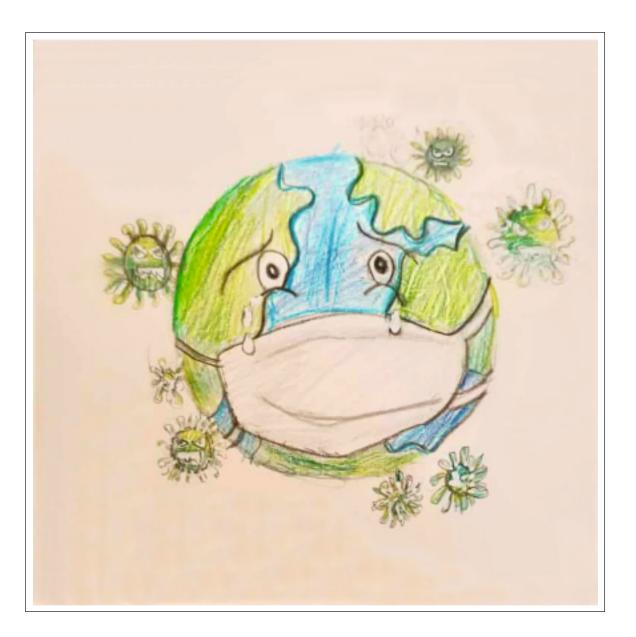
VOLUME 15,2020







2020

VOLUME 15

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

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

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INFORMATION

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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'.

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Cover Illustration

KRITIKA KUKKAR, 11+ years old

WISHLIST !

- <u>For sensory needs</u>: Head phones, trampoline, bean bags, bean bag chair, playdoh, light and sound making toys
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CONTENTS

Page One	I
AUTISM – A Starter's Guide For Allies	2
The balance between helping autistic people and doing it for them (and how to get it right)	8
The Girl with Curly Hair and more	13
Decoding Pragmatics in Autism	23
Autı Speak	27
Travelling Alone	28
Workshops and Trainings	31
Exciting Things at AFA	34
Fliers on Corona Virus	36
Hit the Ground Running and ZOOOOOMM!	37

PAGE ONE

2020 has been a year that will be remembered in history. It has upended lives and created a new world and a new way of living.

Back in March as we were putting the journal together a new term entered the lexicon. As we heard of people getting infected with a strange new virus, since most of our children and families travelled by public transport, we decided to shut down our services for a 'few weeks till things got better'. Little did we know that our action was the predecessor of a common action across the world. Within a few days of our shutting down, the Prime Minister declared a lockdown across the country. And that was the start of a new order of living that seems to now be the norm. Those 'few weeks' have stretched into months, with no end of respite in sight.

When the lockdown happened, what took centre stage was getting our services, which could no longer continue face to face, online. The switch itself was not difficult. Just some technology that had to be harnessed. However, what was not that easy was ensuring that our children continued to get the kind of learning that they were used to when teacher and taught were in the same physical space. Online learning for our autistic learners requires complicated planning from the instructors, meticulous planning for each item that learners would require, the exact instructions to be used, and extreme clarity of communication to ensure that the message is conveyed through the screen. The curriculum had to be modified and adapted to the online format. New resources like demo videos and visuals were created. The entire weeks' instruction plan had to be created and shared much in advance with the learners' families, so that they could plan for the sessions and ensure all material requirements were kept ready. Instructors had to select learning materials keeping in mind that no purchases could be made due to the lockdown; so learning materials had to be things that are easily available around any home. Many of our learners needed physical support during learning. Parent groups were formed through WhatsApp and trainings provided to the parents and primary caregivers on how to best support their children and facilitate the online classes.

Online education programs continue even as we go to press. These include supportive therapies like occupational therapy, psychotherapy, communication \$ speech therapy, and so on.

Many families were in need of emotional support, dealing with changed life circumstances including in many instances with loss of income. Through it all AFA advised and counselled families in coping with the pandemic through online sessions.

Several of our learners did not have access to devices to attend online classes, nor did they have internet connectivity.

Tablets were given to these learners along with sim cards to make it possible to attend classes. We are grateful to our supporters for making all this possible. One of our wonderful donors also made it possible to give a one-time financial assistance to those economically challenged families.

The lockdown played havoc with the lives of many marginalised groups, beyond those that receive direct services at AFA. Action For Autism tried to do its best to help fellow less-privileged citizens in crisis. Through the lockdown and beyond, in collaboration with many wonderful volunteers, AFA provided dry rations and medicines to underprivileged families of persons with disabilities in the NCR regions. In addition, at the height of the pandemic, those on subsistence wages, families of migrant labour who were in crisis were provided with cooked food daily, over the three acute months of April to June 2020.

The pandemic taught us a lot about us and our ways of work.

Firstly, when we look back on those initial days of the lockdown, it seems amazing that the switch to an online mode of learning was not more difficult. It says a great deal about the quality of the AFA team, that they not just took the challenge head-on, but made it their own, and triumphed. Even more amazingly, our autistic learners astounded us by their resilience, given the everyday challenges that they face.

Most interestingly, for quite some time before the pandemic we had been debating the possibility and efficacy of running online classes. The pandemic shows us that the online mode makes it possible for many to attend our trainings who may not otherwise be able to do so due to a range of reasons: cost of travelling to and staying in Delhi, leaving dependant family members behind to come for a training, having to take longer leaves, and so on. What the pandemic has taught us is that whenever we can go back to our old lives, of being physically together and teaching and learning together, the online mode will always remain. Till the pandemic subsides completely we will of course remain online, given the vulnerability of the population that we work with. But postpandemic AFA will definitely move to a hybrid mode of functioning.

After work on the journal came to a standstill early in the year, we realised that due to a fear of the virus many readers were not comfortable receiving a paper journal. Hence we decided to hold on and bring out a 2020 issue that will be purely online. So here it is. Hope you enjoy reading it and checking out all that happened this eventful year.

Wishing everyone a happy 2021!

AUTISM - A Starter's Guide For Allies Rakshita Shekhar

1. What is Autism?

"Autism is a pervasive, neurological, developmental condition".

2. What causes Autism?

Years of research and more than 90% of research funding later, we only know that autism is genetic. In some people, 1 particular gene undergoes a major mutation, causing autism and intellectual disability. But in most people, hundreds of genes undergo very small, independently insignificant changes, giving rise to autism. In the second case, autism is hereditary. Therefore, there is possibility of the mutation having occurred many generations before. Therefore, it exists from birth, cannot be caused by anything in the environment after birth and definitely cannot be transmitted like a disease.

3. What effect does the neurology have?

The difference in neurology causes a radical difference in the way the brain takes in information through the senses, processes it and perceives it.

4. How is Autism recognised?

Autism is characterised primarily by an uneven set of skills; too good in something and the opposite in something else. The identifying features of autism are differences in the following areas:

a. Pragmatic language – use of body language, small talk, turn taking in conversations and communication style etc.

b. Socialising – influence and motivation for socialising – what is considered etiquette, norms, rules, how relationships are formed and maintained.

c. Attention distribution – monotropic attention, difficulty switching between tasks, deep focus etc.

d. 'Information processing – assimilation and application of information and adaptation to new environments and situations'.

e. Sensory processing – intake, processing and perception of sensory stimuli.

f. Repetitive behaviours – tendency to stim or maintain sameness in response to varying emotions.

g. Neuro-motor control – 'could range from clumsiness to complete lack of ability to move parts of body, with intention'

5. How severe can autism get?

Imagine each of the above features to be on a continuum from 0-10, (0 being the least skilled): an Autistic person maybe anywhere on the continuum, in each feature. For eg: a person maybe at 1 in pragmatic language (speaking only 1 syllable sounds), a 5 in attention distribution (able to achieve and get out of deep focus quickly enough to be socially acceptable), and 8 in sensory processing (finding difficulties but also able to find most environments suitable). Thus:

a. Mild and severe or low functionality and high functionality exist in each individual. There is nothing called mild or severe autism or low functioning and high functioning autism.

b. Functionality varies according to situation too. Therefore, functionality in various aspects may see a huge variation even during the course of a day.

c. Each person's autism is unique.

6. Why do these features occur?

Although there are numerous theories on why these features occur, the only theory that explains all of these features and is widely accepted by the Autistic community is monotropism (given by Dinah Murray, an Autistic lady).

a. The Autistic brain is monotropic and the neurotypical brain is polytropic.

b. Monotropic brain has the ability to focus intensely on a narrow set of interests at any given time and by pouring in all its resources to process this set of interests. Everything outside this attention tunnel is ignored, while the brain focusses deeply on the set of interests.

c. The polytropic brain on the other hand has the ability to focus on a wide range of interests at any given time by distributing resources across this set of interests. While very little escapes attention, the focus is rather shallow on each interest, as compared to the monotropic brain.

Some researchers are also using the Bayesian theory from mathematics to argue that the Autistic brain holds no pre conceived notions, which enables it to function as it does.

7. Then why do Autistic people have problems?

a. Most environments are not suited for an Autistic person to live/work comfortably.

b. Current research seems to suggest that Autistic people also have many comorbid issues: attention deficit hyper active disorder, specific learning difficulties, dyspraxia, mental illnesses etc

8. Why do Autistic people behave oddly?

The odd behaviours that most Autistic people are notorious for are natural consequences of the

different ways in which their brain perceives information. It means that if you saw it from their 'eyes', you would realise that these behaviours are not odd at all.

Imagine that you entered a room and a blind person approached you and began to smell + touch you. You wouldn't mind because you would instantly notice the eye, connect it to your memory of what it feels like to be unable to see and realise/understand that smelling/touching is their way of 'seeing' you.

Now imagine that you had entered this room blind folded. Upon being approached by the blind person, you would have probably recoiled, and pushed the person away because in the absence of information about the eye, you would have felt unsafe being touched without consent.

Now consider that when you entered (not blind folded), you were approached by an Autistic person who smelled/touched you the same way. This person also 'sees' you through smell/touch, more strongly than through the information passed on by their eyes to their brain. However, to you, this information is invisible, just like when you were blind folded. Therefore, you would still think this is odd and recoil/push the person away.

9. Is there anything good that comes with the Autistic brain?

Just like the neurotypical brain has strengths and weaknesses; the Autistic brain has them too.

In general, the following are the strengths of the Autistic brain, although they are not universal to all Autistics:

- a. Attention to detail
- b. Deep focus
- c. High absorption and retention power
- d. Visual learning and recall
- e. Naturally directed towards justice
- f. Naturally directed towards excellence

- g. Ability to achieve expertise more quickly than the average peer
- h. Methodological approach
- i. Novel/creative thinking
- j. Tenacity and resilience
- k. Accepting of differences
- 1. Integrity
- m. Self-learning

10. Is Autism rare?

No. It is very common. By the 1940s, Hans Aspergers had already seen more than 200 Autistic people of all ages, in Germany and nearby areas, alone. But Leo Kanner in America, (considered as the father of autism) sought to, for political and personal reasons, project autism as very rare. When Lorna Wing suggested to the diagnostic and statistical manual 4 committee that autism was a spectrum, she was aware that she was just widening the definition of autism to 'catch more fish in the wider net'. Studies estimate that between 1 and 2 people per hundred are autistic. If we include adults (also those who couldn't get a diagnosis in childhood), girls, non-binary gender identifying people as well as those in the low income regions of the world, (where a diagnosis/identification is a privilege), autism will seem to be a common phenomenon.

11. How do Autistic people feel about their Autism?

The majority of Autistic people around the world don't see themselves as impaired because they are acutely aware that they have strengths which neurotypicals generally don't. To most Autistics, the label of autism is a badge of pride for this reason. However, since the majority of people who are supposed to support them don't understand Autism and Autistic differences are still not accepted as a natural phenomenon in majority of the society, Autistic people are not accorded the respect and social standing due to them. They are denied accommodations and appropriate support. For many, accessing basic human rights is a matter of privilege. Thus, Autistic people feel that the real problem is not their autism but the way the society treats them.

12. Should we call them person with Autism or Autistic person?

The difference in neurology gives a totally different personality and the autism colours every aspect of one's life. For this reason, most Autistic people prefer to be called Autistic instead of person with autism. Just like we don't say person with womanhood or manhood but man or woman because it is their identity, most Autistic people like to be called Autistic. However, this is a matter of personal choice and the individual's opinion must be respected.

13. Why do some Autistic people look 'normal'?

Most Autistic people learn very early on in their lives that being different, subjects them to unwanted social consequences: exclusion from friendships, education and jobs; ridicule; bullying/ abuse; denial of opportunities etc. So they learn to camouflage ie pretend to be like neurotypicals. Since our society is majorly neurotypical and the neurotypical brain is programmed to follow the crowd, for safety and survival, it is assumed that being or looking like a neurotypical is 'normal'. The fact is that autism is as normal to the human race as the sun is, to our day.

14. We all must pretend sometimes, just for others' sake, isn't it?

While camouflaging saves Autistic people to an extent, from ridicule as well as abuse and gets them placements in education as well as jobs, it has a very severe effect on their mental health. Neurotypical responses to stimuli perceived by the brain as overwhelming are not natural. Therefore, it takes every second of conscious intellectual effort to behave like a neurotypical. In turn, it produces high amounts of stress, the amounts that can lead to mental illnesses, reducing the life expectancy of the Autistic person or even kill. For this reason, suicide rates are much higher in the Autistic population than in the non-Autistic population.

If you were sent to a jungle without survival gear or tents, what would your experience be? You would be on high alert every second, anxious, overreactive or in a fight/flight/freeze mode constantly, isn't it? And when you came back home, you would thank your stars, isn't it? But imagine a life where there is no return. You would learn to adapt to some extent or expect some trouble in the jungle but still, feel out of place, isn't it? That's because neither are you built for the jungle nor is the jungle built for you.

That's the everyday life of an Autistic person. But ironically, and sadly, the society believes that an Autistic person acting like a neurotypical is proof that he has cured or become better, when in fact, the exact opposite has been true.

15. Why are Autistic people so difficult?

Latest studies and years of anecdotal data suggest that Autistic people across age groups and countries can easily identify each other, share a far greater understanding and feel very comfortable in each other's company but that among neurotypicals, they feel less safe and constantly under threat and stress.

Therefore, it is not that the Autistic person is difficult but that neurotypicals usually fail to understand them like other Autistic people do. If the surroundings were to feel safer, environments made less threatening, and the Autistic brains were put under less stress, Autistic people would feel less disabled (This is called the double empathy problem) and relationships between autistic and non-Autistic people would be much more peaceful.

16. How can I work with Autistic people such that both of us can be happy?

a. The basic principles

i. As a non-Autistic person, trying to understand an Autistic person is like trying to describe an elephant, through touch only.

- You can sense only a partial picture
- Your picture is not the same as another neurotypical's
- The elephant knows best and can give you a better picture of itself

ii. Work with the Autistic brain, not against it. Just as you wouldn't bother trying to teach a blind child about colour, don't bother teaching an Autistic child to become neurotypical or lose his "symptoms".

iii. The priority must be to make the Autistic person feel comfortable, relaxed and stress free around you.

iv. Adapt the environment so that their strengths are utilized and their weaknesses managed without punishment.

v. Meet the Autistic person where they are.

vi. Think like the specific Autistic person you're working with. Stand in their shoes to understand them and their motivations.

vii. Assume you don't know anything about the Autistic person and learn from scratch about them.

viii. Generally, strategies used for neurotypical people are not applicable to Autistic people, but the principles are.

b. Action points

i. Be specific and straightforward. Don't expect them to understand implied meanings/actions.

ii. Say what you mean. Mean what you say. Do what you say.

iii. Encourage stimming if the Autistic person wants it. It is a natural and excellent form of emotional regulation.

iv. Encourage lots of me-time. Socialising can be stressful.

v. Encourage spending time daily on special interests. It regulates emotions, brings immense joy, and also helps get jobs. You can guide/mentor the Autistic person to reach expertise in their special interest or find ways to make it income generating.

vi. When an Autistic person is intensely focussed on something, know that they have entered the deep focus zone of an attention tunnel. Interrupting by pulling them out of the tunnel or not allowing them to enter the deep focus zone of the tunnel is considered very rude. It breaks their thought process and takes them much longer to get back to the point where they were interrupted.

vii. Getting in and out of the deep focus zone of the attention tunnel takes some time. It is acceptable to gain an Autistic person's attention during these times of transition.

viii. Gaining attention by entering their attention tunnel is a highly respectful strategy. One way is to get deeply interested in their subject of attention, and work alongside them to achieve their goals.

ix. You can be their friends by being genuinely appreciative of them, sharing their special interest and respecting their choices. Know that your relationship may not be anything like the ones you have with neurotypical people.

x. As a friend, you may be tempted to constantly correct them, wanting them to change so that people don't treat them badly. You may do this with a very good intention but know that it is highly offending to the Autistic person. Do not insist that they interact or behave like you. Respect them and accept them for who they are. xi. Support them in things they want support in, fight for them when they feel low on energy. But you don't have to be their knight in shining armour. Empower them instead.

xii. Teach them to decode the neurotypical world around them: the social norms, rules, motivations for people's behaviour etc. But also teach the neurotypicals around them to decode the Autistic culture.

xiii. Observe/watch siblings, parents and childhood friends socialise with the Autistic person and learn how to communicate with them from these interactions.

xiv. Endeavour to maintain sameness. Structures, routines and consistency make Autistic people feel calm and productive.

xv. Use your neurotypical social skills to influence other neurotypical people to accept them but most importantly, work on your own perception of right and wrong.

17. But there is so much contradictory information on autism. Who should I believe?

Autism is so diverse in presentation that no book or workshop or training can prepare you fully. And yet, without such knowledge, lots of neurotypical people enjoy valuable relationships with Autistic people around the world. The secret lies in understanding the specific Autistic person you're with. So, it's best to follow the below hierarchical order to learn about the person or their autism.

a. *The Autistic person themselves:* Ask them and listen to them when they communicate, whatever the mode of their communication.

b. *Other Autistic people:* Many Autistic adults around the world are coming forward to educate people about autism.

c. *Other people living with them:* They may have figured out a lot and may be able to bridge your relationship with the Autistic person and explain to you in ways you can understand.

d. *Professionals who are working/have previously worked with them:* They may also have figured out a lot and maybe able to give you insights.

e. Other health /education/allied health professionals having experience working with other neurodivergent people: These professionals may be able to give you general knowledge or strategies only. So be mindful of the suitability of these strategies to the specific person you're working with and adherence to basic principles.

f. *Other neurodivergent people:* Listening to and understanding people having various other

neurodivergent conditions, will open up your thinking about different ways the brain works.

18. Summary

Autism is a subtype of the human race just as the painted stork is a subtype of the bird species. Before you judge us, consider that the way you and I perceive the same information is radically different. Before you correct us, consider that your perception may just be social conditioning and not necessarily correct either.

Great innovators have all been Autistic. So, there is value in nurturing our brain type instead of changing it to become like yours. You need us, just as we need you to function in this world. Together, we can find solutions to the world's greatest problems.

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Rakshita Shekhar is a 32 year old mother of a toddler, who, as she says "is as physically active as I am not". Rakshita's current special interest is to understand and figure out ways to express her autism safely and help other autistic people do the same. She works as a special educator in an inclusive school. In her free time, she tries "to dust off the rust from years of pretending to be 'like everyone else'". Rakshita LOVES swinging and lying down on the cool floor to stare at patterns in the air above her.

The balance between helping autistic people and doing it for them (and how to get it right)

Chris Bonello

During my work in special education, one story that really stuck with me involved a sixteen-year-old girl who came to us after a lifetime in mainstream schools. The most revealing moment of her first week came in an English lesson.

She sat down with the rest of the class. The task was set and the other students began to work. But this girl did not. Further investigation revealed that this sixteen-year-old student was waiting for a member of staff to take her stationery out of her pencil case.

Why? Because it had been done for her throughout her whole life.

To be honest, one of the hardest things to do as a teaching assistant is doing nothing. This is the same school where I was paid to stand in maths lessons with teenagers studying for their GCSEs, and do as little as I possibly could – because the students would not have the luxury of my support in the final exam. However, since it was the same school where I changed soiled pads for students who struggled with basic self-care, there is obviously no one-size-fits-all answer to the main question of this article:

How do I get the balance right between supporting this person and building their independence?

This question is so common among the Autistic Not Weird's Facebook community



<https://www.facebook.com/autisticnotweird> [all links open in new windows], that my Patreon backers <https://www.patreon.com/autisticnotweird> voted for it to be the subject of my next article. So, here's my take as a former teacher with Asperger Syndrome, who still works with students across the autism spectrum to this day.

Oh – and this question may be written from a former teacher's viewpoint, but it's not necessarily for students. It's not specifically for young people either. Read the advice and adapt it to your own situation.

First off, a diagram. Because I like diagrams.

	Advantages	Disadvantages
If you DO give support to an autistic person	 The right support can make learning accessible to them. The promise of support can relieve anxiety. It's just generally a kind thing to do. 	 The person may end up depending on the support. The support may withdraw opportunities to expand their comfort zone. It's often very difficult to tell when the support is appropriate or needed.
If you DON'T give support to an autistic person	 It encourages independence in thoughts and actions. It can be good training for later in life. If they succeed, the confidence boost can be amazing. 	 The person must deal with their anxieties alone. They may feel isolated. They may develop an assumption that others will not help them either.

Did this diagram make things clearer, or did it just highlight how difficult the dilemma is?

I suspect the second, and that's fine. It is a complex issue, and it should be seen that way if we want to make informed choices.

To illustrate, I'm going to offer some example scenarios and ask you to consider them using the diagram. Choose whichever situations may be relevant to you.

Scenario 1: You're driving to the shops to buy some food with an autistic child/teenager, and as you pull up the handbrake a thought passes your mind: *my son/daughter has never gone into the shop alone before, but I wonder if they're ready?*

Look at the diagram, have a think about advantages and disadvantages, and make your decision.

Scenario 2: You're a mainstream schoolteacher preparing a performance where each of your pupils reads out a sentence or two. The autistic pupil in your class is a very capable reader but is frequently anxious. Do you encourage that child to read the sentences independently in front of the class or not?

Scenario 3: Your adult autistic child/friend/ colleague is terribly anxious about applying for jobs. They ask you to fill out certain parts of the job application form. How much do you help, if at all?

So, what's the right answer in each of these scenarios?

Well, it depends on the individual. And even with each individual, it may depend on their state of mind at the time.

If you were expecting me to give definitive answers, I won't be writing any. Never trust anyone on the internet who claims to have answers for everyone on the autism spectrum. But I can give you some extra insights, in no particular order.

1. Continuous support can lead to underestimation

There was one student with severe learning difficulties who struggled with almost every aspect of life. (Oddly enough, to this day he remains the happiest 12-year-old I have ever, ever known. For the record, this is the student who appears in point #1 of Five Ways to Damage Autistic Children Without Even Knowing <https://autisticnotweird.com/fiveways-to-damage/>.)

I was led to believe that he was incapable of most things. On principle though (as I said in the other article), I always engaged him in conversation. A child's lack of speech is not an excuse to avoid talking to them. Ever.

One day, we were tidying up after a cookery session. I say 'we', but he was watching for the most part. After all, tidying up was probably beyond his capabilities. Motor skills, thought processes, to plan ahead, are all very complex when you think about it.

Partway through, I looked at the cups I was holding and asked "hmm, where do the cups go?"

Out of nowhere, he reached to his left and opened the exact cupboard.

I didn't even ask him to – I simply asked where they went. He took that action entirely by his own initiative.

Two conflicting feelings struck me at that moment: sheer joy at how this student had done something I'd never seen him do before (I'm sure plenty of readers can empathise)... but also guilt.

How many other abilities did he have, that his school staff assumed couldn't exist?

How many other things could he have been taught to do, had he not been surrounded by people who opened every single cupboard for him?

As I say during my talks, several years later: if you make negative assumptions about somebody's prospects, it's often a self-fulfilling prophecy.

2. People are 'lazy'

One quote from my mathematics professor has stuck with me to this day:

"I encourage you to be lazy. If you are lazy in a clever way, people will think you're efficient."

— Prof. Anvar Shukurov, 2007

I could go into several reasons why people like to be lazy. And actually, not all those reasons are negative. There's even an evolutionary case for being lazy: in a contest between those who can fulfil their physiological needs without spending energy, and those who need to spend lots of energy, who has better survival chances?

Honestly – and I mean this in no negative way whatsoever – people prefer to be lazy if they possibly can. This means if we get the chance for someone else do something for us, we'll usually let them. Let's face it, if someone offers to fetch us a snack from the fridge, we're more likely to say 'yes please' than 'no it's okay, I'll walk over there and get it myself'.

(This, of course, leaves aside the issue that autistic people can often have the appearance of being lazy when it's actually the impact of executive functioning/anxiety issues. That's a topic for another time.)

So how does this apply to supporting autistic people? Well, the main thing I'm thinking is this:

When offering support to an autistic person, it's better if the support is needed by them, rather than just convenient for them.

If your support is for anxiety relief or as a learning tool, that's great. If it's simply one thing less for them to do, that's not so great.

3. Safety nets help, even if they're not used

Sometimes, it's the simple *offer* of support that enables someone to achieve independence. Let me give you yet another analogy:

Imagine you have to walk a tightrope for fivemetres... over a chasm with a hundred-metre drop. It doesn't matter that you have no tightrope experience. You have to walk it. And there's no safety net.

What do you think your chances are of lasting the whole five metres?

Now imagine exactly the same scenario, but there's a safety net just below the rope that stretches the length of the chasm.

Now that the risk of death has been removed, what do you think are your chances of lasting the whole five metres?

I genuinely believe that with the safety net, I'd be more likely to reach the other side.

Yep, I would be more likely to fall to my death in one scenario than fall into the net in the other. I'd be less nervous, less afraid of failure, more relaxed physically and mentally, and my feet would twitch less.

Even without the need to use the safety net, my chances of success would improve.



Incidentally, the best teaching I ever did in mainstream happened in the weeks after I'd handed in my notice. I spent less time afraid of Ofsted's Righteous Judgement, and more time able to enjoy teaching. Therefore, my teaching improved.

If you find an autistic person feeling really, really nervous, be sure to let them know that support is available: not with the specific intention of giving it, but just in case they need it. Encourage them to attempt the task independently, but let them know the safety net does exist. They may then surprise you by doing everything perfectly anyway, whereas the pressure of no support might have made them too anxious!

4. Responsibility builds people

Speaking as a former teacher and public speaker, who used to be a teenager with no leadership qualities (and a four-year-old with the language skills of a two-year-old), I can absolutely assure you that there is no such thing as a 'natural born leader'. Leadership skills are gained from experience and willingness to learn, not womb magic.



In my case, it was my old Boys' Brigade captain who taught me how to lead people. He is directly responsible for me becoming a teacher, which nobody saw coming when I was a teenager. For those who haven't heard of the Boys' Brigade, we're the people who invented the Scouts.

I wrote a whole article on how my Boys' Brigade company made me more than I believed I was capable of being.

I'll save you some time by providing a link here https://autisticnotweird.com/story-of-an-autistic-teacher/. But one thing I learned and believe without a shadow of a doubt:

Responsibility builds people. Especially the people who "don't seem cut out for it".

Whether it's responsibility over a sibling, or a pet, or part of the family business, giving a young person (autistic or not) some non-academic responsibility can do a hell of a lot to help them play to their strengths. Or, like in my case, develop strengths they didn't even realise they had.

I was thrown in the deep end by my Boys' Brigade captain, but he was always there offering support. *Offering* support, as opposed to giving it by default. And ten years later, I became a primary school teacher.

And to finish:

I occasionally give a talk entitled "Top twenty facts to bear in mind when working with autistic students". With apologies for the massive spoiler, number one is split into two parts:

1a: We need less support than you think

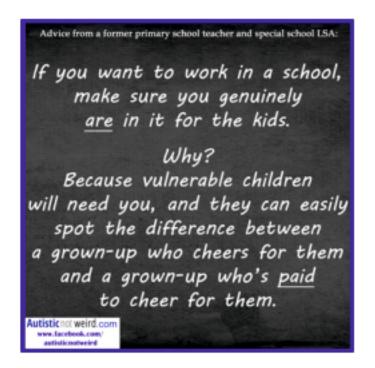
and

1b: We need more support than you think.

Getting this balance right is hard. Most of the time I want to be left to do things without being told how to do them (especially if I'm being told to use a method that doesn't resonate with my brain), but some of the time I really do need clear and specific support.

Sometimes, as autistic people, first and foremost we need our strengths to be seen. Sometimes, when our deficiencies or anxieties take the lead, we need to be supported. And the best way of distinguishing between the two simply lies in knowing us as people.

And genuinely root for us. This picture explains why.



Trust me, autistic children are far more perceptive than they're given credit for.

To be honest, I think 1a is more important. Give autistic people as much independence as you can possibly get away with. But let them know the safety net exists before leaving them alone.

I hope this helps you, in whatever capacity you support an autistic person. If this is your first visit to Autistic Not Weird, feel free to visit **our large Facebook community**

<https://www.facebook.com/autisticnotweird>,

where everyone is really, really nice. And since Autistic Not Weird is soon to be my only source of consistent income, there's **my Patreon page (full of perks!)** https://www.patreon.com/autisticnotweird if anyone would like to help me build my career.

Take care,

Chris Bonnello / Captain Quirk

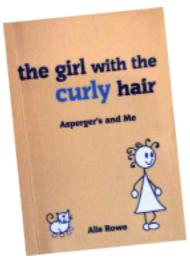
Further reading:

Teacher Balance – Support and Independence

<https://balancechallenge.org/2015/07/31/teacherbalance-support-and-independence/>. This piece is very good. I found it by accident whilst searching for pictures (one of which I have borrowed for this article), and it covers important points about this topic accurately and concisely.

This article was first published in https://autisticnotweird.com/balance/ and has been reprinted with the permission of the author.

Chris Bonnello is a former primary school teacher with Asperger Syndrome who has also worked in special education, now an award-winning writer and international speaker. In 2015 he launched Autistic Not Weird to share his insights from both a personal and professional perspective, a venture which has seen him attract 101,000 Facebook followers, and over 1.9 million page hits on his website (autisticnotweird.com). His first publication, 'What We Love Most About Life', was an uplifting book designed to help autistic young people feel less alone, and his first novel 'Underdogs', a novel with special needs heroes, will be published in May 2019. He was also a nominee for the 2017 National Model for Disability, and a two-time winner at the Autism Hero Awards (Top Journalist 2017, Online Social Community 2018).



The Girl with Curly Hair and more...

An interview with Alis Rowe

Award-winning female autistic entrepreneur, author, scriptwriter, film director and marketeer and founder of The Curly Hair Project

just as it has been a support to other people as well.

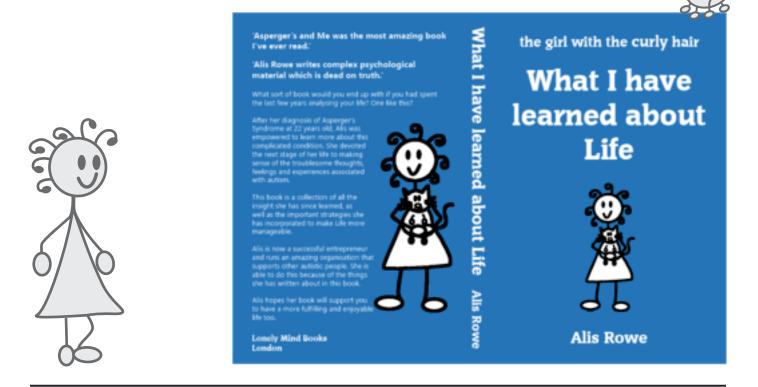
Q. Please tell us about The Curly Hair Project.

The Curly Hair Project is an organisation that supports people on the autism spectrum, parents and family members, and anyone working with autistic adults or children. It is an educational resource that can help anyone who would like to learn more about autism.

I set up The Curly Hair Project in 2013, shortly after being diagnosed with Asperger's Syndrome. Developing the company has been a journey of selfIt was initially merely a Facebook page. People told me I had a really good way of articulating what it is like to have autism. I wrote my autobiography, 'Asperger's and Me', which was really popular, and it all grew from there!

understanding and working out ways to help myself,

Now I have written a large range of books, including two autobiographies and a set of Visual Guides (infographic-type books). They all have excellent reviews and I am very proud of my writing. My autobiographies are called 'Asperger's and Me' and 'What I have Learned about Life' (written 6 years after Asperger's and Me).



The Visual Guides are a series and include the titles: The Visual Guide to Asperger's Syndrome and Anxiety, The Visual Guide to Asperger's Syndrome and Emotions and The Visual Guide to Asperger's Syndrome: Socialising & Social Energy.



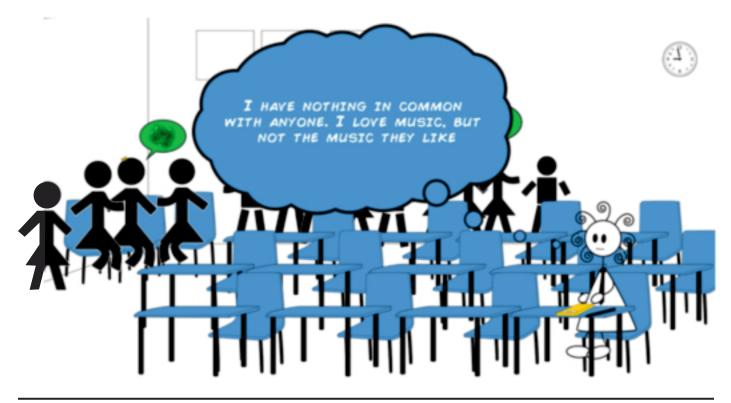
I also have a successful blog on my website where I regularly write new articles.

I have just launched e-courses. These are fun, vibrant courses where you can learn about autism from your own computer or mobile phone. The ecourses contain animations and quizzes and the student will receive a certificate of completion. The e-courses are suitable for autistic individuals (with or without a diagnosis), parents and anyone working with autistic adults or autistic children.

There is a small, enthusiastic team of Trainers who deliver autism training and run webinars for The Curly Hair Project.

E-courses and webinars can be accessed from anywhere in the world and they are full of sensible, practical strategies to make life living with autism easier.

Another unique resource is our animations. I write, direct and produce animated films based on my character, The Girl With The Curly Hair, who is a shy, quiet, anxious individual.She wants to be on her own a lot and feels overwhelmed by normal life. Situations tend to be too busy for her. She struggles with friendships and connecting with peers.



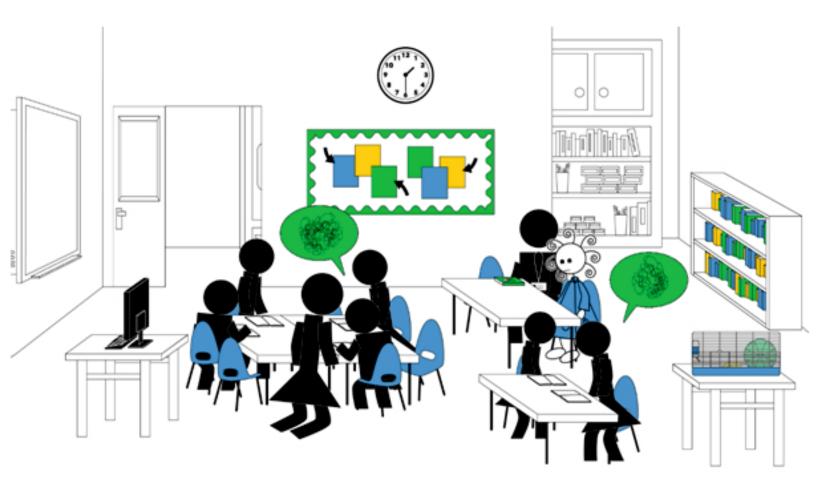
The Girl With The Curly Hair fits the common description of girls and women with ASD, who have a tendency to be very quiet and hope no one will notice them.

These animations are sweet, charming depictions of what life is like for The Girl With The Curly Hair as she goes about her various daily experiences. The animations are incredibly complex and timeconsuming to make, but the process is enjoyable and the end-product is very rewarding.

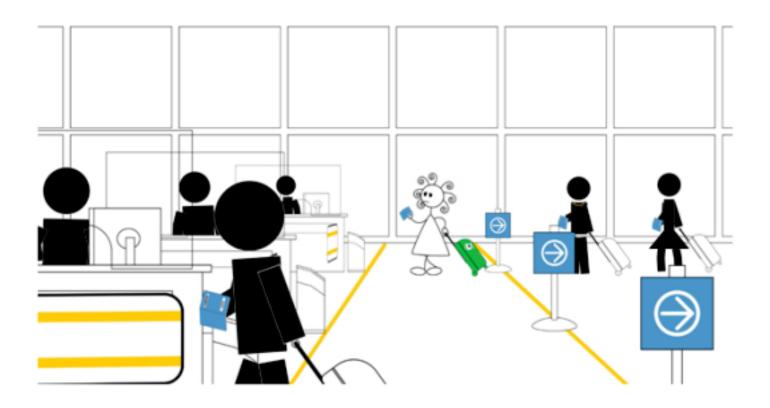
Here is the trailer of 'A Day at University for The Girl With The Curly Hair'. In this episode, The Girl With Curly Hair struggles to manage simultaneous university assignments. She has problems managing deadlines and thinks every assignment must be done straight away. Although very good at analytical work, she finds doing experiments hard because of a lack of visual instructions and not knowing which tubes are supposed to go where. She has problems with planning the steps in setting up an experiment and has difficulty coordinating different items of equipment. This episode demonstrates difficulties with executive function.

This episode also shows some of the problems involved with socialising. There are great social expectations at university and The Girl With The Curly Hair struggles to fit in and relate to her classmates. They like going to the pub and she likes doing university assignments at the end of a university day! She has one friend, Zharnel, but their relationship is still very difficult for her.

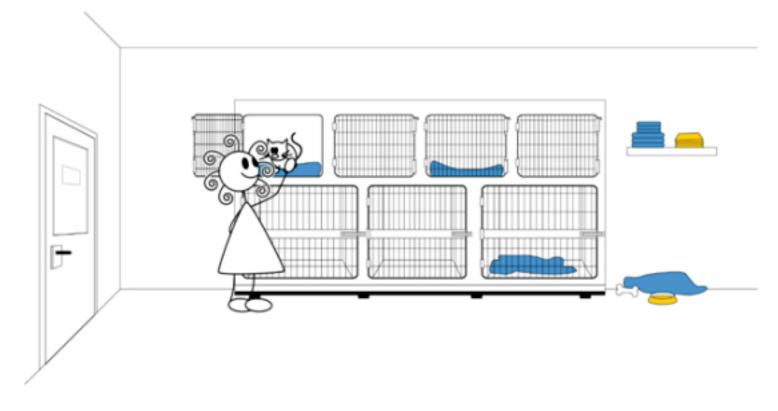
These are screenshots from some of the animations:



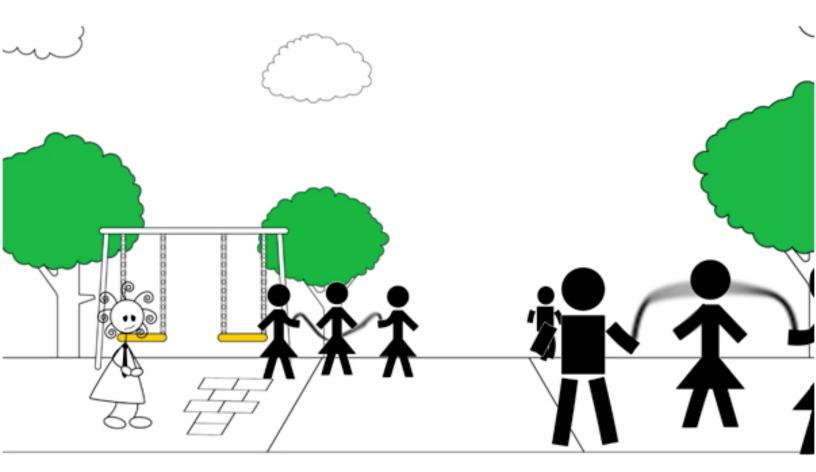
A Day in the Reception Class for The Girl With The Curly Hair



The Girl With The Curly Hair goes on Holiday



A Day Working at the Vet's for The Girl With The Curly Hair



A Day at Primary School for The Girl With The Curly Hair

Q. From a Master's Degree in Chemistry to the Curly Hair Project. How did this shift happen?

Chemistry was only chosen because, like many people, at 18 years old I had very little idea what I wanted to do for a career. Chemistry was my favourite subject, I was good at it, and a science degree equips people well for a good job, so it seemed and sensible and obvious decision.

By the time my degree had ended, I was quite exhausted by the subject. It was very difficult. The whole university experience had been draining for me. Having had a sandwich year working in the chemical industry, I realised that I didn't want to work anywhere full time! Working exhausted me. I did some part time and freelance jobs for a while, then I was diagnosed with Asperger's Syndrome and that led to creating The Curly Hair Project. I don't think I could ever do a typical full-time job. Unfortunately, I do feel that having autism limits me in the type of work I can do. I get tired and stressed very easily. I don't like communicating. I need my own space and I get frustrated working with other people if they don't do their work efficiently.

I'm glad I've been able to turn my true gift, which is writing, into a career. Being able to work from home and being my own boss enables me to work to my full potential.

Q. What is it you hope to achieve with The Curly Hair Project?

I want to teach the whole world about what it's like to be different. I want people to have an open mind to the fact that everyone experiences the world in a different way and that there is not necessarily one single, 'correct' way to be as long as it is respectful of others and within the law! Not everyone is sociable for example. Everyone has different strengths. Not everyone finds the same things obvious or easy.

Many people have difficulty fitting in, or are shy and anxious, and they might not be autistic. Neurotypical people also need others to understand them and need strategies to help themselves and to find ways to accept themselves in order to achieve their potential. My work can help them as well.

I hope my work can make neurotypical people see autistic people in a different way. Neurotypical people may initially see an autistic person as 'odd', 'aloof', 'unfriendly' or 'rude'. However, once they have some understanding of autism or have become aware of my work, maybe they will come to realise that this person might present this way because they have such severe social difficulties, or because they are anxious and find the world overwhelming. They realise that the autistic person's awkward persona is not intentional and that they need a little extra understanding and support to help them with learning, work and relationships.

Often, autistic people will then produce exceptional, useful and very reliable work.

Q. Can you tell us how you came to be diagnosed with Asperger's Syndrome as an adult?

I had suspected I might be autistic since I was about 17 years old, but at the time, no one really knew much about autism and it was never talked about by anyone. I was so young that I probably just thought "I might have Asperger's Syndrome... so what?" I didn't realise how significant a diagnosis would be for me and I didn't fully understand what the condition was. Therefore, I didn't see much point in getting a diagnosis. No teacher or doctor had ever brought it up before either. By the time I had left university, and had matured a little, I understood more about myself. I realised why a diagnosis might be helpful and really wanted to be able to explain to people about things such as 'masking'. Having a diagnosis made me feel that I would be able to do this.

I have had a lot of trouble with relationships my whole life and there had been many misunderstandings with people thinking I didn't really like them because I never wanted to socialise outside of school/college/university and I was such a quiet, withdrawn person. The truth is that it was nothing to do with them, I just needed my space to recover from the stress of daily life. Having a diagnosis has helped me be able to explain things like this.

Q. Different people have different experiences of receiving the diagnosis. What was it like for you to receive the diagnosis? What were your initial thoughts and what was that process like?

The hardest part was probably the fact that I had to request the diagnosis myself to my GP. At 22 years old, no GP had ever suspected that I might be on the autism spectrum. The word had never been mentioned. However, once I told them, they were really proactive and open to what I was saying. I didn't have any problems after that. I was referred to a psychiatrist and received the diagnosis fairly easily a year or so later.

Q. A lot of parents ask us how and when to disclose their child's autism diagnosis to them. What are your thoughts on that?

My personal view is that, if the child is happily progressing in their life, then there may be little point worrying them by telling them they have autism. It might just cause them unnecessary worry.

I would definitely bring it up if the child has difficulties or if the child asks questions such as...

"Why do I not have as many friends as other people?"

"Why does no one like me?"

"Why do I have a teaching assistant?"

"Why can't I ride my bike/tie my shoelaces/walk to school alone like everyone else can?"

"Why don't I like playing with other children?"

"Why can no one else smell the nasty smells in the dining room?"

It can be very helpful to be aware of autism and how it affects you. It is very, very frightening to go through life feeling different and having problems but never knowing what is wrong or feeling that there is something awfully wrong with you.

Regardless of when or whether a parent tells their child, make sure it's talked about in a sensitive and positive way so as not to frighten them. Luckily, so much more is known about autism and it is more frequently diagnosed nowadays, so it doesn't seem as if it would be such a 'big deal' to talk about with a child.

Q. Would you recommend any resources (books, videos, infographics, etc.) designed for young autistic children or adolescents that define and discuss autism in a positive way?

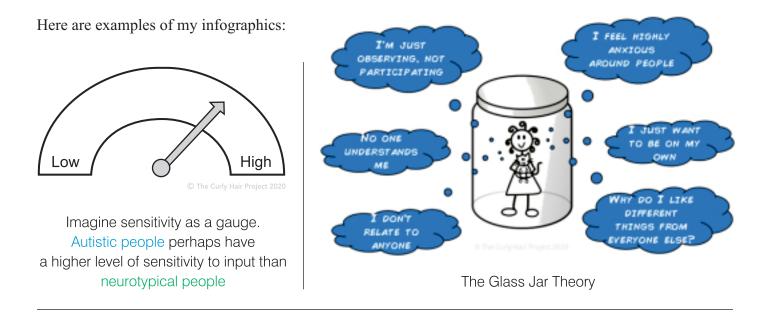
I think my resources are ideal if I can say that! A lot of children and adolescents relate to my work. I'm not really familiar with resources specifically for children but the best books that helped me when I was a young adult were by Tony Attwood, Sarah Hendrickx and Rudy Simone. Professor Tony Attwood now recommends my books and animations. I have a lot of feedback from parents saying how helpful my work has been to their children. Here are some of the feedback I have received from parents:

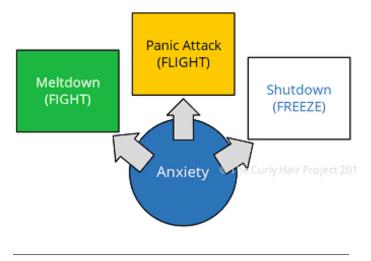
"Daughter has recently been diagnosed and found this book really helpful with some difficulty's we were having."

"I really recommend that anyone with ASD or knows a child with ASD reads this book. It explains everything really well. Me and my daughter read this together, after reading it my daughter opened up about her struggles."

"My 13 year old had a lot of difficulty in accepting her diagnosis, but this book and other Girl with the curly hair books have really helped her understand herself. She's very keen to share pages with us and says, look at this – that's me. It opens up pathways to understanding for both her and us. The clear diagrams and cartoons are just a perfect way to help her communicate and accept herself. Thanks Alis."

"My daughter asked for this book for her birthday as she has several of the other curly hair books. She finds them really helpful to help her to understand herself and answer questions she doesn't always want to ask. As the mother of 3 children with ASD, I cannot say just how much these books have helped my children and extended family to understand the difficulties and superpowers my children have. Thank you Alis Rowe for making life just that little bit easier."





Q. When did you decide to begin disclosing your diagnosis to others?

I told a couple of people before I even received my diagnosis, but no one really understood or took it seriously (myself included, as mentioned before). I told people as soon as I received my diagnosis and my relationships transformed for the better immediately. I think that some people thought I didn't like them or that I was making excuses, when I declined going to social events for example. The diagnosis gave me 'permission' to ask for the Alone Time I needed... (although it shouldn't have been this way!). My diagnosis has also, over time, made me reflect on my relationships. I decided that there are some relationships I just don't really wish to continue as I cannot keep up the masking and those people don't understand the 'real' me. I realise that I need friends who are more understanding and open-minded and those on the same wavelength in some way.

I think one of the most difficult things has been trying to explain to people that the person who tried so hard to socialise and fit in was not the real me and that I found it difficult, exhausting and depressing to keep up the façade. I was masking. Some people think that I did so many activities before and was a lot more sociable before, so why can't I be like that now? If people do not understand my explanations, then I try to distance myself from them.

Q. On your website you say, "I want to make sure that children and families don't have the experience I did, that is why I started The Curly Hair Project." Would you share some experiences that made it hard?

My adolescence was traumatic. I went through my teenage years feeling completely isolated and alienated from everyone. I could not relate to anyone. School was absolutely unbearable for me. I was bullied and misunderstood and the environment was terrifying. I lived with severe anxiety every day for years. I used to force myself to stay awake at night because I knew that if I fell asleep the next day would come quicker and I'd have to go to school again.

I have been suicidal at different periods of my life.

Q. What made things easier while growing up? Any supports?

I had a steady routine at home and could rely upon my family to look after me. I was very close with my grandparents. Being left alone after school to do my homework, do my hobbies, or to just calm down, was really important. I was encouraged to pursue my natural gifts.

Q. In your words, what makes you different from non-autistic people? What would you like people to know about your views on autism?

I understand that we are all different anyway and that we can never truly know how people are because so many non-autistic people 'mask' in their own way... however, I feel I've lived long enough and have observed accurately enough to realise that there is a significant difference between myself and other people:

I am a lot more anxious than other people. I feel anxious about things which might seem very different to others. Activities that other people seem to find 'fun', I seem to find 'terrifying'.

I don't seem to be able to communicate as easily or as fluently as others. I have much stronger senses and find many 'normal' smells overpowering and revolting.

I don't have as much energy as other people. I am not able to get through a 'normal' school or work day without feeling completely exhausted and suffering in a physical way such as having a migraine.

I need a lot more time alone than other people.

I seem to be more routine-orientated and focused on schedules than other people.

I also seem to be more disciplined and selfmotivated than most people. Maybe this is because I do not get distracted and work so well independently. I have very good attention to detail and notice things that others miss. I am meticulous.

My differences are not all negative!

Q. Any across the board supports that you would want to recommend for people with autism?

- Training for employers and colleagues
- Training for educational professionals
- Training for health professionals
- Training for big services such as gyms, shops, airports, trains, banks

Once neurotypical people understand autism, they will be better able to communicate with autistic people, avoid misunderstandings and achieve better work from them. Some autistic people will have special abilities and will be able to achieve exceptional things.

Early identification of autistic traits by health or educational professionals can prevent mental health problems in the future.

Q. Tell us a little bit about your other interests and also about your music.

I have been doing Olympic weightlifting (snatch, clean & jerk) for 10 years. I feel that weightlifting is

a very large component of my identity and it's such a big part of my life! Although I don't compete, I take a very professional approach to it. I enjoy how repetitive it is. There are just a small number of movements that are very difficult, that you have to practice over and over. I like it because it is done alone. My favourite exercise is the front squat.

I have been having a lot of fun learning how to rap and have started writing and creating songs. This is another wonderful outlet of expression for me. Being creative is really important because it is the only way I can communicate. I find normal talking and normal conversation so difficult and stressful. Writing comes naturally to me and I have enjoyed writing in different formats over the years, such as novels, poetry, blog articles, my autobiographies and film scripts. It has been really interesting, fun and challenging to learn how to write to music. I do not have a musical background. Recently I have been learning how to play the piano and how to sing, in order to improve my rap skills.

My favourite rappers include 2Pac, 50 Cent, G Unit, Young Buck, Lloyd Banks, Jay Z, Ja Rule, Chingy and Fabolous. My favourite RnB singers include Usher, Bobby Valentino, Mariah Carey, Christina Aguilera, Ashanti and J Lo.

I like walking and walk 5-10 km every day.

I love cycling.

I trade in Forex.

I have three cats and a big 53 kg Black Russian Terrier dog who I take for walks.

I do a newspaper round.

I have several other jobs.

Q. What would be your advice to other autistic people who want to be entrepreneurs?

I would advise finding a mentor. Running a business can be very lonely and there are a lot of decisions to make. Having someone to talk to and answer questions can be really relieving and supportive.

I think it is important to realise that running a business requires a lot of skills. Some autistic people may struggle with these demands. For example, I have extreme difficulty with communication, but I still have to somehow find ways to communicate with customers, colleagues, suppliers, potential new business leads, etc. This is the worst part of the job for me because of my autism. However, communication is a vital component of running a business, so autistic people must be aware of this.

In order to run a business, you have to be very organised, disciplined, self-motivated, and have lots of different skills and be willing to learn new skills all the time. Some autistic individuals are like this, others are not. *If you are like this*, you might be very good at running a business. You also have to be resilient and to not give up when things feel frustrating, difficult or boring. You need to be very creative and innovative. Lots of new ideas are always needed to expand your business. You have to be flexible and continually willing to change the format of your business depending on whatever the current market and demand is.

Perhaps one of the most important things that I have learned about running a business is that hard work alone does not always get results. **Hard work, alongside direction and focus, gets results.** This is why a business mentor or having people to learn from and support you is so important.

Decoding Pragmatic Social Communication in Autism

Viniti Puri Shrivastava

Introduction

This article aims to better understand the elements of pragmatic social communication skills and highlight significant difficulties in the use of language across everyday settings for individuals with autism spectrum disorders.

Background

Communication is an essential part of our life. Through communication we connect with others, make our wants known, share ideas and let other people know how we feel. Communication is a social situation between two or more individuals. It is more than just being able to speak or combine words together in a proper order (Wilson 1987).

Language is a noun not a verb. People do not language; they speak, write, sign to communicate using language. Language is the medium by which we make contact, socialize with others and regulate our interactions. It includes forming words, learning the rules for combining words together and knowing the purpose or reason for using language. The person who sends a message is the initiator while the listener is the receiver. Communication includes the constant back and forth exchange of messages between the initiator and receiver. To be competent in using language socially, an individual must understand both roles; that of initiating and receiving information (Watson 1987). In the role of initiators of communication, children with autism have a great deal of difficulty starting a conversation (Feldstein Konstantareas, Oxman & Webster 1982). They demonstrate greater success responding to their communicative partners than initiating social interactions during a communicative exchange (Layton & Watson 1995).

Learning language depends on the interaction of form, content and use. The terms are less commonly heard but they provide a more detailed way of looking at an individual's overall communication profile. Language form is the actual shape and configuration of sounds and words. It is the sounds that make up a word for example; sounds /k/, /a/, /t/make up the word /cat/ or small bits of words that add meaning and grammatical structure for example; /cats/. Language content is the meaning created when the words are combined. It includes vocabulary and its associated object or action. Language use refers to the pragmatics or social use of language. These are the subtle rules of how language is used in a social context for example; greeting, initiating a topic, shifting and maintaining a topic, body language etc. The use of language is a social act and depends on the purpose of speaking as well as the ways that individuals take account of the context and form of the message in different speaking situations (Bloom & Lahey 1978).

An integrated view of Communication, Language and Autism

Language and communication are best understood as complimentary parts of an integrated social interaction system. Having difficulty communicating in a social context has been considered a cardinal feature for diagnosing Autism. However, social communication problems do exist within and outside of Autism. In 2013, DSM-5 published a consolidated version of the criteria for the diagnosis of autism spectrum disorders differentiating social communication difficulties with and without autism (Social Pragmatic Communication Disorder).

Autism is characterized by the below criteria that includes:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviour used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual

objects, excessively circumscribed or perseverative interest).

4. Hyper- or hypo-activity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

Communication and social skills are related through an aspect of language known as pragmatics. According to the DSM 5, symptoms of communication impairment associated with social impairment are uniformly present and a defining characteristic of autism spectrum disorders. Pragmatics has been a challenge and serves as a hallmark for diagnosing autism spectrum disorders.

Pragmatics and Autism

Pragmatics is the use of language to express one's intention and to get things done in the world (Gleason 2001). It includes rules for conversation like turn-taking, topic initiation, topic shifting and maintenance, perspective taking and the communication act such as physical proximity and posture, use of eye-gaze, gestures, facial expressions as well as paralinguistic features (intonation, pitch, loudness and stress). Both verbal and nonverbal features of communication are integral parts of a conversation.

Many children with autism have difficulty with the functional use of language. This is mostly evident at the prelinguistic and verbal stages of pragmatics (Baron-Cohen 1988) with difficulties in sharing information and feelings with others around them (Wetherby 1986, Wetherby & Rodriquez 1992). They often tend to request objects, toys, food or adult assistance and rarely spontaneously comment on something of interest, express feelings, or make social statements such as thank you or good bye.

Individuals with autism spectrum disorders experience difficulty understanding the hidden social standards that make up our social environment. They may not be able to understand that we take turns to talk and may interrupt excessively, shift topics abruptly, or talk irrelevantly missing subtle cues of discomfort or interest during a conversation. As a result, they may appear rude, distracted or self-involved.

Pragmatic social communication includes four major skills:

1. Using language for different reasons

- Greeting: saying hello or goodbye
- Informing: saying "I'm going to eat a pizza tonight"
- Demanding: "Give me a pizza right now!"
- Promising: "I'm going to get you a pizza"
- Requesting: "I want a pizza, please"

2. Changing language for the listener/situation

- Talking differently to a baby or adult
- Talking differently in a classroom or playground
- Giving more information to someone who doesn't know the topic while skipping some details for someone who knows the topic.

3. Following rules of conversation

- Taking turns in a conversation
- Staying on topic
- Using eye contact, facial expressions, gestures, and body language
- Rephrasing when misunderstood

4. Understanding non-literal or Figurative language

• Humour, sarcasm, metaphors, idioms

There are aspects of pragmatics such as perspective taking that deals with the children's ability to appreciate that others have points of view that may differ from their own (Getter 1989).

Three areas of perspective taking include, **Perceptual:** others may perceive things differently; **Cognitive:** others may have different ideas and intentions; and **Linguistic:** adjust the form, content and purpose of utterance to suit the needs of the situation and/or listener (Getter 1989).

Difficulty with perspective taking has been linked to the oft-cited unilateral pedantic speech that characterizes many high-functioning children with autism. These children are able to speak fluently on a topic of interest to them with no apparent recognition of cues from the listener regarding the lack of interest and/or need for additional information. They are rarely able to engage in the often inconsequential 'chit-chat' that is so important for normal social interactions. They show little or no interest in others' views, unaware of cues indicating boredom; disrupt ongoing discussions or dominate the conversation in a socially unacceptable way.

This lack of reciprocity and failure to appreciate the two-way nature of conversation is evident in autism and highlighted in this article.

Assessing Pragmatics

Pragmatic impairments tend to become more obvious and problematic as social and educational demands increase with age. It is crucial to assess pragmatic social communication in terms of developmental age expectations. A thorough assessment of social and communicational skills is strongly suggested by a certified speech & language therapist. Assessment type and method should be culturally sensitive, functional and include the collaborative effort of families, teachers, speech therapists, special educators and psychologists. A well-constructed tool that is valid, reliable and norm-referenced for identifying pragmatic language impairment in the child's natural environment is the Children's Communication Checklist CCC-2 Second Edition (Bishop 2006). It measures both verbal and nonverbal communication in children and adolescents who speak in sentences. It is a relatively quick test to administer that usually takes approximately 10-15 minutes.

Best Practices

It is imperative that speech & language support services for individuals with autism spectrum disorders include particular attention to the pragmatic, social communicative functions of language (turn taking, figurative expressions, inference) as well as to nonverbal skills needed to communicate and regulate interaction (eye contact, facial expressions, body language). Significant difficulty in the ability to communicate and interact with others can limit participation and impact an individuals' ability to access areas of the mainstream academic curriculum as well as community activities. Communication intervention is strongly recommended in better supporting pragmatic communication in Autism Spectrum Disorder.

Intervention must target an individuals' ability to be motivated to communicate (personal/social interests), have a means to communicate (gestures, speech, AAC), communicate for a variety of social functions (request, comment, express feelings, respond to others), take the interactive roles of both initiator and responder (initiates, responds) as well as engage in basic conversation/dialogue (initiates, maintains, repairs, terminates).

A key aspect of communication intervention is generalising social use of language across multiple social contexts and people (adults/siblings/peers).

Families could encourage social communication skills at home in line with the target goals set by the individuals' speech & communications therapist.

This may include:

- Take turns in activity/conversation
- Read & discuss using open ended questions (what do you think about what he did?)
- Talk about feelings
- Talk about what will happen next?
- Introduce age appropriate television shows
- Plan structured play dates
- Use visual supports

A cornerstone in designing and implementing a communication intervention program is the measurement of an individual's progress. Progress is defined as changes in level of motivation, engagement, social and communication skills as well as flexibility.

It is of utmost importance to measure effectiveness of intervention using both direct (checklist, frequency data) and indirect measures (parent/teacher interview, videotape of adult-child interaction).

Summary

Individuals with Autism Spectrum Disorders experience the social world to be a challenge. They typically have trouble with back and forth communication in conversations (wait their turn, interrupt the person talking), nonverbal communication (making eye contact with others, body language), social interaction (making and keeping friends) as well as figurative language (sarcasm, irony). This article acknowledged that language and social communication as a whole is a persistent problem for many people with Autism. The aspect of social communication addressed here was known as 'pragmatics'.

Professional intervention along with positive family engagement is crucial and strongly encouraged in better supporting social interaction and social communication skills in Autism. A certified Speech and Language therapist trained in social communication intervention can provide the necessary skills and strategies to be used across various communicative partners (family, teachers, domestic helpers) as well as settings (school, home). It is therefore strongly encouraged for you to work closely with a speech and language therapist to make this learning experience rewarding and beneficial for your child.

Viniti Puri Shrivastava is a Certified Speech & Communications Therapist and has done her Msc in Human Communication Sciences from the UK. Viniti currently works at Action for Autism (India).

AUTI JPEAK

My experience of working in a mainstream school

Neha Uttam

One morning when going to work to the Arunima Projects Training Centre, the Director of Arunima informed me that she had recommended me to work in a mainstream school – the Vidya Niketan School – during my summer holidays in July 2019. I was really excited for the golden opportunity to do so.

I was in touch with the Founder President Mrs. Aruna Naqvi ma'am and I accepted the summer job in Saket, New Delhi.

I started my summer job in Vidya Niketan School in July 2019. I assisted the respective staff (teachers) in Art sessions, computers, and music sessions. I taught the students some Art skills, gave the students some computer information related to their curriculum chapters in their text books and I also taught some Hindi songs in the music sessions in junior classes and 4th and 5th standard classes. For a few days I assisted the prep classes in their morning assembly period.

All the students took a liking to me and the staff of Vidya Niketan School too. They gave me an excellent pay also for the two weeks that I worked there. Aruna Naqvi ma'am gave me a very positive and excellent experience letter of working in Vidya Niketan School, New Delhi.

My experience was fabulous!

Travelling Alone Manjusha Sawant

Siddharth travels alone across Mumbai, coolly boarding and alighting from jam packed Mumbai locals, as any Mumbaiite would do. Nothing great, one would say – except that Siddharth has Autism. Looking back, we, his parents, realise that we had to adopt a lot of risky measures and suffer numerous anxiety pangs in our journey to make Siddharth an independent adult. Although, the whole credit of this achievement goes to our daughter (Siddharth's elder sister), who not only co-operated with us at every step but kept reminding us of our final destination – a self-reliant Siddharth. Let me take you through the time line of Siddharth's story.

1997 (Birth): Siddharth was born in August 1997 – a baby who didn't cry at birth, spent the first two days of his life in hospital with jaundice, never crying for milk/food and was happy playing facing the wall alone. Siddharth disliked playing with other kids on the playground, preferred going for long walks and spinning around himself for long durations of time; he was petrified at the honking of vehicles, we often found him bending dangerously over the balcony – absolutely fearless about the consequences. He did not respond to any stimulus not even when we called out his name; his communication skills were almost non-existent.

2000 (Diagnosis): In February 2000 we came to know the reason for his indifferent behaviour. We were handed a paper by a Neurosurgeon, which said he was diagnosed as a child with autism. 2000 and 2001 saw Siddharth travelling to Cotton Green for occupational therapy and special education (travelling by train did not bother him so much as people cramming and crowding around him. He would howl his head off, resulting in raised eyebrows of the people around us), he also travelled to Thane for occupational therapy and auditory therapy, to Vile Parle for Speech Therapy where one of us or our support staff would be accompanying him. All these efforts saw Siddharth articulate his first sounds; at last, we heard him speak – even if it was only reciting Nursery Rhymes.

2001: In 2001 he started uttering words, labelling items. Once while returning back home from one of our long walks, we hid behind a parked vehicle to check his reaction. We were surprised to see him first look out for us and then run up to our house. We were happy that day, for Siddharth had conquered a significant milestone in his life. We were thrilled that he could reach his house without help from others. Now our little boy was able to travel to a local nursery school without parents or support staff, in a hired auto (on monthly basis) alone. Though, otherwise hyperactive, he sat still at signals – a great achievement. This was also the year when he joined a special school.

2002: Just like other parents, we too looked forward to enrolling Siddharth in a formal school. In 2002, he joined the BCG directly in senior KG. From day one of school, we were instructed to send him alone by the school bus; we were asked not to accompany our child to school. The school bus picked him up and dropped him on the highway which was 1km away from our residence. The school also gave clear instructions that we, his parents should not try to teach him at home. This would help prevent conflicting teaching methods that could create confusion in Siddharth's mind. They also said that they would inform us if they felt he needed assistance. We trusted the school. At home we emphasized on generalization of what was taught in school. May be that is one of the reasons why we could focus more on developing life skills in Siddharth. This was the year when Siddharth started communicating in sentences consisting of two to three words. We also realized that he was hyperlexic. He could read the newspaper!

2004: In 2004, Siddharth joined a conversation skills class. Here too, he travelled alone by the same hired auto. I do recollect one incident when he returned home crying from his class, running all the way through the crowded streets just because his teacher didn't open the door as soon as he reached her house (she stayed on the first floor). Perhaps, he thought that if his teacher was not in and Pravin Kaka (the auto rickshaw driver, to whom we will forever be grateful for supporting us during those trying times) too had left on his rounds, then he would be completely helpless. That day, we too realized the urgency of developing proper communication skills in Sidhharth.

2005: By this time, we had understood that Siddharth needed to expand his skill base. To achieve that he would have to travel to different places in Mumbai. It would have been impossible for us to arrange for a private vehicle as a permanent solution for his travels within Mumbai; so, we decided to make him able to use public transport instead. This year, Siddharth joined swimming and initially travelled with his sister by BEST bus.

2007: In 2007 he joined a local skating class. He travelled alone to the skating class by BEST bus, that was just two stops away from our house and he came back walking alone. Fortunately, he had no roads to cross while on the road. But, travelling by bus needed more skills – communicating with the bus conductor and exchanging cash for buying a ticket were both daunting tasks which he overcame gradually over a period of time. Sidhharth wasn't yet confident of crossing roads. We are all aware, that in India, there are no zebra crossings in the by lanes; besides, by lanes are congested with hawkers, pedestrians and heavy traffic. So, at this juncture, we had to teach him to cross roads.

2010: In 2010, at the age of 13, Sidhharth joined an English language class (thinking skills, writing skills and English grammar). The class was by no means close to our residence – approximately 5 kms away. We stayed in the east and the class was in the west. Our young boy's skills had now been put to test. He had to walk down from our residence to the west using the railway bridge, cross streets, travel across the main road and board the correct BEST bus; I accompanied him for six sessions; gently and quietly testing whether he was well equipped to handle this complex situation. The day I was satisfied that he could manage by himself. I feigned illness and I asked him to go alone. However, that was not easy for a mother anxious about her child's safety; so, for two more sessions, I followed him from a distance before I let go.

2013: We conquered a major milestone when Sidhharth appeared for the SSC (Grade 10) exam, his first public examination and was free for the next 3 months. He was always fond of trains and we wanted to make the most of this fascination. We enrolled him for a drama class at Prabhodan Thackeray Natyagruha, 10 kms away and purchased a second-class train pass for him. He was thrilled. He travelled to and fro, alone by local trains. Here too I followed the same routine – accompanied him for two days and then followed him without being seen before I let go. We were now confident he could be enrolled in a college anywhere in Mumbai. After his results we enrolled him in a college at Vile Parle/Khar into an integrated college. In the middle of the academic year, we shifted residence. We moved away from the main city and the circumstances forced him to adjust to travelling longer distances by himself.

2015: Siddharth appeared for his HSC (Grade 12) examination; he had chosen the Science Stream. After this he did his first internship. He joined his grandmother at her grocery shop. On receiving his result, Siddharth changed college for under graduation studies. Now he had to change two trains

daily for commuting. He needed to use both the Western Railway and the Central Railway; a total of 26 kms each way. Sidhharth has always been an introvert – a shy boy, stealing glances at people. Hence, his long journeys in the local trains were sometimes very painful; in trying to avoid interactions with the railway ticket checker, he often landed up attracting their attention instead. This used to spoil his day. Standing in the queue for college railway concession forms and purchasing a railway pass was stressful, but he did it for his love of trains. In May 2017, he completed his second internship with the Central railway. A dream come true for him.

2018: Sidhharth appeared for his BSc examination, majoring in Statistics. He completed his third internship at Kotak Mahindra Securities and the fourth one at SOPAN, an NGO. He went to Pune alone to meet his aunt, but was nervous about whether other passengers would bully him and take away his money. With the advent of Google Maps it was easy to send him to meet our family and friends with their addresses, informing them in advance and requesting them to inform us on his reaching their place. So along with socialising, his travelling to unknown places to relatively well and some lesser known people was a success. It brought a change in his self esteem because he was treated as an

individual and welcomed as a special guest. He was the centre of attention.

2020: From 2018 to 2020 he overcame all the mental hurdles of engaging a rickshaw driver to take him to a destination or deciding how to travel (local train, bus, auto, cab or Ola/Uber) to a particular destination. It is lockdown all over India, especially in Mumbai. After the lockdown he is preparing for his first maiden trip to his native place, Kudal, which is 640 kms away. In the meantime, as part of his preparations for the 'home alone' stay at Kudal, he has learnt cooking. He prepares a variety of breakfast dishes daily for the family (for the past one month). Since serving and cleaning is a chore that included, the activity is not a particularly welcome one; I can see the zest diminishing. After almost 10 years, he has taken out his keyboard which had been gathering dust; very often we find him dabbling with the keys. Just like in the case of others, the lockdown has given Sidhharth too an opportunity to pursue his hobbies and hone multiple skills.

At the end of the day, I think all that matters in life is overcoming anxiety and fear; first by the parents and then the child. It is this alone that makes 'travelling alone' safe and possible for our children.

MAKE A DIFFERENCE – VOLUNTEER WITH US!

We are looking for people who want to make a difference in the autism community.

You can volunteer on site or off site:

- To teach skills such as music, art and craft, yoga, computers and more
- Be a job coach or a friend to a person with autism
- Contribute to our fundraising or advocacy related activities
- Help us with our website and social media presence
- Help us with our database management systems
- Organise autism awareness programs with us
- Find employment opportunities for people with autism or any other way that you can think of

Get in touch with us at: positions.afa@gmail.com and we can find meaningful opportunities together!

Workshops and Trainings

Snapshots of April 2020 - March 2021

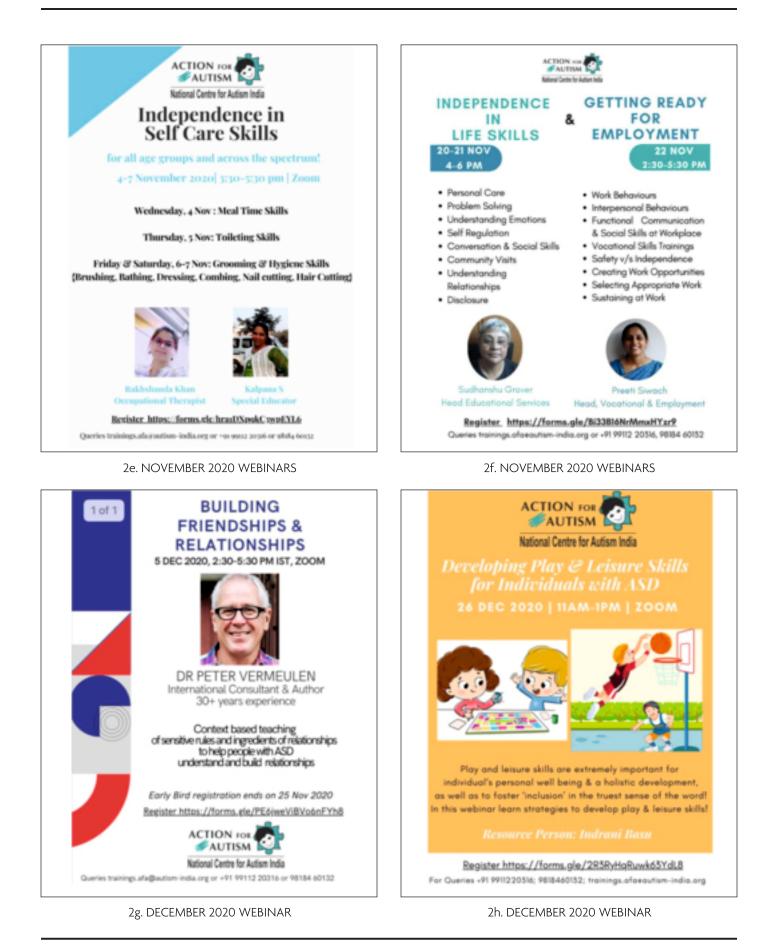
2a – 2l Flyers: June to December 2020 and January 2021 Webinars + Bed, Ded





ACTION TOR CON UPCOMING TRAININGS SEPT-OCT 2020 Referral Canton for Bull IN OUR VOICES: A Panel Discussion by Self Advocates on the Spectrum 20.00 F-8 av SATURDAY, 12 SEPTEMBER 2020 CONTEXT BLINDNESS & LEARNING 10 October, 2020 Anual Training MASTERCLAS Workshop OC PETER VERMEULEN - 3000, 10 am 1 dia.org. Call: +91 99112 201

2d. SEPT-OCT 2020 WEBINARS







2k. B. ED SPECIAL EDUCATION (ASD)

ACTION FOR AUTISM DIPLOMA IN SPECIAL EDUCATION (AUTISM SPECTRUM DISORDER) 2020-22 Certified by Rehabilitation Council of India - Intensive Hands-on Training - Faculty with 15+ years experience - Practical Exposure in other Disability & Mainstream Schools No Aptitute Test Direct Admission for 2020-22 For more information Email: trainings.afbeautism-india.org Calt - 91 9911220516 / +91 9818460152

21. DIPLOMA IN SPECIAL EDUCATION (ASD)

Exciting Things at AFA

Information on various programs and services

Ananda Assisted Living

Ananda Assisted Living for Adults with Autism and other Developmental Conditions consolidated its services during the year. It now opens its doors to welcomea few more adults at its beautiful home. Ananda offers a fun, active and balanced outdoor and indoor life, and engagement through the day that promotes independence in our residents.

Person to contact: Reeta Sabharwal <reeta.sabharwal@gmail.com>



WORKPLACE: The Vocational Centre Ananda, Village Gairatpur Bas Teekli, Gurgaon



Workplace@Ananda invites adults with autism and other developmental conditions to apply.

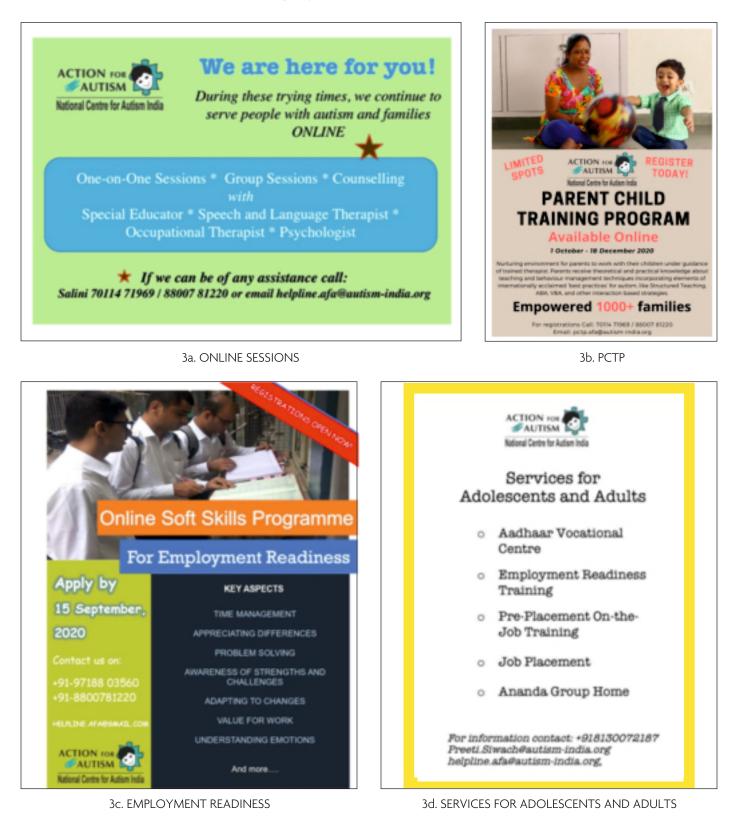
Interns at Workplace participate in an active and productive day: at individual work stations, do group production, join in discussions and fun activities.

Interns will have the opportunity to work at office skills, produce craft items, practice computer skills, work at housekeeping related work, with plants and nature, and food production related work. Most importantly they will learn happy and independent functioning.

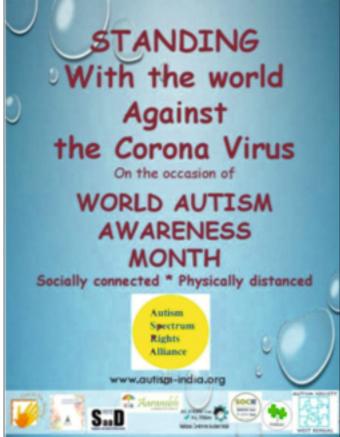
Contact Salini at: helpline.afa@gmail.com, or call on 40540991/40540992 any weekday

Exciting Things at AFA

FLYERS: Online Services, PCTP, Employment Readiness, Services for Adolescents and Adults



Fliers on the Corona Virus



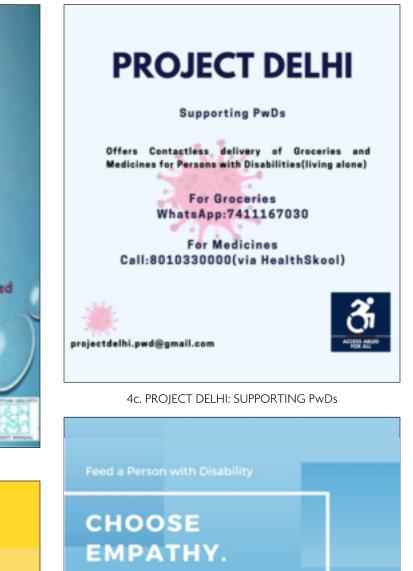
4a. AWARENESS RAISING



In view of the ongoing coronavirus scenario, we are taking preventive measures and cancelling our World Autism Awareness Day Celebrations.

We will not be hosting our Annual Art carnival; or "Celebrate Diversity" our Annual Stage performance; or the awareness raising flash mob.

We hope to host some awareness events as the situation improves.



Support the most vulnerable group during Covid 19

SPONSOR MEALS FOR A WEEK

DONATE INR 600/-



PROJECT DELHI

4b. CANCELLING WAAD EVENTS

4d. PROJECT DELHI: SPONSOR MEALS FOR PwDs

Hit the ground running and ZOOOOOMM!

It would take much more than a mere Covid19Virus to stem the AFA zeal. All our services continue online with the same passion and dedication and of course continually using the 'best practice' strategies to ensure that learning remains fun and useful...



I. OPEN DOOR (The Day Program)

OD 1



OD 2

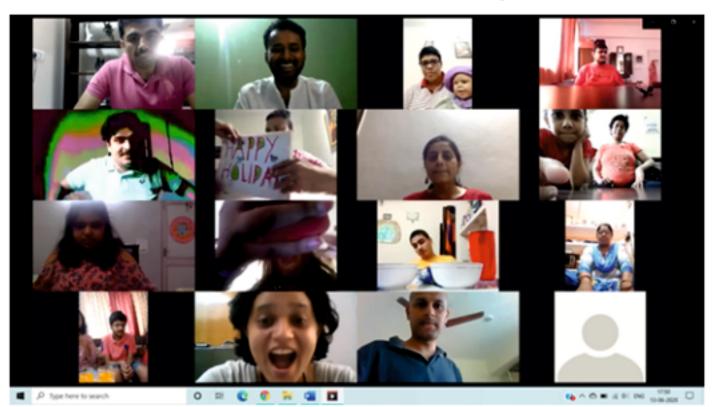


OD 3





OCCUPATIONAL THERAPY



III. Aadhaar – The Sheltered Workshop

AADHAAR 1

Rules we need to follow after coming back to home.

- 1. Take out your mask.
- 2. Keep it in a tray or safe place.
- 3. Wash your hands with soap.
- 4. Take bath.



AADHAAR 2







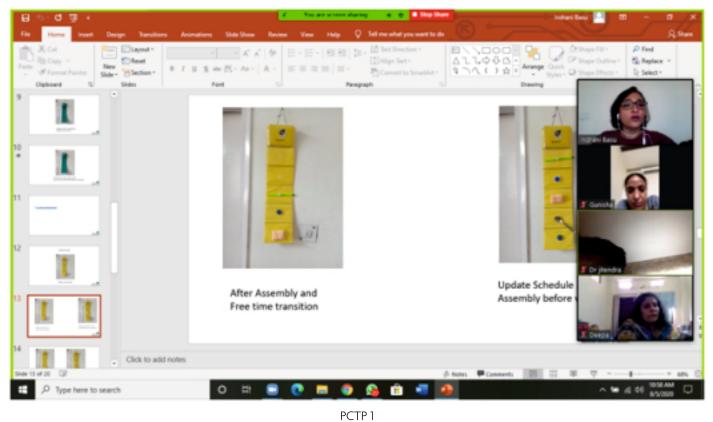


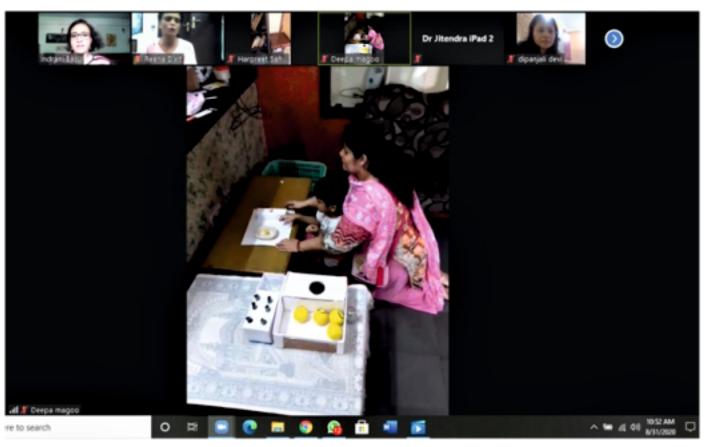
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IV. The Employment Readiness Program

EMPLOYMENT READINESS PROGRAM

V. The PCTP – Parent Child Training Program





PCTP 2

PCTP 3

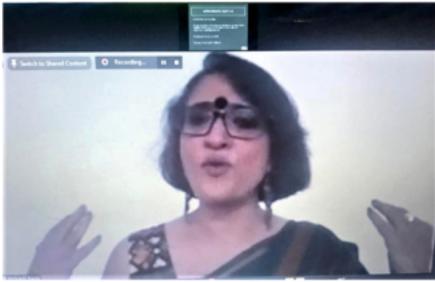


VI. AFA Trainings

WEBINAR 1



WEBINAR 2



WEBINAR 3

AFA MEMBERSHIP FORM

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

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

City	State	Co	ountry	Pin/Zip	
Phone		Email			
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Mother Father	Other (please specify)	Pro	fessional: Name o	f Organisation	
For Parent of a person w	ith autism ONLY:				
Child's Name		Gender: 🗌 Fen	nale 🗌 Male	Date of Birth	
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wish to become a memb	er of AFA. Enclosed is a con	tribution (Check as app	licable)		
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ACTION FOR AUTISM

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