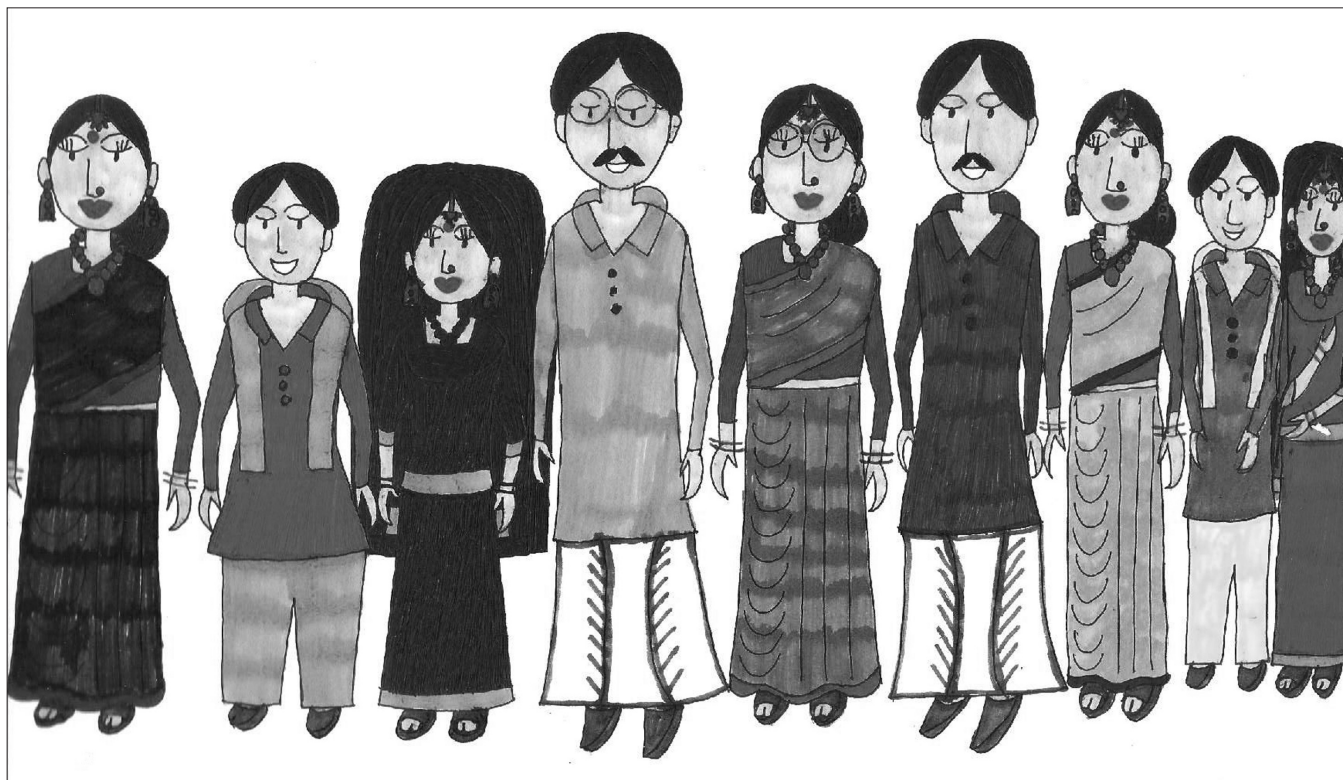


autism network

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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

People dressed up at a wedding by Barsha Deb, 19 years old. She has cleared her Secondary Examination through NIOS (CBSE) and now attends Arohan in ASWB, Kolkata.

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PAGE ONE

The days are longer. The sun is hotter. Very soon schools will close and children will be home. This issue provides some great reading for the coming holiday months.

Stims! Two important experiences shaped my relationship with stimming. One was two decades ago at the Autism Treatment Centre Of America, where I had gone with my son for a training, and for the first time I was introduced to the beauty and meaning of joining my son in his stimming; in trying to see the world from his perspective. I suddenly started making astonishing connections with my intensely disconnected child. And all thanks to his stims which till then I was told were 'bad'.

The other was listening to Ros Blackburn at the 1999 National Autistic Society Conference in London. Then in her late twenties, Ros had the 1000+ audience hooked in hushed silence as she spoke for an hour of her life with autism. Which included her stims. One of these was taking her saliva and smoothing it over the wallpaper. She had taught herself to do it only in the kitchen so that the wallpaper in the rest of the house did not curl up with the damp treatment! Here again was the message: stimming was okay.

No, actually, stimming was necessary for people with autism. Instead of shaming them and trying to force the stimming to stop, we can connect with them; we can acknowledge their need to stim to stay happy, stay focused, deal with stress, or just occupy themselves in their 'me' time; and teach them where and when it was okay to stim and where not. In this issue Kirsten Lindsmith says it so much better.

As Indian mothers, and fathers, one of the first questions we ask when our child gets a diagnosis of autism is, "Will she/he get married?" Not sure why this pops up especially when the person in question is a three year old, but it does. And of course we do not have an answer. No one can say what a child, who is now only three or even eight, will do in adulthood. But would they have the possibility of getting married? The answer would be "Why not!" As someone with a spouse on the spectrum, Maripat Robison is eminently equipped to share her perspective.

The future is not just about marriage. It is about planning for a time when parents are no longer on the scene. It is about acknowledging that with the best of intentions even the most loving and caring of siblings and extended family cannot be expected to take over as carers. Parents have to take action, which Deepa Garwa discusses in the '*After I Am Gone*' Worry!

Like others, Action For Autism (AFA) too has been trying to address this concern of life after parents by setting up *Ananda*, the project for Supported Living for adults with Autism and other developmental disabilities. We hope to pilot an adult stay by early 2017 as we continue to tackle construction-related situations.

On another note AFA will soon conclude the pilot for a *Soft Skills Training For Employment*, with a first cohort of young adults with Autism.

It has been an exhilarating experience. Once we review the outcome of the pilot and make necessary adaptations, we will start training with a second group of adults.

Happy reading!

Dr Tony Attwood in Delhi!

Join AFA for a two-day Workshop in November

I want to share the exciting news that we finally fulfill our long-standing desire to have Dr Tony Attwood in Delhi!

Dr Attwood, the world's foremost expert on Asperger Syndrome and author of the classic *Asperger Syndrome: A Complete Guide for Parents and Professionals* will give a two-day workshop on 25 and 26 November 2016 at the India International Centre in Delhi. More information on the training workshop up ahead in the journal.

• LEAD ARTICLE •

Stimming 101, or: How I Learned to Stop Worrying and Love the Stim

Kirsten Lindsmith*

It's perfectly normal, but often embarrassing—something we encourage our children to suppress, or do in private. Existing on a continuum from healthy, to bad habit, to scandalizing, stimming is as diverse as humanity itself.

What is stimming?

Stimming—short for self-stimulation—is a term that has yet to make it into any dictionary, despite being one of the most commonly understood terms within the autism community. Called “stereotypy” by psychiatrists, stimming refers to: “...*a repetitive body movement that self-stimulates one or more senses in a regulated manner.*” (My favourite definition, from the Autism Wiki.)

I'd first like to make it clear that a stim is not the same as a tic. Where stims are rhythmic and regular, tics are non-rhythmic and sudden. That being said, I've shared anecdotes with several individuals with Tourette's syndrome, and our (nonprofessional) consensus was that tics and stims do seem to have a lot in common. Both can (sometimes) be held back, although holding back both feels very uncomfortable. While holding back a tic seems closer to holding back a sneeze, I would say that holding back a stim could be compared to holding off on scratching an itch (if that itch never went away, and kept increasing with time, like a mosquito with its nose in your flesh that refuses to leave).

While everyone stims *sometimes*, autistic people do it far more frequently than their neurotypical counterparts. To make things even more interesting, autistic people often present uniquely specific types of stimming.

The most famous hallmarks of autistic stimming can be divided into three major categories:

- Hand stimming, including hand flapping, finger waving, and finger wiggling
- Body stimming, including rocking, spinning, and head bobbing

- Vocal stimming, including groaning, screeching, and various forms of echolalia

While these are the some of the most well-known (and most attention-grabbing) autistic stims, stimming is incredibly diverse and often unique to a particular individual or situation.

Other types of stims include, but are not limited to: staring at a blinking or spinning object, rubbing and touching various textured surfaces, licking or chewing objects, twirling or petting hair, cracking joints, tapping the feet, and any number of other repetitive, stimulatory activities.

Neurotypical people stim too! Some notable neurotypical stims include tapping fingers or feet to music, stroking the face when stressed, or rocking in a rocking chair.

When I was a child, my earliest and most noticeable stims consisted of sucking my thumb (often while rubbing the rough part of my precious blankie against my upper lip) and pressing or rubbing my eyes.

I once sat through an entire morning meeting in elementary school with my eyes pressed firmly into my knees. The darkness soothed, and the pressure felt firm and comforting. The other children, sitting cross-legged and watching the teacher, didn't notice until we broke to begin the first lesson.

“*Kirsten's crying,*” one classmate squealed. I looked up, confused, as the message made its way around the room, repeated on the lips of my peers.

“*No, I'm not,*” I protested. But the pressure had turned my eyes red, and “*I'm just pressing my knees into my eyes*” sounded more like a badly-planned childish excuse to the teacher who was by that point trying to comfort a very embarrassed me.

Why do autistic people stim?

I get this question quite often from teachers who work with autistic children. They're excited to meet me, an

autistic person articulate enough to explain the autistic mindset, and want to know the why behind the uniquely autistic behaviors they see in their students.

And they're often surprised by how easy this question is to answer.

I once visited the ASD program at The Ivymount School in Rockville, Maryland, a fabulous place for misfit kids of all types. I remember walking through the classrooms and seeing the tykes politely asking for their three-minute breaks when they felt overwhelmed, leaving their desks to go put on stretchy pressure vests, or play with a stim toys, or lie under weighted blankets or pillows. I thought, what I wouldn't give to have had such an understanding environment as a child.

After touring a few of the classrooms, I found myself amidst a group of young teachers, listening to them tell stories about their many wonderful students. They spoke in particular of an adorable little girl who seemed a universal favorite. The teachers squealed and cooed as they recounted tales of her cuteness: her rosy cheeks, her bright eyes, her Bo Peep curls and squeaky little voice.

"Every time I see her I just want to hug and squeeze her forever!" one teacher exclaimed, hugging her arms to her chest and spinning back and forth on the balls of her feet.

"Oh, I know, I know! She's just the sweetest little thing," said another teacher, squeezing her eyes shut and pulling her bent arms tight against her body, chin on her fists, while quickly bending at the waist and straightening again.

"I just can't handle how darling she is!" said a third, wringing her hands and wiggling her shoulders back and forth.

The conversation eventually progressed to an older student—a middle school boy—who was very fond of anime, particularly shojo romance shows.

"It's just so fascinating to watch how into it he gets," said one teacher of the boy's class, *"I watch with him sometimes, and the stories are all about this G-rated sexual tension that goes nowhere, until the very end when the two main characters confess their love and get together! The whole build up makes him stim like crazy!"*

She throws up her arms. *"He'll just hunch over and wiggle his fingers like mad whenever any major progress happens in the relationships! I just don't understand it."*

"Yeah, I have students like that," says another teacher. *"I don't know if this is too vague of a question,"* a teacher turns to me and says. *"Could you explain why autistic people stim like that? Where does it come from? I just don't get it."*

I laughed.

I explained that they themselves had been 'stimming like crazy' over their darling tiny student with the adorable curls just a few minutes earlier. Perhaps their stims were not as extreme as those of the preteen boy as he watched his favourite romantic comedies, but the root cause was the same.

The build up of emotion, the need to release emotional or physical tension due to an overload (of cuteness, of moe, of anxiety, of anything), is something that everyone has felt at some time or another.

Autistics are easily overloaded, and simply need to release tension more frequently. When I stim, I often feel like an old fashioned boiler letting off pressure — sometimes in tiny bursts, sometimes in huge belches of steam.

Sometimes stimming releases pressure—especially the good kind of stimming. Sometimes a stim will help us focus to block out invasive and overwhelming sensory input, becoming an essential coping aide.

It's a type of self-soothing, whether one needs to be soothed because something is just too cute or because that ambulance siren is just way too loud, the root cause is essentially the same.

In my opinion, the question shouldn't be why autistic people stim, it should be why do autistic people stim in such a specific way. Not every autistic stims, and not every autistic person shares all the typically autistic stims. I'm a finger waver, but I'm not often a hand flapper. I have a vast number of vocal stims, but I'm not usually a rocker or a bobber. I know hair-twirlers who rock back and forth. I know knuckle-crackers and foot-tappers who don't wave fingers or flap hands. Every autistic is as unique as her own personal stimming lexicon.

Public Stimming

As a child, I boasted a large repertoire of stims, though most of them required very particular, coincidentally private environments, and thus spared me embarrassment.

When I was very small, every time I hoisted my little body onto the toilet at my childhood home I would spend my potty time croaking like a frog, in long, drawn out vocalizations, enjoying the echo of the buzzing vibrations against the tiles. Whenever I flushed, I rapidly pressed my fingers into my ears over and over, making the terrifying bellow of the toilet into the ‘whoosh-whoosh-whoosh’ of an ocean at an impossible 300 BPM—a trick I learned from a preschool teacher to make using the big kid bathrooms easier, and I still do this every time I flush a toilet. Stims like these never caused me problems, because they required a private setting.

But as I grew older, one of my bathroom rituals made its way into my public life.

Besides croaking like a frog, if I were feeling particularly energetic, I would wiggle my fingers before my eyes in front of the white background of the bathroom. Not only did the motion seem to provide an incomparable degree of relief from pent-up energy, but the palinopsiac trails left by my fingers created of two pink fans, a visual stim that pleased me for no reason I can properly name.

The satisfaction I derived from stimming this way before a white surface is utterly indescribable—and it had to be a white surface, or at least very light in color, for the pink fan to work properly.

At some point after discovering this amazing activity, I began to need it more and more. It went from a stim confined to the bathroom at home to a stim that happened in every bathroom, and eventually to a stim that happened in front of almost every white surface, regardless of who might be present.

Because I was now doing it in public, especially when stressed, I also began doing it in my most stressful environment: school.

By the time I made it to the 6th grade I was doing it multiple times per hour. As you can imagine, I was made fun of quite a bit. My teacher eventually contacted my mother, expressing worry that the other kids were giving me a hard time, and his own personal worry that I literally couldn’t control it. I told my mother that of course I could control it.

But even I didn’t understand why I seemed to need it. All that hubbub was enough to convince me to try it in

front of a mirror, and I quickly realized why it was so controversial among my peers. After that, I never did it in public again.

I still do it in my car, in the bathroom, and other times when I’m alone. And of course, always in front of a white surface (my computer monitor is absolutely perfect, for example).

Once in a blue moon, when I have a good, easy day and I feel comfortable, calm, and connected, I’ll start to think to myself, “What if I’m not ‘really’ autistic? I feel pretty normal today!”

Then I’ll head to the bathroom and dissolve into a compulsive fit of finger waving, or drive home after a day of socializing and screech, squeal, and shriek to myself in my car, and think, “Oh, right. I don’t think neurotypical people do this.”

By now, the only stims I do in public are small, and relatively ‘normal’. I crack my knuckles, bite my lips, hum and whistle, tap my foot or fingers, and clean under my fingernails (instead of biting!). I save my serious stimming for private venues.

Unless of course I have a particularly bad day, and then I’m that girl on the subway rubbing my forehead, massaging my jaws, and clenching and unclenching my fists in front of my face. Hi! Don’t mind me, it’s just a little crowded today!

But not every autistic is able to save their serious stims for the bathroom. By ‘serious’, I mean ‘socially inappropriate’.

Stim Shaming

Another question I commonly encounter comes most often from parents: How do I make my child stop stimming?

First, I try to direct the parent or guardian away from the impossible goal of literally stopping their child’s stims. For one thing, this goal is unattainable (the wonderful Cynthia Kim, author of the blog *Musings of an Aspie*, compares controlling stimming to playing whack-a-mole in her blog post on this topic).

More importantly, demonizing stimming and attempting to stop it is incredibly cruel. This is like telling a person to stop dancing to music, to stop even tapping their foot to the beat. It’s like telling a child to never scratch his itches, to never yawn, to never sneeze.

And it's even worse than all those things, because stimming is essential to autistic happiness in a way that simply can't be explained to a neurotypical incapable of imagining what it feels like.

Attempts at preventing stimming teach an autistic child that an essential trait of her person, an uncontrollable, essential, natural inclination, is wrong, and needs to be stopped at all costs.

If you are the parent or guardian of a stimmy child, and your goal is to stop your child from stimming—to teach her to stop flapping her hands, or repeating her cat's meows, or chewing on her shirt sleeves in the grocery store—know that you are aiming for an impossible standard.

Stimming is a valuable tool for autistics to self-regulate, self-soothe, and gain familiarity and control over their bodies and environments.

Think of how a baby stims: head-bobbing, arm and leg flailing, making faces at strangers, repeating syllables, chewing and licking everything they can get their hands on. Would you try to stop a baby from stimming? If you can see your child's stimming as equal in importance to the 'innocent' stimming of a baby then you are 90% of the way there.

Yes, other adults will sometimes give you and your child that look when they see a child "old enough to know better" chewing holes in her coat, getting up to walk around at mealtimes, or jumping up and down during story time at the library.

But a stranger's opinion—or even your mother-in-law's opinion—of your family pales in comparison to the value of your child's health and happiness.

To follow Cynthia Kim's whack-a-mole analogy: if you keep your child from stimming, the stim will always come up in another (usually worse) way. You are plugging up the boiler, as though the steam should not exist. At the end of the day (if he can wait that long!) your child is going to explode into a meltdown, and you'll have taken zero steps forward and a hundred steps back.

I find this mentality most common among what I call 'anti-autism' parents or specialists. These are the people that say, "I love my child, but I hate my child's autism." They are usually well meaning (if misguided)

parents who only want to spare their child a difficult life.

But autism is not like depression, anorexia nervosa, or PTSD. Autism is not the demon we should be fighting. The true demons are disability, anxiety, and misery. Autism is an integral part of who a person is. Just as extrovert, male, or gay are all defining personality traits, autism is not in-and-of-itself a disability; it is a type of person. A child who grows up with a support network that hates a core part of his identity is going to have serious self-esteem issues, at the least. And a parent who hates his child's autism is going to have a miserable life, always at war with his child. It is the anti-autism attitude that creates the real demons of depression, PTSD, and self-hatred.

Many parents who do accept and cherish their children, autism and all, will still ask how to control stimming. They understand that stimming is not an inherent evil, something to be stopped, or something that can be stopped. But they watch their child flapping and shrieking on the playground, groaning and wailing at the hair salon, or rocking and humming in church, and they see the stares. They imagine with dread their child's future job interviews, dates, and college classes with people who equate stimming with 'unstable' and 'crazy.' They just want to know if there's anything that can be done to make their children a little more socially acceptable, and their lives a little easier.

There are two approaches to this problem....

On one hand, a 'high-functioning' (and in this context I mean self-aware) child may be taught to stim like this in private, the way that I taught myself. Allowing a child to watch himself stim in a mirror, and divide stims into public and private, can sometimes work. Public stims may include foot or knee tapping, finger waving under the table or in pockets, jumping, wiggling, rocking, and spinning back and forth on a pivoting chair or on foot. Private stims—things that 'disturb' or 'distract' others—may be things like screaming and groaning in quiet environments, or nose picking (a private stim many neurotypicals are guilty of, if my observations of my boyfriend are any indication). If parents can teach their children not to masturbate in public (a very common stim in autistic and neurotypical children), then perhaps the same principles can be applied to stims that disturb neighbors in church or frighten peers on the playground. But again, this may not be possible, and it definitely isn't possible or healthy in very young children.

On the other hand, many (I would argue most) children cannot control their stimming. For some, sensory processing difficulties are simply too overwhelming, and there is just no way to hold back those essential self-calming behaviors. For children like this, the only real problem is other adults. As Cynthia Kim discusses in her post on socially acceptable stimming, it's not autistic behavior that's the problem, it's the reactions of strangers, and the embarrassment of parents.

I've heard countless heart-breaking stories from parents whose children were assaulted and harassed in public by adults who misread autistic behavior as naughty behavior. One mother described a woman approaching her screaming son and shaking him, while chastising his mother for not controlling her child.

Children may stare at or taunt autistic peers, but from the stories I hear it seems to me that adults are the main perpetrators of outright (and often dangerous) abuse. Having a spiel at the ready to explain the situation (either verbally, or on printed cards that can be handed out) can help a naïve neurotypical avoid making similar mistakes in the future. Preparing an explanatory presentation for you or your child's teacher to give to her class can be similarly helpful. (Note: This is one of many reasons why I oppose hiding a diagnosis from a child. You need to be able to discuss these things in front of them concisely and safely!)

And when it comes to job interviews, I advise autistics to follow the advice of Temple Grandin, who always says that she couldn't sell herself, so she made sure to sell her accomplishments. Build a portfolio, make yourself an expert, showcase your invaluable skills. Also, stimmy children don't have to control their behaviors to make stimmy friends. While an autistic child may have a harder time making friends, and have fewer friends than their same age neurotypical counterparts, autism is a powerful selective pressure when it comes to finding true and loyal friends. One of my best friends in high school was a beautiful caricature of ADHD, a never ending source of class-disrupting verbal stimming and flailing. We got along swimmingly and stimmed together, repeating phrases and sounds and generally torturing our poor math teacher.

Stimming is normal, healthy, and fun. And it's not something to be feared or stopped. Can you imagine life without spinning in circles barefoot in the grass, or bobbing your head to the beat of your favourite song?

It's just another part of life. So don't be afraid to just keep stimming.

This article was first published on <https://kirstenlindsmith.wordpress.com/2014/05/16/stimming-101-or-how-i-learned-to-stop-worrying-and-love-the-stim/> and has been reprinted with the permission of the author.

**Kirsten Lindsmith is an author, artist, consultant, and autism advocate. After receiving an ASD diagnosis at the age of 19, she began co-hosting the online television show Autism Talk TV, and speaking about her experience as a young woman on the spectrum.*

Kirsten has written columns for WrongPlanet.net and AutismAfter16.com, and was profiled in The New York Times in a feature titled Navigating Love and Autism. She is a member of the board of advisors for the Yale Child Study Center's Initiative for Girls and Women with Autism Spectrum Disorder. Kirsten currently works as a special needs nanny in partnership with Melody of Autism, and as a consultant for parents, professionals, and individuals on the spectrum.

She maintains a blog at: KirstenLindsmith.Wordpress.com where she writes articles about ASD.

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“Who will marry my autistic child?”

Maripat Robison*

When John and I were in New Delhi for the South Asia International Autism Conference (SAIAC) last year, this was the most-often asked question I heard from the parents of autistics. In America, the number one question I am asked is, “What will happen to my child, how will they live independently?” If I didn’t have an understanding of the importance of marriage in Indian culture, I would have been mystified at the difference.

To me, the Indian parents’ question demonstrates the beauty of familial society in India. It is resolute, extended, and can be counted on. The parental concern wasn’t primarily about independent living, because once married, the family would be there, absolutely. I think that’s admirable, and beautiful. I wish we had that in the United States.

But back to the question: *Who will marry my autistic child?* The only way I can answer that is with the sum of my experience as a parent of children with special needs, my observation of many families affected by autism, my understanding of the importance of neurodiversity, and as a woman who’s happily married to an autistic husband.

First, I would have to say that if my mother-in-law (whom I miss dearly since her passing some months ago), was asked the same question before my husband John was an adult, she probably would have said, “I don’t think he’ll ever get married.” This would have been her answer - not because she didn’t love John - but because she *had absolutely no idea of the man he would become*.

There are myriad reasons this is so. First, the majority of her experience with John in his childhood was with the difficulty his ‘being different’ caused her and the family. Of course this was over fifty years ago, without diagnosis, support or information about the characteristics of autism. Still, the context of John’s mom raising him was borne in the difficulty of his fulfilling society’s expectations. It wasn’t until John was an adult that she was able to appreciate his neurological difference (autism).

Second, it is hard for us to look down the road at people with developmental delays. That’s why they’re called

‘delays’. Like the rest of the world, autistics learn, change, and develop with the passage of time. We can observe that, if we let go of our expectations of the ways we want them to change and embrace the truth of their actual and different development.

Consider that Dr. Stephen Shore’s parents were advised by the experts to institutionalize him. Instead, his parents accepted that he was autistic, and did everything in their power to help him to mitigate his disability and find his special interests. Nonverbal as a child, today Dr. Shore is a famous autistic self-advocate, travelling the world giving hope and focus to thousands of people, on and off the autism spectrum. He is also happily married. Imagine what might have happened had his parents bought into the negative thinking of the professionals and put him in an institution.

Then there’s the story of Jacob Barnett. Born in the United States in 1998, Barnett’s parents experienced the devastating pain of seeing him change from a happy, bright boy to a withdrawn and nonverbal child. He was diagnosed with moderate to severe autism when he was two years old. Doctors told his parents that he was likely to never talk or read. Further, they predicted that he would not be able to manage even basic activities, like tying his shoes, without help.

Jacob’s parents learned everything they could about autism, and like Dr. Shore’s parents, they fought hard against his seeming retreat from the world. In addition to various therapies, every effort was made to give him ordinary childhood experiences with abundant chances to play. His special interests in astronomy and math were encouraged.

By the time he was eight years old, Jacob was sitting in on math classes at Indiana University -Purdue University, but he says he didn’t begin speaking ‘normally’ until he was twelve years old. Today, Jacob is a researcher and honors student at that same University. His research area is quantum mechanics.

In his TedTalk, *Forget What You Know*, Jacob Barnett basically says that while it looked like he was staring at walls and not speaking, he was actually thinking about

physics and writing mathematical formulas in his head. Could this be happening with other nonverbal children, too?

Jacob also says he didn't wake up one day 'cured' of his autism. He still has difficulties that he has to overcome every day.

We never know how someone will turn out. When I met John decades ago, I was different than I am now. I was less mature, quicker to judge, and slower to understand. In short, I was not yet tempered by a life that would unfold to create a more compassionate and loving heart. In contrast, what was John like in his early adulthood? John was incapable of eye contact back then, he can do it more now. John couldn't tolerate any clothing labels whatsoever; he has a higher tolerance now. John could not go to a movie, speak before a crowd, write books, be in loud restaurants, spearhead social justice for autistics, or do so many other things that he does today. I am so proud of him!

Is he still autistic? Absolutely, and today I appreciate some of the characteristics that come with his autism. I don't do this perfectly, but I do it enough to keep our relationship loving and strong.

For those families dealing with severe disability, I am filled with empathy and understanding. When my daughter was 3 years old and having seizures, I was in despair, and overwhelmed. Even so, once I had the knowledge and information on how to deal with her disability and then focus on her more positive attributes, I was no longer hopeless. In my experience, acceptance, knowledge and action are the antidotes to despair.

So, I just said I appreciate John's autism, and that's because I am able to see the good things that come with some of John's autistic traits. What good things? Here's a partial list:

- John is authentic and tells the truth
- John is one of the kindest people I know
- John is peaceful, and slow to take offense
- John is brilliant, especially about his special interests
- John is a very hard worker and able to stay focused
- John is generous
- John is funny and makes me laugh
- John makes a difference in the world for other people; he gives them hope
- John is a great stepfather
- John's logical thinking is very helpful

Another question I was asked last year during our visit to India was: "Should I tell potential families that my child is autistic?" That's a good question, because there can be stigma associated with an autism spectrum diagnosis. For instance, I wouldn't recommend that someone talk about their autism on their first job interview, because that might prejudice the employer to dismiss them out of hand, and not really evaluate their qualifications for the job. Instead, I would advise them to think about the traits they have that would help them to excel at the job, and talk about those instead.

John and I were friends for years before he got his autism diagnosis. Perhaps that helped me to appreciate him as a person whom I just considered 'eccentric.' On our travels, I meet so many people who have children diagnosed with autism, and as they find out more about it, they begin to believe that their spouse is on the spectrum as well, just undiagnosed. I think that's fairly common for my generation.

Until I knew about John's autism, I never considered that we could have a romantic relationship, because I thought that some of his less desirable characteristics (like talking about himself constantly) were his whole personality, instead of his autistic neurological wiring. I wondered what he thought about my less desirable characteristics, like my ADHD! But thanks to his autism, he hardly noticed. Or so he says.

Focusing on positives is so important to the way we view the world, our families, and especially our children. *How we view our children shapes how they view themselves.* They must know that we appreciate their strengths. This doesn't mean that we deny disability, but instead we look for ways to give supports for difficulties, and just as important, support growth opportunities for their strengths.

When we are trying to get someone to do something we want him or her to do, don't we talk about how good it could be rather than how bad it could be? It always makes sense to look at the good in situations when we are trying to put our best foot forward. And when was the last time a diagnostician presented us with any positive aspects of our child's autism? It's no wonder we are set up to feel badly about it.

I'm not advocating lying about someone's autism. But I am certainly suggesting that there is more to a person than a diagnostic label, and it is best if we can look at the positives instead of being overwhelmed by the

negatives. I would invite anyone to make a list of those positives, and practice thinking about them. And it does take practice to overcome negative thinking, because we all do it. We probably wouldn't have survived as a species if we didn't have the capability to do so.

In the spirit of thinking positively, consider that most of the people on the following list are speculated to have Asperger's Syndrome, primarily because of their ability to think 'differently' than others. What would the world be like without them?

- Mark Zuckerberg, founder of Facebook
- Bill Gates founder of Microsoft
- Jane Austen, Novelist
- Michelangelo, Renaissance artist
- Ludwig van Beethoven, Composer
- Albert Einstein, Physicist
- Alexander Graham Bell, Inventor of the Telephone
- Vincent Van Gogh, Artist
- Isaac Newton, Mathematician and Physicist
- Satoshi Tajiri, Inventor of Pokémon

If we could start looking at our autistics as a sector of humanity that has benefitted society, we have a chance

to achieve the inherent potential in every human being. Knowledge is power, and acceptance brings peace, which actually makes us stronger, not weaker. Instead of fighting the idea that someone we love has autism, we can take action, and action drives all of the change in the world. We don't have to apologize for our differences. Let's make the most of them, and perhaps the question will become: "Who will be good enough to marry my autistic child?!"

**Speaker, writer, poet, seeker, healer, advocate for special education and autism, erstwhile media executive and publisher, mother, wife, Maripat Robison wears many hats with aplomb. She supports the neuro-diversity movement and believes that focusing on what individuals can (rather than cannot) do is the next step in autism awareness, acceptance and admiration.*

The author of 'I Married a Geek' - a humorous memoir about her life with John Elder Robison, one of the world's foremost Aspies, she also writes a popular satirical blog of the same name (<http://maripatrobison.blogspot.in/>).

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एसपरजर सिन्ड्रोम—एक भारतीय दृष्टिकोण

लेखन—इन्द्रानी बासू

प्रेजिडेंट आटिज्म सोसाईटी, पश्चिम बंगाल

अनुवाद — पूजा खन्ना

एसपरजर सिन्ड्रोम (asperger syndrome) एक मस्तिष्क सम्बन्धी स्थिति है और इसकी पहचान एक समूह आटिज्म स्पेक्ट्रम विकार (autism spectrum disorder) के अन्तर्गत होती है। आटिस्टिक व्यक्ति की ही तरह इन व्यक्तियों के भी संवाद, मिलनसरिता, रूचि के तरीके और व्यवहार क्षतिग्रस्त होते हैं। एसपरजर सिन्ड्रोम वाले व्यक्ति अच्छी औपचारिक भाषा के साथ अच्छा व्याकरण और शब्द संग्रह का प्रदर्शन करते हैं। इसके बावजूद वो भाषा की बारीकियां नहीं समझते हैं और उनको व्यवहारिक बोली में मुश्किलें आती हैं।

ऐसी मान्यता है कि सारे लोग जिनको एसपरजर सिन्ड्रोम होता है, उनमें उच्च कोटि की बुद्धिमत्ता होती है। इस छाप की उत्पन्नता "रेन मैन" (Rain Man) और कुछ अन्य प्रशंसनीय एसपरजर सिन्ड्रोम वाले व्यक्तियों के कारण है जो अपनी अनोखी अकलमन्दी के लिये प्रसिद्ध हुए हैं। परन्तु इसका यह कतई मतलब नहीं है कि एसपरजर सिन्ड्रोम वाले हर व्यक्ति के भीतर एक अति प्रतिभावान व्यक्ति छुपा हुआ है। जिस प्रकार हम जैसे लोग इस स्पेक्ट्रम में नहीं हैं उनमें भी कुछ अति प्रतिभावान होते हैं, कुछ अकलमन्द और बचे हुए बौद्धिक रूप से सामान्य मनुष्य होते हैं और ज्यादातर के साथ अच्छी भाषा के बावजूद मिलन सरिता कठिनाई का एक मुख्य क्षेत्र है खासकर जब बात सामाजिक व्यवहार के नियमों की आती है। एसपरजर सिन्ड्रोम बहुत प्रकार से एक अदृश्य विकार है।

भारत में यह एक ऐसी स्थिति है जिसकी ज्यादातर पहचान छूट जाती है, अथवा जिसका पता बहुत देर से चलता है जब बच्चा किशोर अथवा व्यसक हो जाता है। नीचेयुक्त लेख एक प्रत्यन है उन साधारण परिस्थितियों का सम्बोधन करने का जिनमें एसपरजर सिन्ड्रोम वाले व्यक्ति और उनके परिवार वाले अपने को पाते हैं।

स्कूल/विद्यालय

कुछ माता पिता के लिये जब बच्चा बहुत छोटा होता है उनका ध्यान किसी भी चिंताजनक चीज पर नहीं जाता। कुछ अन्य के लिए एक नुक्स निकालने वाली भावना आती है। जिसे वो इस आशा में अनदेखा करने का प्रयत्न करते हैं कि जो कुछ भी मुश्किल है वो आगे अपने आप चली जायेगी। अगर बच्चा इकलौता है तब यह भावना आती है कि विद्यालय और सहपाठी इस मुश्किल को सुलझा देंगे। जब बच्चा विद्यालय जाना शुरू करता है तब इस बात का आभास होता है कि बच्चे में कुछ 'गड़बड़' है या बच्चा बोलने के बावजूद कुछ अलग है। और इससे भागना सम्भव नहीं है और उन नुक्स निकालने वाली भावनाओं का सामना करना ही पड़ता है।

स्कूल में ऐसा समझा जाता है कि बच्चे को कुछ परेशानियां हैं इनमें से कुछ है कि बच्चा बैठता नहीं है, इधर उधर निकलने की चाह रखता है कक्षा की दिनचर्या नहीं मानता है, कहाँनियां सुनने में कोई रूचि नहीं रखता इत्यादि। सबसे आम शिकायत जो स्कूल से आती है वो यह कि बच्चा अपने सहपाठियों के साथ मेल जोल नहीं करता। लेकिन कुछ महीनों के बाद बच्चा शान्त सा दिखने लगता है।

कक्षा में शान्त होने के बाद, एसपरजर सिन्ड्रोम वाला बच्चा शैक्षिक कार्यों के परिचय के बाद अच्छा प्रदर्शन करता है। वो अपने अंक व अक्षर और कवितायें जल्दी सीख जाते हैं, ज्यादातर अन्य बच्चों से जल्दी। इस चरण में पढ़ाई साधारण होती है। और यह बच्चे अपनी असाधारण यादाश्त के कारण अत्याधिक अच्छा प्रदर्शन करते हैं। जब लिखाई का परिचय करा जाता है तब कुछ बाधाएँ आती हैं, ज्यादातर बच्चों को इस कला में

निपुणता पाने में मुश्किलें आती हैं। अन्त में काफी अभ्यास और कोशिशों के बाद जब बच्चा लिखने में निपुणता हासिल कर लेता है, बाकी विद्यार्थी सामान्य लेख में प्रवाही लिखाई (cursive writing) पर पहुंच चुके होते हैं और इन एसपरजर बच्चों को फिर से लिखाई सीखनी पड़ती है। इस चरण में कई इम्तिहान भी होते हैं जिनमें बच्चों को भाग लेना होता है। इन इम्तिहानों में सदा ही सीधे सवाल होते हैं, जो एसपरजर वाले बच्चे अपनी तेज यादाश्त के कारण बहुत अच्छे से करते हैं।

मां-बाप को जल्दी ही एक चक्र सा दिखाई देने लगता है जैसे ही उनके बच्चे अच्छा करने लगते हैं, शान्त दिखाई देते हैं जैसे ही उन्हें एक नई परिस्थिति का सामना करना पड़ता है और एक चक्र का आरम्भ हो जाता है बच्चा लड़खड़ाता है मां बाप व बच्चा मिलकर सारे मामलों पर कड़ी मेहनत करते हैं और शैक्षिक साल के अन्त की तरफ चीजें जगह पर दिखाई देने लगती हैं और सब एक चैन की सांस लेते हैं। फिर नया शैक्षिक साल नई कक्षा के साथ शुरू होता है। नई किताबें, नया माहौल नई टीचर और शायद पढ़ाने का अलग तरीका। बहुत से एसपरजर वाले बच्चों और उनके मां बाप के लिए इसका मतलब हुआ फिर से उनके संघर्ष की शुरुआत।

बहुत से मां बाप को लगता है कि उनके बच्चों पर बहुत भारी मांगें डाली जा रही हैं। और इसके साथ ही स्कूल का यह शक जाहिर करना कि बच्चा अगले क्लास के लिए उत्तीर्ण होगा भी या नहीं। अचानक हमारी शिक्षा प्रणाली की कमीयां बहुत साफ दिखने लगती हैं। जब मां बाप को एसपरजर वाले बच्चे का लालन-पालन करना होता है।

सीखने का तरीका बनाम पढ़ाने का तरीका

भारत में ज्यादातर स्कूल में पढ़ाने का तरीका अभी किताबी है, जिसमें रटने पर ज्यादा जोर दिया जाता है बनाव अनुभव कर के चीजें सीखने पर ज्यादातर पढ़ाई में एसपरजर वाले बच्चों को कठिनाई इसलिए आती है। क्योंकि यह उनका सीखने का तरीका नहीं है।

एसपरजर वाले व्यक्ति देखकर तस्वीर द्वारा बहुत अच्छा सीखते हैं। ज्यादातर अक्षरों की ध्वनि व ज्ञान के बिना

ही चीजें पढ़ लेते हैं। (Hyperlexic) उनकी रटने की शक्ति अति उत्तम होती है। मां-बाप व शिक्षक दोनों की इनके प्रदर्शन से बहुत प्रसन्नता अनुभव करते हैं। अधिकतर एसपरजर वाला बच्चा नर्सरी में प्रथम स्थान पर बात की थाह लेना बहुत मुश्किल होता है कि जो बच्चा बाल कक्षा में फराटे से पढ़ता है और सारे सवालों के जवाब देता है उसे पढ़ी हुई चीजों का तत्व व मतलब की बहुत कम समझ है।

उनकी तीव्र यादाश्त उनकी ताकत है और एसपरजर वाला बच्चा अधिकतर इसका इस्तेमाल उन चीजों को याद करने का सामना करने में करता है जो उसे अच्छे से समझ में नहीं आयी है। जैसे बच्चा उच्च कक्षा में जाता है उसका निर्माण एक हिली हुई नींव पर होता है। और अचानक जब वो चौथी या पांचवी कक्षा में पहुंचता है वो पढ़ाई कासामाना नहीं कर पाता है। जैसे-जैसे पढ़ाई जटिल होने लगती है वो लड़खड़ाने लगता है ऐसी बहुत सी चीजें थी जो उसने असलियत में छोटी कक्षाओं में सीखी ही नहीं थी बहुत से अवधारक और उसके मतलब जो छूट गये जिसे सीखा नहीं गया और फलस्वरूप एक बहुत बड़ी खाई उसके मन में बन जाती है। अवधारकों को समझने के लिए।

यह गुलाबी टुकड़ा इस लेख का एक केन्द्र बिन्दु है एसपरजर वाले बच्चे ज्यादा अच्छा सीखते हैं। जब उन्हें साकार/ठोस चीजों के द्वारा चीजे सीखायी जाती हैं। जैसे वस्तुओं का उपयोग कर के सिखाना कि किस प्रकार अंक आगे बढ़ते हैं, जोड़ने से और कम होते हैं हटाने से। जब पौधों के बारे में सिखाना हो तो, उन्हें उसे सम्भालना और किस प्रकार गमले में उगाना है दिखना चाहिए। एसपरजर वाले बच्चे को चित्रों की जरूरत होती है और ठोस चीजों के द्वारा सिखाना ज्यादा बेहतर होता है। यह जैसे भी हर प्रकार के बच्चों को सिखाने का सबसे अच्छा तरीका होता है।

स्कूलों का पाठ्यक्रम बड़ा सख्त होता है। एक और मुश्किल तब आती है जब दो और कभी-कभी तीन भाषायें भी पढ़नी पड़ती हैं। एसपरजर वाले बच्चों को जो अंग्रेजी माध्यम से पढ़ते हैं, उनके परिवार को घर में भी अंग्रेजी भाषा का माहौल बनाने की सलाह दी जाती है

और बहुत से यह नहीं कर पाते क्योंकि घर के बुजुर्ग इस भाषा में असुविधाजनक महसूस करते हैं। और एसपरजर वाला बच्चा जिससे वैसे ही आदान-प्रदान की भाषा का विकार है उससे अंग्रेजी माध्यम की पढ़ाई और हिन्दी, बंगाली, तमिल जो भी मातृभाषा है उसमें बात करने की उम्मीद की जाती है। वैसे तो बच्चे जो अपनी मातृभाषा वाले माध्यम के स्कूल में पढ़ते हैं। उन्हें भी कभीकभार वैसे मदद मिलती है जो एसपरजर वाले बच्चों को चाहिए होती है। जो मुद्दे एसपरजर के दृष्टिकोण से अहम होते हैं वो नान-आटिस्टिक सीखने वाले के लिए महत्वहीन होते हैं। पर एसपरजर के लिये यह बहुत बड़ी बाधा बन जाते हैं। जिसे उन्हें पार करना पड़ता है। कुछ उदाहरण स्वरूप बहुत से स्कूल अंक सिखाते समय एक और एक को ग्यारह और एक और दो को बाहर और आगे ऐसे सिखाते हैं, पर वास्तव में 10 और 1 ग्यारह होता है। एसपरजर वाले बच्चे के लिए यह एक सीखने का गलत तरीका हो जाता है। जो उसे फिर से भुलाकर दुबारा सीखना पड़ता है।

- पढ़ना और सीखना ध्वन्यात्मक रूप से phonetically एसपरजर वाले बच्चों के लिये बहुत अस्पष्ट होता है। एसपरजर वाले बहुत से बच्चे पढ़ना बहुत जल्दी सीख जाते हैं। और खुद को लिपि को देखकर पढ़ना सिखा देते हैं। और उन्हें वर्तनी में कोई कठिनाई नहीं होती है। लेकिन जब पढ़ना ध्वनि अभ्यास द्वारा शुरू की जाती है तब इनके लिये यह बहुत कुण्ठा और अस्पष्ट हो जाती है क्योंकि वो अभ्यास और पढ़ने में सामानजस्य नहीं बिठा पाते हैं।

- वो शिक्षक से मदद नहीं मांग पाते, और न ही यह कह पाते हैं कि *मुझे समझ नहीं आता।*

- क्लास के बीच में रुकावटों का सामना करना इनके लिए बहुत मुश्किल होता है। जैसी की एसपरजर वाला बच्चा बहुत ध्यान से क्लास में शिक्षक का सुन रहा है और वहां अचानक रुकावट आ जाती है जो किसी भी सामान्य कक्षा में अक्सर होता है। जब शिक्षक वापस रुकावट के बाद पढ़ाना शुरू करेगा बच्चे के लिए उस जगह से वापस ध्यान लगाना और समझना मुश्किल हो जायेगा।

अगर एसपरजर वाला बच्चा कक्षा कार्य कक्षा काल में नहीं पूरा कर पाता है, भावनापूर्ण व देशभक्त करने वाली शिक्षिका उन्हें अलग से ले जाकर उनका काम खत्म करने में मदद करती है पर इससे एसपरजर वाला बच्चा यह निष्कर्ष निकालता है कार्य कक्षा काल के बाद टीचर के आमने सामने बैठकर ही पूरा करना होता है।

यह गुलाबी टुकड़ा इस लेख का एक महत्वपूर्ण केन्द्र बिन्दु है। ज्यादातर बच्चे अपना गृहकार्य घर पर मां-बाप की मदद से करते हैं और उन बच्चों को बाकी बच्चों के समकक्ष रखने के लिए ज्यादा समय पढ़ाई पर देना पड़ता है। सबसे महत्वपूर्ण आपसी आदान प्रदान बच्चे और मां बाप का पढ़ाने के दौरान होता है और उनकी आपसी सम्बन्ध एक शिक्षक और विद्यार्थी जैसा हो जाता है। दोनों बच्चे और मां बाप के लिये यह भावनात्मक रूप से थकाने वाला होता है।

परन्तु ऐसा नहीं की एसपरजर वाले सारे ही बच्चों को शिक्षक के दौरान मुश्किल आती है। पर बहुतों को चुनौतियां आती हैं और सबसे अच्छा है उनके बारे में पहले सोच कर रखना। बच्चे को उनके कौशल क्षेत्र में मजबूत कर के तैयार करना उसकी भाषा कौशल को बढ़ाना और इसकी सामाजिक समझ पर काम करना।

एसपरजर वाला बच्चा सामान्य स्कूल से जरूर फायदा प्राप्त करता है। पर उसमें इतनी भावनात्मक शक्ति नहीं होती कि वो एक सामान्य/नान आटिस्टिक पढ़ाई के माहौल का सामना कर पाये जब तक उसके अनुकूल बदलाव नहीं किये जाते और उसकी खास जरूरतों का ध्यान नहीं रखा जाता।

सबसे जल्दी इस चीज की जरूरत है कि हमें स्वीकारना है कि आटिस्टिक और नान आटिस्टिक बच्चे अलग होते हैं और हम उन्हें एक ही सोच में नहीं ढाल सकते। स्कूल के हिसाब से उनके लिये थोड़ा लचीलापन चाहिए। जैसे सुनने देखने में विकारता वाले अथवा dyslexia और cerebral palsy वाले बच्चों को एक ही भाषा सीखने की छूट दी जाती है। अपने विषय के चुनाव की छूट तो हर बच्चे के फायदे में है सिर्फ आटिज्म स्पेक्ट्रम वाले ही नहीं।

इन बच्चों की लिखाई अच्छी न होना इन चीजों को भी प्रधिकार्य वर्ग को स्वीकारना होगा। यह बच्चे इमतिहान में शायद लिख ही न पायें। एसपरजर वाले बच्चों को एक लिखने वाले की अथवा कम्प्यूटर का इस्तेमाल इमतिहान में करने देना चाहिए।

कभी-कभी सारणी/सूची अथवा एक प्रतीक का जैसी साधारण चीजों का इस्तेमाल भी इनके लिये बहुत उपयोगी साबित होता है। बच्चा जब अपना काम खत्म कर ले और बैचन होने लगे तो उसे कुछ ऐसा देना कि वो अपने को व्यस्त रख सके और ऐसे व्यवहार की तरफ न सरकने लगे जो बाकी बच्चों के कार्य में विघ्न डाले। हिदायत देते समय टीचर बच्चे का नाम लेकर उसका ध्यान अपनी तरफ खींच सकती है।

बहुत कुछ बच्चे के सहपाठी, उसके माता पिता व शिक्षकों के दृष्टिकोण पर निर्भर करता है। अगर बच्चों को एक बेचारा बना दिया जाता है तो बाकी बच्चों का व्यवहार उसकी तरफ वैसा ही होगा। अगर मां बाप और शिक्षक उसे एक परेशानी के रूप में देखते हैं तो बाकी बच्चे भी उसे वैसे ही देखेंगे। और अगर व्यस्क उसे एक ऐसे बच्चे की तरह देखते हैं जिसे उनकी मदद की जरूरत है तो अचानक बहुत सारे मां उस बच्चे को गोद लेने के लिये तैयार रहेंगी।

सिर्फ स्कूल की पढ़ाई ही एक मुद्दा नहीं है। जैसे-जैसे एसपरजर वाला बच्चा बड़ा होगा उसकी मुश्किल बढ़ेगी। बहुत की इच्छा परस्पर बातचीत की होती है, कुछ दूसरे लोगों के प्रति आकर्षित होते हैं। यह सब कभी-कभी एक दूसरे में मिलकर अजीब और मुश्किल व्यवहार उत्पन्न कर देता है। जिसको नान-आटिस्टिक लोग गलत समझ लेते हैं।

LETTERS

I am a mother from Pune of a 10 year old child who is on the spectrum. Last week, from 24 to 26 January 2016, I had the privilege of attending AFA's workshop on 'Addressing needs of Adolescents and young Adults with Autism' organised by Forum For Autism in Mumbai. The workshop will be a great help in terms of organising ourselves to help our children in their adolescence.

A Spectacle

*Ronak Sringeri**

My brother is a hurricane
ravaging the coastline
slamming through building after building
gusting up winds at extreme velocities
covering the coast in a foot of water
pulverizing everything in its path
until there is complete obliteration
and a transformed and desolate landscape

My brother is a rollercoaster car
Ascending up the steep incline
Until it reaches the highest point
and it comes crashing down releasing
all of its energy
As it makes all the loops and twists
The feel the G-force slamming against
the body
until there is not enough energy left to move
it forward
and it all comes to a screeching halt

My brother is an island
Hundreds of miles away from
any large landmass
With vast stretches of ocean in every direction
However it contains abundant greenery
lush rainforests, sand-lined beaches,
and rugged hills
with flourishing and diverse wildlife
A true spectacle to witness
but it takes an endeavour to find it .

**Ronak Sringeri from Detroit, USA is 14 years old
He has a 12 year old brother with autism.*

I would really like to thank the AFA team for helping us change our perspective towards our child. It has enlightened us that our child not only deserves respect and affection from us but also from the society. The disclosure and advocacy part has really made us rethink on our attitude towards Autism. Your approach and attitude towards children with autism is really worth learning. Proud of being associated with AFA.

Suchitra Thipse

Special Needs Parents Here Is Your Answer To *'What After I Am Gone' Worry!*

Deepa Garwa*

While cleaning a cupboard, I came across an old piece of news in the paper where a pilot father and an air-hostess mother died within a year of each other leaving their two kids orphaned. When the relatives only laid claim to the bank accounts and family property, the kids called their father's friend, another pilot for help. This man took the children under his wings by taking the legal guardianship and now they are living with his family. What a story of loss, faith and humanity!

Being a parent my heart went out to the little kids who had to go through so much at this tender age, but this also shook me to the core thinking if this can happen to two healthy, working individuals in their early 30s then it can very well happen to me or to anyone else.

We all have heard the quote 'Death is inevitable' but we never think it can come this soon or can wipe away all that we've built over the years. The kids who we protect from every possible harm can be left to destiny and mercy of others. But what are our choices? Being a parent of two adorable children; one who wants to explore the world and the other with special needs, the spectrum for us parents is extra huge. Yes, God forbid if something were to happen our typical children will find a way to bounce back sooner or later and we should be glad that they will. But they will also have the responsibility of their special sibling whether they are ready or not and we can't deny the possibility that our extra special kiddos might never hold any gainful employment and may need financial assistance all their life. And as parents we need to make sure that we think of all these scenarios today to help them get back on their feet if and when the need arises.

I know it may sound weird but thousands of times I have tried selecting the right set of people from my family, friends and relatives who I could trust about taking care of my kids in case of an unfortunate incident. And I've always found it difficult to trust anyone one hundred percent. But it is important that we prepare ourselves mentally for delegation of the most important responsibility of our lives. There have been a few things that have made some sense to me while speaking to other parents and doing some research online and I

would love to know if you have given any serious thoughts to these possible choices...

Writing A Letter Of Directions Or Intent

Writing all about your savings, their maturity, the whereabouts of the documents, about someone who would work as a care taker till your typical child attains adulthood. This letter should most definitely also have a list of contact information for your child's physicians, therapists, and other medical support people as well as current medications and their dosage. It should also include the medical history of your child, various medical interventions, allergies, food preferences and any or all information that might be important for the caretakers.

Write A Will

While a few of us might think that the will is only for multi billionaires, but the truth is that in case of a tragic event, the family goes through the unimaginable and in absence of directions or a will it becomes extremely challenging for rest of the family to get back to the old life. A WILL will not only help you in making an informed choice well ahead of time but will also give the children the directions to move on.

Start A Trust

A lot of parents of children with special needs start a trust for their children however there are many do's and don'ts which parents need to ponder carefully before plunging into anything. Things like who they would want to be the trustee of the trust or if they would want a single trustee or a co-trustee or when and how money can be distributed to the children, should be thought out very carefully. There may be other considerations based on the state laws and regulations which need to be researched too.

Apply For Guardianship

Once children turn 18, they're considered adults in the eyes of the law. Many a times the adult in question is not capable of taking independent life decisions and may need your guidance. By applying for a legal guardianship you can maintain the same supervision and control you had over your child when he/she was younger. While still alive parents can approach National Trust for the same and they in turn can appoint a committee of members like

a district collector, a doctor, a psychologist and others to look into the needs of the person in case of a sudden demise of parents.

Start Saving Early

Be it mutual funds, savings accounts, fixed deposits, shares or any other way which suits your future financial needs but it is extremely important to start early and not just for your child with special needs but for their siblings too. A lot of times we overlook the needs and demands of our 'typical' children assuming they don't need us or can take care of themselves but when it comes to paying for their higher education and aspirations, we cannot NOT have the funds saying it all got used with their special sibling. So striking a fine balance between what is important for who is a decision every parent should very carefully make.

Making An Informed Choice

There was a recent video that was shared by another parent where an interesting experiment was initiated with a group of parents and their children. Children were asked to draw a picture of what they would like to become in future while parents were asked to paint what they would like their children to become in future. They were told not to interact with each other during the course of the activity. At the end of the experiment, parents and children were asked to reveal their ideas.

And to everyone's surprise the pictures were contrasting. This little experiment tells us all about the future challenges and how we need to be well prepared and encouraging for alternate careers that our children might choose. And it might not only be for our typical children. Our children with needs too need looking after longer than others and to be prepared in advance for the same is paramount.

P.S. I was recently told about this interesting app called 'The homework app' which helps you find out the education cost for various professions across different countries both in current time or in the future thus helping you calculate the right amount to start saving.

Build Your Network

Building a network of friends for your child from the community is extremely important. The child should be taught to interact and be comfortable in the community, with the people who know and regularly interact with him. This can do wonders for your 'after I am gone worry.' The neighbours, the mall guy, the grocer, the ice-cream man, other special needs parents and even

children at the park should interact socially with your child. Such connections not only build the self esteem of your child but also help him/her stay safe in case of no direct supervision.

Train Your Child

Every parent should train the child to be meaningfully engaged. This might not only be for financial independence but to stay engaged and have a routine. This training and exposure should start early and the transition training should be provided along with pre vocation and vocational skills. A lot of adults with special needs are finding work, getting engaged in employment and also living semi independent lives either in group homes, with their parents or in assisted living set ups. The parents should prepare their child for this life, for training them with all the household work and other important things that these children might need to live on their own with limited supervision. A few years ago a set of 5 parents came together and helped their daughters set up an independent house with a housekeeper. The arrangement was expensive but it paved a way for many similar social experiments. You can read more about it in one of my old post here...<http://www.twominuteparenting.com/a-parent-of-child-with-down-syndrome/>

The gist of all the pointers above is a sound financial planning. For the child's aspirations and future whether typical or special needs, a parent needs to plan well ahead of times and explore all the available options. It could be child education policies, mutual funds or any other choice that deems fit. Researching, exploring, discussing, comparing and starting with your action plan will not only give you peace of mind but will also help you get over with your ever mounting worry of 'What after me'. So, sit with your partner to know your goals, hire a planner or go research but be prepared and do your homework well in advance.

This article was first published on <http://www.twominuteparenting.com/special-needs-parents-here-is-your-answer-to-after-i-am-gone-worry/#comment-11548> and has been reprinted with the permission of the author.

**An opinionated blogger (<http://www.twominuteparenting.com/>), advocate for Down syndrome, writer, teacher and mother of two (one with special needs and the other a math enthusiast), Deepa Garwa is passionate about the spoken and the unspoken of parenting."*

UPCOMING  WORKSHOPS

My Child is Older... I am Older... What Now?

Date: Friday, 29 April 2016; 9 am – 5 pm • Venue: The National Centre For Autism, New Delhi

As children on the autism spectrum grow older, parents are often at a loss and worry as to what the future will hold. There are no easy answers, but planning is essential. Using a strength-based approach, through a hands-on, this interactive workshop aims to help parents and professionals understand and begin to prepare for life beyond school.

The workshop will be conducted by Dr. Sushama Nagarkar.

Sushama Nagarkar has two daughters, Aarti, who is 28 and has autism and Divya is 26 and lives in Houston, Texas. Aarti and Sushama moved back to Mumbai from the US in July 2013. Sushama has spent much of her adult life working in the field of psychology and special education with a brief foray into the world of journalism as well.

Currently she is a registered Rehabilitation Psychologist (RCI) and works part-time with Morris Foundation in Pune and with other entities such as the Gateway School, Mumbai and Bubbles Center for Autism in

Bangalore. She also works with families who have a child with a disability. Besides this she teaches graduate level classes online for the University of Missouri. Her terminal degree is a Ph.D. in Special Education from the University of Missouri and she is a nationally certified school psychologist (USA). Most recently she has set up a small NGO (Yash Charitable Trust) with the mission to provide an enhanced quality of life to adults with developmental disabilities.

Who Should Attend?

Parents, family members, relatives of children over 10 years old; educators, clinicians who work with them; and those who want to understand more about autism and how to support children and adults with an ASD.

*There are
no easy answers,
but planning is essential.
this workshop ...
aims to help
parents & professionals
understand
and
begin to prepare
for life beyond school.*

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



Empowering the Child with Autism

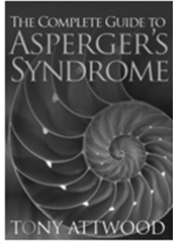
Dates: 7-9 July 2016, 9 am– 5 pm • Venue: The National Centre For Autism, New Delhi

Whether you are a parent of a newly diagnosed child or whether you are a more seasoned parent, the bottom line in helping your children learn is to understand autism beyond theoretical explanations.

Here is an opportunity that will help you understand autism and your child better, and empower you to help your child learn more effectively. Teachers, shadows

and other professionals wishing to understand the world of autism from the child’s perspective and explore approaches to enjoyable learning are welcome to register.

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Asperger's & High Functioning Autism Training by Tony Attwood

Dates: 7-9 July 2016, 9am–5 pm

Venue: The National Centre For Autism, New Delhi

Action For Autism brings you the rare opportunity to learn with **Professor Tony Attwood**.

Prof Attwood is recognised internationally as one of the leading specialists in Autism Spectrum Disorders, especially the high functioning end. He has authored several books including *Asperger's Syndrome – A Guide for Parents and Professionals* which has sold over 350,000 copies and has been translated into over 25 languages. His subsequent book, *The Complete Guide to Asperger's Syndrome*, is one of the primary textbooks on Asperger's syndrome.

Prof Attwood is regularly invited as a keynote speaker at International Conferences. He presents workshops and runs training courses for parents, professionals and individuals with Asperger's and High Functioning Autism all over the world. He has worked with many thousands of individuals of all ages. He is adjunct professor at Griffith University, Queensland and senior consultant at the Minds and Hearts clinic in Brisbane.

Over the course of two days, the **training will focus** on issues across the lifespan, especially strategies to:

- Make friends
- Improve social understanding and relationships
- Reduce being bullied and teased
- Build upon cognitive abilities
- Manage feelings and facilitate emotion management
- Sustain employment



Who Should Attend?

Parents, family members, relatives, educators, clinicians - anyone wanting to understand more about Autism Spectrum Disorder and how to support children and adults with an ASD.

For more information, Email: <anvay.trainings@gmail.com>
or Call us on <+91 99531 13208; +91 11 4054 0991-92>
or visit our website: <www.autism-india.org>

AUTI SPEAK

My Unique Sensory Experiences

Neha Uttam*

I am on the autism spectrum, I have high functioning autism. I have quite a few unique sensory issues and I have learnt to deal with them very positively.

For instance, I have favouritism towards the summer season as far the clothing is concerned. I find it difficult to handle woollen clothing like full sleeve sweaters, sweat shirts and jackets. I feel very suffocated when I wear such full sleeve clothes in the winters. Such clothing items poke me when I wear them and irritate the sensitive skin that I have. I also find wearing socks very difficult. When I wear socks, the creases that form

below the feet feel like 'gulabjamuns' and I find it very difficult to deal with wearing socks.

I like winter for only one reason and that is to do with my sweating. I sweat a lot in the summers. My sweat glands are overly active in the summer season, so much so, that I need a handkerchief at all times to wipe my sweat. To be more precise, I need a handkerchief every second of my life in the summers to wipe my forehead and face and neck and keep them dry from the sweat. It's like never ending sweat trickling down my forehead and temples; it's really embarrassing at times. It

doesn't look smart at gatherings, meetings or family gatherings or even wedding functions or big parties or official workshops. I feel uncomfortable most of times when I see myself sweating so profusely. I wish there could be treatment for people who sweat like me. I am very comfortable wearing short sleeve or sleeveless t shirts all the time. I wish God could make summers such so that I don't sweat at all. I also wish that I could wear half sleeve or sleeveless t shirts and cool clothes and not have to wear socks in the winters and yet not feel cold or freeze in the winters in Delhi.

I also have an issue with high pitched sounds. When I hear them, my ears hurt and the hurting feeling goes upto my heart. The sound of furniture being dragged bothers me. When people drag tables and chairs and other furniture to move them from one place to another, instead of picking them up, I need to cover my ears with my hands to avoid the loud disturbing sound. Also when

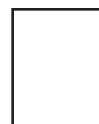
I go to the dentist and he fills my cavities with the drilling instruments, I need to cover my ears with my hands. I feel disturbed when I feel the high pitch sounds entering my ear drums. I sometimes cover my ears when the blender is on in the kitchen. The high pitch sounds coming from a mike, when it is not working very properly disturbs me. But, I love to talk on the mike.

I also don't like certain strong and bright lights like the spot lights you can see on the ceilings in some shops and some homes. I feel scared in sleeping in a totally dark room in the nights and I also feel scared watching scary scenes on the television like ghost scenes.

I have autism. I am different.
Come, let's celebrate differences in all.

* *Neha Uttam is a teacher aide at Action for Autism*

BOOK POST



ACTION FOR AUTISM

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