopping to think about what actually they bring to life. Each individual role come with a host of activities that comprise the role, and thus much of life is spent doing the activities that are inextricably linked to roles. These roles bring immeasurable meaning and value to people's lives, and all sorts of benefits, and yet most people with a valued status hardly consider what they bring into their lives.

Social Role Valorization asserts a simple yet elegant premise:

1. That the 'good things of life' tend to come to people with many valued and strong social roles.
2. Those 'good things' are generally universally desired and valued by most people, in other words, they are not relative. They include things like reasonably good health, true home, belonging, acceptance, a good reputation, personal growth, opportunity, a good self-image, material stability, a full lifestyle, to name a few.
3. If one wants people who are devalued to have those 'good things of life', they must assist people to fill

valued social roles. This will not assure those 'good things' come, but it does increase the probability.

4. Without having values roles, it is highly unlikely and perhaps impossible that a person will gain those 'good things in life'. This is an often unpleasant reality which people who desire change need to come to grips with.

It is not surprising that many people with autism, often segregated and congregated into special programs just for people with autism may get many opportunities within such programs for activities. Activities keep people busy and may offer certain benefits, but do not offer the rich benefits to which valued roles offer an open door. The difference between a valued role and an activity is a bit subtle, but exceedingly clear once understood. A simple example – a trip to a local football match is an activity, but being a 'cricket fan' is a role.

Someone may enjoy a trip to a football game, but the many potential good things in life that come from being known as a real 'football fan' are much deeper, have greater impact, and open up the door to the good things in life. Doing an art activity may be enjoyable, but being in the role of an 'amateur painter' or 'sketch artist' is vastly different. Activities are important as a part of a valued role, but without resulting in a valued role, lose most of their benefit. Nearly all group activities in the myriad of programs that can be seen across autism services – dance therapy classes, music therapies, recreational trips, art projects, are done in groups, and are not at all geared towards helping people discover and move into individualized valued roles.

A number of organizations primarily committed to assisting people living with autism to take their place in India society have invested learning and sharing SRV as part of the progression towards more positive futures are Action for Autism and Ashish Centre in Delhi, Autism Society of West Bengal in Kolkata, Bubbles Centre for Autism in Bangalore, and Transcendent Knowledge Society in Kolkata. Each has emerging SRV expertise and leadership, is using SRV to inform service design and organizational values and philosophy, and is a part of the leadership movement across India in SRV.

We invite you to contact people who are exploring these ideas within India, and check out the International SRV Association website for resources at [www.socialrolevalorization.com](http://www.socialrolevalorization.com).

*...cont on page 7*

# Simon Says, "Play a Game"

Maithri Sivaraman

The growing awareness about the early signs of ASD has made it possible for an increasing number of children to be diagnosed by the age of three (Stahmer, 2011). Considering the difficulty in building social relationships and peer play that is often associated with autism, it is important that specific instruction on social behaviours in various play situations is provided. Extensive interaction with peers has been shown to facilitate social coordination. At ages below ten, this interaction primarily occurs during play.

There is a lot of research that has been done on teaching socio-dramatic play, functional play, and cooperative play skills to children with ASD. The previous article in this series (Autism Network December 2016) dealt with a rationale for teaching play skills to children at all levels of functioning. The current article deals with an aspect of play that is an important activity among typically developing children — games.

Games serve as a useful opportunity for children with ASD to practise and develop social skills (Davis-Temple, Jung & Sainato, 2014), but there is very little information available on the effective methods of teaching games. Teaching games, though recognised for its importance, often involves many challenges - the play situation not being motivating to the child, the need for intrusive prompting, and having to teach the rules of each game and handling problem behaviour, to name a few. Some of these challenges can be overcome by using the evidence-based strategies listed in this article.

## How to teach ANY game?

### *Modeling*

Provide the learner with opportunities to observe others playing the game. This doesn't necessarily mean that the learner stands apart and watches others playing the game. He could be put directly into a pool of players involved in a game. At this stage, the only expectation from the learner is to stay within the play area for a few minutes. No other form of participation/engagement might be required.

Additionally, providing a video model of a group playing the same game will serve as a form of priming and prepare the learner for the actual experience.

### *Shaping (Gradually increasing expectations)*

The learner could initially engage only in those play actions (relevant to the game) that he can do independently. Subsequently, better performances in these actions can be modeled and expected (Ward, 2011). For example, in a game like 'Red Light/Green Light', the learner may initially just run along with all the other players. It does not matter that he does not stop at the 'Red Light'. But if the learner is successful at this level and shows independent participation, over the course of the next few instances, a play partner could be made to hold hands with the learner and have him stop at the Red Light. Gradually, the partner could stop holding hands and independent performance in 'red' and 'green' can be probed.

### *Using perseverative interests during the game*

Having interests with a narrow focus is a fairly common phenomenon in children with ASD. Games are an avenue to provide functional utility and an appropriate social context to such interests (Koegel et al., 2012).

If the learner has a keen interest in vehicles, the 'Red Light' game can be modified to be played with cars rather than people. A perseverative interest with names of washing machine brands can be accommodated in the same game — take a step forward every time a correct brand name is said or move back when a wrong name is said. For a child who likes twirling threads, the thread could be at the finish line to motivate the child to 'go' during the 'Green Light'.

## Assessing motivation - How to tell if the child is interested?

Being able to gauge learner motivation is as important as knowing how to teach a game. Not assessing a learner's interest level and being too focused on the process can impede a learner's ability to play games. A fairly common occurrence during game-instruction is over-prompting. The overwhelming urge to teach the child to play by ALL the rules of the game on the very first instance can be truly aversive and lead to problem behaviour. A closer observation might reveal that over-prompting usually occurs when the child's interest in the game starts to wane and continued engagement is expected.



This can be overcome by taking motivation into consideration - choosing games where the learner's interest lies. It increases the likelihood that the learner exhibits independence in at least one of the expected play behaviours during the game. The 'Red Light/Green Light game' might work well for learners who like to run or be outdoors; 'Simon Says' might work for learners who have a good action word repertoire; simple board games like 'Tummy Ache'/'Pizza Pizza' (Orchard Toys) for learners who prefer visual stimuli and matching.

Additionally, here are some ways of measuring motivation during the game (Ward, 2011):

1. *Requests*: Did the child request for the game after a few exposures?
2. *Initiations*: Did he make any initiations during the game (ex - asking for a turn to hold up the cards and say 'red' and 'green')
3. *Responses to partner initiations*: Does the child respond to play partners? (example - moving forward when a partner asks him to do so)
4. *Affect/Mood* : Does the child seem happy? Is he smiling, jumping, laughing?
5. *Nature of play actions*: Does he run fast or does he have to be pushed to run? Does he wait expectantly at the starting line or is he indifferent?

If there are no initiations or no independent play actions, these are clear indications of low motivation in the game. If such situations persist, it is best to choose a different game.

Identifying a learner's disinterest and knowing when to stop, or modifying a game in a manner that might develop motivation will help assure student success. Motivation is fleeting - what was fun yesterday might not be fun today. But being proactive about gauging these variations is what should be lasting.

*cont from page 5...*

\* The description of *Social Role Valorization* adopted in this article is adapted from a manuscript of SRV submitted for publication.

*Betsy Neville is the Director of Keystone Institute India, a values-based educational institute working across India to fuel the movement towards full, rich, and*

A number of strategies to teach games and assess motivation during play have been discussed. However, the ultimate goal for a parent/teacher who decides to teach a game to a child is to be 'process-oriented' rather than 'product-oriented'. There are no points for playing the game the *right* way; it is not a destination.

One has got to do whatever it takes to show the kids that games can be fun!

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*meaningful lives for and alongside people with disability. Betsy blogs at:*  
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*You can track the activities of KII on facebook at*  
<https://www.facebook.com/keystoneinstituteindia/>.

*KII is a collaboration of The Hans Foundation and Keystone Human Service International.*

# MAHER

[An excerpt from the book I'll never write]

*Sakeena Fiza*

I have been staring at my laptop screen for almost fifteen minutes now, figuring out how to begin this. My mind is a whirlwind of thoughts begging to be heard. Then I thought I don't need this to be scripted or to be perfect. I want this to be raw, true and real.

My name is Sakeena and I have an older brother with autism.

Autism. What is it? How does it occur?

These are the questions I have been asked every time I've told someone my brother is autistic. I've been dumbfounded as to what explanation I should give them, so I tell them a few challenges that my brother faces and they nod and show sympathy. But they never understand. No one ever does and I don't expect them to.

Despite autism being such a common occurrence nowadays, there isn't awareness amongst people. But I don't think awareness would allow a person to truly feel the emotions that arise in your heart when you are near a child with autism.

People usually come to conclusions such as mental illness and exclude these children from society, they become outcasts. This irks me to a very great extent. My brother can't go to a mall because people are disturbed by the noises he makes which are not considered normal. My question to all those people who stare shamelessly with judgmental expressions; aren't these children who don't have the clarity of words allowed to express their emotions without being treated like creatures from another planet, isn't their way of communication accepted in this world filled with millions of languages, aren't they humans just like us? At the same time, I'm truly grateful to those who try to understand these beautiful children and put in their efforts to help them integrate themselves into society. People don't understand that even small things like, turning your head away instead of staring when a child has a tantrum will encourage the families of these children to bring them out more often because they feel they aren't disturbing the peace of others.

I'm no saint either. Whenever my friends come over, I usually lock my room so my brother doesn't come in and start jumping making a scene. Sometimes I'm annoyed by him because our family can't go out to dinner together or for a movie, he might throw a tantrum and we might have to suffer the embarrassment. So someone always stays home while the others go out. And I get vexed at times when I can't eat in peace, he's always hovering over me asking for food or when I can't hear the TV because he's laughing too loudly and making noises. Especially when he has tantrums, the entire atmosphere in the house gets dull and we have to lock him in while we sit in our rooms praying him to be quiet.

Then when I really think about it, guilt washes over me and this sadness rises from somewhere deep in my body covering me like a shroud. I've been thinking of how his presence affects me but in that moment I never thought about him. How must he feel when I shout at him to move or when I can't understand what he's trying to say? How must he feel when there is noise and there is an insistent pounding in his head? How must he feel when we go out and leave him behind? How must he feel when he has a headache or stomach pain and isn't able to tell us? How must he feel to be excluded from everyday life and follow a strict routine without experiencing the world because fickle mindedness seems to have taken over the world? How must it feel to not be able to cross a road or run when there is danger? How must it feel to not be able to do things that come to us naturally? How must autism feel?

I remember an instance when he was having a tantrum and he was locked in his room, we usually don't go inside as he might get violent. That day I went in, I felt bad that he had to be locked up like some animal until he calmed down. I sat down before him and I saw tears in his eyes as he wept, they were bloodshot. His face was pure agony. A gut wrenching feeling clawed at my insides and I couldn't help the tears in my eyes. This child cries like all of us, we all have tantrums, we all need to let out our frustration and we need have many ways to do that but this child only had a few. In that moment I decided that whenever he has a tantrum, I won't pray for him to stop instead I'll pray that I understand why he is crying and that I can help my brother in any way I can.

There have been days when I wished that I could have been autistic instead of my brother, just so he could grow up to become successful and utilize his brain to its

fullest potential. But what I failed to realize that he is already the most successful and accomplished person I have met. Everything he does now was a huge hurdle for him at some point and I am not determined or persevered enough to have pulled through all that and come out smiling. I am convinced that my brother will do accomplish more great tasks as he progresses in life.

My brother is twenty years old and was given the name Maher by my father. I have to tell you, he has the most beautiful laugh. He was first diagnosed as deaf as he did not respond to his name. But later after relentless efforts by my mother to find out why her child wasn't progressing like other boys, Maher was diagnosed with severe autism. The journey after that was a long walk off a short ledge, to most people.

But my mother wasn't most people. No... she is superwoman, she is what Marvel comics should be written about.

I would like to tell all mothers with children having autism, physical disabilities, Down's Syndrome, quadriplegia and sadly the list is longer. You all have the biggest and most courageous hearts, it isn't an easy task raising these children and I don't know how you did it and what kept you going but all I know is you all are truly an inspiration and you all must be so proud of giving birth to angels.

I have to give credit to my father, he loves my brother so much it has no bounds. Be it buying his favourite food or building a business so my brother can have a secure future. He is such a wonderful man. My parents have been through the most turbulent times but have come out victorious and will always be my role models, the amount of pride and respect I have for them is unreal. I always hope they love Maher more because he deserves more love; he deserves all the love in the world.

My younger brother and I are blessed to have a gift from the heavens as our older brother. To all the siblings out there, your brother or sister might be a bit different from your friends but don't treat them indifferently. They are a reminder that there is still good in this world.

All my dreams and ambitions are only due to my brother; he arises in me passion and gives me fuel to succeed. I have a reason to do good. I have a reason to be good. Children that don't have siblings with autism don't have the capability of understanding people from a small age, they don't develop a sense of responsibility

that will help them throughout their life; they don't have someone who will love them unconditionally with a pure heart under all circumstances.

That person to me is Maher. There is so much more to write but I will end it on this note.

**Seven billion people in this world and God allowed me the honour of being Maher's younger sister and I'm as proud as you can get.**

*Sakeena Fiza is a 17 year old science and computer student living in the United Arab Emirates. A true bibliophile, Sakeena has been a voracious reader from her childhood. She writes the blog SakeenaTalks (<https://sakeenatalks.wordpress.com/blog/>) where she presents her perspective on life.*

## Enhancing Your Child's Communication at Home

*Indrani Basu*

Parents often get very focussed on teaching their child with autism primarily at the table. We think table work is the only way our child will learn. But we need to remember, that though table work is one very important aspect of our children's learning, there are other ways our children can learn too.

Opportunities for learning occur throughout the day and we need to be perceptive and able to seize these opportunities when they happen. The best learning happens when the child and parent are relaxed and having fun, rather than being tense over what is a correct response and what is not.

A very important part of a child's learning is communication. In fact communication is something that needs to be worked on throughout the day. Cause and effect toys (if your child enjoys them) are often a good place to start since they help a child start to learn about reasoning. These can be musical toys, where if a button is pressed, music plays. It can also be something lights up upon the button being pressed or a combination of the music as well as the lights coming on. It need not be an electronic toy, there are plenty of other manual

*...cont on page 17*

## आगम/वृद्धि करने वाला संचार

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

**हिल्डीर डे क्लेरक** (Hilde De Clerq)

अनुवाद – पूजा खन्ना

हिल्डी डे क्लेरक Opteidigscentrum Autisme नाम के प्रशिक्षण केन्द्र, एंटवर्प, वेल्जियम में एक प्रोफेशनल है। वो माता-पिता एवं प्रोफेशनल की अंतरराष्ट्रीय स्तर की प्रशिक्षण और थामस नाम के ऑटिस्म वाले एक युवा की माता है।

‘बात करना’ और संवाद स्थापित करना’ इनके बीच बहुत बड़ा फरक है। एक गैर मौखिक ऑटिस्म वाली युवा महिला के पिता ने एक बार मुझसे कहा कि वह अपनी बेटी के लिए अभी तक यह सपना देखते हैं कि वो एक दिन बोलेगी” इस प्रकार का सपना सामान्य, मानवीय, समझने के योग्य और न्यायोचित है, भले ही यह लड़की बोलने लगे परन्तु वो फिर भी एक ऑटिस्म वाली महिला ही रहेगी।

ऑटिस्म वाले मौखिक व्यक्तियों के पास “बोल चाल के शब्दों” की बड़ी शब्दावली हो सकती है, परन्तु वो हमेशा अपने शब्दों का उपयोग संवाद स्थापित करने के लिए नहीं करते। उनकी भाषा की विशेषता है कि वो अन्य लोगों द्वारा बोले वाक्यों को दोहरा सकते हैं। (Echolalia) उनकी अपने पसंदीदा विषय के बारे में अपने आपसे लम्बी बातें करने की प्रकृति हो सकती है, उन्हें निराकार धारणाओं का ना समझना भाषा के व्यावहारिक व सामाजिक इस्तेमाल में मुश्किलों का रहना इत्यादि हो सकता है।

खासकर संवाद स्थापित करना और सामाजिक कौशल के क्षेत्र में यहां तक की ऑटिस्म वाले बहुत कुशल व्यक्तियों को भी बहुत प्रकार की मुश्किलों का सामना करना पड़ता है। मार्क सेअर, ऑटिस्म वाले एक व्यक्ति है और ‘कोपिंग’ सरवाईवल गाईड फोर पीपल, विद एसपेरजअर सिंड्रोम के लेखक हैं, ने ऑटिस्म की एक बड़ी ही दिलचस्प परिभाषा दी है। ‘ऑटिस्म वाले

व्यक्तियों को हर बात एक वैज्ञानिक तरीके से सीखानी पड़ती है जिसका ज्ञात साधारण लोगों को सहज ज्ञान से ही हो जाता है।”

संवाद स्थापित करने की परेशानी कुछ मामलों में शब्दों के न होने की तुलना में बहुत अधिक लगती है। ऑटिस्म में यह एक अहम मुद्दा होता है कि ऑटिस्म वाले बच्चे व वयस्क पर्याप्त रूप से इस बारे में जागरूक नहीं हैं, कि वो संवाद द्वारा अपने परिवेश को प्रभावित कर सकते हैं और संवाद जरूरी नहीं है कि शब्दों द्वारा ही हो। बहुत से अन्य तरीकों का इस्तेमाल संवाद स्थापित करने के लिए किया जा सकता है।

**टीच (TEACH)** – संवाद पाठ्यक्रम ऑटिस्म वाले बच्चों में स्वाभाविक संवाद की समीक्षा करने का एक उपयोगी साधन है। यह अर्थपूर्ण संचार के कई आयामों का उल्लेख करता है, जैसे रूप, कार्य, प्रसंग और अर्थ सम्बन्धी श्रेणी।

संचार पर इस लेख का लक्ष्य पाठकों को यह सुझाव देना है कि हम कैसे संवाद, सम्बन्ध की इन अलग-अलग आयामों की अवगत समीक्षा कर सकते हैं और उद्देश्यपूर्ण अवलोकन की शुरुआत से ही किस प्रकार संवाद सम्बन्धी लक्ष्य को विकसित कर सकते हैं।

रूप – इसे संचार को ‘किस तरह’ के रूप में देखा जा सकता है। ऑटिस्म वाले व्यक्तियों का अधिकतर अपने माहौल से संवाद स्थापित करने का एक निजी तरीका होता है।

और ज्यादातर मां-बाप व भाई बहन ऑटिस्म वाले बच्चों के अनुवादक प्रतीत होते हैं। इस क्षेत्र में एक अत्यन्त

रोचक प्रयोग डेरिक रिस्क का है जिन्होंने सामान्य एवं ऑटिज्म वाले बच्चे को चार परिस्थिति में एक साथ रखा :

- क – वो गुब्बारा देख सकते हैं (खुशी की अनुभूति)।
- ख – वो खाना देख और सूँघ सकते हैं (उन्हें वो खाना अच्छा लगता है)
- ग – उनका खाना हटा दिया गया (वो निराश हो गये)
- घ – उन्होंने अपनी मां को देखा (वो घर जाने से खुश थे)

रिक्स ने सारे बच्चों का स्वरोच्चारण इन चारों परिस्थितियों में रिकार्ड किया। उसने बाद में बच्चों के मां-बाप को बुलाया और उन्हें दो सवालों के जवाब देने थे।

– पहला सवाल था, “क्या आप अपने बच्चे को पहचान सकते हैं” ? ऑटिज्म वाले बच्चों के माता-पिता अपने बच्चों के स्वरोच्चारण को आसानी से पहचान गये, परन्तु सामान्य बच्चों के मां-बाप नहीं पहचान पाये। सामान्य बच्चे लगता था एक सार्वभौमिक और आदर्श तरीके का उपयोग अपनी भावनाओं की अभिव्यक्ति के लिए कर रहे थे। ऑटिज्म वाले बच्चों का इसके लिए एक खास व्यक्तिगत, गैर सार्वभौमिक तरीका था। यही कारण था आदर्श मां-बाप का अपने बच्चों को पहचानने में मुश्किल का।

– दूसरा सवाल था, “क्या बच्चे के स्वरोच्चारण से आप बता सकते हैं, कि वो किस परिस्थिति में हैं” ? सारे मां-बाप अपने न्यूरोटिपिकल बच्चों की सटीक परिस्थिति पहचान गये न सिर्फ अपने बच्चों की परन्तु दूसरों के बच्चे की भी। परन्तु ऑटिज्म वाले मां-बाप सिर्फ अपने बच्चे की परिस्थिति ही पहचान पाये। ऑटिज्म वाले बच्चों ने संवाद बनाने का एक ऐसा तरीका अपनाया था जो दूसरों की समझ से बाहर था। इस निजी संवाद स्थापित करने का मतलब है कि आपका बच्चा क्या महसूस कर रहा है यह सिर्फ आप ही समझ सकते हैं अगर आप अपने बच्चे को बहुत अच्छे से जानते हैं। इस प्रकार शुरुआत से ही ऑटिज्म वाले व्यक्ति एक खास तरीके द्वारा संवाद स्थापित बनाने की कोशिश करते हैं,

जो सार्वभौमिक संकेतावली के अनुसार नहीं होता। अक्सर यह निजी संवाद स्थापित करने का तरीका, बच्चे की उमर के साथ बढ़ता जाता है, बेशक ऑटिज्म वाले बच्चों को एक सार्वभौमिक तरीके से संवाद स्थापित करना सिखाया जा सकता है, सार्वभौमिक समझे हुए प्रतीक जैसे शब्द व चित्र परन्तु उनकी विशिष्ट बोधक शैली के कारण (जैसे कि मेल बनाना) वो अधिकतर अपने भावों की अभिव्यक्ति एक बहुत खास तरीके से करते हैं।

उनके संवाद स्थापित करने की चर्चा में एक अहम भाग निभाता है। टीसीसी में इसे पूर्व संचार कहते हैं। पूर्व संचार व्यवहार एक ऐसा संचार है जो सार्वभौमिक नहीं है, निजी है और अजीब है। इन्सान को ऐसे बच्चे की ‘नियमावली’ अथवा ‘उपयोगकर्ता गाईड’ का उसे समझने के लिए पता होना चाहिए। उसका अर्थ निकालने की जरूरत होती है और हो सकता है कि अलग-अलग व्यक्ति इसका अलग-अलग अर्थ निकालेंगे। इस कारण यह असली नहीं है, यह संचार का पूर्ण रूप नहीं है, और यह ऐसा तरीका है जिसे आगे बढ़ाया नहीं जा सकता।  
उदाहरण स्वरूप : जब थामस ग्रैन्ड मटर के साथ किचन में होता है वो तनाव वाला व्यवहार दिखाता है। ग्रैन्डमा यह नहीं समझ पाती कि वो क्यों तनाव में है और रो रहा है। ऐलिजाबेथ उसकी बहन ग्रैन्डमा को बताती है कि थामस पूरे समय से उनसे कोका कोला मांग रहा है। ग्रैन्डमा बोलती है कि परन्तु उन्होंने कुछ भी नहीं सुना। और ऐलिजाबेथ जवाब देती है कि “परन्तु ग्रैन्डमा, उसके चेहरे पर कोका कोला झलक रहा था” और वो सही है। थामस एक छोटा लड़का है और उसके चेहरे पर कई ‘दृश्य’ जिसे हम कहते हैं : ‘कोका-कोला दृश्य’ पिज्जा दृश्य’ ‘पानी दृश्य’। परन्तु यह किसी भी वस्तु को मांगने का सार्वभौमिक तरीका नहीं है यह अत्यन्त निजी तरीका है और भविष्य में उसे “काफी दूध और चीजों के साथ लुक” सिखाना नामुमकिन होगा।

बार्ट एक मानसिक मदंता व ऑटिज्म वाला लड़का है जिसे कुछ शब्द आते हैं और वह ‘शाबास’ बोलता है। जो व्यक्ति उसे गुदगुदा रहा है उसकी नियमावली को नहीं समझता है और गुदगुदाता जाता है। परिणाम ? वह

गुस्से का आवेश हो जाता है। दुर्भाग्य से बार्ट के लिए 'शाबास' शब्द का मतलब है "रुक जाओ"। बार्ट की मां यह समझा सकती है। बार्ट एक ऐसी कक्षा में है जहां हर बार बार्ट का काम खत्म होने पर उसकी टीचर 'शाबास' कहती है। इसलिए बार्ट के लिए "शाबास" का मतलब "खत्म" या "रुक जाओ" है बजाय इसके की तुमने अपना काम बहुत अच्छा किया"। जैसा कि हमने इस उदाहरण में देखा कि कुछ निजी अभिव्यक्तियां कुछ मामलों में अन्य द्वारा बोले गये शब्दों का दोहराना/एकोलैलिक होती है।

संवाद स्थापित करना एक पूर्व संचार के तरीके से ऑटिज्म वाले व्यक्तियों को परेशानी में डाल सकता है। खासकर जब उनका माहौल यह नहीं समझता है। कभी-कभी एक परेशानी वाले व्यवहार और संवाद बनाने की क्रिया में एक सम्बन्ध होता है। कुछ मामलों में परेशानी वाला व्यवहार एक प्रकार का संचार का तरीका अथवा कम से कम उस विशिष्ट परिस्थिति में ऑटिज्म वाले व्यक्ति की एक कोशिश होती है। अपने उस तरीके से समझाने की।

रेशल ऑटिज्म और प्रचंड मानसिक मदंता वाली वयस्क महिला है जो हर बार भूख लगने पर अपना हाथ काटने लगती है। हम यह कह सकते हैं कि रेशल हाथ काटकर संवाद स्थापित करना चाहती है। बताना चाहती है। "हां" और "नहीं"। चलिए हम इस व्यवहार को 'पूर्व संचार' बोलते हैं। उसे कभी भी खाना मांगने का कोई और तरीका सिखाया ही नहीं गया है। काटना उसका एक सबसे बड़ा परेशानी वाला व्यवहार है, परन्तु उसके नजरिये से यह एक अपनी बात बताने की कोशिश है। यह खाना मांगने का एक सार्वभौमिक तरीका नहीं है। उदाहरण स्वरूप आम अपना हाथ तब काटता है जब उसे टॉयलेट जाना होता है। यह परिस्थिति पेशेवर/प्रोफेशनलस के लिए बड़ी उलझन वाली है और निश्चित रूप से इस तरीके का विस्तार नहीं किया जा सकता। जैसे कि आप उसे पानी मांगने के लिए खुजलाना नहीं सिखा सकते। मैंने पूर्व संचार व्यवहार पर जोर दिया है क्योंकि यह संवाद स्थापित करने का एक ऐसा तरीका है जिसका हमें मतलब निकालना है और

अपने अवलोकन से हमें अपने लक्ष्य पर ध्यान देना है। हलांकि हम ऑटिज्म वाले हर बच्चे को बात करना नहीं सिखा सकते परन्तु उन्हें संवाद स्थापित करना सिखा सकते हैं। हमारे ऑटिज्म वाले लोगों की हम आगम संचार द्वारा मदद कर सकते हैं : "दृश्य समर्थन की मदद से संवाद स्थापित करना।"

हर ऑटिज्म वाले व्यक्ति के संवाद स्थापित करने का तरीका व्यक्तिगत होना चाहिए, हमारा लक्ष्य यह होना चाहिए कि ऑटिज्म वाला व्यक्ति उस तरीके को संवाद स्थापित करने के लिए आत्म निर्भरता से इस्तेमाल कर सके। इसलिए यह जरूरी है कि हम संवाद स्थापित करने का कोई ऐसा तरीका न चुने जो हमारी इच्छाओं के अनुकूलन हो (अधिकतर बोलचाल के शब्द सबसे निराकार) परन्तु ऐसा रूप चुने जो ऑटिज्म वाले व्यक्ति की समझ के अनुकूल हो। यह तार्किक है क्योंकि हमें पता है कि बच्चे पहले शब्द समझते हैं और फिर जब वो बोलने लगते हैं तब उसका इस्तेमाल करते हैं। समझ पहले आती है। इसी प्रकार हम ऑटिज्म वाले व्यक्ति से बोल-चाल/संचार का वह तरीके (उदाहरण तस्वीर) जिसको वो समझता नहीं है। उन तस्वीरों इस्तेमाल की उम्मीद नहीं रखते हैं। शायद बहुत सारे प्रशिक्षण सत्र के बाद वो कर ले, परन्तु दुर्भाग्य से इस मामले में हम सिर्फ बच्चे की कंडीशनिंग कर रहे हैं, और यह हमारा लक्ष्य नहीं है। ऑटिज्म वाले बच्चे जो एक पुर्वानुमेय वातावरण में रहे हैं और जिनको दृश्य समय सारिणी और अन्य प्रकार के मानसिक दर्शन की जो उनकी समझ के अनुकूल है, उनका आधार ऐसे मानसिक दर्शन का अर्थपूर्ण संचार के लिए भी अच्छा है।

ऑटिज्म वाले व्यक्ति इन तरीकों द्वारा संचार स्थापित कर सकते हैं :-

**मोटर संचार** – जैसे कि बच्चा किसी का हाथ पकड़कर उस चीज के पास ले जाता है जो उसे चाहिए, अथवा शरीर के हाथ-पांव यथा प्रतिष्ठित इशारे जहां अर्थ इशारे में ही है और उसका निष्कर्ष नहीं निकालना है। इशारे जैसे "वहां देखो" अथवा "यहां आओ"। साफ दिखाऊ व प्रतिष्ठत इशारे है। दूसरी ओर हाथ से व्यक्त

इशारा जैसे 'सात्वना' जब मैं किसी को अपनी बाहों में लेता हूँ जैसे कि यह बहुत मामलों में ऑटिस्म वाले लोगों के लिए बहुत मुश्किल है, क्योंकि ये इशारे बहुत 'खुले' हैं और इनका मतलब निकालना पड़ता है। इनका मतलब इशारों में तुरन्त स्पष्ट नहीं होता।

**सांकेतिक भाषा** – जैसे कि सुनने में परेशानी वाले व्यक्ति के साथ इस्तेमाल असाधारण मामलों में ही समाधान है क्योंकि यह बोलचाल की भाषा की तरह ही निराकार होता है। हम यह खतरा लेते हैं कि बच्चा नकल करके कुछ संकेत बिना मतलब समझे ही सीख लेता है। एक और परेशानी है कि सांकेतिक भाषा समाज में सब लोग समझ नहीं पाते हैं।

**वस्तुएँ** – इसकी हम कुछ पैराग्राफ बाद चर्चा करेंगे।

**चित्र** – जैसे कि तस्वीर, चित्रकारी, चित्रिय आरेख इत्यादि।

**लिखे और छपे शब्द** – जब ऑटिस्म वाले मौखिक बच्चों को शब्दों को पुनः याद कर इस्तेमाल करने में मुश्किल होती है तब उनका कागज और पेंसिल देना मददगार हो सकता है। कभी-कभी उनके लिए लिखकर समझाना ज्यादा आसान होता है। ऑटिस्म वाले मौखिक विद्यार्थियों जिनका जरूरत अनुसार बौद्धिक स्तर है कि कम्प्यूटर द्वारा बहुत मदद की जा सकती है। अगर उनके लिए शब्दों को बोलना या ढूँढना मुश्किल है, तब वो कम्प्यूटर द्वारा अपनी अभिव्यक्ति ज्यादा अच्छे से कर सकते हैं, बेशक यह उच्च कार्य पद्धति वाले विद्यार्थियों के लिए ही उचित व योग्य है, जो बिना मदद के लिए कम्प्यूटर पर कार्य कर सकते हैं।

**बोले हुए शब्द** – हम हमारे अधिकतर बच्चों के लिए संचार का मुश्किल तरीका है और कुछ मामलों में वे शाब्दिक तरीका है और कुछ मामलों में वे शाब्दिक दोहराव द्वारा ही स्वयं को व्यक्त करते हैं। इकोलेलिया (शाब्दिक दोहराव) केवल ऑटिस्म वाले बच्चों में ही नहीं होता है परन्तु यह सामान्य बच्चों में भी 18 से 36 माह के विकास के दरमियान होता है। यह पहले सुने हुए शब्दों का वैसे ही शाब्दिक दोहराव होता है। ऑटिस्म

वाले व्यक्ति इसका प्रयोग बिना पूरी तरह इन शब्दों का अर्थ समझे कर सकते हैं। इकोलेलिया तुरन्त अथवा विलंबित दोनों हो सकता है। यह संवाद स्थापित करने का उद्देश्य भी हो सकता है। जैसे कि पूल से निकलते वक्त एक ऑटिस्म वाले लड़के को चाकलेट निकालने वाली मशीन दिखायी देती है। वो इतना अच्छा बच्चा रहा है कि मां तुरन्त उस मशीन में चाकलेट के लिए सिक्का डाल देती है। दुर्भाग्य से कुछ भी नहीं निकालता है। बच्चा और मां दोनों हड़बड़ा जाते हैं। जैसे ही बच्चा फैलना शुरू करने वाला होता है, मां तेज आवाज में बोलती है "परन्तु मशीन तो काम ही नहीं कर रही है" उसी समय एक चाकलेट बार मशीन से निकल जाती है। उस दिन से जब भी उस बच्चे को चाकलेट की बार चाहिये होती वो उसी आवाज में चिल्लाता है, "परन्तु मशीन तो काम नहीं कर रही है"! तथ्य के हिसाब से यह वाक्य का दुहराव एक प्रकार से अपनी बात समझाना/संचार है, परन्तु इसे हमें पूर्व संचार मानना होगा क्योंकि सब लोग इसे समझ नहीं सकते। परन्तु हाँ माँ के साथ इसका उपयोग करना ठीक है।

**अलग-2 तरीकों का मिश्रण** : यह तरीके ठोस और दिखाऊ हैं और इस प्रकार ऑटिज्म वाले व्यक्ति के दृष्ट्य देख कर सोचने के तरीके के अनुकूलन है। क्योंकि यह साफ/दिखाऊ हैं इसलिये ये स्थानिक भी है, और इसको हमारे विद्यार्थियों को कहीं अपने दिमाग में जाकर ढूँढना नहीं पड़ता है। यह सूचना हमेशा सामने रहती है।

यह तथ्य कि संचार दो या अधिक लोगो के बीच की सामाजिक गतिविधी है यह ऑटिज्म वाले व्यक्तियों के लिए और ज्यादा मुश्किल है। ऑटिज्म वाल व्यक्ति हमेशा स्वयं को उस व्यक्ति के सम्मुख खुद को प्रत्यक्ष नहीं कर पाते जिसके साथ वो संवाद स्थापित करना चाहते है। "वृद्धि करने वाले संचार" के द्वारा (जैसे बच्चा एक वयस्क को दूध के लिये कप देता है) हम इस मिलनसार कार्य को एक प्रकार से मानसिक दर्शन करते हैं। अन्य शब्दों में संचार की प्रक्रिया व उस संचार का असर दिखाई देता है। यहाँ पर असली परस्पर क्रिया हो रही है। बच्चा संवाद स्थापित करने के लिये एक सहायता (कप) देता है और उसे कुछ (दूध) बदले में

मिलता है। हम यहा पारस्परिक क्रिया व उसका परिणाम तुरन्त देख लेते हैं। ठोस चीजों और चित्रों के द्वारा संचार सार्वभौमिक तरीके से समझा जाता है और इस पर आसानी से विस्तार कर सकते हैं। अगर बच्चा पीने के लिये कप देकर संचार करता है तो हम उसे खाना माँगने के लिये प्लेट देना सिखा सकते हैं, या बाहर घूमने जाने के लिये जूता देना। अगर ऑटिज्म वाला कोई चित्र दिखाकर अपनी बात समझता है तो हम भविष्य में इसमें और चित्र डाल कर इसका विस्तार कर सकते हैं। और इस प्रकार हम इस बच्चे की शब्दावली की बात करते हैं। बच्चा बोल नहीं सकता इसके बदले निकाले के पिता ने हमें कहा कि वो बहुत प्रसन्न है कि उनके पुत्र की पहले से 23 तस्वीरों की शब्दावली है। हालांकि सारी शब्दावली 'बिस्कुट की ही थी क्योंकि निकलास के लिये वो सबसे ज्यादा प्रेरना का स्रोत थे। संचार हमारे बच्चों के लिये इतना मुश्किल है कि हम उनकी सबसे बड़ी प्रेरणा और सबसे प्रेरित शब्द से ही शुरुआत करते हैं। सबसे बड़ी चिंता माता पिता व पेशावरो/प्रोफेशनलस की यह है कि बच्चा अपने शब्द खो देगा अथवा उसकी बोलने वाली भाषा का विकास आगे नहीं होगा अगर 'अंगम संचार' का इस्तेमाल होगा। हमारे अनुभव से हम 'अंगम संचार' की मदद से इसका उल्टा ही अनुभव करते हैं। अगर बच्चे में बोलने की क्षमता है तो इसके मौखिक संवाद स्थापित करने के अवसर ज्यादा होंगे अगर इसके संवाद को दृश्य की मदद मिलेगी। डेविड एक ऑटिज्म वाला जवान लडका है जो अपनी दौड़ के चक्कर लगाने के बाद हाफता हुआ, प्यासा कक्षा में यह शब्द बोलते हुए आता है, "मुझे चाहिये...मुझे चाहिये" परंतु 'पानी' शब्द कभी नहीं बोल पाता जो कही उसके दिमाग में है। उसकी टीचर ने उसे चित्रों द्वारा संचार करना सिखाना शुरु किया। डेविड के सारे चित्र उसके एक छोटे 'एल्बम' में हैं। दौड़ने के बाद वा कक्षा में आता है, एल्बम लेता है और बोलता है (पन्ने पलटते हुए बोलत का चित्र दूँते हुए), "मुझे पानी चाहिए" इस दृश्य सहायता से उसे कम निराशा होती है। यहाँ हम देखते हैं कि दृश्य सहायता उसके बोलने के अवसरों को ले नहीं जाती है, बल्कि बच्चे को उसकी क्षमता इस्तेमाल के लिये उत्तेजित करती है। साथ ही व सामान्य बुद्धि वाले बच्चों को इस प्रकार के संचार से मदद मिलती है। थमस जब अवकाश के समय बच्चों द्वारा चिढ़ाने जाने पर परेशान होने पर

'हेल्प' कार्ड का इस्तेमाल करता है जो वो खेल के मैदान में अपने प्रोफेशनल/पेशावर को दे सकता है। यह तथ्य कि उसके पास यह कार्ड है उसे बहुत भावनात्मक सहारा देता है। और अगर वह बहुत ही परेशान हो कि उसे अपने शब्द ढूँढने में परेशानी हो जाये, उसके साथ फिर भी यह कार्ड रहेगा। सिर्फ एक बड़ा दुख, "माँ अगर मेरा हेल्प-कार्ड खो जायेगा तो मैं क्या करूँगा"।

कभी-कभी ऑटिज्म वाले बच्चों के शब्द होते हैं, वो हमेशा स्वयं को उस व्यक्ति की तरह जाहिर नहीं कर पाते जिससे वो संवाद स्थापित करना चाहते हैं। यह फिर से दृश्य सहायता बहुत उपयोगी है। मैरी अपने कमरे में घण्टों 'फ्रुट जूस' 'फ्रुट जूस' कहते हुए कमरे में रहती है। दुर्भाग्य से उसकी माँ नीचे है और उसे सुन नहीं सकती। परेशानी का समाधान मिल गया जैसे ही चित्रों की शुरुआत की। मैरी अब नीचे जाती है और जब वो अपनी माँ को देखती है, वो उनको चित्र देती है और कहती है 'फ्रुट जूस'। यह असली अर्थ में संचार है।

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 खाना चाहिए होता है तो वो रोता है: और माँ अलग अलग तरीके रोने को समझ लेती है। कब वो भूखा है, कब उसे उठाना है, कब उसे दर्द है। सामान्य रूप से विकसित होने वाले बच्चे ने बोलने से पहले ही बहुत सारे संचार के कार्यों का विकास कर लिया है हमारे बच्चे हमेशा इस संचार की शक्ति को सहज रूप से नहीं खोज पाते। इसका उन्हें यह सिखाना हम पर है। इसलिये संचार के क्या कार्य है को समझना बहुत जरूरी है। यह सिखाना कि असली संचार खुद को मारने से, चीजे से फेंकने से, गुस्सा करने आदि से ज्यादा प्रभावी है। ऑटिज्म की इस मूल परेशानी को समझना यह हम पर है। हमे 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।

————— *To be continued in the* —————  
*December 2017 Issue of Autism Network*



# HELPLINE



**Q** My 15 year old son often cuts electrical cords and throws electrical bulbs. How to stop or discourage him from doing this?

**A** Before trying to stop or discourage your son's behavior of cutting electrical cords and throwing bulbs it would be important for us to understand the reason why he does this. In the absence of information on the purpose behind his behaviour, let us try and help you to find the answers yourself.

All behaviours occur for a reason: at times the reason for the behaviour occurring will be clear to the observer, at other times it may not be obvious. But understanding why a behaviour may be happening is the first step to stopping or discouraging it.

Understanding the purpose behind your son's behavior will also help us to identify appropriate behaviours that may be encouraged to take the place of the ones you want to change. Every behaviour satisfies a specific need. The alternative behaviour that we will want him to learn must fulfill the same need that the challenging or inappropriate behavior was meeting. If it does not then your son will simply develop another alternative behaviour to help meet that specific need; this other behaviour may also turn out to be an inappropriate one.

A simple way to understand the function of his behavior would be to see what happens before a specific instance when your son does the cutting or throwing and also to observe what follows the behavior. Let us see the example of a behavior where the child picks up toys and keep them by in the toy box, and the antecedent and consequence of that behavior.

- Antecedent: Mother asks child to pick up toys and put in toy box.
- Behaviour: Child picks up toys and puts them into the toy box.
- Consequence: Mother praises child and gives him a cookie.

The antecedent is anything that happens before the behaviour that may be a trigger for the behaviour and consequence is anything that happens after the

behaviour that helps maintain or increase the behaviour, or reduce or extinguish it. The reason why a behavior occurs or persists is dependent on both the antecedent and the consequence.

When collecting information on the antecedents of your son's behaviours, it would be important to note when, where and with whom do the behaviours usually occur? Does anyone do or say anything before he cuts or throws? For example does someone in the environment give an instruction to him or maybe asks him to stop doing something and then he cuts wires of thros bulbs? Has there been a change in the day's routine? Did he have disturbed sleep? Did a parent leave town on a work trip? Was it a school day that was called off because of heavy rains? You want to have detailed information on antecedents each time that the behaviours occur.

When collecting information on the consequences, it would be important to note what do people do when your son cuts electrical cords or throws bulbs. For instance do people leave whatever they were doing and approach him to reprimand him? Or try to stop the behavior? Or do people try to distract him by switching on music, or giving a favoured food or access to computer? Does someone scold him? Do the adults at home have a discussion on what he has done? Does he get out of or can avoid something he does not like to do? For instance, if the behaviour occurs during his mealtime or maybe when he is completing a chore, does he get to leave his food or the activity without completing it? Does he get to stay home instead of going to school?

When you have the above information it will help us understand why the behaviour may be happening.

Sometimes children engage in a challenging behaviour to get something tangible. For instance, if a child throws things on display in a shop and is bought a packet of chips or given the mobile to play games on, the child may learn that throwing things in a shop gets him chips or the mobile. Sometimes children may engage in challenging behaviour to escape from situations, tasks or people. For example; a child throws food on the floor and is told "Dinner is over" and the child may learn that throwing food on the floor means that he doesn't have to eat the dal and chawal that he did not want anyways! Sometimes children engage in challenging behaviour to

get attention from others (e.g., parent, sibling, teacher, peer, etc.). Attention can take many forms (e.g. looking at your child, talking with your child, giving help, laughing at the child, and even using a firm voice with or yelling at the child). Sometimes your child may be looking for attention in any way possible. This could mean looking for praise or looking for a reaction, even if that means an angry one. For example; a child cries whenever the parents are on the phone, and then the parent yells “Stop crying, I’m on the phone!” The child may learn that crying when parent is on the phone will result in getting attention from their parents. Sometimes children may engage in challenging behaviour as it provides them a sensory input they may seek. For example, a child might rock back and forth because that rocking motion is enjoyable for him.

Since we do not know exactly WHY you son is cutting electrical cords or throwing electrical bulbs, it is difficult to advise precise strategies to change this behaviour and suggest appropriate replacement behaviours. But your observation of the antecedents and consequences may suggest an answer. You could of course also send us a note of all antecedents and consequences. This would help us in identifying the function maintaining the challenging behaviour and devise strategies to change this behaviour and find suitable modification/ replacement plan for them.

In addition, please find below some general suggestions to encourage appropriate behaviours and apprehend the possibility of challenging behaviours:

- Teach the child new and more appropriate ways to seek attention (e.g., tap on shoulder, say “look at me”, if the child is verbal) and reinforce when these new behaviours occur
- Give positive attention many times throughout the day
- Try not to give any attention when undesired behaviour occurs
- Notice and praise desirable behaviour using specific statements e.g. Saying “Good Sitting” vs “Good boy”
- Try not to give instructions if they cannot be followed through.
- Specifically work on the child’s communication so that he can ask for items, activities, information, others to do or stop an action and ask for help

- Increase the variety of activities/items the child is interested in so there are more things to help motivate the child and keep him occupied.
- It is essential that the child is told well in advance as to how much work he has to do. Use a visual schedule/ to-do-lists to tell the child how much work he has to do, in what sequence and when will it get over
- Introduce the child to self-management techniques
- Setting of social rules and using social stories can tell the child what is expected from him and what he should do in a particular situation
- It is imperative that all family members deal with the challenging behaviours in a consistent manner

We hope you find the suggestions useful. We will be happy to provide any further guidance you may require in data collection, identifying function of the behaviour and plan formulation for replacement of the behaviour.

## *<Upcoming Workshops>*

VENUE:

THE NATIONAL CENTRE FOR AUTISM, NEW DEHI



## MAINSTREAM EDUCATION FOR CHILDREN WITH AUTISM

*by Indrani Basu*

Dates: 25-26 August 2017

Founder and director, Autism Society West Bengal, Ms Basu regularly conducts workshops at inclusive schools creating awareness and understanding for children with Asperger’s.

The workshop will focus on finer nuances of difficulties that Aspies face in classrooms and necessary accommodations. The workshop will be useful for professionals who facilitate an inclusive learning environment and for parents as they prepare for mainstreaming.

*Early Bird Registrations ends 21 August 2017*



## GETTING READY FOR VOCATION & EMPLOYMENT

by Preeti Siwach

Dates: 8-9 September 2017

Looking ahead to a fulfilling adult life for individuals with autism.

The workshop will help you understand the changing needs and focus across the adolescent and adulthood. Learn the use of assistive and visual devices to enhance communication, reduce anxiety, facilitate socialization...

Also prepare the adults with autism for a successful transition to independent living without parents.

*Early Bird Registrations ends 4 September 2017*



## KNOW ME TEACH ME Annual Training Workshop

by Merry Barua & the AFA TEAM

Dates: 4-6 October 2017

'Is he really autistic?'

'Can he really study?'

'Why does he not learn like other kids?'

'Will he get married?'

'Why is he so rude?'

'Why doesn't he play with other kids?'

**If you have any such questions, then  
this workshop is for YOU!**

*Early Bird Registrations ends 4 September 2017*



For more information on the workshops:  
Email: <anvay.trainings@gmail.com>  
call us on <+91 11 4054 0991-92> or visit  
our website: <www.autism-india.org>

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toys as well - inexpensive toys that available in local markets and stalls rather than the standard toy shops.

There are cause and effect behaviours the child often picks up without much effort. If the child has his shoes on, he knows that he will go out. Or, if the TV is to be turned on, the remote is to be used. If the child wants to drink juice, often times he may bring a glass. Cause and effect learning will help him understand that by doing something, another thing happens. Therefore the child learns an action has a consequence.

An important part of communication development is to enhance joint attention through joint activity routines.

These can be activities where the child is engaged with the adult in such things as blowing bubbles, singing some action songs the child enjoys, tickling games, sitting on the swing and the adult pushing the child or blowing a balloon and then letting it go. During such joint activity or activities, anticipatory behaviour can be developed in the child by delayed response. Anticipatory behaviours are the basis of developing communication and social skills.

There are many situations throughout the day where we can use delayed response. For instance every time a child - verbal or non-verbal, pulls at the adult's hand, often to lead the adult to what s/he wants, the adult usually allows the child to take him wherever s/he wants. If the adult delays the response by a few seconds, there is a good chance the child will look at the adult. In which case the adult can then complete the response by getting up or giving whatever the child wants.

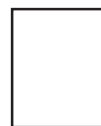
If the child enjoys looking at bubbles and the adult is blowing bubbles. The adult can at times delay blowing the bubbles by a few seconds, so the child has the opportunity to give eye contact.

If the child enjoys being tickled by the adult, the adult can play tickling games but at times pause between tickles, so that the child looks at the adult in anticipation of the tickle.

*...cont overleaf on page 18*

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## BOOK POST



The parents or the care givers know the child very well and therefore always know what the child may want. These situations need to be used to create situations where the child has opportunities to anticipate the next step or part of the routine. There are many predictable routines in the day that may be used, such as going to the washbasin to wash hands- a routine followed every day before meal times. In this situation, if the parent can delay in going to the wash basin or pause before allowing the child to turn on the tap, the child will get the opportunity to give eye contact and maybe, even ask for the routine to be initiated by saying the word/s or by using signs /pictures

Bath times are fun for most of the children. In this situation, instead of just completing all the expected steps of the routine at a single go, a parent can pause at certain times, so the child has the opportunity to look or ask for what he anticipates as the next part of the activity/ routine. These joint activity routines may be the beginning for children with autism understand and appreciate shared experiences and the development of social communication.

Another very useful activity that may be done by parents and family members is just simply talk to the child. NOT ask questions repeatedly but talk about what the parents see in the child's environment and talk about it in short simple sentences. This could include talking about an event that is going to happen or has happened without asking questions to the child. If the child is interested in looking at pictures, then the parent can just talk about what he/she sees in the pictures and once again not ask any questions. If at all a question is asked and the child is not able to answer, then the parent can answer the question herself and carry on.

These are some simple strategies that can be used multiple times in the course of each day and used consistently will definitely enhance communication in our children. And to remember at all times that our children will learn communication through interaction and fun far better than through questioning and stress.

*Indrani Basu is the Founder Director of Autism Society West Bengal. A parent to two young men with autism, Indrani is considered to be one of the leading experts in autism asperger's syndrome in India.*



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