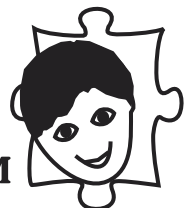


# autism network

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ACTION FOR AUTISM



# autism network

2023

VOLUME 18

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.

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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](mailto:actionforautism@gmail.com)

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In referring to the child with autism, Autism Network often uses 'he', 'him' and 'his', not as a prejudice against the girl child with autism but for reasons of simplicity and because the vast majority of children with autism are male. However, many articles also use 'she', 'her' and 'hers'.

### Cover Illustration

Cockatoo by Vishu

Vishu, 26, is an intern at Aadhar Vocational Centre, Action for Autism. He enjoys painting, designing, cooking, making new friends and exploring new places.

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PAGE ONE
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It was the early 1990s when Action For Autism had started its advocacy for autistic people. Autism at that time was a barely known term and an even less understood condition. The limited understanding leaned towards viewing it as just a 'more difficult' form of intellectual disability (or mental retardation or MR, the term in use at the time), and well-to-do parents (whose children were the only ones getting a diagnosis) were largely advised to pack their children off to an 'institution', have another child and carry on with their lives. There were also those who saw autism as a manifestation of psychosis brought on by poor parenting! Professionals at some important institutes insisted that autism did not happen in India. And that the 'few' cases were an anomaly largely due to parents whose lifestyles led to their children being autistic.

Acquiring a 'voice' in this milieu was a challenge. The focus therefore around 1994 was largely on getting autism recognized as a disability.

The very suggestion that autism was not the same as MR or intellectual disability would lead to anger and ridicule. "Do you mean that autism is better than MR?" "You are trying to make autism fashionable." I recall being at pains to explain, at different fora, that no condition was better or worse than another. They were all just different – people with different experiences and different needs. Autism was not the same as intellectual disability or psychosocial disability (or mental illness or MI, the term then prevalent). Most importantly, autistic children (no one spoke about adults then, as if they did not exist) needed different supports in education and life skills from those with intellectual disability or psychosocial disability. Confusing autism with other disabilities was damaging to the growth and learning of autistic people.

Consistent and persistent advocacy led to the first major breakthrough with the inclusion of autism as a discrete condition when The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, was passed. Following that autism began to find its own small, but nonetheless heard, voice. It was many more years, 2010 to be precise, to the formation of the committee for the Rights of Persons

with Disabilities Bill. It felt amazing to see 'Autism' included in the nascent act as a discrete condition, as was Specific Learning Disability and other conditions, to unanimous agreement. The bill went through several amendments and was finally ready in 2013 and put up on the Ministry's website. But in the maze that is Indian politics, its passage was held up by different interests. In the meantime, several consultations took place along with comments from civil society and each time the resulting draft of the bill was placed on the ministry's website. However, when the bill was finally passed into an act in 2016, it was a version that was different, and disturbing. Autism, along with learning disabilities like dyslexia, dysgraphia etc were now all lumped under intellectual disabilities.

In the initial euphoria of the Rights of Persons with Disabilities Act (RPDA) being passed we had not looked at the Schedule that listed specified disabilities. When we did, we realised that in one stroke the act had dismissed the needs of several million citizens. The years of work in getting autism its own unique identity had all come to naught. According to the RPDA, if you are autistic (or have a specific learning disability) and do not have an intellectual disability, then you are not disabled. It does not matter how much you struggle to get through each day, it does not matter if you are not allowed by our institutions to have an education, it does not matter if your life is messed up with medications that you really do not need, it does not matter that employers discriminate against you so that you do not have a livelihood, you cannot ask for or expect any accommodations. Because you do not have an intellectual disability.

Would you get a Unique Disability Identity Card (UDID)? The magic one card identity for disabled people? No. Because by the RPDA no physician will acknowledge that you have a benchmark disability that would entitle you to the UDID. We will leave the whole UDID challenge for another issue.

In the meantime, we bring to you some wonderful reads by autistic people themselves. People who will not be considered autistic under our law.

Happy reading.

# The Experience as Co-Travellers in Narrative Practices

Dr Manisha Bhattacharya and Ranjana Chakraborty

Narrative practices, as the name suggests, is not a therapy, rather a philosophy that tries to explore the untouched territory of people's agency over their lives, their decisions and also over the problems that they are experiencing in their lives. Narrative practices focus on people's expressions of their lived experiences and how do they give meaning to these. Narrative practice views life as multi-storied; with layers of narratives to be unfolded and told. Narrative practice believes that people's experience cannot be depicted by others – by the therapists or other professionals or even by so-called well-wishers who readily tell us what to do. They can only be depicted by the people who are going through the experiences. Narrative practices can be seen as the third-wave therapies which came up as a result of the right-based movements; a shift from the medical model to more social, contextual and person-centered model. And this is a respectful and truly collaborative approach in which the therapist and client re-author the client's problem story (Madigan, 2011).

## History

The Narrative practices have drawn its essence from a broad range of scholarship, including feminist theory, sociology, anthropology, and post-structuralism. And it has helped Narrative therapy in fashioning a unique approach to direct practice. The feminist theory reminds us

to strive for equal footing; and sociology has shown us the seams and tears in the fabric of the social order (Marsten et al., 2016). Sociology further looked into how invention makes its way in, from small openings at the edges of convention. Anthropology reminds us of the diversity in the world and the importance of learning about different cultures. This further helps us to see these cultures in a new light, where our own culture is not at the 'centre' position. And post-structuralism tells us there is always more than one reading of the self. We learn to see things with an eye of wonder-ness and not with the medical eyes, as we unlock the multiple expressions of identity.

Narrative practices teach us to connect to and respect people and respect their imaginative know-how, the out-of-the-box ideas, unique techniques, the innovative strategies that they come up with to get away from different problems. And also, replacing the psychiatric nomenclature with people's own descriptions.

## Narrative practices and the application in Autism Spectrum Condition (ASC)

Narrative, as the name suggests, is the process of story-telling, thus, when we speak of narrative practices, the first idea that comes to our mind is people sharing their stories, their lived experiences. And stories mean language!

Communicating through language, through lots of verbal communication! And language being a difficult area for people experiencing Autism, it might be difficult or impossible to try narrative ideas with them. And that was the first thought that came to our minds as well.

To be honest, when we first experienced the power of narrative practices, we remember a feeling of excitement to try out this new practice. We realise that this was because we felt a strong connection between some of the commitments and purposes that were important to us as professionals, and the practices that we were introduced to. The decentred and yet influential position of the therapist in narrative conversations (White 1997) was one of the first things we noticed about narrative practices. Narrative conversations are not about giving advice, making judgments or suggesting a solution. It is not about evaluating people or positions of authority. Rather, narrative practices hold people's ideas, their own know-hows at the forefront; and believes that people are the 'experts in their own lives'. It keeps people's views, perspectives, opinions, preferences, dreams and hopes at the upmost priority. And this is what we also wanted to do with the people we work with- people who are experiencing Autism Spectrum Conditions (ASCs). Knowing and putting more importance to their hopes and dreams, their purpose of life, what they value! We were excited about trying it but felt daunted about how to do it; how to start, what if we could not do it 'properly' and the most important thing- how to enter into narrative conversations – with minimal usage of language!

But as we always tend to do, 'we just jumped into it'. We knew its power and wanted to

experience it first hand and to see the changes in people's lives!

Narrative practices involves externalizing the problem to help us gain a better perspective; rather than personalizing it as we are often want to do. Through externalising people can separate themselves from the problem at hand.

Externalization involves techniques to personify the problem; using specific language or even giving it a name (eg 'Mr. Negative Thoughts', 'Ms. Guilt', or simply 'Mr. Depression!'). The intention of this technique is to help people to see that they are not the problem but the 'problem' is the problem. Thus, there comes a huge shift in people's way of thinking, from 'I am depressed' to 'what this **depression** is doing to me'!

We started with the *externalization conversation* on 'Mother Blame'. Mothers tend to blame themselves for not being able to do enough for their children and feel guilty. Society also adds on to it. Keeping this in mind, 'Mother Blame' was enacted in front of almost 100 participants who were mostly parents. 'Mother Blame' was interviewed to explore her power, origin, how she works and her effect on people. How society plays a role in strengthening her power. Mothers in the audience participated in the play. They could see how this 'Mother Blame' actually acts and affects their lives! And, how they can play an important role in keeping her, i.e. 'Mother Blame', away. It was a fulfilling experience where almost everyone could relate to the act and started looking at the problem as problem; and not believing themselves as the problems! This was a huge confidence booster for us, as we realised the space for practicing Narrative ideas was ready. The people were ready!

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We then moved from enacting to starting narrative conversations with families, in particular the mothers! In these small narrative gatherings (which we hopelessly tried to keep to 1 hour, but would often continue for 3 hours!), mothers spoke about their stories. And it was an amazing experience to witness the shift from the problem stories to the preferred stories! They started re-authoring their stories. The mothers explored their agencies, their ideas, their values and beliefs behind what they were doing for their kids. Then these values and beliefs were explored more deeply through which they could reflect on their own principles of life! Our sessions with the fathers were even more surprising eye-openers! The often quiet but sturdy and sometimes side-lined parent got a chance to express themselves. How they connect and relate to their children, the strategies they follow, how they are transferring their values to the children. There were conversations on what were their hopes, dreams, vision and what their journey looked like. These logical insightful thoughts shattered many preconceived myths and were the game-changers! It was much appreciated and we got to see so many possibilities!

After testing the waters with the families, we slowly shifted to the people experiencing ASC. We started with what are called the *'Wonderfulness Conversation'*, and conversations on *'Special Something'*. Narrative practices disrupt the structure of conventional therapeutic interventions for young people and their families, which tend to take on a problem-focused approach. While a traditional intake interview might begin with a description of the 'presenting complaints' a family brings to therapy and discussions about possible

interventions, narrative practices may begin by requesting the family to keep the problem aside for a little while. Instead, almost paradoxically, the therapist may elect to interview the family on their child's 'wonderfulness' or 'special something' or their abilities, skills and know-hows. We explored the wonderfulness in the person observed by others or Outsider Witness. Outsider witnesses can be neighbours, other family members, children in the neighbourhood or at school, or others in the individual's environment. These outsider witness gatherings were done in groups where co-families commented on each other's strengths, talents, wonderfulness, and these alternate stories were documented creatively. These changed the family's perspectives about their children. They changed their perspective from what their children cannot do to what they actually can and are capable of doing, and all the other little often missed yet heart-warming traits each child has! They started narrating stories where the children could do things that they never expected them to do, which actually had surprised them. And they started calling their children 'sensitive', 'keen observer', 'happy', 'intelligent', 'bright' instead of only 'naughty', 'hyperactive', or 'restless'. People around them started believing in those alternative stories, shifting away from the problem stories. And their attitudes changed! We can well imagine how that affected the lives of people who were experiencing autism. It always helps when people presume competence. The 'Pygmalion effect' does play an important role!

Till then, we were practicing narrative ideas with parents and not directly with people experiencing autism. But that day also came! We started with a child who was

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communicating with us verbally. He spoke about him being 'angry' and we tried an externalizing conversation with him. Once he realized that it is not him rather the 'anger' who's visiting him and making him do all sorts of stuff, he started building his own 'army' to resist 'Mr. Anger' from visiting him or becoming powerful! That was our breakthrough. And we started working more enthusiastically with autistic children and adults, helping them externalizing the 'problems'.

Once the problem is seen as not a part of us anymore, it helps us shed light on how huge an influence they have on our lives. This shifting of the narrative begins to provide people with a lot of information and a richer understanding of how they might be able to reclaim their lives from the influence of problems. We also externalized strengths, personality characters, concepts to explore what people think about these. These conversations also have been tried successfully with people who use alternative and augmentative methods for communicating. We remember one externalizing conversation on 'friendship' where a non-speaking teenager put his mom's photograph on the board to indicate what friendship means to him!

Bubbling with confidence, we next stepped into the territory of 're-authoring' conversations; mostly with adults, young adults and teenagers. The child who externalized 'Mr. Anger' also spoke about why he did not want it to be near him most of the time. He spoke of 'Mr. Anger' making him hurt his parents which he didn't want to do as he loved them and would not want them to get hurt. But he also explained that sometimes 'Mr. Anger' had helped him to protest for himself when he and some of his

friends were getting bullied in class. With guided exploration it was revealed that the child believed that everyone should be respected and treated accordingly. Thus, his values and principles of his life was explored through loitering more and more on that subject. And that's what this re-authorisation conversations can do! Making these hidden yet very powerful values, beliefs and principles of their lives visible to people.

Re-authoring conversations included identifying and co-creating alternative story-lines of identity. The practice of re-authoring is based on the assumption that no one story can possibly summarize the entirety of a person's experience, there will always be inconsistencies and contradictions. There will always be other story-lines that can be created from the events of our lives. As such, our identities are not single-storied – no one story can sum us up. We are multi-storied. And Michael White's 're-authoring conversation map' (White, 2003a) is assisting to give direction to how the conversation will create an opportunity for the co-authoring of a preferred story of identity. A re-authoring conversation highlights events in a person's life (termed 'the landscape of action') as well as exploration of the meaning, hopes, values, preferences, lessons, commitments, and importance to that person (termed 'the landscape of identity').

Re-authoring conversations brings a huge shift in our mindsets, of how we see ourselves, our hopes and dreams, relationships and values in life. Watching out for the 'unique outcomes' leads to acknowledgment of our own know-hows, and agencies. We remember, a mother from a village who appeared to be shy, timid, a

bit aloof and in one of these re-authoring conversations she explored herself to be a person who is a fighter, who had gathered all the courage to travel all the way from her village, all alone, to learn how to support her son. She identified herself as an advocate for her son who believed her son also deserved to be treated well and should not be looked down upon because of his condition. Every time she was challenged with some opposition from her family, she came out of it! We remember how her stories reminded us of a phoenix- being born and rising from its own ashes?again and again!

This journey has been bumpy with some and smooth with others! Asking questions in the correct language is crucial for a successful narrative session and we were apprehensive at first if we were doing it correctly or not. But the whole idea about Narrative practices is to be 'curious'. And we did ask questions – not random ones – but with intentions which are influential. And whenever we struggle to understand, we simply ask questions! That's what narrative is – not making judgments, not making assumptions – but being curious with an intent, being a good listener and being a co-traveller in people's journey.

And what a journey we are having! Watching so many landscapes – different ones! Exploring them – and shifting from the problematic ones to the preferred ones!

So, let's not reject the opportunity to the people on the spectrum to experience the magic of narrative in the name of 'ableism'. Let's not either subtly or directly, portray individuals as being defined by their conditions; or individuals with disabilities as inherently inferior to non-

disabled people. When we just start by assuming that they won't be 'able' to do it just because they are experiencing certain conditions, then we rob off the opportunity to let them explore their stories! We have so many different ways to tell our stories. But yes, learning to communicate with them is definitely the first step. And the second step is, learning to understand the differentness in communication!

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# Don't You Know?

Aalap Deboor

In his moving article '*Don't Mourn For Us*', autistic self-advocate Jim Sinclair writes about expectations.

Let's say you're a parent expecting a child. Your default expectation might be to have a typical one. You expect this child will grow up typically, and see the world and naturally understand and adapt to its ways. And when you discover your child is autistic, you might grieve and talk about how it was the most traumatic thing that ever happened to you. Naturally, none of the expectations you have of your child see the light of day. Expectations themselves are a tricky concept.

Picture a vast, uncertain piece of land with lots and lots of roads branching out in all directions, and people in it scattered everywhere. Kind of like the dream city from *Inception*. Let's even give it a name – Uncharted. There are no signboards anywhere in Uncharted, so you never know which road is leading where. And even if there were signboards, all that would be written on them are the words 'Don't you know?' Because in Uncharted, nothing is clear, everything is implied. Out here, you see the vast majority of people scampering along with a wide smile across their face, going about their daily lives just knowing where to head off to and what to do next. They all seem to be on a mission. And you? You're left dawdling about – a few steps here, there, in every direction – before you backtrack and find yourself right where you started. You want to progress, and you want to go places. But how is that ever going to happen when there are no directions and the instructions are next to none? You want to ask someone the right way, but no one here is willing to stop and listen. Even the few that do end up laughing at you because they can't believe how something so obvious is so lost on you. They think

it's simply attention-seeking behavior. They call you out for it. And you can't figure out why they need to be this way. You can't figure out what could possibly be so difficult about just helping someone out. At its core, it's an expectation mismatch.

Figuring out expectations requires a keen intuition for the way Uncharted works. Because in Uncharted, nothing is absolute. Across Uncharted, along different intervals, the rules arbitrarily change. In some places, you're expected to talk softly. Other times, you're expected to walk gracefully and never run. In some places, you can be loud and brash, and as soon as the situation changes even slightly, you have to put on a formal demeanor. Language changes depending on who you're talking to. And people are quick to take offense. The problem is that the rules are arbitrary. And there is no curriculum on them. No study material exists on meeting expectations correctly. Literally every problem seems out of syllabus. You're just expected to know all this.

Now picture your small child in Uncharted. No more than five or six years old, extremely impressionable and supremely ambitious. As he/she/they – somehow – make their way through this cold mess, they come across two other kids – Wally and Tom. Wally and Tom look as bewildered and confused as your child (YC), as they try to navigate Uncharted without much help. Thankfully, they have each other to keep them going.

YC: Hey, are you guys lost too?

Wally: Yes, we are! This place is so confusing.

Tom: It really is. And the people are mean too.

YC: Did anything happen?

Tom: Yeah! I keep getting told by my teachers in school that I'm too stupid to learn anything!

Wally: I've had the same experience. A recent drawing I turned in as part of an assignment came back with the remark: "You have neither imagination nor good ideas."

YC: I'm sorry about that. Can I see it?

Wally: Sure. Here you go.

YC: Wow. This is so... different from anything I've ever seen. It's beautiful and unique. It makes you wonder what you're trying to express through it.

Wally (pleased): Really? You think so? Well, Tom here felt the same way, and that's how we became friends. Maybe you could join us too? We're on a mission to find others like us.

YC: I'd be happy to. I was kind of lost here as well, and it would be good to have friends for the rest of my journey.

It was in 2022 that Aditi (my wife, 24) and I (34) discovered our autism. A late diagnosis doesn't really come out of the blue – by the time you get around to receiving your official diagnosis (if you choose to; self-diagnosis is valid too) you're pretty much certain you're autistic. Because by then, you've probably read countless books and articles from self-advocates, joined WhatsApp groups, made LinkedIn connections, and spoken to at least a dozen others who have had the exact same lived experiences as you.

I, for one, discovered that, like me, there are at least 10 others my age who have a background in journalism and non-fiction filmmaking, and are musicians themselves. An overlap of literally that many intersections existed among at least 10 of us!

YC: And you thought you were the only one!

Like YC found Wally and Tom, you realize there are many, many others like you. Others who don't just know things. Others to whom invisible signboards are... invisible, not obvious. Others to whom Uncharted is like navigating Mars.

Finding out about your autism, honestly, is one of the best feelings on earth. But it's also very confounding. It's a great feeling because you've now found that missing part of your identity that nothing else seemed to adequately describe. 'Quirky' is a loose word, 'eccentric' is a softer word for crazy, 'asocial' is too one-dimensional, and 'gifted'... well, it makes you feel like you came into this world neatly covered in decorative wrap. It's amazing to have a neutral word that describes you, how your mind works, and how you see things. You feel emancipated by it, and it becomes something that forms the bedrock of what popular culture so loudly proclaims as 'being yourself'. I mean, if everyone's so proudly showing themselves off, why shouldn't I, right?

And that's where things start to get a bit muddy.

YC: Don't you know about autism?

Tom: No. What does that mean?

Wally: I've heard some people here use that term... I think to them it means that there's something... 'wrong' with someone.

YC: Well, I am autistic.

Tom: Really? Is that so?

YC: Yes.

Tom: Well, rest assured we don't think the way others do. Maybe that's why we're two of a kind, eh?

Wally: Three of a kind now!

(They exchange smiles)

Wally: So wait... does that mean everything that is not autistic, then, is... 'right'?

Tom: Well, I think there's no right or wrong way to be. It's too narrow to think that way. Besides, the way you are is not really the problem. The way the world fails to understand you is.

'Autism,' by default, is a neutral word. But unfortunately, the people of Uncharted don't look at it that way. To them, our world is a pastiche of templated blocks. An assembly line. Every living thing in Uncharted is given a label and tucked away in a filing cabinet, and thought to be just like everyone else stuffed in that cabinet. Many of one kind. Individuality is seen as a threat. As an act of rebellion against the system. An act of demanding a separate cabinet for yourself, demanding space that is so precious and scarce. To Uncharted, autism is no more than a defect. A life that fell just short of life.

A manner of being that – by default – refuses to conform to templates. That doesn't happily take the shape of whatever mold it is poured in. The truth is – we demand our own shape, size, form. And we expect to find place in Uncharted. We expect to be appreciated. Why shouldn't we? Why shouldn't we 'be ourselves' and be celebrated for it when literally everyone else does?

Tom: But don't you know that's not how it works? People are either amused or scared or weirded out by anything they can't immediately label and file away.

Wally: People's minds are like cabinets, and if they can't find a cabinet for a piece of fresh, new information, they don't know how to react to it!

YC: Okay, I get that. So why isn't love or curiosity their first reaction to anything then? Why don't they

try to understand another's perspective? That doesn't seem too hard, does it?

Tom: Oh, I don't know.

Wally: I think I might know why. It could be because... life here seems like a never-ending competition of sorts. Everyone's doing the same five or six things, and fighting really hard to get better at them.

Tom: But I don't want to do the same five or six things.

YC: Me neither. So you're saying that love might make them look weak and give someone else an edge over them?

Wally: I think so.

Tom: I think you're being a little pessimistic here. It could just as well be that... just like we never learnt love in school, they didn't either. Now they don't know how to rectify it because they're... so old."  
(All laugh)

Autism is so dynamic, so different in each individual, and such a vast spectrum that it's difficult to adequately describe it. After we started our Instagram community Much Much Spectrum – and quickly grew to a collective of more than 30,000 folx in less than a year – we learnt so much about the world. Autism, to some of us, is a different way of doing things. To some others, it's a host of different kinds of sensitivities. To me, most often it's major communication challenges. To some others, it's being in a state of constant anxiety and not really even realizing it. To some people, it's all of these things, and to yet some others, it might be none of these or only a few. So we asked ourselves – how does someone, then, even advocate for themselves when so many people within the same community don't even always relate to each other's lived experiences?

Where's the baseline?

Sometimes we get so immersed in trying to address an issue, we put it under a microscope and examine every little detail trying to find a solution. In doing so, we forget the larger space that the issue exists in – the system.

YC: Don't you know you can always zoom out?

The Uncharted system proclaims the need for a baseline – 'build a ground of commonality where we accumulate everyone,' it says.

Tom: Make a filing cabinet and throw them all in!

Wally: That's such an 'Uncharted' way of looking at things!

And that's when we had an epiphany: let there be no baseline. If everyone has a different experience with autism, so be it. That's the beauty and the challenge of this experience. And everyone's experience is valid. None of us needs a cure. We're complete the way we are. We just have to make room for ourselves and others like us out here in Uncharted.

Over the past year, we've spoken to a lot of people who identify as being autistic. We've put all this content out on our socials – Instagram, YouTube, LinkedIn. Cisgender, trans, non-binary, old people, adolescents, teenagers, 20-somethings – individuals at different intersectionalities have candidly shared their lived experiences with us. Almost all of them speak about their social struggles: being bullied, misunderstood, marginalized, ridiculed. And, as a result, finding themselves mostly alone. One big reason for this, as Sinclair very rightly points out, is the expectation mismatch. The system around an autistic child is not unhappy because of the autism itself. That's nothing to be unhappy about. The system around an autistic child is unhappy because their expectations weren't met. They would have the individual, but without their autism. What they don't

realize is that the individual is not the same person without the autism. And by the same token, the autistic individual is unhappy with the system around them because his or her or their expectations from this world are never satisfactorily met.

YC: So guys, what do we do? We're just the three of us. Who's going to listen to what we have to say?

Tom: And even if they do, who's to say they're going to help change things? I mean, it's Uncharted. Things don't just change around here.

Wally: I get what you guys are saying. But... I mean, there's no harm in trying, is there?

Tom: What do you mean?

Wally: Sure, things might not change for everyone all at once. But what if we do one little thing, which changes one kid's life. And what if that one kid and two others group up and do another little thing that changes two other kids' lives? And what if they...

YC: Yeah, yeah we get it. A chain reaction, right?

Wally: Kind of. That's how these things work, right?

Tom: But where would we start? What's our... baseline?

YC: What's a baseline?

Tom: Like... a point in the conversation that's simple enough for everyone to understand. Something that everyone identifies with, relates to, something that... everyone feels... whether they're different or not?

(The three think real hard as Uncharted goes about its business as usual.)

YC: I got it! You said 'different or not', right? That, exactly there, is our baseline!

Tom: Difference?

YC: Yes!

Wally: So you're saying we ignore everything else and just start talking about how everyone's different? Sure, we're all different, but there's more to it than that, don't you think?

YC: Well, of course there is! And the entire Uncharted system right from the ground up will need to change for people to understand all the complex stuff. I'm just saying a good place to start would be to tell everyone that...

Tom: That we need to look at it through a lens of love for what's different?

YC: Kind of!

Wally: That makes sense. Sympathy is a good way to understand what people might be going through.

YC: I think you mean empathy?

Wally: Oh, that's right! I get confused.

Tom: So how do we get on with this? I'm kicked about our new idea!

YC: I think a good place to begin would be to start speaking openly about what we think in and believe. To see people not as unidimensional creatures who are worth only as much as they're able to contribute in Uncharted currency.

Wally: But instead to see them as multifaceted beings who live nuanced lives and have dynamic experiences.

Tom: Who can contribute in multiple different ways, if only we chose to identify and support their skills and talents.

(A round of enthused hi-fives)

YC: Guys, heads up. The people of Uncharted may tell us we're only a bunch of idealistic kids who don't know what the real world is like. But anyone who thinks like that doesn't get much done, you know."

Tom: True! Well, I've got a good feeling about this. We may be on to something here. What do you guys think?

For all practical purposes, this is a parallel universe in which this same story is unfolding. Except, it's me, my wife Aditi, and everyone else we have met on our journey running Much Much Spectrum. At times it's been challenging, invigorating, exhausting... but what it's always been is enlightening. Just like Wally and Tom needed each other to get through Uncharted, each of us needs at least one other person who understands us and whose attitude towards us is prefaced with empathy. Just one other person. That's really not a big ask in a world that comprises over 8 billion of us. A world of over 8 billion differences we are.

Much Much Spectrum is not a company. We are a culture. A culture of understanding, empathy, and appreciation. A way of life that listens, doesn't judge, and is keen on putting out as many authentic lived experiences as we can. A voice that sparks conversation. Because Aditi and I believe our stories are what we are all about. Our stories are us. On some level, we're all lost. Whether neurodivergent or not, we'd all love someone who truly understands us and with whom we can be our truest selves. And so, all of life becomes an act of figuring out who that person is to whom you could go up and say, "Hey, I was kind of lost here as well, and it would be good to have friends for the rest of my journey."

"Would you be that friend to me?"

The scene cuts to 50 years later. We're still in Uncharted. But it's a different place than where we started. Well, slightly. Wally is now a famous cartoonist. He's a film producer, director, screenwriter, voice actor, animator, and entrepreneur. He's credited as the creator of the first full-length animated feature film, and the winner of the most Academy Awards ever. The world knows him better as Walt Disney.

As for Tom, he became an inventor and businessman who is credited with developing many devices in fields such as electric power generation, mass communication, sound recording, and motion pictures, and holds a record 1,093 patents for his inventions. The world knows him better as Thomas Edison.

While history does speculate about the possibility of Edison and Disney having developmental challenges, the point here goes beyond that. Various historical accounts suggest that growing up, both Edison and Disney faced systemic challenges and stigma because of their personalities. But their work, their inventions, their imagination did underscore the importance of inclusivity – making entertainment and science accessible to all.

Now take a minute and consider this:

Go to that part of your brain – that filing cabinet – where you've stocked up all your knowledge about neurodiversity. About everything you think you know about autism. Open it, and empty it out. Literally purge that cabinet of all its contents and keep the empty drawer on a desk in front of you. You've now unlearned any ableist biases you might've had, and can start over. Pick up some books by autistic writers. Listen to autistic-led podcasts. Watch films made by autistic individuals. You have the internet, and on it, at least a million #ActuallyAutistic voices.

What's your excuse?

And as for YC – or your child – the world is poised to become his or her or their proverbial (inclusive) oyster.

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*Aalap Deboor is a self-advocate and the Co-Founder & CEO, Much Much Media/Much Much Spectrum. Diagnosed in 2022, he is a storyteller who started Much Much Spectrum as a platform for individuals to connect, relate, and share their mental health journeys and lived experiences with neurodivergence and disabilities.*

(<https://linktr.ee/muchmuchspectrum>)



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# My Experience as a Self-Advocate with Autism

Asha Sreedhar

My name is Asha Sreedhar. I have autism spectrum disorder and Asperger's Syndrome and here is my story of my life and journey as a self-advocate with autism. This is what I went through in the past with challenges and struggles to reach where I am today.

I was born in a country called Malawi which is located in south-central Africa next to Mozambique. When I was in pre-school, a teacher noticed that something was wrong with me because I was not in the classroom learning with other students and instead outdoors trying to catch butterflies and playing with the farm animals. She mentioned this to my parents but couldn't figure out what was the problem.

My parents took me to South Africa as it was a more developed country than Malawi, to meet with many doctors and specialists and they diagnosed me as having possibly dyslexic and lack of motor skills since autism wasn't known back then during those years. They recommended that I go through some different types of therapies back in Malawi.

My parents brought me back and enrolled me in an institute where a therapist from South Africa provided me different types of therapies (games, speech, etc.). After the therapy sessions got over, I started attending a private school with a British Education System. The school staff and students were encouraging, supporting, friendly, inclusive, and accepting of me despite my disability and made me participate in many extracurricular activities while focusing on academics at the same time.

But as the academics started becoming harder and challenging, my family and I took a big decision

and step to move to the United States (especially for me).

I felt heartbroken, anxious, and scared at the same time as I was leaving my home country with good individuals and lifestyle to pursue help for my autism disability. I didn't know how life was going to be for me in US.

After I moved to the US at age 9, I got enrolled in a public school with normal students which was a completely different experience. The school staff gave me many tests, assessments, paperwork, etc. and diagnosed me as having Autism Spectrum Disorder and Asperger's Syndrome which were at the borderline level. They provided speech therapy sessions and special education services for me until 6th grade which helped out and made improvements. After that I was on my own for academics from 7th till 12th grade.

I had a difficult time making friends as I was different from the other kids and went through extreme bullying, teasing, taunting, and exclusion where they wouldn't talk, interact, or play with me, and exclude me out from all of the activities. They didn't understand my autism disability and which country I was from as their thinking was different and totally lacked general knowledge about other places outside the US. Not only that, I was new to the country and didn't have any knowledge about the culture, customs, language, education system, etc.

But despite all of these problems, the school staff was helpful, encouraging, and supportive of me throughout my school years. Somehow, I focused

on my education, participated in many extracurricular activities, served as an epitome of the country, learned driving and obtained a driver's license, and graduated from high school.

After completing high school, I enrolled myself in a local community college in the same city as I was not ready to attend a 4-year university due to the fast-paced environment. I had a hard time making friends with the college students as I was unique. But I continued to focus on my education, participated in a student practicum related to my field, and got inducted into the honor society based on my good grades where I took part in many community service activities. I graduated from community college with highest honors and a two-year college degree.

After struggling to get employment for many months I worked at a few jobs related to my college major, but had a tough time sustaining those occupations due to the requirement of extensive multi-tasking and customer service interaction. However, one of my managers observed me on the job and told me that I should pursue a new career in the IT field/sector since I was good with computers and IT devices. Coincidentally, I also met Dr Temple Grandin, a famous autism advocate at an event, and she also gave the same advice to me.

At this time my parents decided to move back to India and took me along with them.

I found a software testing institute and joined it for the theory courses and internship. I received two certificates for completing both the course and internship but struggled searching for employment due to issues with qualifications, competition, and lack of knowledge about autism in India.

With my aunt's miraculous help, I reached out to a local non-profit organization called EnAble India (which helps individuals with disabilities by providing training for employment opportunities)

and enrolled myself for the Autism at Work Employability Training Program where I was the only girl among boys. It was fun and we were like a family. After the training got completed, I was one of the first candidates to be selected for SAP Labs India Pvt. Ltd. in Bangalore, where I am still currently working today.

After joining SAP Labs, the trainers from EnAble India gave a sensitization session, which focused on basic understanding of autism and how to work with people who have autism, to my teammates and manager. I also created a Self-Advocacy PPT about myself and presented it to them. My manager and some of the team members were all shocked to learn that I have autism. They and other teammates didn't know about autism since they were hearing about it for the first time.

My manager, mentor, and workplace colleagues are amiable, helpful, inclusive, accepting, understanding, considerate, concerned, encouraging, and supportive of me. I am proud to be working for SAP Labs India Pvt. Ltd.

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*Asha Sreedhar has been working with SAP Labs India Pvt. Ltd. as a quality associate through EnAble India's Autism at Work Program for over 8 years now. She is also part of Eka Educational and Charitable Services and Rotary Club. She has written many blogs about autism and other different topics. She has been awarded the Rotary Vocational Diversity Unsung Heroine Award and Karnataka Women's Achievement Award for Outstanding Influencer. Being an incredible orator, she delivered speeches and participated in many panel discussions at many organizations and companies. She has also hosted the Autism Summit Event with SAP Labs India Pvt. Ltd. and India Inclusion Summit.*



# Own Lane, Own Race, Own Pace (Starting out as an autistic entrepreneur)

Sudhanshu Grover

I am a newly identified autistic individual.

My excellent masking skills helped me to slip under the radar for a majority of my life. I found this out, not very long ago, in 2019, right after my second major burnout. Since then, I have been processing, bit by bit, what my diagnosis means for me and my life. I have been learning a LOT, understanding aspects of myself, re-narrating my past, and re-imagining the future.

After my diagnosis, I knew that my fragile mental health would not be able to support me in carrying out the role and responsibilities of the Department Head. In June 2022, almost immediately after I resigned, I started my private consultation services...any delay would have led to unhelpful negativity. The shift to remote work during Covid times made us embrace and adapt new gadgets and applications. I too had become a 'zoom expert'.

Armed with newly learnt digital skills, I started providing 'online' support and training services to autistic children, teens and adults as well as parents of autistic people (all of whom I refer to as 'families'). These unique services would help me pay my bills and provide a platform for many 'families' to hear and learn from other autistic adults.

With the deeper sense of self-awareness that my diagnosis brought me, I recognized that I had to do things differently. To guard my mental well-being, I needed to respect my needs, play by my strengths and manage my challenges. I tailored my venture accordingly.

## **Respecting my needs**

Just like Dr Stephen Strange's mansion, my home is my "sanctum sanctorum" (Dr Strange is my favourite marvel comics superhero). I have created the environment I need to work effectively: where I can control the sensory environment, where I can lock in myself and focus on work uninterrupted, where the overwhelming social interactions are not continuous, nor unpredictable. I can work barefoot, wearing loose pyjamas and a t-shirt.

I changed my schedule to my ideal hours. Morning is when my mind is least creatively alive, so this is the time I spend on self and family care. I exercise, do household chores, spend time with my sons. After my cuppa at noon, I see families. I spend my evenings planning for future sessions (writing educational programs and designing activities) and doing mundane tasks like writing reports, replying to mails and messages. By late evening, my brain needs rest and separation from all incoming information (people and programs alike). I make sure not to have any social commitments. I rejuvenate by watching TV, listening to music and cooking. The silence of late nights helps me work creatively – this is the time to write, create posts, think, brainstorm, and do all of the good stuff.

I am trying to set a limit of no more than three families in a day. I space them apart; my mind needs 15-20 minutes break to restore and get ready. Earlier I would 'push myself' and 'challenge myself' to do back-to-back sessions. Though it was not obvious then, I realize now that it was mentally and emotionally taxing. By the end of the work day,

I had no energy to do anything else. I also realised, having families spread throughout the day was not convenient. With my own enterprise, I can construct my schedule the way it works best for me. I am now trying to learn that I will grow far more when I give myself more space and rest.

I ensure that on weekends, I do not have more than two families. I do not like being busy when my friends and family are free and wanting to spend time together. Also, my brain needs breaks where nothing is expected of it. Prior to my own business, I had never thought about this. I would work incessantly.

I try having one day in a week that is a 'no families' day'. On this day, I also try not to have any scheduled meetings. I reserve this day for other things I need to get done with my business or personal chores.

I have actively started saying 'NO'.

I have some upcoming events that I know will need preparation and renewal periods, so I have been refusing certain projects that will absorb my mental energy. I have cut from people and projects that do not regard my time or respect my skills. I have concluded tasks that were not a good fit for me. I have removed any extra meetings from my schedule. I decline work that does not feel good or align with my goals, values or ways of working.

### **Playing by my strengths**

Autistic individuals usually have intense, specific interests and the best jobs are those that allow them to be involved with those interests. My work as an autism consultant/ educator is a perfect fit as autism is one of my special interests.

I have a lot of self-discipline. I work very hard, never slacking or resting. Whatever I do, I do with deep focus and commitment.

Having autistic family members and navigating my own autism helps me understand what my families are experiencing. It helps me come up with new ideas and strategies. After my diagnosis, I see autism with new lens. I am able to take into account all my previous learnings as an educator and select the ones that are effective with my families. I exercise a neurodiversity-affirmative approach.

I see some families weekly, others bi-weekly and some monthly. My consults last 75-80 minutes because I feel the usual 50-minute sessions are not long enough when any learning is involved. I want my families to have enough time to feel at ease, discuss their concerns, learn well, and leave feeling satisfied.

The time that I save by not doing the stuff that I don't like, I spend learning more about autism (through self-education with webinars, courses and books). I feel I have now become far more equipped to support my families. I get some more time to prepare for and reflect on sessions as well.

I maintain a monthly budget where I allocate my funds and build up savings for specific 'interests' like certain autism related books and webinars/workshops I want to buy and attend. I focus on doing the things I love: creating social media posts, making teaching materials, books and games for autistic children and educators and organising autistic support group meet-ups. This makes me feel energized.

### **Managing my challenges**

I delegate the administrative work and all the other work that I do not like, to people who are volunteering with me. I concentrate on delivering the services and programs.

I have created all sorts of organizational systems. I make a clear to-do list at the beginning of the day, which reminds me of the tasks I have to do and

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helps me prioritise. Striking off something I have done from the to-do list is very reassuring and reinforcing. I use a calendar planner as a reminder for consults, meetings and deadlines.

To check my progress, I write monthly reports. I do an autopsy of where I fared well and what can be improved. The months my business does well, I celebrate with my friend and family.

### **Glitches and hitches I face**

Let us talk about some roadblocks that I encounter as a self-employed autistic person.

Sometimes, as a part of my work, I require to be in contact with people whom I may not be offering consults. I need to network with others to spread the word around and get more families. There are times when I am required to make phone calls. Such human interactions (autistic or allistic alike), are stressful and greatly impact me. Though I try to pass these situations over to the volunteers, I am trying to learn some tricks to feel more relaxed.

People use nuanced language, which I struggle to understand. The intended meaning of others' communication confuses and frustrates me. On the other side, I provide very literal and honest answers which can be challenging for allistic people and can be perceived as rude, leading them to not choose me. I am trying to work out a way where I can be myself and not appear rude.

I am responsible for literally every aspect of the business. I have to take all decisions. This is extremely stressful and scary.

For the past 6 months, I have been working longer hours for less pay.

Despite the challenges, I like being my own boss. I like to do things my own way. I love the freedom of designing and implementing my ideas without

needing to get anyone else's approval first. Running my own business is validating; my successes are my own (of course my failures too!!). When I'm doing things in a way that makes sense to me, I work more efficiently and responsibly and I am much happier.

With my current schedule, I feel more rested, energized, and creatively inspired than most other stretches of my life. I have also experienced more personal growth in this period than I have ever in a long time. With more time to myself, my mind gets space to wander, explore new thoughts and ideas and that are fun and enriching. I have become exceedingly self-aware and assertive. I no longer feel pressurised to conform to neuro normative standards.

So,

**HAVE I FIGURED OUT EVERYTHING ABOUT MY RUNNING MY VENTURE?**

No I haven't....I am still navigating.

When you are in your own lane, there is no traffic. You just keep going and you WILL reach there!

**AM I SUCCESSFUL?**

YES!! By all means... Isn't Success liking yourself, liking what you do and liking how you do it?  
(Quote by Maya Angelou)

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***Sudhanshu Grover** is the Co-Founder of Powered By Autistics (@poweredbyautistics) – an Autistic led online support and training provider. She is an Autistic trainer, mentor and consultant. She is a mother of twin Autistic young adults. Sudhanshu strongly advocates for positive attitudes for the Autistic community.*

# On Writing Neurodivergent Characters

Meg Eden Kuyatt

When my first novel went on submission, I heard a lot of "this feels somewhere in between middle grade and YA." At the time, I was completely baffled by this comment. I literally wrote the book as a high schooler, about being in high school. How could it be anything but YA?

I ignored the comment and kept writing, but the comments continued. "The voice feels a bit young for YA," I heard about my next project. "The scene with her mom would make for a tender middle grade novel, but feels too young for YA." My next agent called my protagonist 'too naïve,' 'vulnerable,' and 'childish,' asking why my protagonist was at her first party, and had her first boyfriend, as a high schooler. But what bothered me the most was that I also began to hear a rising chorus telling me again and again that my protagonist was 'unlikable.' All of these comments completely confused me. Since I started writing, I was told my strength was in my compelling, realistic characters. I had poured so much of myself into my protagonist, Lotus. When my agent called her childish, naive, and vulnerable, I couldn't help but feel she was calling me childish, naive, and vulnerable. And why? Lotus embodied what I perceived in high school as my strengths: my blunt honesty, my conviction to follow my own interests instead of following trends, my lack of fear.

As I sat with her feedback, I did see parts that she was right about-parts I had thought were strengths but instead reflected my own ignorance-but I still couldn't understand this idea that Lotus was too young, vulnerable, and unlikable. Eventually, my agent parted ways with me over the manuscript, but beta readers only came back with comments echoing similar concerns. I tried sending to other agents that showed interest in the past to nothing. It was clear I needed to move on from this manuscript.

But Lotus continued to tug at my mind. After I wrote my middle grade novel-in-verse *Good Different*, I returned to Lotus, but added the point of view of her best friend Prue. The narrative took on new life. The previous critiques of Lotus haunted me every time I sat down to write, but a new realization occurred to me. Writing *Good Different*, I focused on my neurodivergence, and in the drafting process was formally diagnosed with autism. With this new knowledge of myself, I turned to Lotus and now saw a reason why some readers didn't like or get her: she was neurodivergent.

It's important to note that not everyone hated Lotus. Her first few iterations were loved by my close readers and friends. I realized now it was because they are probably also neurodivergent, or from a similar marginalized experience in high school (likewise, I realized my former agent was probably neurotypical). It's also important to note that I tried to label Lotus as autistic in earlier drafts but was discouraged from doing this, and at that time, I was not formally diagnosed as autistic, so I didn't feel fully comfortable labelling Lotus. So I tried to write a neurotypical Lotus, and this I realize was my big mistake. One reason is because I clearly know nothing about how neurotypical people think. But the other reason is because Lotus was so innately, incredibly neurodivergent in my head. Trying to make her neurotypical squelched the life out of her, the very reasons why I loved her in the first place.

Hearing from other neurodivergent writers, it doesn't sound like my experience is that uncommon. Neurodivergent protagonists are often labelled unlikable, naive, young, or another host of negative traits. What I'm coming to read that to mean is: "I don't understand your neurodivergent perspective."

If we have largely neurotypical gatekeepers, judging neurodivergent experiences from their neurotypical perspective, I'm concerned this trend will only continue. As shows like 'Girl Meets World' and 'Sia's Music' show, we still have such a limited, problematic understanding of what it means to be neurodivergent (specifically, autistic).

I still struggle, trying to understand the comment that my protagonist was naive and vulnerable. What makes a neurodivergent protagonist inherently naive, or vulnerable? When I look at Lotus, I see her neurodivergence as her strength. Her faithfulness to her own convictions, and her stubborn loyalty to her best friend, despite all odds, are positives in my eyes, not negatives. Her unique angle on life, and her authentic interest in people who are so opposed to their social standing makes her likable. Her hatred of fakeness makes her (in my opinion at least) less likely to fall for social flattery or manipulation.

She is of course flawed. She takes too much pride in her academic intellect, which can be at the expense of her social intellect. It also sets her up to proudly think she's invincible from anything 'going wrong', that she 'knows all the answers', and falls hard when she's proven wrong. She can be impulsive when she gets caught up in a cause she's passionate about. She can be so blunt it can come across as hurtful. She can get so caught up in her agenda that she forgets to think of how others might feel about her actions.

But if our protagonists only have likable attributes, how human are they? I'm drawn to complex characters that have strengths and weaknesses, likable and unlikable traits. I want my characters to make mistakes. But I also want them to learn from those mistakes. Vulnerability is critical to a compelling character-vulnerability, I'd argue, is a strength, not a concern, in writing.

It seems that as neurodivergent writers, we have to pay particular attention to spelling out the thought process of our characters. Neurotypical readers won't make the same jumps we will. When writing

neurodivergent character, we may take for granted how intimately we understand our characters. Lotus is such a real, living and breathing person to me. She's been with me as a character for over ten years. Sometimes, as I revise, it can be hard to explain on the page explicitly who Lotus is. It feels obvious to me after all, she's Lotus. As frustrating as it is, feeling like I have to do extra work to explain characters like Lotus to my readers, I know that it can only make my books stronger. Having to explain Lotus pushes my craft to be more specific on the page. Digging into why Lotus is the way she is (read: why I think the way I do), I've had to confront ugly sides of myself I wasn't aware of. I've come to better understand myself. I've had great "aha" moments, and Lotus is a better, more developed, and nuanced character as a result of that work.

Not everyone will like Lotus. I doubt my previous agent will ever understand the Lotus Spaulding she signed on in the first place. But I'm also learning I don't need to win everyone over. I can't win everyone over. Writing a book is taking a stance. It's choosing sides. We write because we have an argument, something we need to say. That means not everyone will be on my side, or Lotus's. And at this point, I'm OK with that. I don't have any interest in people-pleasing in my writing anymore. I want Lotus to just be...Lotus.

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***Meg Eden Kuyatt** is a 2020 Pitch Wars mentee, and teaches creative writing at colleges and writing centers. She is the author of the 2021 Towson Prize for Literature winning poetry collection *Drowning in the Floating World* (Press 53, 2020) and children's novels, most recently *Good Different*, 'a JLG Gold Standard selection (Scholastic, 2023). Find her online at [www.megedenbooks.com](http://www.megedenbooks.com) or on Twitter at @ConfusedNarwhal and Instagram at @meden\_author.*

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# सान्निध्य की कहानी: औटिज्म को हरा देंगे

BA पास 24 साल का सान्निध्य एक हसमुख ,मेहनती और विश्वास से भरा हुआ लड़का जो अकेले मेट्रो से आता जाता है और UPI लेनदेन बाजार में अकेले करता है, पिछले 6 माह से अमेज़न के साथ कार्य कर रहा है, उसका जीवन सुनने में जितना प्यारा लगता है, पहले वैसा बिल्कुल नहीं था।

जब जन्म के दो साल तक उसने बोलना शुरू नहीं किया तो हम ENT स्पेशलिस्ट के पास गए। उन्होंने परीक्षण के बाद बताया कि इसके स्पीच संबंधी अंग बिल्कुल ठीक हैं। उन्होंने हमें चाइल्ड सायकलॉजिस्ट के पास भेजा। उन्होंने सान्निध्य के बारे में कुछ सवाल पूछने शुरू किए जो शुरुआत में हमें बड़े अजीब से लगे। जैसे क्या यह आँखें नहीं मिलाता, क्या अकेले कमरे में रहना पसंद करता है, क्या सिर्फ गोल और घूमने वाली चीजों से ही खेलता है। हमें आश्चर्य हुआ कि हमारे बच्चे के बारे में इन्हें इतना कैसे पता है, पर फिर उन्होंने बताया कि यह बहुत से बच्चों के साथ होता है, जिन्हें आटिज्म की समस्या होती है। आटिज्म का नाम भी हमने नहीं सुना था,यह भयावह था क्योंकि उन्होंने यह भी कहा कि शत प्रतिशत ठीक शायद कोई नहीं हो पाता।जैसा इस हालत में सब करते हैं, सबसे पहले हमने इंटरनेट लगवा कर, जो 2001 में आसान नहीं था, गूगल का सहारा लिया और गूगल ने हमें आटिज्म की बेसिक जानकारी भी दी और ये भी बताया कि इसकी कोई दवा या इलाज नहीं है। बहुत से लोगों ने इसे मेडिकल सेक्टर की धोखाधड़ी बताते हुए 2nd ओपिनियन की सलाह दी, लेकिन कई डॉक्टरों से मिलने के बाद यह आश्चर्यजनक तथ्य सामने आया कि 10 में 6 डॉक्टर भी आटिज्म के बारे में कुछ नहीं जानते। पास के एक प्ले स्कूल में भेजने का प्रयास किया लेकिन ये किसी के कंट्रोल में नहीं आता था और जमीन पर सर पटकता था। आखिर स्कूल जाना बंद करना पड़ा। मैंने नेट पर देखा कि बहुत से लोग अपने ऑटिस्टिक बच्चों की स्पीच थेरेपी करवाते हैं, हम एक स्पीच थेरेपिस्ट के पास गए और उनको धन्यवाद जो उन्होंने हमें सही दिशा दिखाई। उन्होंने कहा कि ऑटिस्टिक बच्चे को स्पीच थेरेपी की कोई जरूरत नहीं होती है, क्योंकि वह बोल सकता है। जो स्पीच थेरेपी देते हैं उन्हें भी पता है लेकिन नहीं बताते सिर्फ पैसों के लिए करते हैं, उनसे बच्चे को कोई फायदा नहीं होता।ये अपने आप ही बोलते हैं। उन्होंने हमें OT की सलाह दी लेकिन यहां भी थेरेपिस्ट के रूप में लुटेरे ही मिले जो registration और 3 माह के एडवांस के नाम पर पहले ही मोटी रकम ले लेते थे और कुछ नहीं करते थे। फिर किसी ने हमें AFA के बारे में बताया। वहां असेसमेंट कराने के बाद हमने हफ्ते में एक बार असेसमेंट के लिए जाना शुरू किया।

फरीदाबाद से चिराग दिल्ली वीक डे में छुट्टी लेकर जाना मुश्किल था पर कुछ दिन जाने के बाद हमें उम्मीद दिखाई देने लगी। उस

वीकली एक घंटे के इंटरवेंशन में बेटे में चेंज दिखने लगा और हमे भी समझ मे आने लगा कि उसके साथ क्या करना है और कैसे। जो वो थेरेपिस्ट 90 मिनट में सान्निध्य को कराती थीं हम उसे सान्निध्य के पीछे एक खिड़की से छुप कर देखते थे और मेरी पत्नी घर आकर वैसी ही और एक्सरसाइजेज डिज़ाइन कर के पूरे हफ्ते दिन भर रोज घर मे कराती रहती थी जिससे बहुत जल्दी फायदा हुआ। हमें पता था कि वो रास्ता दिखा रहे हैं, पर चलना हमे खुद है। अक्सर सान्निध्य गुस्सा होने पर जमीन पर सर पटकता था।फिर वहां हमने IGNORE और DIVERT की पावर भी सीखी जो किसी भी माँ बाप के लिए पहली बार बहुत मुश्किल होता है लेकिन बाद में इसका महत्व समझ मे आया। उसका बिहेवियर, eye कांटेक्ट, IQ धीरे धीरे सुधरते गए और इसी बीच वो धीरे धीरे बोलने भी लगा। फिर हमें 2 अच्छे इंकलूसिव स्कूल मिले, पहले नर्सरी स्कूल जहां उसे शैडो टीचर भी मिले और डांस जैसी एक्टिविटीज के द्वारा सोशल होना भी।इस स्कूल ने आगे बड़े स्कूल के सफर के लिए सान्निध्य को तैयार कर दिया। अफसोस ये स्कूल अब संचालिका मा बेटे दोनों के covid से देहांत के बाद अब बंद हो चुका है। फिर क्लास 1 से 10 तक सान्निध्य फरीदाबाद के एक लीडिंग स्कूल में था जहां एक सामान्य बच्चे का एडमिशन भी बहुत मुश्किल था। हमारे बड़े बेटे का एडमिशन भी यहां नहीं हो पाया जिससे वो सान्निध्य की मदद कर सके। लेकिन ऑटिस्टिक बच्चों को वह मना नहीं करते पर सिर्फ क्लास 1 में बीच मे नही। सान्निध्य जिस क्लास में था वहां टीचरों से भी पहले बाकी बच्चों को सिखाया गया कि सान्निध्य के साथ क्या प्रॉब्लम है और उसके साथ क्या करना है और क्या नहीं। पूरी क्लास 10 सालों तक उसकी हर तरह से मदद करती रही और उन्ही बच्चों का सान्निध्य के विकास में सबसे ज्यादा योगदान है। उन्होंने उसे पढ़ने में, होमवर्क में, स्विमिंग सीखने में मदद की और कभी कभी अगर किसी नए टीचर ने गलती से सान्निध्य को डांटने की कोशिश की तो पूरी क्लास के बच्चे एक साथ उस टीचर से भिड़ भी गए। एक बार हमने मेगा विटामिन थेरेपी के बारे में आटिज्म नेटवर्क मैगज़ीन में पढ़ा और डॉक्टर की मदद से B6, B12 और मैग्नीशियम की हाई डोज दी, जिससे इसके कंसंट्रेशन में सुधार आया। गर्मी की छुट्टियों में 40 दिन तक लगातार HBOT भी हमने दो बार दिलवाई जिसका कुछ तो फायदा जरूर हुआ।

इसी बीच डिसेबिलिटी सर्टिफिकेट के लिए हमने कोशिश शुरू की लेकिन 2004 में जिला अस्पताल ने यह कहकर मना कर दिया कि आटिज्म का सर्टिफिकेट नहीं बनता। 2008 में दोबारा कोशिश की और जिला अस्पताल ने भी सर्टिफिकेट बनाया और AIIMS ने भी जो 2022 में परमानेंट UDID कार्ड में कन्वर्ट हो गया। 10th की परीक्षा पास करने के लिए कुछ रिलैक्सेशन पाने के लिये

CBSE के पंचकुला आफिस भागदौड़ करनी पड़ी पर बाद में कुछ लोगों का कहना था कि ये तो स्कूल की मदद से पास हुआ, अपने से नहीं पर सान्निध्य ने NIOS से प्राइवेट घर में पढ़कर 12th पास करके अपने को साबित कर दिया। 12th के बाद सान्निध्य MS आफिस की ट्रेनिंग ले रहा था कि लॉक डाउन आ गया। इससे पहले अपटेक अरेना से डिजाइनिंग का कोर्स किया लेकिन विशेष सीख नहीं पाया। लॉक डाउन से पहले उसने कैसियो बजाना और गाना भी सीखा और स्टेज परफॉरमेंस भी दी लेकिन म्यूजिक टीचर के covid से देहांत होने पर आगे संगीत सीखना रुक गया।

लॉक डाउन में AFA के ऑनलाइन एम्प्लॉयमेंट रेडीनेस प्रोग्राम ने इसे नौकरी के लिए तैयार कर दिया। इसके बाद रिटेल ट्रेनिंग प्रोग्राम जो AFA ने अमेज़न के सहयोग से कराया, उसमें उसने स्टोर की वर्किंग को सीखा जो AFA ने अमेज़न के साथ मिलकर करवाई। इसके बाद उसे कई इंटरव्यू और फिर इंटरनशिप आफर मिलने लगे। एक मल्टी नेशनल कंपनी में 3 महीने इंटरनशिप करने के बाद सान्निध्य अब नवंबर 2022 से अमेज़न के साथ कार्य कर रहा है और एक इन्वेस्टमेंट मैनेजर के माध्यम से ट्रेडिंग भी। अब वह अपनी सेविंग से कुछ बड़ा खरीदना चाहता है और ITR भी भरना चाहता है।

## इंसानों की बस्ती

### अकरम हयात

इंसानों की बस्ती में

हर शख्स दुसरे से अलग था

क्योंकि खुदा ने उनको अलग ही तो बनाया था

मगर इंसान सिर्फ अपने को ही सही समझ रहा था

बाकी दूसरों को अपने से कमतर

ऐसे में कुछ इंसान ऐसेभी थे जो थोड़े थे मगर दूसरों से कुछ ज्यादा अलग थे

मगर इंसान ही थे

इंसान

जो प्यार चाहता है दुसरे इंसान से

प्यार करना

और प्यार चाहना

वो जो अलग से थे मासूम भोले भाले

वो कुछ ज्यादा ही प्यार चाहते थे

वो नहीं जानते थे कि नफरत क्या है

वो नफरतों से दूर रहना चाहते थे

ऐसे में खुदाने एक फ़रिश्ता भेजा

जिसने इंसानों की बस्ती में

बहुत प्यार से

प्यार करना सिखाया

उनसे जो अलग थे जो उपेक्षा के शिकार थे

उसने कहा कि उन्हें हमदर्दी की नहीं प्यार की ज़रूरत है

उस फ़रिश्ते ने कुछ इंसानों को चुनकर उनकी ट्रेनिंग की

इसलिए कि वो और इंसानों की ट्रेनिंग करें

ताकि मुहब्बत का यह पैग़ाम सब तक पहुंचे

उन लोगों की तरफ से जो कुछ ज्यादा अलग हैं

या जिन्हें हम ज्यादा अलग समझते हैं

मगर वो अलग नहीं हैं

कि हमें समझा जाए प्यार किया जाए

बिना शर्त प्यार

की यह इंसान की

हम सब इंसानों की फितरी ख्वाहिश है

कि हम सब इंसान हैं

हम सब की कुछ कमजोरियां हैं कुछ ताकतें हैं और हम सब से गलतियाँ होती हैं

ऐ इन्द्रानी

ऐ खुदा के फ़रिश्ते

तुझ पर लाखों सलाम

तुझ पर लाखों सलाम

### AFA MEMBERSHIP FORM

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

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

**Please complete in BLOCK letters and mail to Action For Autism**

Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_

Country \_\_\_\_\_ Pin/Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

I am a: *(Check all that apply)*

Mother  Father  Other (please specify) \_\_\_\_\_

Professional: Name of Organisation \_\_\_\_\_

**For Parent of a person with autism ONLY:**

Child's Name \_\_\_\_\_

Gender:  Female  Male Date of Birth \_\_\_\_\_  
dd mm yr

Diagnosis \_\_\_\_\_

Diagnosis received from \_\_\_\_\_

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

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

Online Transaction/Draft No \_\_\_\_\_ Dated \_\_\_\_\_

Drawn on \_\_\_\_\_

Amount in Words \_\_\_\_\_

**Annual Membership Charges:**

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

Online bank transfer may be made to:

*Beneficiary: Action For Autism*

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

*SWIFT No: VIJBINBDDCD IFSC Code: VIJB0006005*

*MICR Code:110029007*

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