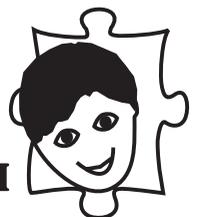


autism network

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ACTION FOR AUTISM



autism network

AUGUST 2018

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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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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

'Merry Barua'

A sketch, by Poshla from Bangladesh

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PAGE ONE

At a consultation on the Rights of Persons with Disabilities Act this month, viz July 2018, attendees learnt from the Secretary in the Department of Disability Affairs that a National Trust amendment bill was to be shortly introduced in parliament. It then transpired that even as the Committee that had been constituted to amend the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 is yet to come up with their recommendations, this was another amendment that was being hurriedly introduced in the Rajya Sabha to merely fix the tenure of the Chairperson and members of the Board, without touching any of the substantive issues that need addressing. Further, instead of undertaking such an exercise in consultation with stakeholders the government appears to be introducing a piecemeal legislation.

The National Trust Act was the outcome of active lobbying by stakeholders. Parents of persons with disabilities including your writer and other activists, were involved in the drafting of this legislation. When the law was passed in 1999, it brought hope for the segment of persons with disabilities who were outliers in the Persons with Disabilities Act of 1995, and who remain outliers in the discourse around persons with disabilities. We were excited by what the National Trust had the scope to achieve for this population. The initial years were full of hope. But with time the powers of the National Trust has been slowly eroded.

Under the Act the Chairperson of the National Trust is meant to be the final authority. And the CEO (who has to be a Joint Secretary from the ministry) had to defer to the chairperson. Not surprisingly, the implementation of the Act faced some hurdles.

A few years back the Chairperson was retired out without any serious effort at appointing a new Chairperson. The law Ministry came in to raise questions on the powers of the Chairperson, and the National trust continued operation without a Chairperson for several years. Currently, the Chief Commissioner for Persons with Disabilities in addition to holding that post, officiates not only as the Chairperson of the Rehabilitation Council of India but also of the National Trust. The board too has been rendered toothless. Its function now is to merely rubber stamp whatever the CEO puts before it.

When the National Trust amendment bill was placed in parliament this week, it was fortunate that some members, one of whom is a parent of a child with autism, raised pertinent issues. They questioned the Minister's claim that in 'a country of 130 crores no suitable candidate could be found' for appointment as a Chairperson of the National Trust during the last four years despite repeated attempts, whereas in reality persons with knowledge, experience and international standing who had 'applied for the post four years ago were never called for interview, did not even receive a telephone call, and never informed why their application was not considered'. Instead persons who have no 'specialization, no comprehension, no sensitivity to' the needs of the disability groups that are meant to be served under the act were now exclusively heading the Trust.

As Mr JP Gadkari of Parivaar points out, it is indeed unfortunate that the government has sought to introduce a Bill to amend the National Trust Act without going into the substantive issues. Also worrying is the fact that one of the proposed amendments proposes to give authority to the government to fill a vacancy without following the due procedure for such an appointment. The period for which such appointments will be made is also deliberately left out. This is a telling reminder of the seriousness with which the government treats matters concerning one of the most marginalised sections of our society.

The intervention by the Members of Parliament succeeded in getting the Deputy Chairperson to refer the Bill to the Select Committee. But what happens next?

In the light of India having ratified the United Nations Convention on Right of Persons with Disabilities (UNCRPD) and the passage of the Rights of Persons with Disabilities Act, 2016 (RPDA) it is incumbent on the government that the National Trust Act be amended to harmonize it with the UNCRPD and the RPDA. And the government must do this in consultation with all stakeholders. But will the government do all this?

Not unless stakeholders put pressure on the Ministry to bring about these changes. Unless the sector wakes up and decides to act.

Will it? Will we? For the sake of the sector?

Autism: Sensory Issues and Communication

Dr Wenn Lawson

This article aims to explore why communication in autism can be so difficult. It also emphasises why and how sensory difficulties impact autistic communication and highlights the areas of good communication expressed by autistic individuals that are often overlooked.

When clinicians are exploring possibilities of whether, or not, individuals are on the autism spectrum (AS), they are guided by the description in the Diagnostic and Statistical Manual of Mental Disorders, edition 5 (DSM-5; APA, 2013) and in Europe, the ICD-10 (ICD-11, an update on ICD-10 is in progress-<http://www.who.int/classifications/icd/revision/en/>). These manuals help describe criteria for many mental health disorders (DSM-5) and health and related disorders (ICD-10). As noted, at the time of writing the ICD-11 (European Manual: World Health Organisation, 2018) is yet to be finalised, but it's thought it will be in line with the DSM-5.

The DSM-5 houses criteria for many different 'neurological' dispositions from the autism spectrum to specific learning difficulties/disabilities (previously known as: dyslexia; dyscalculia; dyspraxia, Attention deficit disorder with or without hyperactivity (ADHD) and so on) to personality disorders, depressive disorders and clinical mental health disorders (e.g. bipolar disorder, generalized anxiety disorder, schizophrenia, and anorexia nervosa) to other neurological issues such as Alzheimer's and so on.

Although AS is not thought of as 'an issue of mental health' but rather as a pervasive developmental disorder, it qualifies for the DSM-5 due to the influence of AS on a variety of areas in a person's life. For example, a mental disorder may refer to: *"a health condition characterized by significant dysfunction in an individual's cognitions, emotions, or behaviors that reflects a disturbance in the psychological, biological, or developmental processes*

underlying mental functioning" (American Psychiatric Association, 2012:465)

In the DSM-5 a section referring to 'sensory issues' now adds to the profile of how AS may impact some individual's communication. Sensory dispositions in AS may mean an individual's 'senses' (sight, sound, smell, touch, taste, movement, and various interoceptive senses) are either off line, reduced in connective capacity, mixed with other senses to distort or misconfigure a 'pure' sense, (synaesthesia) are hyper-sensitive or a mixture of these.

The criteria for assessing autism says individual's must have difficulties with social understanding and social communication as well as difficulties owing to narrow, repetitive interests. So, if an AS person has a brain 'wired' to be single minded (repetitive interests), with senses that might be seeking sensory stimuli or over reactive to sensory stimuli, this combination will lead to a cognitive style of thinking which often misses the bigger picture needed for broader connective communication (Happé, 1999; Happé & Frith, 2006). Such a cognitive style will have many strengths though and, provided AS is accommodated for the person (e.g. environmental adjustments are made, and sensory accommodations are made, school and work schedules adjusted to individual needs and the person has appropriate motivation), AS can be a legitimate lens to see and engage with the world both within and around us (Lawson, 2011; Prato et al., 2018). In fact, some of the communication differences in AS have created walls to communication between autistic and non-autistic people, **not because of autism** but because we have 'missed' what is being communicated by autistic individuals (Wood, 2018).

Rethinking Autistic Communication

In Wood's 2018 research study it was found the autistic children communicated very well, just not in ways expected or desired by a teacher. (e.g. they made it

clear when they were not interested, for example, they chose an activity from a choice card that a teaching assistant didn't want them to choose; they enjoyed silence when they were focussed and motivated to read or employed in a motivational activity they enjoyed, but might not have known how or when to be quiet otherwise). Wood noticed from her study children who were said to be 'non-verbal' would respond to another by using sounds, babble, or a jumbled mix of words that were an obvious attempt at communication, which was not understood by others.

An example of this can be illustrated through this extract from one of Wood's semi-structured interviews with a 5 year old, a lively and engaging talker, who enjoyed conversation, but struggled with pronunciation, language recall and narrative order:

Boy: *The ra, the ra. . .another day (i.e. the other day) there is, there is a man sitting at the road, there's, there is a, there is a man sitting at the road and he got really rundover(. . .) An ambulance got in and he went to hospital. Boy (shaking head) He didn't, he really didn't, he, he, he, he looked at the road, he didn't dowan like that, he, he, he crashed the road, he was looking, and he went crosh the road to our house.*

Similarly, a 9 year old found it difficult to relate anecdotes and pronounce words:

But I'm still. . .I'm still old. . .I'm still. . .I know how to. I know how to. . .like. . .use the. . .mysister's compers(i.e. computer). . .she didn't. . .she won't ask me. . .she always. . .she wants. . .her ones

Then a 7 year old, the only female participant amongst the children in Wood's study, sometimes struggled to answer the questions during the interviews, of which the extract below is an example:

And what about Maths? Do you like Maths?

Yeah

Do you find Maths easy or difficult?

(pause)

Or sometimes easy sometimes difficult

(pause)

You're not sure about that one?

Yeah

OK, that's all right.

These short extracts exemplify some of the difficulties in speech and communication (Wood, 2018; 5-7)

Wood (2018) suggests the noise in schools creates places for mis-understanding, confusion and mis-communication (it can be at home or anywhere). For example, noise from children playing, school bells, musical instruments, children screaming, equipment such as air conditioners, hand driers, doors opening and closing or from noisy activities such as assembly, dancing, sports and so on. Yet, school often complained of the 'noise' made by autistic children. Somehow school yard noises or screams of other children were not considered 'noise' but if an autistic child cried, screamed or shouted this was considered 'strange' or 'difficult,' or abnormal.

When individuals live with a sensory system which doesn't build typical (polytropic- multiple) connections but is dictated to by a brain wired to process stimuli one at a time (monotropic-single), it's very difficult to multi-task. Noise interferes as an added dimension because it calls away attention, often 'highlighting' the noise and exaggerating it.

Yet, communication (between self and someone else) requires multi-tasking. Individuals need to notice the person, sign, device 'speaking' to them; decode what is being heard, seen or offered, then take any action, if one is required. These are hard things to do in autism, especially if your attention is called away by added extras, such as 'noise'! Interestingly, as many families have noticed, autistic children WILL multi-task when they are working, playing or acting in an area of interest that motivates them. This is probably one reason in Wood's (2018) study, children communicated well due to motivation (e.g. when **they wanted** something different to that on offer etc).

A study by Kiser, (2013) undertaken as part of a Masters' dissertation found GAMMA to be scattered and in excess in the autistic children in his study. Of interest though is how this changed when the children were motivated or interested. Interest (motivation) 'switched on GAMMA'. For humans to make sense of the information being communicated to and with them, they need to notice the bigger picture it connects to. The brain wave band width 'GAMMA' is the one responsible for connecting information from the other bands and enabling an individual to put the information together so they can access the bigger picture, rather than individual details provided when differing brain waves act on their own (they usually act together but this is dependent upon the circumstances).For example, if the door bell rings it might mean someone is at the

door, requesting it be opened. If you are autistic and single minded, you may not notice the door-bell being rung, especially if you are otherwise engaged. If you do notice, you might not realise something needs to be done with this information. This is part of being monotropic (Murray, Lesser and Lawson, 2005). In Kiser's (2013) study he found GAMMA was scattered and in excess in autism. This would make it difficult to shift attention, especially when sensory issues are present, in autism. So, accessing the bigger picture, outside of motivational interest, is difficult to do.

Communication

Information is carted around the brain by means of electrical impulses, or brain waves. These 'pulses' operate at differing band widths and are responsible for relaying sensory and motor (information from the muscles) in ways so we can make sense of the information. For communication to be affective, it must be taken on board, be understood and then be appropriately acted upon, if necessary. Communication also depends upon good working memory, short and long-term memory, and good retrieval from memory. In autism sensory information can infiltrate memory and actually knock out context. For example, even when an individual knows what to do, when and how, if their senses are over whelmed, the retrieval of such information isn't available to them.

One person (see: <http://www.autism.org.uk/sensory>) said: 'If I get overload then I just shut down; you get what's known as fragmentation.... It's weird, like being tuned into 40 TV channels'....

Brain Waves responsible for conveying information in electrical format:

Beta waves (12 to 38 Hz) **Beta brainwaves** dominate our normal waking state of consciousness when attention is directed towards cognitive tasks and the outside world. **Beta** is a 'fast' activity, present when we **are** alert, attentive, engaged in problem solving, judgment, decision making, or focused mental activity.

Alpha waves predominantly originate from the occipital lobe during wakeful relaxation with closed eyes. **Alpha waves** are reduced with open eyes, drowsiness and sleep.

Theta waves generate the **theta** rhythm, or signals, recorded either from inside the brain or from electrodes glued to the scalp. ...**Theta** waves with a lower

frequency range, usually around 6–7 Hz, are sometimes observed when a rat is motionless but alert.

Delta waves, are usually associated with the deep stage 3 of NREM **sleep**, also known as slow-**wave sleep** (SWS), and aid in characterizing the depth of **sleep**.

A **gamma wave** is a pattern in humans with a frequency between 25 and 100 Hz, though 40 Hz is typical. According to a popular theory, **gamma waves** may be implicated in creating the unity of conscious perception (the binding problem) (see: <https://lucid.me/blog/5-brainwaves-delta-theta-alpha-beta-gamma/>) helping us draw together 'the big picture' from information associated with the other brain frequencies. If GAMMA is scattered, in excess or off line, the bigger picture information isn't available to us.

In autism we have the same brain waves as in typical development but, the communication between them is different. We are not 'as connected' in general as non-autistic people and we can be deeply connected at other times. So much so we don't hear when our name is called. But, if we *are* motivated we hear better! As autistics we operate from 'the narrow beam' of a torch with an intense narrow focus that takes in details of interest. Non-autistic people more readily access the wider 'beam' of the torch so are privy to more information with wider connectivity but often miss the detail. So what does this have to do with sensory issues and communication? Everything!

In autism if one's sensory system is in over drive this takes up all ones' attention. There won't be any 'spare' attention to notice when someone speaks or even walks towards you. The way past this is to accommodate the sensory profile for autistic people. Taking time to work through a sensory check list, for example, will aid in understanding any sensory issues a person may have (See: <http://www.aetraininghubs.org.uk/wp-content/uploads/2012/05/37.2-Sensory-assessment-checklist.pdf>) When schools are too noisy it might be useful for our autistic students to wear ear defenders, a baseball cap, sun glasses and so on. Using a squeeze jacket (see: <https://www.squeasewear.com/>) could be helpful for some. A 'Squeeze Jacket' is a garment that an individual can wear that allows them to 'pump' air into special channels which puts air pressure into the garment which 'pushes firmly' onto their upper torso. This acts like a 'squeeze' and can help calm someone. When I wear mine I feel like there is a distance between myself and others. It's like having a force field

around me and not only do I feel protected and safer I also feel enabled to be more present around others. So, for me this is helpful in crowded places. Sometimes weighted blankets or/and soft toys can be useful. But, after about 20 minutes or so, the brain accommodates the weight so they only work for a short time. With my 'Squease Jacket', I can pump it up or let out the air... so, my brain always accommodates the pressure because it's freshly pumped up when I need it, rather than being there all the time

Interoception

Sometimes thought of as our eighth sense, interoception, is a lesser-known sense that helps you understand and feel what's going on inside your body. Kids who struggle with the '**interoceptive**' sense may have trouble knowing when they feel hungry, full, hot, cold or thirsty. Having trouble with this sense can also make self-regulation a challenge. For a fuller description of interoception and the sort of exercises used to connect students to their inner bodily senses see: <https://autismawarenesscentre.com/what-is-interoception-and-how-does-it-impact-autism/>
And <http://web.seru.sa.edu.au/pdfs/Introception.pdf>

Some brief interoception exercises I have done with my own children, to help them recognise when their bladder was full, when they were in pain (earache) or when they were hungry, included the following:

The need to urinate: When I asked my youngest son if he needed to use the toilet he just looked at me. It was as if he were asking me 'how can I tell if I need to pee?' So, I said to him, each time I asked him this question, "when you press on your tummy low down, is it comfortable or uncomfortable?" When I asked this question I gave him about 10 seconds to experience and interpret the feeling from the pressure of his hands on his tummy. "If it's uncomfortable", I would say "it might feel better if you pee into the toilet. Go to the toilet and pee and see if it does."

Pain: There were times when my son seemed 'out of sorts' or possibly unwell. I used to say to him: "Do you have pain; does it hurt somewhere on your body. Do you have some discomfort?" **At this question he would look at his hands to see what he had..what he was holding...** it was obvious he didn't understand so I rephrased my question. "Does it hurt here if I press?" I did this for various places on his body, such as his arm, his head, his tummy ... I gave him time to connect

to any 'feeling' he was having. If he was too apprehensive about me touching him I asked him to use his own hand. It helped too if he closed his eyes. This was helpful because he could tell what was comfortable and what wasn't and then he could point to where his discomfort was.

I remember thinking 'he must be hungry' but he didn't respond when I said: "...are you hungry?" So, instead I made him his favourite, a snack I knew he liked, made sure he wasn't absorbed in a favourite activity, then asked him to close his eyes. I waved the fruit or meal under his nose and I made sounds of enjoyment and pleasure. I asked him to breathe in and smell the lovely fragrances from his food and as he took his time to connect, I'd say: "...You are hungry, that's why your mouth is making saliva (watering) and your body is telling you to eat this." His smile told me he *now knew* that he was hungry.

If an individual's interoceptive sense is disconnected it's important to build interoceptive exercises into the school day. In one South Australian School they quoted their 'school exclusions' were down by 64% (personal communication, 2018) due to practicing interoception during school hours. I know (we all know) excluding a student from school achieves nothing, except to confirm to that student they are not valued and no-one is listening to them!

Self-regulation is vital for good communication. How can we know it's our turn to talk or when we need to be quiet? We depend upon our sensory and motor systems being in sync; (not over or under stimulated) and upon accessing the big picture. So, creating an autism friendly environment that allows the building of such connectivity is essential to the processes of inclusion and allows sensory modalities to be monitored and good communication to take place.

Sometimes communication happens best when we don't look at someone. Looking at someone may accost the senses. Sometimes communication works best via text, email, comic strip stories, video and TV. Communication in autism must consider the sensory systems we live with, must give us time for processing and must be autism friendly.

Conclusion

Communicating with autistic individuals makes the most sense when we are in a position to attend to the message being given. This will mean if we have sensory issues

taking over or attention, that they are accounted for. For example, when my autistic granddaughter came to visit, we glued green snooker table felt to the ‘bottoms’ of the chair and table legs. This meant she didn’t cover her ears in pain each time a chair was moved at the table, because the chair no longer ‘scraped’ the floor. When we went out to the shopping Mall, my granddaughter wore her ear defenders so the noises in the shopping centre were dulled, allowing her to help me with the shopping. At times my granddaughter needs to follow her lessons on her iPad with her headphones, rather than be attending to teacher in a noisy classroom. There are times she needs instructions texted to her or emailed because she can take her time over this type of communication and can re-read it as often as she likes. This gives her time to check in on her understanding and the content/context.

Technology is so often a very useful tool for autistic individuals. It comes without body language (which can confuse) is a single focused piece of equipment (not talking, walking and waving hands about all at the same time) and can be text or picture based.

(See:<http://www.spectronics.com.au/product/20032/popup>)

True communication needs all concerned parties to hear and be listened to. Are we trying to make autistic individuals fit into a mould they are not designed for or are we adapting our communication styles to fit in with them so both our communication styles can be understood?

True inclusion says: ‘I accept you where you’re at and will walk with you to our mutual destination at the pace you need me to.’

REFERENCES

- *American Psychiatric Association. (2012). Definition of a mental disorder. Retrieved from <http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=465>*
- *Happé, F. and Frith, U. (2006) The Weak Coherence account: Detail-focused cognitive style in autism spectrum disorders. Journal of Autism and Developmental Disorders 5-39*
- *Happé, F. (1999) Autism, cognitive deficit or cognitive style. Trends in Cognitive Sciences – Vol. 3, No. 6.*
- *Lawson, W. (2011) The passionate mind. JKP: London*
- *Lawson W. (2013) Autism spectrum conditions: the pathophysiological basis for inattention and the new Diagnostic and Statistical Manual of Mental Disorders. OA Autism 2013 Mar 01;1(1):1.*

- *Murray, M., Lesser, M. and Lawson, W. (2005) Attention, monotropism and the diagnostic criteria for autism 2005 May;9(2):139-56.*
 - *Prato, J., Coelho, R. and Lawson, W (2018) How the Attitude of Acceptance, Enthusiasm and Learning through Motivation Affects Brain Development in Children with Autism: A Literature Review: Journal of Intellectual Disability - Diagnosis and Treatment, 6: Vol 1, 1-6*
 - *Widiger, T. A., & Gore, W. L. (2012). Mental disorders as discrete clinical conditions: Dimensional versus categorical classification. In M. Hersen & D. C. Beidel (Eds.), Adult psychopathology and diagnosis (6th ed., pp. 3–32). New York: John Wiley & Sons*
 - *Wood, R. (2018) The wrong kind of noise: Understanding and valuing the communication of autistic children in schools. Educational Review, DOI: 10.1080/00131911.2018.1483895*
- To link to this article: <https://doi.org/10.1080/00131911.2018.1483895>

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Autism and the Pursuit of Happiness

Ray Hemachandra

Part 3: Support or Save

(This six-part series is adapted from a talk the author gave at the Autism and the Pursuit of Happiness Conference in North Carolina in the United States. Parts 1 and 2: 'Accept or Reject' and 'Grieve or Live', respectively, were published in the April 2018 issue of Autism Network)

The third value contrast I want to talk about is: SUPPORT OR SAVE. Save also means cure. Save also means control. We are raising a child—as a parent, as a family, as a community, as a society. What are we working toward?

Generally, with the autistic population, we are working toward neurotypicality. That framework is generally how we define best outcomes.

In other words, we are mostly working toward making these people exactly what they are not, and we measure success by what degree they can become unlike themselves.

This is the save model: these autistic children need saving because they're lost. It's the cure model: let's find a cure to this epidemic called autism that is stealing our children. It is the fix-it button, the magic pill—the 'promise' of swimming with dolphins, laser therapy, or chelation—and it is also boot camp and the drill sergeant of ABA (Applied Behavioral Analysis): Militaristic routines, training, and demands will drive the autism out of you and make you 'normal'.

What we should be working toward, instead, is recognition of who you are and a shared goal of happiness. To be fair, many wonderful therapists and teachers—ABA and otherwise, including some of the most heart-centric people I have ever met—absolutely do make happiness the organizing principle of their work, and they frame support goals in ways that help parents make that transition in sensibility, too. But many don't. Most don't.

What's the difference? The actions taken might be—*might be*—exactly the same. But the language and the intent—the emotion and the very essence of the work

and teaching being done, as well as the parenting being done—are emphatically different.

The difference is in wanting to cure your child's autism versus wanting to support your autistic child. That difference is deep and profound.

Now one might say as a parent that this autistic child will be happier—will fit in better, function better, and have a better life—by maximizing her or his presentation of neurotypicality. We often do say that as parents.

This approach by itself, though, is akin to trying to make gay people present as straight so they will be accepted. And that's exactly what we did as a society for a very, very long time and what some places still do today! The truth, though, was and is that people can conform, be in a heterosexual marriage, present as straight, have kids...and still be gay. But they do not get to be their fully realized selves living fully realized lives, and they clearly do not get to live their happiest lives. We can take all the data we want, drill all the quirks and nonconformities out of an autistic child or adult, and that person will still be autistic.

Happiness requires respecting the individual. It also requires people accepting and respecting themselves and not being convinced that who they are is wrong. Does that mean we don't do any therapies or parenting work to help someone diminish harmful or self-injurious behaviors? Or that we don't develop positive supports to give these children every opportunity for well-being and happiness? Of course not.

But it means we treat them with respect and let them participate in the decision-making, even as children, to the best extent we can, so we are valuing what is important to them, not just what is important to us. It means we respect the fact of their autism as an integral, essential aspect of who they are. It means we assess their well-being on their own terms, not on neurotypical terms that don't reflect their authentic selves.

It means we attend to their communications of all kinds. We listen.

This is equally true even for nonverbal, high-support-needs children.

This is equally true even for very young children.

To make decisions for oneself is a fundamental human and civil right. It is essential we consciously work to empower autistic children and of course autistic adults in every way possible, continually.

As parents, though, we certainly do make choices for our young children all the time, whether they are or aren't autistic. That's part of what parenting is.

But for nonautistic parents of autistic children, we are making decisions for people who are unlike ourselves in a very important way. Are we qualified to make decisions for them?

Are we competent to do so?

By some measures, anyway, the answer is obviously no. Our experience, our knowledge, our expectations and understandings are too unlike: our minds and neurologies work too differently. We receive and engage the world differently. We are making decisions based on what may be an almost flipped worldview.

So, to some extent, we don't know what we're talking about. Responsible, kind parenting asks more of us. Fortunately—and far more so than even a decade ago and certainly than two decades or more ago—there is a tremendous educational resource available to us: the voices of autistic adults.

These voices are available to us at forums in local communities and at all times online through blogs and adult autistic community networks and social media. These are the most important sources of learning possible for parents of autistic people, for family members and community members, and for therapists and teachers.

What helps autistic people? What hurts them?

Which supports were actually supports to autistic adults when they were children, and which were torture devices? Did some approaches prove to be both?

The 'whys' we guess at about the way autistic people respond to the world—what are their 'whys' to the extent they can be explained? What were they when they were children?

Each autistic writer or speaker isn't every other and isn't our own child or friend or student or patient. Each person is an individual, of course.

But when you discover a consistency in messaging in some areas among autistics, you feel like you are discovering at least general truths for the population. The shift in perception and in values as a parent can be profound.

I have had my own lessons along the way. My son Nicholas was a flapper. He flapped his hands a lot. It is a form of stimming, helping provide sensory and emotional regulation and expression.

In elementary school, Nicholas desperately wanted friends and was extremely sensitive to teasing. Teasing was completely devastating and debilitating to him. At some point in early to mid elementary school, I worked with Nicholas to reduce his hand flapping, which was yet another thing that differentiated him from other children and made him prone to teasing.

Two or three years ago, I noticed Nicholas flapping more again when he came back from one of his week-long autism sleep-away camps. Other children's behavior there seemed to give him permission.

Recognizing that, and affected by something I had read online not directly related to flapping but of a similar kind—it was about chin grabbing and eye-gaze seizing as a form of violence—I shifted.

I told Nicholas he could flap all he wanted at home, and he could make a choice about it at school: flapping might feel good, or necessary, and it also might make him more likely to be teased. He was old enough to make a choice about it for himself. We revisited the conversation several times. He did flap a little more at home, but at school he didn't change his behavior much.

Then Nicholas got an autism mentor, an adult autistic woman who gets together with him sometimes. She flaps, and, like with that camp, I've noticed that Nicholas' flapping increase a lot during and after his interactions with her, as do his general stereotypic movements. Again, he seems to have permission to be himself then, and I am so glad for that.

That is increasingly the conversation with my son now: You are a teenager. Try to be self-aware. And you are the one who then gets to make choices.

That's my job as a parent: to support my son in his choices, in his self-determination of his own life and in what he chooses for his well-being.

Autism and the Pursuit of Happiness

Ray Hemachandra

Part 4: Acceptance of Self-Acceptance

The fourth value contrast I want to describe today, which might initially seem like an especially false dichotomy, is: ACCEPTANCE OR SELF-ACCEPTANCE.

My son started juggling a few years ago. I can do a three-ball juggling cascade—awkwardly and for a short time in a burst—and I showed Nicholas. And then he *really* wanted to do it.

He practiced and practiced...and practiced and practiced...and practiced some more, every single day behind his closed bedroom door. His developmental worker Sarah juggled with him, a day camp counselor named Dane juggled with him.

Nicholas *loved* juggling and then loved succeeding at it. His dedication and determination were awesome. He became good enough to start trying it at camp talent shows, and then he performed in community settings and at school talent shows in fifth and sixth grades. He received raucous applause at events, and I was told that his schoolmates burst out in huge cheers when Nicholas performed during programs at school during the day. His teachers were very surprised and impressed, too. I feel guilty about this.

Kids were wowed by his talent and by the fact it was Nicholas, this—strange? disabled? weird?—kid. He became more accepted, better appreciated, and better liked. Children treated him with greater kindness. He had a burst of new friendships and playdates around the time, which he wanted so much. And I feel guilty because that was all exactly my intention.

Nicholas was thrilled by the cheers, by the admiration of his classmates and the compliments and affection. It made him feel great about himself. But of course that feeling reveals dependence on the acceptance of others: the conditionality of being affirmed by others.

Most of us have that need. Most children, especially those approaching and then in their teens, struggle with their need for affirmation.

But I feel guilty because if he couldn't juggle, Nicholas would not be one ounce less worthy of love and acceptance. And there are children and adults very similar to Nicholas who can't juggle.

Nicholas, who has IDD (intellectual disability, what was once called MR, or mental retardation), has a surprisingly rich intellectual capacity—but that is less easily discerned by most people than are things like his juggling and deft spinning of basketballs.

I feel like I helped Nicholas receive external acceptance but didn't do the harder work that would have led to greater acceptance for Nicholas even without his juggling talents—or at least that I didn't do that work as successfully.

It reminds me of the whole autistic savant idea—the common Rainman-type question that's often asked when someone finds out about a person's autism.

For autistic people who do have special talents, it's right and good to share them and to have them appreciated. But of course such talents don't make anyone more worthy of kindness and acceptance.

If someone like Nicholas is treated better because of those talents, it's at least worth pausing to support the more noble notion that any affirmation of self-worth is coming out of what sharing a talent says about the quality of one's character—bravery, kindness, connection—so it's more about who someone is, not what someone can do.

And not what we look like, either. Lookism (biasing toward children or people who are 'good looking' by whatever standard) is another societal and cultural albatross upon both special needs children and children generally.

Somewhat similarly, earlier, throughout elementary school, Nicholas' Individualized Education Plans (IEPs) noted his strengths and weaknesses, as IEPs do, and one of Nicholas' strengths was that he was a handsome child.

When this first appeared on an IEP, I asked about it. It seemed odd to me at the time more than anything. One teacher—a great teacher of his and now a dear friend of mine—explained its relevance: being good-looking was a strength for Nicholas because he would be treated better by peers and teachers. That's just the way it was, she said.

And she was right.

That did work for him. It benefited him. But again, taking advantage of lookism was affirming a value system I abhor and wanted Nicholas to feel no part of.

Children—and adults, too—shouldn't require exceptionality to be loved, accepted, and included.

As parents and community members, I hope we teach, and hopefully maintain a healthy respect for, the idea that everyone is equally precious and valuable, deserving of acknowledgment and respect and love, including all autistic people—autistic people with and without obvious talents or what a culture currently deems as good looks.

As parents, the responsibility is to raise your child, yes, but also to help others and so to raise the culture. And then, too, I hope we teach that acceptance and love ultimately have to originate from within if they are going to be authentic and lasting.

That all said, and sincerely so, I am very proud of how hard Nicholas works at his juggling and how good at it he has become due to his dedication. He is proud of it, too.

When he was younger, he had difficulty even tracking a ball: before he'd even move a muscle to respond, the ball would roll by him or hit him in the head.

Now, due to his hard work and perseverance, his coordination in this area is well beyond most people's, including mine. And when Nicholas accomplishes a new juggling skill or routine at home, he's very proud of it on his own terms, without applause.

I'm most glad for that.

RAY HEMACHANDRA is an autism writer, speaker, and consultant and parent of an autistic teenage son. Ray serves on a half-dozen boards and committees in support of autism and disabled populations, and he has extensive experience as a trade show and conference speaker and interviewer.

Ray has a professional background in business leadership. He has worked for newspaper, magazine, and book publishers, and he is the author of a Publishers Weekly Book of the Year and an Amazon Best Book of the Month. Read Ray's articles about autism and other topics at www.rayhemachandra.com

MUSINGS

Shubhranil Das

Shubhranil Das is a 15 year old from Kolkata. He is an artist extraordinaire who painstakingly creates detailed works in pen and ink, using swift yet deft strokes.

Shubhranil had no pencil grip till age seven when he did palm and finger painting with various textures and different types of brush on different kinds of paper, cloth etc under guidance of an art teacher. At the age of 14 he on his own started a new style of drawing that has now become his signature.

Shubhranil also enjoys music and singing. Shubhranil is on the spectrum and often articulates his experiences with autism and his sometimes-unusual perceptions of the world around him. In this issue we share some of his musings with you

I have a great problem with this world. I have peculiar sensations in my body. I have a great problem with different sounds. Those sounds hurt my ears like anything. I feel like a cut. I feel to flee away. I am always trying to avoid those. But if I have to hear all those, I have to cover my ears with my fingers.

Sometimes I hide my head under a pillow or bean bag.

Those sounds that hurt my ears are the sounds of the radio, TV, sound-making balls, guns, cars, dolls, computer, railway announcement, school bells, door bells, space sounds, human voices.

Sometimes, I make a horrible sound with my throat. That is very annoying for everybody. They cannot tolerate that sound and scold me. I produce those sounds to make me safe from sounds of different animals, birds and the shaking of the earth.

I make this sound to cancel those noises. I never do that intentionally. But, I have to make those to keep me safe. I have a great problem with this world. I wish I could go to a lonely silent place with my mother.

Recently, I have a great problem with cuckoo chirps. That sound badly hurts my ears. I have to cover my ears instantly with my fingers. If not sufficient, I have to make some continuous sound in my mouth to cancel that.

This is a great discomfort on the roads. People on the road don't understand my problem and stare at me. Many time they ask my mother what is happening. Sometimes I overhear that people are saying that I am a mad boy.

I have a problem with voices of small children and women. That makes a big chaos in my family.

Sometimes, I cannot tolerate the voice of sister, my grandmother, and our maid servants. I feel I want to hit them. But, I try not to do that.

I throw my tantrums. That makes a big chaos. They never understand my problem and try to control my anger in words. That multiplies my problem. I get more hurt.

That really overstresses me.

When I cannot control myself I drag the chairs from one place to another or shake the doors and make a different type of noise. On the way to drag chairs, I hit the leg of the person whose voice is painful to me. They become very annoyed with me and make bad comments about me.

I don't like the chewing sounds of humans and animals. I get very anxious at the dining table and stand up from my chair during having food. In the restaurant I try to control myself, but sometimes I cannot. If I can manage all those, I really feel secure.

I can hear a few sounds which are generally not heard by others. Sounds of very distant cars, running trains, running aeroplanes, jet planes. I can even hear some space sounds. Like sounds of moving planets, sounds of moving body of stars, moons. I can hear upcoming storms. I can hear the earth shaking due to the movement of earth plates.

I can hear the sounds of different animals and birds. Sometimes, I can hear that trees are having food.

I like to hear the sound of a moving fan, that soothes my ears. For that I switch on fans in winters, too. I like to hear the sound of ocean and sounds of moving trains. Train is my lifeline.

I am a train fan. Train is my lifeline. When I was at Kalyani, I regularly went to the station with my father to see the trains. I sat on the platform, hearing the

sounds of train's wheels, the coupling sounds, signals and the diesel engine. I was then full of concentration and felt relaxed.

Whenever I boarded trains, I enjoyed the whole journey. I am exceptionally calm and quiet in trains. Sometimes people ask my mother why I am so quiet. My mother answered that her son has autism and he is enjoying the moving train.

I cannot tolerate the lightning and thunderstorm. I feel discomfort in my eyes and ear. I hide inside my room and feel really scared.

I cannot tolerate brushing on my head and body. I feel very stressful during combing my hair. I feel that I am massaged by an ugly monster.

I have to walk with more pressure as I feel I will fall on the ground. So I have a great problem with my foot. I have big hard painful areas in my foot. My mother removed those with blades.

I feel pain to look at other's moving eyeballs. In my childhood days, I could not tolerate others' eyeballs movement. I wanted to stop their eye movement with my hand. They got hurt in their eyes with my fingers.

They got very angry with me.

I cannot tolerate the smell of the human body and of animals. I feel very uncomfortable with body odour of our maidservants and our pet. I feel a great suffocation on their presence. I feel like hitting them. I feel very tense when our maidservants are coming. I sometimes hit them when they enter. They get very annoyed with my mother and throw bad words to my family and give up their job.

Sometimes they beat me in the absence of my parents. They know that I am a mad boy and with no understanding. Sometimes they steal dresses, father's money, mother's ornaments, my toys in my presence. As I cannot report to my mother they think that I have no understanding. But, I have my Sabitapisi and Susumapisi (household helpers). They are too good. I love them a lot.

I cannot mix with other children. I understand that they have a different level of understanding. They are different from me. I want to avoid them. I have a big problem with my cousin brother. I understand that he is

a normal boy and I tend to hide from him. I cannot estimate his level of thinking.

I sometimes talk to myself. I hear someone is talking with me. I feel that someone is my friend who is not visible. He is my costume, my autistic costume. I am actually not related with my autistic costume. I am a born saint, who wears this costume.

I spin like a planet, moving on my own axis. I spin to control my body, my costume. Sometimes i feel that someone is attached with my body who is not desired. I lose my body control. I feel

I am floating away in space. That is very scary situation. I have a perception that my body is a feather and floating in air. This is very much disturbing.

I can feel the earth is rotating and I am falling. I see everything swing in front of my eyes. Sometimes, I say this to people, but they cannot understand my language.

I can understand the inner thinking of other people. This is very much disturbing for me. I get overstressed.

Sometimes I see what they think, but what they say is different. Then, I cannot resist my laughing.

How I Made my Way into the World of Autism!

Shivangi Khattar

I walked in the Action for Autism building with multiple emotions; an excitement to work with specific people with excellent training in research and clinical experiences, nervousness about if I could live up to even an umpteenth of expectation I had placed on myself, and a few others. Little did I know that I would come out with a completely different perspective on not only autism, but also neurodiversity as a concept.

I was greeted with a smiling Salini, but I was distracted by a wonderful young man constantly repeating his name. This was followed by what sounded like someone singing the opera, someone else speaking their own jargon, and another individual running around greeting everyone because that was her exercise in class that week.

I was later introduced to some of our staff that were also on the spectrum. This was pleasantly new for me, because inclusion to this extent was not something I had seen before. While being introduced to these individuals, no one labelled them with their diagnosis, in fact if you walked in for the first time at AFA you could probably not even tell.

Instead, everyone at AFA was introduced as part of the WHOLE, and for the role they played to complete this very whole. The “labels”, the “deviation from the normal” was not given any importance at all.

Weeks went by, and the nature and functioning of the organization started to make more sense. My

understanding of how AFA functioned was perhaps my greatest learning. Although I had read, learnt and understood how to better conduct research on autism in enclosed spaces and centrally air-conditioned buildings, I was so divorced from actually working with individuals with autism first-hand.

From trying to grasp what the young man was saying to me at the cafeteria the other day, and what he was feeling when he changed his pitch from low to high, what excited him to flap his hands wildly; the desire to understand what he was experiencing and wanting to be a part of his world someday, to understanding that it was okay to let him be, because the world he was “lost” in, was his.

Perhaps he was not lost after all. He is as active and functioning in his world as I am in mine.

People at AFA respect differences, value diversity, and believe in interdependence. Since none of us is truly independent, we are all interdependent on each other.

We at AFA have come to understand this and be content in it. There is no stagnation, we do not stop, we are constantly exerting to spread this awareness that we have gained here, this understanding to the “outside” world as well, and this gives me great hope for what we strive to do looking at the future; to continue working to strengthen the rights as well as the voices of individuals with autism and their families.

व्यवहार संबंधी “समस्याएं” और ऑटिज्म

मेरी बरूआ

अनुवाद-रीचा जोशी

हमारे समझने के लिए ऑटिज्म एक जटिल स्थिति है। “हम” से मेरा संदर्भ उन सब से है जिनको ऑटिज्म नहीं है। और जिनको ऑटिज्म है, उनके लिए उनकी स्थिति ना जटिल है, और न ही अजीब, वो उनके लिए एक स्थिति है। जिनको ऑटिज्म है, उनके लिए वो उनका जीने का तरीका है, ठीक वैसे ही जैसे भारतीय होना मेरा जीने का तरीका है, अगर मैं नीदरलैंड रहने चले जाऊँ तो मेरा भी वहां के निवासी लोगों की तरह एक घर हो सकता है, मेरा पहनावा भी उनकी तरह हो सकता है और मैं वैसा ही खाना खाऊँ जैसा वहां खाते हैं। लेकिन फिर भी मेरी संवेदनशीलता भारतीय ही रहेगी।

उदाहरण-जैसे मेरा 30 साल का बेटा मेरे साथ घर में रहता हुआ, मेरी भारतीय संवेदनशीलता के लिए एक दम ठीक है। लेकिन वंही नीदरलैंड के लोगों के लिए यह बहुत अजीब होगा कि एक 20 साल के ऊपर का व्यक्ति अपनी मां के साथ रह रहा है।

मेरी दाल और चावल बनाने की इच्छा कोई अलग नहीं होगी, जो कि नीदरलैंड के लोगों के लिए नहीं होगी। और ना ही मेरी भारत जाने की चाह को “पूर्व स्थिति” करना, जैसा हम जानते हैं कि सिर्फ भारतीय ही पूर्व स्थिति करते हैं और जिस तरह “डच” का पहनावा मुझ में से भारतीयपन नहीं निकाल सकता।

क्यों मैं अपने इस टुकड़े की शुरुआत इस तरह कर रही हूँ क्योंकि शुरुआत में ही मैं कुछ चीजें प्रमाणित कर देना चाहती हूँ, पहली की, ऑटिज्म कोई समस्या नहीं है, यह एक जीने का तरीका है, यह एक स्थिति है, सिर्फ इसलिए कि लोग ऑटिज्म या किसी और स्थिति को एक समस्या की तरह देखना चाहते हैं, इससे वो एक समस्या नहीं बन जाती है। ठीक उसी तरह जैसे मेरा

नीदरलैंड या आस्ट्रेलिया में भारतीय होना, भारतीयता को समस्या नहीं बनाता, दूसरा, ऑटिस्टिक होना दुःखमयी स्थिति नहीं है। मैं जानते हुए यहां “ऑटिस्टिक” शब्द का प्रयोग कर रही हूँ। ऑटिस्टिक होना एक व्यक्ति को सीमांकित करता है। जिन लोगों को ऑटिज्म है, उन्हें खुद को ऑटिस्टिक बुलवाना ठीक लगता है। उनको कोई परवाह नहीं कि आप उन्हें क्या बुलाते हैं। मायने यह रखता है कि आपकी भावनाएं क्या हैं जो भी आप बुलाते हैं उसके पीछे हम “ऑटिज्म वाला व्यक्ति” कह सकते हैं और हाँ, क्या दुःखी, बेचारा, अजीब व्यक्ति है” सोच सकते हैं और हम

मैं बस इतना कह रही हूँ कि हम सब प्रयास कर सकते हैं उन्हें समझने का और वो क्या और क्यों कर रहे हैं उसे समझने का और उन्हें जवाब दे सकते हैं, उन्हें रास्ते दे सकते हैं खुद को समझने के, जिससे ऑटिस्टिक और नॉन ऑटिस्टिक दोनों ही एक-दूसरे के लिए आधा-आधा रास्ता तय करें।

“ऑटिस्टिक” कह सकते हैं, बिना किसी नकारात्मक धारणा के इसलिए शब्द महत्व नहीं रखता महत्वपूर्ण यह है कि हम क्या सोचते हैं।

जब व्यावसायिक के परिचित व्यक्ति ने सुझाव देते हुए कहा कि हमें “व्यवहार संबंधी समस्याओं” और ऑटिज्म के ऊपर विचार

विमर्श शुरू करने को कहा तो मैंने सोचा कि मुझे क्या संबोधन करने की आवश्यकता है। चाहे प्यार करने वाले माता पिता हो या परवाह करने वाले शिक्षक सब ऑटिज्म वाले व्यक्ति के व्यवहार को “समस्या” ही समझते हैं, और फिर हम सब और व्यावहारिक समस्याओं को जन्म देते हैं, सिर्फ इस वजह से की हम सबसे पहले उन समस्याओं से छुटकारा चाहते हैं। जबकि हमारा ध्यान ऑटिज्म को “ठीक” करने की बजाय ऑटिज्म को समझना होना चाहिए और जिन्दगी के अनुभव कैसे होंगे। यह ऑटिज्म वाले व्यक्ति के लिए उसे समझने का प्रयास करना चाहिए।

(Workshop) जो व्यवहार का व्याख्यान करती है कि जो “नॉन ऑटिस्टिक” दुनिया जिस व्यवहार को चुनौतीपूर्ण

समझती है, वो शुरूआत है ऑटिज्म को समझने की, पर हम में से काफी लोग (workshop) इस हिस्से में उपस्थित ही नहीं होते क्योंकि हमें लगता है कि वो ऑटिज्म को समझते हैं, हम असल में ऑटिज्म की क्लिनिकल परिभाषा ही जानते हैं और वह यह है कि ऑटिज्म में सामाजिक बातचीत में कमी जो कि व्यापक है बार-बार होने वाले व्यवहार और क्रिया से, वास्तव में यह हमें ऑटिज्म के बारे में बहुत कम बताता है और खास कर कमी देखने का उन्मुख बिंदु है। यह हमें व्यक्ति को समझने में सहायक नहीं है। यह हमें ऑटिज्म वाले व्यक्ति के अलग तरीके से बात करने को समझने में सहायक नहीं है और ना ही यह समझने में कि वे अनोखे हैं और उनका दुनिया को समझने का तरीका हम (neurotypical) से अलग है।

फलस्वरूप यह होता है कि हम ऑटिज्म को क्लिनिकल दृष्टिकोण से समझने लगते हैं, जो ऑटिस्टिक दुनिया को समझने के लिए मान्य नहीं है। तो जब हम बच्चे को कुदते और हिलते हुए देखते हैं तो सबसे पहले हम उस व्यवहार को "रोकना" चाहते हैं क्योंकि वह हमारे लिए शर्मनाक है। हम यह नहीं देख पाते कि वह उनके लिए उतना ही सही है जितना एक बच्चे के लिए नयी स्थिति से मुकाबला करना है और शायद खुशी जताने का तरीका और शायद शारीरिक आवश्यकता या और कोई कारण भी हो सकता है।

हम में से कई लोग उस "आवांछित व्यवहार" को सजा देते हैं, जिससे की व्यवहार को दूर किया जा सके, और कई बार उन व्यवहार को मेडीकल कारण देते हैं ताकि उसे खान-पान या दवाईयों के प्रयोग से हटा सके। हम यह नहीं सोच पाते कि बच्चे के व्यवहार के अपने मान्य कारण भी हो सकते हैं। हमें जरूरत है ऑटिज्म को समझने की, बच्चे को समझने की और फिर व्यवहार को।

अगर हम अपने बच्चों की सहायता करना चाहते हैं, तो हमें पहले उनकी दुनिया को समझना होगा, जिन व्यवहार को हम समस्या की तरह देखते हैं वो एक प्रयास होता है अपनी भावनाओं को व्यक्त करने का तो बच्चे का कूदना और हिलते रहने का, अलग-अलग समय पर अलग-अलग कारण हो सकता है और एक ही समय पर

एक से ज्यादा कारण भी हो सकते हैं। ऊपर दिये गये कारणों में से। अब तीन अलग-अलग स्थितियों को देखते हैं—

शीला अपनी माँ का इंतजार कर रही है तो उसे लेने आने वाली है, उसकी माँ आमतौर पर 1 बजे आ जाती है, पर आज दिन के 2 बजे गए हैं। किसी ने शीला को नहीं बताया कि आज उसकी माँ देरी से आयेगी। उसकी शिक्षक ने बताया पर बहुत जल्दी में जो शीला समझ नहीं पाई। किसी भी तरह का विजुअल अनुदेश नहीं दिया गया और जैसा हम जानते हैं कि ऑटिज्म वाले व्यक्ति ज्यादा से ज्यादा सीखते हैं अगर उन्हें विजुअल वातावरण दिया जाये तो अब शीला थोड़ा तनाव में है, अभी तक माँ नहीं आई है। जिस समय शीला की माँ आती है उससे काफी वक्त ज्यादा हो गया है, वो कब आएगी ? क्या वो आएगी भी ? और इस अस्तवस्त दुनिया में सिर्फ वो ही कर सकती थी जो वो जानती थी, जैसे की कूदना और हिलना (हम में से काफी व्यक्ति इस स्थिति में या तो सिगरेट जलाते या अपने नाखून चबाते या ऊपर-नीचे चलते और यह सब करना नॉन-ऑटिस्टिक समाज में स्वीकार्य होता)।

रमेश ने बहुत प्रयास किया कक्षा में शांतिपूर्ण बैठने का पूरे दिन और अब उसका शरीर सुन पड चुका है। अब विराम का समय है और रमेश को आराम करना है। जो तरीके रमेश जानता है वो या तो झुले पे बैठ कर या हिल कर आराम कर सकता है। झुला ना होने के कारण, रमेश अपने शरीर को हिला कर आराम कर सकता है।

शिक्षक कहता है कि तरुण अपना खाने का डिब्बा लो और बैठ जाओ", तरुण अपना बस्ता खोलता है, पर आज उसका नीला खाने का डिब्बा बस्ते में नहीं है। और इससे वह तनाव में आ जाता है और flapping करता है ताकि कोई उसकी इस उलझन को सुलझा सके। जबकि उसकी शिक्षक लगातार यह कहती जा रही है कि "तरुण ऐसे बेवकूफ जैसा व्यवहार मत करो। अपनी उम्र के अनुसार व्यवहार करो। इससे तरुण का तनाव और ज्यादा बढ़ने लगता है जिसके कारण वह ज्यादा कूदने लगता है और flapping करता है। (अगर इस स्थिति में तरुण की जगह उसका भाई रक्षित होता तो वह अपनी शिक्षक से बोलता की "मेरा नीला खाने का डिब्बा बस्ते में नहीं है। शायद

किसी ने वह निकाल लिया है) क्योंकि रक्षित को ऑटिज़्म नहीं है पर तरुण को है।

क्या प्रतिक्रिया होती नॉन-ऑटिस्टिक समाज की इस स्थिति में ? शीला को बोला जाता "अगर तुम चुप-चाप नहीं बैठी तो तुम्हें माँ के आने के बाद भी घर नहीं जाने दिया जायेगा", इस प्रतिक्रिया से शीला का तनाव और ज्यादा बढ़ जाता और वह ज्यादा flapping करती। तरुण को बोला जाता "ठीक है तुम्हें नाश्ता नहीं करना है तो फिर जाओ और बैठ जाओ"। और निराशा में वह बगल वाले लड़के को मार देता, उसकी व्यावहारिक समस्या बढ़ी क्योंकि वह नाश्ता करना चाहता था।

तो क्या मैं यह बोल रही हूँ कि हमारे बच्चों को पूरे दिन रॉक और फ्लैप करने दिया जाए? (खैर अगर वह किसी को कोई हानि नहीं कर रहा है सिर्फ हमारे अहंकार को) पर नहीं, मैं यह सुझाव नहीं दे रही हूँ। मैं बस इतना कह रही हूँ कि हम सब प्रयास कर सकते हैं उन्हें समझने का और वो क्या और क्यों कर रहे हैं उसे समझने का और उन्हें जवाब दे सकते हैं, उन्हें रास्ते दे सकते हैं खुद को समझने के, जिससे ऑटिस्टिक और नॉन ऑटिस्टिक दोनों ही एक-दूसरे के लिए आधा-आधा रास्ता तय करें।

एक मात्र रास्ता है हमारे लिए हमारे बच्चों की मदद करने के लिए जिनकी व्यावहारिक समस्याएँ हैं कि हम उन्हें समझे और उनको खुद को हमसे व्यक्त करने के रास्ते दे, उनको हमारे नॉन-ऑटिस्टिक समाज से खरीद फरोख्त सिखाए और इसको मैं एक ही नाम दे सकती हूँ cross-cultural interpreter बनाना सिखाए।

और इसको मैं एक छोटी सी घटना के साथ समाप्त करती हूँ। पिछले सप्ताह मीरा ने जतिन से कहा कि "चलो आइसक्रीम खाते हैं। ज्यादातर वह आइसक्रीम तब खाते थे, जब वह बाजार में होते थे। क्योंकि आज वो घर में है तो मीरा रास्ता बता रही है, आइसक्रीम वाले के पास जाने का।

जतिन भ्रमित हो जाता है। और आश्चर्य करता है कि हम उस सड़क पर क्यों जा रहे हैं जिससे हम स्कूल जाते

हैं ? माँ ने कहा था कि हमें आइसक्रीम मिलेगी, पर अब तो हम स्कूल जा रहे हैं। एक नॉन-ऑटिस्टिक व्यक्ति इस स्थिति में पूछता कि "हम स्कूल क्यों जा रहे हैं ? या "क्या हम आइसक्रीम खाने नहीं जा रहे हैं ? या और कुछ पूछता। जतिन इस स्थिति में वह नहीं पूछ पा रहा है। और उसकी जगह वह तनाव में आ रहा है क्योंकि उसके लिए योजना/स्थिति बदल गई।

मीरा को जतिन की परेशानी दिख जाती है और वह कहती है "हम इस रास्ते से स्कूल जाते हैं, तुम यह सोच रहे होंगे की हम कहां जा रहे हैं ? तो तुम पूछ सकते हो कि हम कहां जा रहे हैं ?

तभी जतिन अपनी माँ की तरह किनारे से देखता है ओर दोहराता है" हम कहां जा रहे हैं ? मीरा समझाती है कि हम आइसक्रीम खाने जा रहे हैं, और आइसक्रीम वाला रास्ते में है। और अब जतिन मुस्कुराता है अपनी माँ को देखकर।

दूसरी स्थिति में जतिन तनाव में रहता कि आइसक्रीम की जगह उसे स्कूल जाना पड़ रहा है, और उसकी उलझन का उसे कोई जवाब नहीं मिलता जिसके कारण उसका तनाव और बढ़ता और 6 - फूट का एक नौजवान किसी को मारता है जो कि वह तब करता है जब वह उलझन में होता है। और मीरा उस स्थिति को कैसे नियंत्रण करती, यह पूरी स्थिति काबू से बाहर हो जाती।

ऐसा कुछ नहीं हुआ क्योंकि मीरा ने अपने बच्चे के ऑटिज़्म को समझा और स्वीकारा और जतिन की उसकी दुनिया को अलग तरीके से समझने की समझ को भी स्वीकारा और एक cross cultural interpreter की तरह व्यवहार किया।

हम जो हमारे ऑटिज़्म वाले बच्चों को सिखाते हैं, हम अपनी दुनिया को जानते हैं, अर्थात् हम नॉन ऑटिस्टिक दुनिया को जानते हैं। और हम ऑटिस्टिक दुनिया को समझना भी सीख सकते हैं।

दोनों दुनिया की हमारी यह समझ, के साथ हम ऑटिस्म वाले व्यक्ति की मदद कर सकते हैं, उन सभी सामाजिक जटिलताओं को समझने के लिए, जहां उन्हें मुश्किलें आती हैं।

ऑटिज्म और एक माँ की भूमिका

नीना बाघ

हमारे भारतीय समाज में माँ को बहुत ऊँचा दर्जा दिया गया है, उसके प्रेम के ऊपर अनेक गाने लिखे गये हैं, अनेक फिल्मों में बनायी गयी हैं, नर्गिस का अपने कंधों पर हल उठाये हुए "मदर इंडिया" का वह पोस्टर आज भी हमारे मानस पटल पर अंकित है।

ऐसे सामाजिक परिवेश में "ऑटिज्म" रूपी हल का बोझ हमारे कंधों को और भी बोझित कर देता है क्योंकि अब हम केवल माँ नहीं हैं, अब हम एक "स्पेशल नीड" बच्चे की माँ हैं जिसका उत्तरदायित्व शायद हमें अपनों कंधों पर आखिरी सांस तक उठाना पड़े। ऐसे में हम से समाज की अपेक्षाएं और भी बढ़ जाती हैं और संभवतः हम और आप स्वयं को कभी-कभी बहुत अकेला और मायूस पाती हैं।

तो यह बात तो तय है कि यह सफर लम्बा और कठिन है और हमें हर समय कमर कस के रखनी है। लेकिन इस लम्बे समय को तय करने के लिए हमें छोटे-छोटे पड़ाव लेने की आवश्यकता है, थोड़ा दम भरने की, ताकि हम भी लम्बे समय तक उत्साह और जोश से आगे बढ़ती रहे। ऐसे में कुछ बातों को ध्यान में रखने की बहुत आवश्यकता है :

अपने स्वास्थ्य का ध्यान रखना : क्योंकि अक्सर हम सबका ध्यान रखने के फेर में खुद को भूल जाते हैं, लेकिन इस महिमागान करने के अपेक्षा आपको सबसे पहले स्वयं के स्वास्थ्य का ध्यान रखना जरूरी है, भले ही यह आपको दूसरों की दृष्टि में स्वार्थी बनाये, ठीक वैसे ही जैसे उड़ान के समय एयरहोस्टेस हमें इमरजेंसी के समय बच्चों से पहले स्वयं ऑक्सीजन मास्क लगाने की हिदायत देती हैं।

अपने लिए समय निकालें – ऑटिज्म आपसे बहुत समय मांगता है, आप रात-दिन इसी उधेड़-बुन में लगी रहती हैं कि कैसे अपने बच्चे के जीवन को बेहतर करें, कैसे उसे और अधिक सक्षम बनाया जाये, लेकिन ऐसे में आप अपने आप को कहीं खो देती हैं, और यह ना आप के

लिए ठीक है ना ही आपके बच्चे के लिए, बहुत अधिक कुछ करने की आवश्यकता नहीं है, अपनी सहेलियों के संग एक सिनेमा देख आईये, कोई पुरानी हॉबी को फिर से शुरू कर दीजिए, जब आप खुद के लिए जियेंगी तो आप अपने बच्चे और पूरे परिवार को अधिक बेहतर तरीके से संभाल पायेंगी।

तीसरी और सबसे अधिक महत्वपूर्ण बात : पारिवारिक संतुलन बनाये रखना, जिस तरह खुद के लिए समय निकालना आवश्यक है, ठीक उसी प्रकार अपने पति तथा अपने दूसरे बच्चे के लिए समय निकालना भी उतना ही आवश्यक है, अक्सर मायें और ऑटिस्टिक बच्चे के लालन-पालन में इतना अधिक व्यस्त हो जाती हैं कि वह एक पत्नी के रूप में अथवा एक सामान्य बच्चे की माँ की भूमिका निभाने में संतुलन नहीं बना पातीं, आपके परिवार में ऑटिस्टिक बच्चा केवल आपका ही उत्तरदायित्व नहीं है, उसमें आपके पति की, आपके दूसरे बच्चे की (यदि है तो) तथा परिवार के अन्य सदस्यों का भी उतना ही उत्तरदायित्व है, जब यह उत्तरदायित्व को सही अनुपात में बराबर संभाला जायेगा तो अप माँ, पत्नी, बहु होने के सभी उत्तरदायित्वों को आनंदपूर्वक निभा पाएंगी तथा अपने जीवन में संतुलन बना पाएंगी। तो इसलिए आवश्यक है कि आप मदर इंडिया का प्रतीक न बनकर एक सामान्य, संतुलित और और स्वस्थ जीवन जियें – एक "हैप्पी मदर"....।

SOCIO-COMMUNICATION CLASSES

An opportunity to learn daily routines of the mainstream classroom along with the typically developing peer group! The classes will help your child overcome difficulties in following instructions in a group, copying from the board, taking out notebooks from the bag, waiting for a turn in classroom activities, asking for help when required, interacting with peers and even answering the questions which he may know, but may not be able to answer unless specifically called out and asked to respond.

These unique, inclusive classes will run every day from 1st August 2018, 3:00 pm to 4:30 pm

Action For Autism, Pocket 7 & 8 Jasola Vihar, New Delhi

Contact: Salini

Email: helpline.afa@gmail.com Phone: 01140540991

<UPCOMING WORKSHOP>

Know Me, Teach Me...

AFA's Annual Training Workshop

- Dates: 26 - 28 September 2018 • Time: 9 am - 5.00pm
- Venue: The National Centre for Autism, New Delhi

Our flagship workshop is an eagerly awaited event each year!

The workshop is designed to help participants understand the world of autism from the child's perspective and apply that understanding to help their child/ student progress in a holistic manner to the best of their capacity and in varied situations and environments.

BASED on techniques, internationally recognised as 'Best Practice' for teaching people with autism, adapted to our own cultural needs, the workshop will explore the approach to teaching, keeping in mind the varying learning styles; and ways to keep the learning process an enjoyable and successful experience while learning any skill - communication, social, cognitive, self-help skills, independence as well as give an understanding to address challenging behaviours - a priority both in classroom situations and at home.

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

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

For more information call: +91 9833885899; +91 11 40540991 or email<anvay.trainings@gmail.com>

Action For Autism Invites applications for

CORE FACULTY for BEd & DEd TRAININGS

The candidate will be responsible for the coordination and implementation of all trainings at AFA.

We welcome candidates who are:

- Motivated and self-starting
- Organized
- Fluent in English and Hindi
- Good at documentation & basic computer applications
- Able to correspond effectively and tenacious in dealing with external officials
- Able to work independently in a low resourced hands-on environment
- Open to new learning and experiences
- Have good people skills
- Sensitive to the needs of individuals with special needs

AFA offers:

- An extremely positive work environment

- A unique opportunity to learn about working with children with Autistic Spectrum Conditions and their families
- The opportunity to grow as a trainer and rights advocate, and contribute to a rapidly growing field

Requirements:

- M.Ed. Degree in specific disability area(OR an equivalent degree from a foreign (university recognized by RCI
- Masters Degree in any discipline
- Dissertation in the field of ASD or Diploma in ASD
- Valid registration with RCI(

Some background in working with children with ASD and/or other developmental disabilities desirable. Applications from exceptional post graduates who have a strong interest in working in the area of developmental disabilities and in particular in autism will be considered.

Applications with complete CVs may be submitted to <positions.afa@gmail.com> by **20 August 2018**.

Please mark subject line of email:

'Core Faculty – Trainings'.

AFA MEMBERSHIP FORM

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

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

Please complete in BLOCK letters and mail to Action For Autism

Name _____

Address _____

City _____ State _____

Country _____ Pin/Zip _____

Phone _____ Email _____

I am a: (Check all that apply)

Mother Father Other (please specify) _____

Professional: Name of Organisation _____

For Parent of a person with autism ONLY:

Child's Name _____

Gender: Female Male Date of Birth _____

dd mm yr

Diagnosis _____

Diagnosis received from _____

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

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

Online Transaction/Draft No _____ Dated _____

Drawn on _____

Amount in Words _____

Annual Membership Charges:

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

Online bank transfer may be made to:

Beneficiary: Action For Autism

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

SWIFT No: VIJBINBDDCD

IFSC Code: VIJB0006005

MICR Code: 110029007

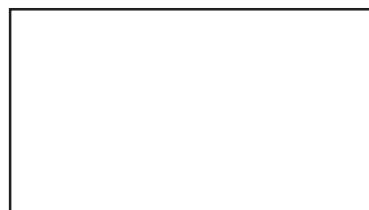
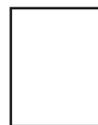
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