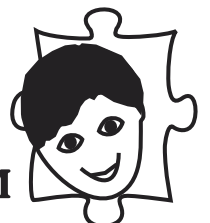


# autism network

VOLUME 17, 2022



ACTION FOR AUTISM



# autism network

2022

VOLUME 17

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](mailto:actionforautism@gmail.com)

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In referring to the autistic individual, Autism Network uses 'she', 'her', 'hers', 'he', 'him', 'his', 'it', 'they', 'theirs' interchangeably. There is no intention to be prejudicial to any gender.

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PAGE ONE

2022 started in the retreating shadows of a tough 2021. The gradual opening up of services at Action For Autism acted as a catalyst for us all to throw ourselves back in the swing of things and continue healing. We were excited to deploy all our new learnings from the past two years, ushering in a new way of working. Our services reopened in hybrid mode catering to autistic individuals and their families in a comprehensive and effective manner. Coming back to the centre and seeing and interacting with everyone was a marvelous feeling that stayed with us through the year.

The Autism Network 2022 Issue presents a diverse collection of articles, all barring one from autistic authors, as many more late-diagnosed neurodivergent adults come forward to share their experiences of growing up without the knowledge of their neurodiversity. Many of them are women and we are pleased to feature several in this issue. As the anonymous interviewee (she/her) in our lead article 'You don't look autistic' writes, "Finally, I knew that I wasn't the problem. I wasn't just broken. There was a reason, and there were other people like me." In the interview she also shares experiences of how she felt discriminated against, alienated and not given adequate support in her largely neurotypical environment.

Writer and advocate for mental health, Emily Katy, writes about her experience at school. Despite being a 'perfectionist' which made her more 'acceptable' to teachers, lack of reasonable accommodations and poor understanding among the teaching staff created an environment rife with anxiety and stress. Katy shares simple yet effective steps – regular breaks, sensory adjustments and reduced time tables, among others – that can help create an accepting environment at school and prevent drop outs.

Autism is a term which has gained significant traction these past years. However, due to a severe lack of representation of autistic individuals in the generation and dissemination of information about the community, a deficit-based perception of the condition continues to predominate. Samantha Craft

passionately addresses this critical problem and shares what it means to be autistic living in a world where prevalent perceptions are dictated by neurotypicals.

Often times, autistic individuals are surrounded by people who advocate for inclusion but may not understand the felt needs of autistic persons and have a false understanding about the accommodations required. Self-advocate, Dan Edmunds shares some of these perceptions and suggests a new approach of listening and understanding.

Stories with autistic protagonists have the potential to create lasting impact and break stereotypes. Young Dominic Perera has authored a novel with an autistic superhero. In a candid conversation, Dominic talks about his creative aspirations and his plans for the future. Neha Uttam shares her story of working at a premier recruitment agency and earning a livelihood that has given her a sense of purpose, pride and happiness.

Featured in this rich collection of lived experiences of autistic individuals is a translation for our Hindi readers, of Jim Sinclair's seminal article "Don't Mourn Us". This radical piece is about the diagnosis that leads parents to mourning the change in expectations for the child they expected to have. Sinclair implores parents to not mourn for their child's disability, but rather to embrace their child's differences and work to meet their needs. Our watershed Parent Child Training Program (PCTP) tries to lead parents to a similar understanding. Most times the diagnosis is given to parents in the manner of handing out tragic news. This along with the accompanying stress and uncertainty tend to chip away at their ability to enjoy their day-to-day lives with a focus on acceptance of their child's neurodivergence. We conclude the issue with one of our parents sharing a heartwarming story on her implementing her learnings from the PCTP to enjoy a Goan vacation after a really long time.

Happy reading.

# “You don't look autistic”

## On stereotypes and late diagnosis

Anonymous, Lacuna Magazine

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*What is it like to be autistic? And why are a growing number of women receiving late diagnoses for autism? After spending most of her life not knowing she was autistic, our writer describes her experience of being neurodivergent. In this honest and original piece, she explores the discrimination she faces because of preconceptions, stereotyping and a lack of adequate support.*

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The lights are like sandpaper. Each noise piles on top of the one before it. The clattering of plates, the child dropping a whole pile of cutlery with a crash, the beeping of checkouts, the insistent buzzing of the lights, the repetitive clanking of wonky-wheeled trollies, the babies screaming, the constant background chatter, the rustling of plastic packaging, the squealing complaint of the broken checkout conveyor belt in aisle 5. The clattering, crashing, beeping, buzzing, clanking, screaming, talking, rustling, squealing, buzzing, beeping, chattering, building up and up and up, piling higher and higher in my head. I can smell coffee. I can hear a child scream as a chocolate bar is prised from their fingers. It's too bright. I've forgotten to get bread. The lights scrape my eyes. I can't do this. I need to leave. Now.

I'm autistic, and this is a trip to the supermarket.

*I always knew that I was different. When I was young, the blissful ignorance of childhood hid the giggles and the stares, the comments behind my back. When I was older, I noticed, and I knew.*

I figured I knew what it was. I just wasn't 'girly' enough. I didn't want to wear the scratchy pink

tutus and serve the imaginary ladies imaginary cups of tea in imaginary bone-China cups. I didn't care. It was more fun mixing potions by myself, mumbling spells as I sat cross-legged in a muddy puddle at the end of the garden. I had friends, anyway – the fairies living in the tiny stone huts I diligently rebuilt after every storm.

But I got older, and I began to care. No matter how hard I tried, I wasn't quite 'right'. Somehow, everyone else had been given a guide, a script to this all-enveloping performance, and I'd just been shoved onto the stage, stumbling blinking into the lights and faced with the expectant looks of my fellow cast.

I watched, I copied and I learnt.

But I got older, and something still wasn't right. I'd see the pictures of parties, shopping trips, brunches, weekends away, all of my friends hugging and grinning at the camera. I wasn't invited. I couldn't seem to join in when the girls were giggling about their latest crushes, picking the petals from daisies in some bizarre ritual ("he loves me, he loves me not") or coating their eyelashes with the dark, itchy mascara that made me rub my face until I resembled an

exhausted panda. I went to a sleepover, threw up after less than an hour and promptly returned home. Unsurprisingly, I wasn't invited back.

*She's weird, they say. Maybe she's not quite all there. A bit slow. Or a genius. She's just not trying. She's being difficult on purpose. She's rude. She's just looking for an excuse. I'll accept 'weird' – and while I'd love to accept 'genius' too, that's sadly not true.*

However, what I am is 'autistic'. Put simply, my brain works differently. I'm more sensitive to sounds, and bright lights. I sometimes find it hard to socialise in the way people expect. I can be more literal than most people, and I might find it tricky to work out hidden meanings or unspoken expectations.

People don't seem to like the word 'autistic'. Even when you've been diagnosed, and when they know, and when they believe you, there's a reluctance to say the word. ASD, my mum always says euphemistically, when she can't avoid it. People don't like to talk about it and, particularly, people don't like to talk about the things many autistic people find hard. Either you're low-functioning, and they dismiss you and do them for you, or you're high-functioning and can't possibly need any support. "Stop taking things so literally," my dad huffed the other day, exasperated as I somehow failed to understand that obviously he had requested I do the opposite of what he actually wanted to happen.

Job interviews are the worst. "Your CV is great!" they tell you. "Your cover letter was so impressive!" they say. Then you sit there as they ask question after question and the words come out jumbled. You aren't really sure what they're asking but you try, and you ask them if there's

anything else they would like to know, and they shake their head but you see your failure written on their faces ahead of the inevitable email. It's fine. You add it to the folder, clearing your inbox of your inadequacy.

"You don't look autistic," they say.

When you feel nothing. Not bored, not tired, not happy, sad, angry, frustrated. You just exist, waiting.

Someone has pressed pause, and there's nothing you can do. You can't hold on to a thought. When you speak, the words are as muddled as the thick, gloopy mud inside your head. You had plans? Forget about it. This is today. You're not ill. You just can't.

But what are you supposed to say to your seminar tutor to explain your absence? What do you tell your best friend who's been looking forward to drinks all week? How do you explain to your future employer that no, you're not 'pulling a sickie', you just can't today?

"It must be very mild," they tell you.

The friends you've never made because you thought that "let's get coffee!" meant getting coffee, and you don't like coffee.

The time the teacher asked if you thought you knew better, and you said you did, because you knew you were right that the UK voting age was 18, not 16 (you were right, but she didn't care).

The food you burnt because you were told to watch it, and you did - watching the tendrils of smoke curl upwards and the edges slowly crisp and blacken (you did what you were asked to!).

The time your friend joked you should run under the closing barriers at the level crossing as a train approached and you did, tears in your eyes, watching their face suddenly whiten (how were you supposed to know they didn't mean it?).

“I'd never have guessed,” they exclaim.

Just because I can speak and live largely independently, doesn't mean I'm not autistic, and that I don't have any challenges. My brain is different, undoubtedly. But I don't think it's disordered. But, just like people won't talk about the challenges, they won't talk about the good things either.

I'd like to think that, at least sometimes, my literal understanding makes me funny (even if sometimes I don't intend to be). My tendency towards black-and-white thinking means I have a strong sense of justice that I physically feel through my entire body. I tend to be pretty honest too.

Nothing can compare to the happiness I can get from the simplest sensory delights – running tiny smooth pebbles through my fingers, burying my face in a soft, fluffy blanket (as long as it hasn't been washed with scented detergent), walking through long grass in bare feet and gently wiggling my toes into the cool ground. I'm great at thinking outside of the box and coming up with innovative solutions to problems.

*While experiencing very strong emotions can be difficult and painful, it can also allow me to feel pure, intense, unadulterated joy. I love that I can get so intensely absorbed into an interesting topic that I completely forget about everything else for hours on end.*

So, that's me. I have no idea what you were imagining, but perhaps someone quite different.

Why is it, then, that these misconceptions remain so prominent?

Thirty-five years after he first appeared on cinema screens (twelve years before I was born), Dustin Hoffman's Rain Man continues to have a profound effect on the way the general public think about autism. I'm not a man. I'm terrible at maths, I don't like collecting things, and I definitely can't tell you more than three interesting facts about anything at all, let alone talk your ear off about airplanes or something. I don't live at home with my parents. I'm definitely not a savant. I actually don't have any talents at all (or at least, no more than anyone else). I am at university, living independently, and with a successful romantic relationship.

But still. I'm autistic. And nobody knew until I was 20. Not even me.

Let me paint you a picture. Imagine a four-year-old boy living just down the road from you. He had an elaborate train-shaped cake for his birthday party (which no other children attended), and any time you see him he tells you at great length about Thomas the Tank Engine. Often, he's sat outside in the front garden, lining up his model trains for hours on end. He loves maths, and his parents tell you that they don't want to brag, but he's definitely a genius. Sometimes, you see his parents dragging a screaming child in ear defenders around the local supermarket. He's autistic. No surprise. He's what you expect.

But let me describe someone else. She was a gifted, kind and curious child who loved reading, even when other kids her age were still

struggling to learn, and she adored writing poetry. She was clever at school, but very clumsy and quite fidgety, and teachers found her to be overly sensitive and rather dramatic. She hid in the toilets at break times. She grew up, found herself fitting her personality to the situation she was in and the people she was with. She still loved writing. She was lonely, anxious and depressed and still felt like she never fitted in. She sold 3.4 million books worldwide, mostly to an audience of adoring teenage girls. She's autistic.

This is author, Holly Smale, who was diagnosed at the age of 39. Holly Smale. Melanie Sykes (diagnosed aged 51). Christine McGuinness (diagnosed aged 33). Sara Gibbs (diagnosed aged 30). Susan Boyle (diagnosed aged 51). Kate Fox (diagnosed aged 42). Anne Hegarty (diagnosed aged 45). Hannah Gadsby (diagnosed aged 38/39). Maybe you recognise some of these names off the TV, off the covers of books on your shelves, or off the news. All of these women were diagnosed with autism, long into their lives and careers. Comedians, writers, singers, poets, TV personalities... autistic women are everywhere.

Currently, around three times as many men than women are diagnosed as autistic. Often, autistic women are only identified after years of misdiagnosis, being passed from support service to support service and accumulating a smorgasbord of misdiagnoses along the way – an alphabet soup of anxiety, depression, eating disorders, BPD. They have spent years trying desperately to fit in, but always falling slightly short. Maybe they've gone through life wondering why it is they find everything so much harder than everyone else – or maybe they've realised they're autistic, but been dismissed by friends, family members or even

the GP who thinks back to that four-year-old boy and says, “you can't be autistic”.

Women can't be autistic. Except, we are.

The autistic spectrum is diverse, and we need a full spectrum of autistic representation – which includes women, and nonbinary people.

*You might ask if it really matters. After all, if someone has made it to their 40s, 50s or even later without a diagnosis, what's the point?*

Even high-profile researchers are quoted explaining that you only need a diagnosis if your autism is interfering with your ability to function and causing you distress. Others argue that autism is becoming so over-diagnosed as to become meaningless. That four-year-old is autistic, sure, but maybe all these late-diagnosed women are just jumping on the trend?

Not only is this argument misleading, it is dangerous. Imagine knowing that you're different, growing up feeling that there is something ‘wrong with you’, unable to fit in, struggling with friendships and holding down jobs. If you don't know why, it's so easy to conclude that you are the problem.

Research suggests that high levels of undiagnosed autistic traits are common among those who attempt suicide.

*Newly diagnosed adult women report having experienced significantly higher levels of suicidality and depression than the general population. Late diagnosis kills.*

Last week, my friend questioned me about getting an autism diagnosis. “Do I just go to the GP?” she asked me. I had to laugh. Current

waiting times for a first diagnostic appointment are upwards of two years – and that's once you've managed to convince the GP that yes, women can be autistic and yes, you really do want a referral. Private diagnoses can cost nearly £1,000.

“Congratulations, you're autistic,” I was told.

Like so many women, all I felt was a great sense of relief. Finally, I knew that I wasn't the problem. I wasn't just broken. There was a reason, and there were other people like me. And finally, I could get the right support.

“You might like to read these books,” the doctor said to me.

Excellent, I thought. There are few things I enjoy more than deep diving into a topic, reading books and following link after link right into a corner of the internet that clearly hasn't seen a visitor since 2002. Except, apparently that was it. The books were the totality of the support on offer (and I had to buy them myself).

Despite the fact that at least 1% of the world's population is autistic – around the same percentage as there are ginger people – autistic people and autism researchers agree that support is inadequate. On a global level, the UN has highlighted discrimination against autistic people, with ‘treatments’ or ‘cures’ that often amount to torture.

In the UK, only 22% of autistic adults are in any kind of paid work. Autistic university students are 25% more likely to drop out of their studies than their non-disabled peers. Even a typical work environment may be traumatising. A 2014 study suggested that at least two thirds of autistic adults will experience

suicidal ideation – and autistic women are three times more likely to die by suicide than their non-autistic peers.

*Over 2,000 autistic people are currently detained under the Mental Health Act – on average, they will be detained for five years. Many of them do not need to be there – but no other services are available.*

This is what happens when there is no support.

Society does not like autistic people, it seems. I think of the articles explaining to desperate parents how to ‘cure’ your autistic child. I remember how studies that suggested it's possible to reduce autism diagnosis numbers have been heralded positively across mainstream, reputable media outlets. I am told that I ‘lack empathy’. I think of anti-vaxxers, who would apparently prefer to have a dead child than an autistic one. And of the GP surgeries who applied blanket Do Not Resuscitate orders to their autistic patients during the pandemic.

This is what it is like being autistic. The way my brain works can be amazing and beautiful. I am capable, strong, independent, unique and funny. I am resilient, because I have to be. But I – and other autistic women – need support. And we need you to understand what it's like.

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# What I wish schools knew about supporting autistic and ADHD children

Emily Katy

Disclaimer – my school experience was varied. My experience in my earlier years was very different (not all good, not all bad) to my experience in sixth form, when I felt more understood. But this was a question I was asked, so I will try to answer based on my earlier years!

I struggled a lot at school. This started with anxiety and panic attacks when I was 13. I was eventually diagnosed with autism at the age of 16. I ran away from school, struggled to go into lessons, was described as on the verge of a school refuser and then missed a lot of school when I was unwell.

## **So what do I wish that teachers (who didn't already know) had known?**

I wish that teachers knew I wasn't trying to be rude when I said things bluntly or needed an answer there and then – that was how my autistic brain worked, and I didn't understand that was rude.

I wish they understood that I wasn't trying to be difficult when I couldn't engage with certain parts of the school day, like assemblies or P.E. or busy school events. I found many of these far too overwhelming.

I wish they knew that shouting and trying to scare me into conforming was never going to work. I needed gentleness and compassion. Using fear as a control tactic just increased my anxiety drastically and reduced my trust of them.

I wish they knew that sitting me next to a friend made it so much easier for me to feel less anxious and safe in lessons. When this adjustment was made, it helped me to stay in lessons.

I wish they knew that I wasn't deliberately going against the uniform policy when I wore leggings instead of tights. It was cold, but because of my sensory sensitivities I found tights incredibly itchy and they would bring my legs out in rashes.

I wish they knew that when I needed instructions clarified, it wasn't because I wasn't "using my initiative", it was because my autistic brain finds it very hard to carry out a task when I don't know exactly what I need to do and what is expected of me.

I wish they knew that I wasn't deliberately interrupting people or talking over people. And I didn't mean to keep getting distracted and talk too much. Perhaps this is ADHD, or perhaps my autistic brain not getting the social cues everyone else did.

I wish they knew that I was trying my absolute hardest in everything that I did and the school environment just didn't suit me. Forgetting homework or equipment caused me such extreme anxiety. I wish that had been understood.

Supporting neurodivergent children at school can be really hard. There are so many children in one class for a teacher to manage that it can be very hard to give individual students the support they need, especially if that student's needs are unknown. But, when my teachers got to know me and listened to me, it made my school life so much easier. When I was able to identify the places I felt safe to go to when I was struggling, instead of being told where I had to go, I was less likely to run away and felt safer in school. I spent much of sixth form hiding in a cupboard in the curriculum support block. Or in a teacher's office. There I felt safe, and I was less

likely to meltdown or panic or run because I knew I could leave lessons and go there whenever I needed to. The pressure was off.

I was, in some ways, lucky. I was never painted out as a naughty or disruptive child because my perfectionism, love for learning and studiousness meant I was usually a "pleasure to have in class" (until I started to meltdown). There are so many children seen in this light. ADHD kids, especially. Many of whom are seen as naughty, disruptive or just not trying hard enough. When their body simply doesn't allow them to sit still, or their brain just cannot concentrate. It isn't their fault that the school environment just doesn't suit their brain.

Autism and ADHD are both disabilities. These children are all legally entitled to reasonable adjustments. When these are in place, it can help them to thrive. These might include:

- Missing certain overwhelming lessons
- Regular mentoring

- Having a time out card to leave lessons
- Movement breaks
- Having fidget toys
- Having somewhere safe to go to when needed
- Specific seating plans (e.g. by a door)
- Uniform adjustments due to sensory issues
- Extensions on deadlines/homework
- Having a reduced timetable
- Allowances for forgetting things
- Exam adjustments.

The school environment is a difficult one for many neurodivergent children. Understanding, compassion and adjustments can make a world of difference. I am very lucky to have had that when I most needed it, and I hope that one-day all neurodivergent children have that too.

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*Emily Katy is an autistic writer and advocate for mental health and autism. She is a trustee of the community @AutisticGirls and hosts the tag #NotAloneTalk on twitter.*

## Working for a premier recruitment agency

Neha Uttam

One day in October 2019 Aparna ma'am, Director of Arunima Organisation, Dehradun, came to my flat and informed me that I am getting an offer to work at Cynet Systems Pvt Ltd Company in Dehradun and that it's a night job. She told me that I will be getting a fabulous salary every month.

I accepted the job offer right away and then joined the Cynet Systems Private Limited Company on 14th October 2019. I do data entry through an official email address that the company helped me make. Slowly the number of tasks in data entry increased for me to work on. My in-charges and respective managers shared with me many times that they are happy with my work via the official Gmail chat.

One day the CEO'S friend came to Cynet Systems' office in Dehradun to record me on YouTube while I was working on the computer in the office. He introduced himself as Mr Subhadip Mazumdar. He happened to be an author of a book who I met in Arunima Organisation where I worked and he stay too in Dehradun. He came to Arunima Organisation to launch his book and I was extra happy to be recorded on YouTube by Subhadip Mazumdar sir that also in midst of the whole office of Cynet Systems.

The team is fabulous and are extremely understanding towards me. I am truly happy working in the Cynet Systems Private Limited Company and It's a fabulous experience working in a mainstream company in Dehradun.

# The Real Voice of Autism

## A speech by an autistic

Samantha Craft

### **What is autism?**

Once I say I am 'autistic', I understand I will never be perceived the same again. And that is both my sword to bear and light to share.

There is no way to fully understand autism, unless you are autistic. But there are numerous ways to raise your personal awareness. Particularly useful are first-hand accounts by actual autistics and historical perspectives by respected journalists. While it is hard to pin down the term 'autism' in a short interval of time, I can tell you what the average autistic is not. They are not 'Rain Man,' and they are not the stereotypes perpetuated in the media. We are typically, in my experience, caring, loving human beings with great potential. And, like all individuals, given the proper support systems and acceptance, we can excel to great heights; and like all people, given repeated oppression and bullying, we can plunder to the depths of self-injury and self-persecution. Today, autism is represented in all shapes and sizes, all ages and creeds, all genders; we include LGBTQ, African Americans, the physically disabled, and other marginalized minorities. We include the unemployed and the professional with multiple degrees. We include doctors, lawyers, and teachers. We include experts in technology and literature.

If we are different, then we are different in the way we process the world, including information and encounters with others. We are often visual thinkers. Typically, with heightened sensory systems and the ability to conceptualize and link facts at rapid speed. But, overall, we share more commonalities than differences with the average citizen. I myself have a vast imagination, a powerful force to love and empathize, a strong need to protect the voiceless, and a tendency to think in complexities,

and present as intense and honest. There are many autistics like myself. And there are many that are not. We vary in our interests and values. We vary in our struggles and triumphs.

So then, what is the defining factor of autism? If we are so much like our neighbour, then what is it that sets us apart? In short, it is our neurological makeup—the makings of our brain—the way we interpret and filter stimuli. The way we logically approach situations. And the way in which we sometimes forget the majority of the populations' brains don't function like ours.

Today, I am one voice of autism standing before you. To date there has been a lack of autistic voices in the representation of our people. In truth there is an ongoing exploitation of us to attract viewership and consumers, including organizations that know little-to-nothing about autism, that charge top dollar, ranging in the thousands, to teach about autism. We, as an autistic people, are being taken advantage of in the media and by money-hungry big business and entrepreneurs. We are the victims of yellow journalism; vacuous articles unsubstantiated by careless facts and filled with escalated jargon, spoon-fed to an unsuspecting readership. Studies and statistics regurgitated that often have their roots in (admittedly) biased studies and limited control groups; absent are the representation of the growing late-age diagnosed and female autistics. Increasing are the glooming statistics that are not fact-checked and paint a doomsday predicament, generally without solutions or direction.

And, yes, in case you are wondering, there are far more females on the autism spectrum than first recognized. For the most part, we go undetected as children and in adulthood, as we are good at fitting

in and ‘pretending’ to be ‘normal’, to avoid ridicule and persecution. Something sadly, that every autistic I have met has encountered-the persecution. As you might well know, it is common for autistics to be tagged as ‘lacking empathy’ and ‘absent of imagination’. Nothing could be further from the truth. We present our empathy differently. We have keen imagination. Furthermore, we are pinned as loners and unable to make friends. We are depicted as individuals who do not make eye contact and clumsily move about the world in our oddities and frailties. We are linked to fear: to murders, to criminals, to cancer. We are coined ‘unable to hold down a job’, ‘tech geeks’, and ‘unstable’.

As an autistic, I am here to say the tides have changed. We, as a collective, will no longer be cornered into less than and not enough. We will no longer accept others tainted and biased tellings and teaching about who we are. We are not a collective ‘disorder’, nor an inferior race that needs a cure. We have been here for centuries and did not just come into existence-a normal child turned abnormal.

In corresponding with over 5,000 autistic adults worldwide, and having had, with great zealous, read thousands of pages related to autism, I have taken in the outdated classifications and definitions of autism, the fear-mongering, and spreading of stereotypes.

A primary agreed upon perception of autism has its roots in the DSM. It is commonplace for journalist and mental health professionals to refer to the DSM-V, The Diagnostic and Statistical Manual of Mental Disorders (DSM), in referencing autism, particularly recently, as the term Asperger's Syndrome has been placed under the broader classification of ‘Autism Spectrum Disorders’.

It is important to note, in considering the concept of mental disorder, that the Diagnostic Manual has a natural bias – a bias that is influenced by deep pockets and special interest groups, a bias most prevalent in the profit goals of health insurance agencies and pharmaceutical companies, and a bias further inflated by the educational lobbyists

working to fund higher-education research projects. A bias stemmed also from cultural influences and human nature-the inability to remove the definition of ‘disorder’ from a personal value judgment based on cultural and individualized perception.

Despite the natural biases, today's revised DSM, the DSM-V, is largely referenced as the bible of psychiatry and psychology. But we must remember, the DSM-V is not a neutral entity with the interest of mental health clients and patients in mind. In strong contrast, the DSM-V is dependent upon outside influencers with vast economic and political power. It is a ‘bible’ with some arguably practical and applicable data, set in a broth of bleeding conjecture and greed.

Here are some lesser-known information about the DSM:

‘The origins of the DSM date back to 1840 – when the government wanted to collect data on mental illness. The term “idiocy/insanity” appeared in that year's census. The manual went through 10 editions until 1942.’

(Source:  
<http://psychcentral.com/blog/archives/2011/07/02/how-the-dsm-developed-what-you-might-not-know/>)

‘Although widely used, the DSM has come in for fierce criticism, with many commentators believing it to be conceptually flawed in a variety of ways.’

‘. . . the DSM is theory-laden’ and has been ‘shaped by social and financial factors.’

‘The DSM definition of mental disorder was born out of the 1970s debates over homosexuality. In the DSM-II (APA, 1968), until 1973 homosexuality was listed as a mental disorder . . .’

‘The problem with the DSM definition (of mental disorder) is that the genetic bases of some conditions that we would normally class as diseases may confer an evolutionary advantage (Wilson, 1993: 45 in reprint).’

‘The fact that third-party payers only reimburse treatment for patients with a DSM diagnosis provides an incentive for psychiatrists and patients to lobby for new disorders to be included in the DSM. When such lobbying is successful, new diagnoses come to be included in the DSM as a direct result of insurance pressures.’

‘Once a diagnosis is included in the DSM, the diagnostic criteria may be altered between editions so that more or fewer patients fall into the category.’

(Source: What is wrong with the DSM? Rachel Cooper, Lancaster University  
<http://journals.sagepub.com/doi/pdf/10.1177/0957154X04039343>)

Part of the DSM-V Autism Spectrum Disorders (ASD) states:

- Persistent deficits in social communication and social interaction across multiple contexts (e.g., social nuances of language and facial expressions)
- Restricted, repetitive patterns of behaviours, interests, or activities (e.g., hand flapping, insistence on sameness and predictable routine)

(Source: Autism Speaks)

But what is a *deficit* by definition? Who is to determine the right way of communicating? What is such determination based on? I ask what is wrong with hand flapping and with a need for predictable routine? If, by definition, an autistic person is impaired socially and occupationally, can this impairment be eradicated by proper supports and acceptance? If so, is the eradicated impairment indication of an eradicated disorder? Case in point, since I have developed meaningful relationships and success in my chosen vocations, have I subsequently outgrown my disorder? Am I now disorder-free? Am I now non-autistic? Has my brain somehow been altered?

And what of all the other traits? The common traits of autistics the DSM-V has overlooked and not classified, (perhaps in attempt to appease special interest groups, e.g., insurance companies), such as the list of character traits thousands identify with worldwide?

<https://everydayautistic.wordpress.com/2016/05/02/females-with-aspergers-syndrome-checklist-by-samantha-craft/>

Is autism a disorder? In my anecdotal experience, a large proportion of the autism community would proudly say ‘no’. In my opinion, it is at its worse a neurological condition and at its best, simply a different way of processing the world. Does autism and/or Asperger's Syndrome come with hindrances and challenges that justify services and render some ‘disabled’. Indeed. This is not to be understated. There is a growing need for accessible and affordable support services and resources. Parents and individuals are struggling. And awareness has the potential to bring much-needed support.

Discussing the subject of autism, sometimes leads to more questions than answers. But questions are good. Questions are necessary. In closing, I ask you to remember the voice of autistics. I ask you to erase your stereotypical notions. I ask you to remember this teacher standing here, this mother of three, this author, this community manager, this leader, this singular voice that has an army of voices behind her. We are not the autistic you have been shown. We are your neighbours, your committee members, your faith house friends, your organizational volunteers. And I ask you to leave with this singular question: Who should define autism? Shall it be special interest groups? Journalists? Self-proclaimed experts exploiting a people for profit? Or should the voice of autism come from actual autistics, those who live and breathe it daily?

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*Marcelle Ciampi (aka Samantha Craft) is a DEI specialist, an international educator, a published author and a neurodiversity expert. She is currently pursuing her doctorate in learning and leadership.*

# Autism: Moving from Tolerance to Acceptance to Empowerment

Dr Dan L Edmunds

## **Really Listen to a Voice of Autism**

They said to persevere. I began to perseverate. They discouraged me.

Be joyful they said. I flapped my hands with a joyful feeling. Not like that they said.

They used a lot of words whereas I had not many.

They said I needed to speak like them and when I did they said it was the wrong words...

You need more friends they said as they forced me into the circle of bullies they called my 'friends'.

You need to be independent they said. So I tried.

No, not like that. No, you cannot possibly do that.

Share your interests they said. So I did. We do not find that very interesting they said. Stop repeating yourself!

You are in your own world they said. And with that final statement, it occurred to me- their world is not kind. Why is it better? Why must I be like them?

So whereas they refused to embrace or understand my world, I was forced to assimilate into theirs, each day giving up a part of my very being.

It was then I decided to be empowered, to embrace that which they refused to embrace, to be as I was, am, and will continue on to be. And I sought to share a piece of my world with those who dare might understand.

## **Autistic Empowerment**

There is a gradual a process in the ability to adopt an attitude of autistic empowerment. It begins with

the idea that autism is a thing that is to be eradicated. This is ignorance. I do not blame some persons for holding such an idea initially as it is pervasive in the messages in society and maybe all they initially know. From this emerges the idea that one might be able to accept autistic person but has an attitude of pity and feels bad that they are different. ... This is tolerance. The next stage is where one is able to see autism as not a thing but a mode of being the person. This is awareness. Beyond this one begins to not focus merely on challenges but to also see strengths. This is acceptance. One then starts to understand the diversity in means of communication and no longer expects the autistic person to conform to contrived standards of communication. This is a furtherance of acceptance. From this point, one is able to incorporate respect, dignity, presuming intellect, embracing diversity, and promoting self-advocacy. This is empowerment.

So one moves from ignorance to tolerance to awareness to acceptance to empowerment.

## **Autism is Not a Disease**

Autism is not a disease or an entity. It is not something that we must seek out to eradicate. Rather, it is a mode of being, the word 'autism' simply being an umbrella term to describe how one relates (or does not relate) to the world. When autism is viewed as an entity, a 'thing', professionals are then led to developing programs that seek to transform the person into something they are not, nor will – or can – ever be. This errant perspective may prove dangerous, as it can function as the impetus to alter the affected person by force, coercion, or manipulation.

If an American travels to a foreign country and knows nothing of the culture or language, he is

bound to struggle. If an American travels to a foreign country having learned something of the language and culture beforehand, then relating to others and navigating one's way become much easier. This illustrates the direction in which I believe that programs to aid autistic persons should be geared – not to change the individual, but rather to help them to be themselves, while also having an understanding of the ‘mainstream’, and being able to navigate within that realm.

### **An Approach to Autism**

In my approach, there are some core principles that I find of utmost importance:

**Presume intellect:** Because a person is nonverbal or struggles with communication does not mean they are not intelligent or have nothing to say. Their unique strengths and passions must be explored and utilized.

**Behaviour is communication:** In my opinion, the psychiatric community may be making a grave mistake when it simply seeks to ‘shut down’ or suppress what it judges to be ‘unwanted’ behaviours with powerful psychiatric drugs. Behaviours, even those which may be deemed ‘unwanted’, could be, for some, the only means to convey their needs or distress.

**Self-Advocacy:** If professionals, friends, family members of the individual, and people at large wish to understand autism, there must be a willingness to enter the autistics' world, not force them to enter the ‘public world’ deemed acceptable. We must validate self-advocacy and seek knowledge about the autistic mode of being from those who actually live it each day.

**Relationship:** To help autistic persons forge emotional connections, make their way through the mainstream, and learn new skills, the keys are relationships. We all must be inclined to forge a bond with the person, to truly seek to understand his experience, unique world, and how he finds meaning – that is, to get to know the autistic

individual as a fellow human being. Once a bond is forged, a common healing ground can be created.


**Respect:** It is paramount for respect to exist and abound, which means that we do nothing to force, coerce, or manipulate those with autism. They should be regarded at all times as being worthy of dignity. Again, the ‘outsider's’ role is to advocate for and support, not seek to modify the person into someone they are not, or need not be.

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*Dr Dan L. Edmunds is an autistic self-advocate and mental health professional for 22 years. He has presented at numerous professional conferences and authored articles on autism, social justice, spirituality, and mental health. He presently serves as a High-Risk Behavioural Health Counsellor. Dr Edmunds can be reached via e-mail at [batushkad@yahoo.com](mailto:batushkad@yahoo.com)*

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# A Conversation. A Graphic Designer. A Storyteller

Dominic Perera

**You are a skilled graphic designer and a movie maker. How did you discover your interest in graphic design and stop motion filmmaking?**

I was eight years old when I first discovered how to get into motion filmmaking. I used to design a lot on Minecraft and that gave me the idea. I studied it online and started my first project. I was always an artist so when I discovered programs like Photoshop and Paint, I began exploring and turning my hand made art into digital design. Since then, I have included special effects and various techniques to make the designs look more professional.

**What is your favourite thing about being in a creative profession?**

It gives me a sense of joy and confidence. I love bringing things to life and make it stand out and actually speak to the person who is looking at it as in have meaning and a deeper sense.

**What made you want to create a brick film? (A brick film is a lego stop motion picture)**

I first thought of it because I love lego and I love making my original designs using random bricks. I wanted to see how it would work if I could make the bricks move so I began taking frames with the tablet.

**Besides being a graphic designer and an animator, you are also a published author. What made you want to write?**

I have a very lively imagination and whenever I did Art, I used to see a story in it and wanted to depict what was within the art. So, I decided when I was eight years old to illustrate and write my own children's books which were then published by Amazon.

**You chose an interesting genre for your writing. What interests you about writing fantasy adventures?**

I love adventures and mysteries and the pull between Light and Dark. I have always believed that autistic children have very high senses hence the story came together in my mind to do a novel that had Autistic characters with super powers fighting on the side of Light.

**Your latest literary work is very in line with adventures of Indiana Jones and Han Solo. How did you come up with the concept?**

As a child, Indiana Jones always excited my imagination with the way he solved mysteries and the traps and artifacts. I love anything historical and pertaining to ancient history going back to mythical times. I became a fan of the character, Han Solo because I love Star Wars and the fact he is played by the same actor as Indiana Jones.

**What do you hope to achieve with your creative works across different mediums?**

I drive immense happiness and confidence. For ten years, the Lego Company has always encouraged me and given very personal positive responses about my movies and creations. I have done some projects specially for kids with terminal illness like once I did a farm movie for a young boy in Tasmania, Australia who had cancer and loved farms and animals. His mum wrote to me and asked if I could create a movie for him. My movie was shown in his school and a lot of people reached out to me. It makes me very happy that my creations make other people happy. I particularly want to inspire Autistic kids through my creations and help them believe that they can do the same.



**When did you learn of your autism diagnosis and how?**

What I can recall of my early childhood was that I could hear sounds and voices but could not figure out how to respond or show signs of how I felt and what I needed. Most I would do was to wriggle my hands a lot and focus on spinning things on the floor. When I was 2 and a half years old, my mum took me to a specialist and he, after observing me for an hour, advised her to take me to a counsellor as he suspected I had Autism. When I went to the counsellor and she observed my patterns and did some more observations for a few days after which she confirmed I had autism.

**Can you suggest any web links or books to share with autistic children and adolescents that can help them understand their autism better?**

I did not know of any web links or books as I did not grow up with those but my mum got me the movie 'The Son Rise program, a living miracle'. It is about the stages of life of a boy who is autistic. The movie relates how every doctor had given up but his mother did not and made every effort to help him develop and understand his world. In the end he is able to conquer the hurdles of his Autism. I learned many ways of communicating and subjects like maths, language, words etc when my mum introduced me to a tablet in which she got me Dolch words, numbers with pictures and sound, word jumbles, riddles in a creative way etc. There are many creative programs and games that can be downloaded on a tablet that can help Autistic children. Since they are visual and verbal learners, you will be amazed at how quickly they adapt and learn as it is more in line with their way of understanding. Flash cards, sensory toys, obstacle courses and awareness techniques also help a lot in development. Generally, mothers have to make many sacrifices and a significant effort to help her child develop. My mum gave her 200 percent to help me and understand my world. I am like this today thanks to her never give up attitude.

**You have shared previously that you want to inspire autistic kids with your work. Why is that so important to you?**

It is very important to me because I know how clever and gifted autistic kids are. Given a chance to be creative, they can do amazing things. Through motion filmmaking and designs, I do what I can to help them do the same. They are born creators and with time and patience can help them find and realize their potential.

**Growing up, what made things easier for you? Any supports?**

My mum was my best friend and support. If not for her efforts, struggles and sacrifices I would not be like this today.

**What do you think makes you different from non-autistic people? What would you like people to know about your views on autism?**

Autism is not a disability it is an ability. I am different because nothing fazes me or worries me. I do not dwell on things and I do not hold a grudge or envy or sadness. I feel emotions but I do not let life get to me. I always like to be happy and positive and this is how autistic children are. They live in their own world; happy without fear, worry, doubt, confusion and anger. Focus and patience are the keys.

**What advice would you give to young autistic people?**

I wish to help other autistic children realize their potential and innate genius. I want them to embrace their uniqueness and regardless of what others say, have a voice, be heard and make a difference. Their intelligence is a gift to mankind. They can make a difference and can contribute so much into further developing this world. Through their infinite wisdom, they can spread kindness and basic human values amongst people.

**Any future work, we should be on the lookout for?**

Yes, I have done a script based off my novel, the Relic Hunter: the X Masters Saga. I am also looking to get into animation. Barnes and Noble Press have also published my book again and I designed the cover page.

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*Dominic Brendon Perera is an eighteen year old from the Island of Sri Lanka. He lives with his mother, a single parent, who home-schooled him through the British Council and IDM Computing. Although Dominic attended regular schooling for*

*three years, he was bullied and could neither understand nor learn anything. Hence his mother and special educator decided on home-schooling which greatly benefitted him. After years of perseverance, setbacks and a never give up attitude, Dominic has achieved far more than expected and has very high awareness of sensory skills. He is a visual and verbal learner, a Graphic Designer, a Video Editor, a Movie Maker, an Amazon Author and an Animator with interests in special effects. He has personally been in touch with the Lego Company, Denmark for ten years and is a professional Lego Movie Maker on YouTube. He has passed several Cambridge exams and obtained several diplomas in computing.*

## Our first true holiday in a long time

A Parent Child Training Program Parent

Somewhere during the Parent Child Training Program (PCTP) there was a moment when I was too overwhelmed with all that was going on: pressure at work, the PCTP – three hours every day for three months can be intense, and life in general! That time Hari, my loving husband, decided that I deserved a break and we booked our Goa vacation, scheduled right after the PCTP got over.

Interesting note: Till before we did the PCTP we had always joked about how our vacations didn't feel like vacations anymore. Vacations were far more stressful than normal days, as the responsibility of caretaking during vacations rested solely on the two of us, unlike our normal non-vacation days with the regular support system of grandparents and general caretaking/domestic help. Vacations always became overwhelming, with is a lot of crying, regrets, and the resolve to not go for a holiday again!

However, using all that I had learnt in the PCTP, we started prepping for our first post-PCTP holiday.

We marked the holidays on the calendar well ahead in time, with pictures of an airplane, the beach etc, giving Kiaan the predictability he needed.

On the day of our flight, we had a work-system in place which demonstrated step by step all the things that were going to happen (like cab to airport, check in, security check etc). We also had a similar system for landing, right till check in at the hotel.

To my surprise, all through waiting in the queues and at the boarding gate, Kiaan was standing/sitting with me, without the need to get up or run around (not even once!). This for a child who is constantly on the move was almost unbelievable. Hari and I just kept exchanging 'surprised' glances, too afraid to voice our inner delight, lest we might jinx it.

We used work-systems also to give predictability throughout the vacation for those parts of the days where at least we knew what the plan was. Not even once, did we have a 'tantrum' for not wanting to get out of the sea/ pool. We just used the counts (I was

too lazy to carry the timer). When he wanted to run to the sea, I made him sit (using the physical structure we learnt in music time) and we sang together...

We crossed the poolside several times in the day to go the restaurant etc. Never did he ask us to take him to the pool. If he did stop by the pool side, I showed him the worksystem and he just moved along.

It took us almost half a day and half a suitcase to plan for all this, to make the cards for all the possible activities, carrying blank cards (should we lose any and we did), velcro, etc. And it was all worth it.

But PCTP is not just about work-systems. Of-course providing visual support for my child was one of the major learnings, but there are other things which are more intrinsic and which I believe is what made a big difference.

While waiting at the airport and during hotel check-ins, we were chatting with him, singing to and with him, being silly with him. People watched and we smiled. Kiaan's stimming didn't bother us. When Kiaan was screaming with joy in the pool or sea and people thought that someone was drowning, rather than getting embarrassed, we were amused and laughed hard. We didn't fuss about what he wanted to eat. If he wanted to eat just plain bread with chopped onions for his lunch, so be it. I have to admit what a disappointment that was for my husband, who wanted to share the yum seafood with his beloved son.

We met him 'half-way' in everything. Our daily schedules included tons of things that he liked such as water play and playtime with us. So simple are his needs! And then a couple of things that we would have liked to do:

- We went to the shacks to listen to some music and were out till 10:30 pm. For those who know us, would know what a feat this was, with our little one who was two and a half hours past his bedtime.

- We took our afternoon naps, while he just played or lay next to us, without disturbing and letting us be.

After all this, when Kiaan was having a difficult moment (which happened all of three times in a matter of six days!), instead of getting hassled, we were calmer than usual, and tried to help him by understanding and addressing his needs.

These are just examples and there are plenty more...

But the most important and biggest change that helped us to have our most fun holiday in a long time (since Kiaan's diagnosis three years ago), was 'acceptance in it's true sense' and the realization that 'happiness is a choice'. Something that PCTP helps you understand....

**“True love is an acceptance of all that is, has been, will be and will not be.”**

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# हमारे लिए शोक न करें

जिम सिनक्लैर

अनुवाद – पूजा खन्ना

इस लेख का प्रकाशन हमारी आवाज, ऑटिस्म नेटवर्क इंटरनेशनल कांफ्रेंस टोरान्टो के व्याख्यान की रूपरेखा है और यह मुख्यतः ऑटिस्टिक बच्चों के माता-पिता को सम्बोधित है।

माता-पिता कहते हैं कि इनका बच्चा 'ऑटिस्टिक' है यह बात उनके साथ हुई सबसे पीड़ादायक घटना है। बिना ऑटिस्म अथवा सामान्य लोग ऑटिज्म को एक बड़ी त्रासदी की तरह देखते हैं और ऐसे मां-बाप अपने ऑटिस्टिक बच्चे और परिवार के जीवन काल के हर पड़ाव पर लगातार निराशा व मायूसी महसूस करते हैं।

इस दुःख की उत्पत्ति का कारण सिर्फ ऑटिस्टिक बच्चे का जीवन में आना नहीं है। यह मां-बाप की उम्मीद किये हुए एक सामान्य बच्चे के न होने/खोने का है। ऑटिस्टिक इन्सान के साथ वास्तविक जीवन की जटिलताओं के बजाय माता-पिता का नजरिया, आशायें और एक खास उमर में इस बच्चे के विकास में विभेद मुख्यतः उनकी तनाव और पीड़ा का कारण है।

थोड़ी मात्रा में दुःखी होना सामान्य है क्योंकि मां-बाप को इस हकीकत का सामना करना पड़ता है, कि जिस घटना व सम्बन्ध की वो आशा कर रहे थे वो असलियत में नहीं होगी, और इसके अनुकूल खुद को बनाना पड़ता है। परन्तु अपने मनोवांछित सामान्य बच्चे के न होने के दुःख के प्रति अनुभूति उन्हें, अपने ऑटिस्टिक बच्चे से अलग रखने की जरूरत है। उस ऑटिस्टिक बच्चे को जिसे व्यसक कार्यवाहकों के साथ सुअवसर मिलने पर वह एक सार्थक सम्बन्ध बना सकता है। लगातार अपने दुःख की जड़ का केन्द्र ऑटिस्म को मानना मां-बाप व बच्चे दोनों के लिए हानिकारक है और यह दोनों के बीच में स्वीकारता और विश्वसनीय सम्बन्ध नामुमकिन कर देता है। स्वयं के लिए अपने ऑटिस्टिक बच्चे के लिए माता पिता के समक्ष तीव्र इच्छा रखता हूँ कि वो ऑटिज्म के प्रति अपने दृष्टिकोण में जड़ से परिवर्तन लायें। मैं आपको हमारे ऑटिज्म और आपके दुःख को हमारे दृष्टिकोण से देखने के लिए आमंत्रित करता हूँ।

## ऑटिज्म एक लटकन/जोड़ नहीं है

ऑटिज्म किसी व्यक्ति के द्वारा एक जोड़ी हुई वस्तु या लटकन अथवा एक कवच के अन्दर फंसी हुई कोई चीज नहीं है न ही किसी ऑटिस्टिक बच्चे के अन्दर एक सामान्य/

नान-ऑटिस्टिक बच्चा छुपा हुआ है। आटिज्म अपने में एक अलग जीवन है जिसका अपना एक अस्तित्व है। यह बहुत व्यापक है। यह जीवन के हर अनुभव हर एहसास, हर अनुभूति, हर विचार, हर भावना, जीवन के हर पहलू से सामना, उसके अस्तित्व सब पर अपनी छाप छोड़ता है। ऑटिज्म को किसी के अस्तित्व से अलग करना मुमकिन नहीं है, और अगर ऐसा मुमकिन होता तो आपके प्रयत्न के बाद यह ऑटिस्टिक व्यक्ति जो आज आप के पास है उस व्यक्ति से बिलकुल अलग होता जिसके साथ आपने शुरुआत की थी।

यह बहुत जरूरी है कि आप एक क्षण का समय लेकर इस बात पर विचार करें। ऑटिज्म का अपने में एक अलग अस्तित्व है और ऑटिस्टिक व्यक्ति को उसके ऑटिज्म से अलग रखना मुमकिन नहीं है।

## इसलिए जब मां-बाप कहते हैं:

“काश मेरे बच्चे को आटिज्म नहीं होता” तो असलियत में यह कह रहे हैं कि “मेरी इच्छा है कि मेरा यह ऑटिस्टिक बच्चा न रहे और इसके बदले मेरे पास एक अलग/सामान्य बच्चा हो”।



इसे फिर से पढ़ें। हमें यही सुनाई देता है जब आप हमारे जीवन पर शोक मनाते हैं। हमें यही सुनाई देता है। जब आप हमें ऑटिज्म नाम के रोग से मुक्त करने के लिये दुआयें मांगते हैं। हमें यही समझ आता है जब आप हमें हमारे लिये देखें अपनी सबसे प्यारी आशाओं और सपनों के बारे में बताते हैं और यह कि आपकी सबसे बड़ी इच्छा है कि हमारा ऑटिज्म का अस्तित्व खत्म हो जाये और आप फिर हमारे चेहरे के भीतर छिपे नान – ऑटिस्टिक बच्चे से प्यार कर सकें।

### ऑटिज्म एक अप्रवेशीय दीवार नहीं है

आप बच्चे के साथ व्यावहार बनाने की कोशिश करते हैं और वो आपको उत्तर नहीं देता है वो आपको देखता नहीं है। आप उस तक पहुंच नहीं पा रहे हैं। कोई तरीका उसे समझने का नहीं दिख रहा है। यही सबसे कठिन चीज है जो आपके साथ हो रही है पर असल में यह सत्य नहीं है। इस पूरी प्रतिक्रिया को फिर से देखें गौर करें।

आप अपने ऑटिस्टिक बच्चे से एक सामान्य बच्चे के प्रति अपनी समझ, स्वयं के लालन पालन की भावनायें, रिश्तों के बारे में अपने तजुर्बे और अन्तरज्ञान के हिसाब से रिश्ता बनाने की कोशिश करते हैं। और आप का बच्चा किसी भी उपरोक्त मापदण्ड के हिसाब से जिसे आप पहचान सकें खरा नहीं उतरता है।



परन्तु इसका यह मतलब नहीं है कि बच्चा किसी प्रकार से सम्बन्ध बनाने में सक्षम नहीं है। इसका सिर्फ यह मतलब है कि आप एक ऐसी सहभागी आपसी तालमेल व्यवस्था की कल्पना कर रहे हैं – जो आपसी सहभागी संकेतों की समझ और मतलब को जानता हो जो आपका बच्चा समझ ही नहीं पा रहा है। यह ठीक उसी प्रकार है जैसे कि आप किसी के साथ बड़ी अन्तरज्ञ बातें कर रहे हैं और उसे आपकी भाषा का कोई ज्ञान ही नहीं है। जाहिर है उनसे आप किस बारे में बात कर रहे हैं बिल्कुल समझ नहीं आयेगा और उसका जवाब बिल्कुल आपकी आशा के विपरीत होगा। और हो सकता है उसे यह पारस्परिक संपर्क बनाने की क्रिया बड़ी बुरी व अस्पष्ट लगे।

किसी भी प्रकार की पारस्परिक संपर्क क्रिया जहां दूसरे व्यक्ति की मूलभाषा आपसे अलग है। उसमें ज्यादा परीश्रम लगता है और फिर ऑटिज्म तो भाषा और सभ्यता से भी गहरा है। ऑटिस्टिक लोग हर समाज के लिए एक परदेशी ही है आपको अपनी इस कल्पना को बदलना होगा कि आप और आपके बच्चे की समझ के मापदण्ड एक ही है। आपको इतनी बुनियादी स्तरों पर वापस जाना होगा जो आपने कभी सोची भी न होंगी। चीजों का अनुभव अपने बच्चों के हिसाब से करना होगा।

और यह जांचना होगा कि आपका उसे समझ आ रहा है कि नहीं। आपको अपने परिचित क्षेत्र की निश्चितता छोड़नी होगी। आपको अपने बच्चे को उसे अपनी भाषा सिखाने का मौका देना होगा जिससे वो आपका अपने ऑटिस्टिक जीवन में मार्गदर्शक बने। अर्थात् वो आपका शिक्षक बनकर अपनी दुनिया में आपका पर्दापण करें और अगर इन नतीजों में आप सफल हो गये फिर भी यह एक सामान्य (नान-ऑटिस्टिक) बच्चे और उसके मां बाप जैसा सम्बन्ध नहीं होगा जो बात करना सीख लेगा एक सामान्य बच्चों वाले विद्यालय में जायेगा। शायद कॉलेज में भी गाड़ी चलायेगा, स्वतंत्रता से रह लेगा अपनी जीविका होगी पर वह कभी भी आपसे एक सामान्य इन्सान की तरह संबंध नहीं बना पायेगा। या ऐसा भी हो सकता है कि आपका ऑटिस्टिक बच्चा कभी न बोले, एक विशेष केन्द्र से स्नातक होकर एक सुरक्षित गतिविधि या आवासिक सहूलियत वाली जगह रहे, पूरे समय देखभाल और निरीक्षण चाहिए हो पर फिर भी वो आपकी पहुंच से बाहर नहीं होगा। हम जिन अलग अलग तरीके से सम्बन्ध बनाते हैं यह सब उस पर निर्भर है आप जोर देकर उन चीजों के लिए जो आपकी आशाओं के अनुरूप है व आपको सामान्य व सही लगती है के लिए अपने ऑटिस्टिक बच्चे से सम्बन्ध बनाने की कोशिश करेंगे तब आप कूटित हताश नाराज शायद गुस्सा और नफरत महसूस करेंगे। आप उनके पास इज्जत से, बिना किसी पूर्व कल्पना और एक खुले

दिमाग से नई चीजें सीखने की अभिलाषा के साथ जाये तब आपको एक ऐसी खूबसूरत दुनिया दिखेगी जिसकी आपने कभी कल्पना भी नहीं की होगी।

हाँ! इसमें ऑटिस्टिक बच्चे के साथ सम्बन्ध बनाने में नान-ऑटिस्टिक बच्चे के मुकाबले बहुत ज्यादा काम करना पड़ता है। पर हां यह तभी मुमकीन नहीं है जब हमारे नॉन ऑटिस्टिक मां बाप के सम्बन्ध बनाने की क्षमता हमसे भी कम है। हम तो पूरा जीवन सिर्फ आप लोगों से सम्बन्ध और रिश्ते बनाने में बिता देते हैं। हम में से हर एक जो आप लोगों से थोड़ा भी बोलना सीख लेता है हम में से हर एक जो थोड़ा भी आपके समाज के हिसाब से अपने को संचालित कर लेता है। हम में से हर एक जो आपकी ओर कदम बढ़ाकर एक बन्धन बनाता है वह एक अपर देशी व अनजाने इलाके में काम कर रहा है और अनजाने लोगों में ही रिश्ता बन रहा है। और हम अपनी पूरी जिंदगी इस सम्बन्ध को बनाने में लगा देते हैं और फिर आप कहते हैं कि हम सम्बन्ध नहीं बना सकते।

### ऑटिज्म मृत्यु नहीं है

माना कि किसी भी नये बच्चे की उम्मीद कर रहे माता पिता कभी भी ऑटिस्टिक बच्चे की आशा नहीं करेंगे। वो एक ऐसे बच्चे की उम्मीद करेंगे जो उनके जैसा हो और उनके जैसे ही दुनिया देखे और समझ ले और कि उन्हें आजीवन उस अजनबी बच्चे को प्रशिक्षण नहीं देना पड़े।

ऑटिज्म के अलावा अन्य विकलांगताओं में भी मां बाप बच्चे के साथ उन्हीं शर्तों पर सम्बन्ध बनाना चाहते हैं जो उनके नजरिये में सामान्य होता है। और अकसर अन्य विकलांगताओं में कमियों के बावजूद वो कुछ हद तक अपने बच्चों से अपनी आशा अनुसार एक जोड़ बना ही लेते हैं। पर एक ऑटिस्टिक बच्चे के साथ इस तरह का बन्धन भी सम्भव नहीं होता। ज्यादातर मां बाप की मायूसी का कारण उनकी आशा अनुसार उस ऑटिस्टिक बच्चे से जिसके सामान्य होनी की उन्होंने उम्मीद की थी उससे सम्बंध का न बनना है।

यह दुख एक बहुत बड़ी सच्चाई है और उसका निवारण करना जरूरी है जिससे लोग अपनी जिन्दगी जी सके।

पर इस दुख का ऑटिज्म से भी कोई ताल्लुक नहीं है। असल में होता यह है कि आपने अत्यधिक रूप से किसी महत्वपूर्ण चीज की आशा की है और उसका बहुत खुशी और जोश से इन्तजार कर रहे हो और शायद कुछ पल के लिये आपको लगे कि वो खुशी आपको मिल भी गयी है। पर फिर शायद धीरे से, शायद अचानक आपकी पहचान में आया कि जिसका आपने अभी तक इतना इन्तजार किया था वो न हुआ है और



न आगे कभी होगा। आपके चाहे अन्य जितने भी सामान्य / नान ऑटिस्टिक बच्चे हो जाये इस तथ्य को आप कभी नहीं बदल पाते कि इस बार आपने अपनी योजना अनुसार जिस बच्चे की आशा व उम्मीद करी व सपने देखे वो आपको कभी नहीं मिला।

यह ठीक उसी प्रकार का अनुभव है जो एक मां बाप को एक मृत शिशु पैदा होने पर होता है या उनको बच्चे को बहुत ही कम देर के लिए पकड़ने का मौका मिलता है वो बचपन में ही परलोक सिधार जाता है। यह बात ऑटिज्म होने को नहीं है। यह आशाओं के चूर-चूर होने की है। मैं यह सलाह देता हूँ कि इन का निवारण करने के लिए सबसे सही जगह ऑटिज्म संस्था न होकर ऑटिस्टिक बच्चों के मां बाप द्वारा मिल कर बनाये गए मदद और सलाह के ग्रुप हैं।

ऐसे लोगों के बीच मां बाप अपने इस दुख को स्वीकारने में ज्यादा समर्थ होते हैं। इस दुख को भूलने के लिये नहीं परन्तु इसको एक बीती घटना की तरह लेने के लिए जिससे कि यह दुख उन्हें जीवन के हर क्षण में परेशान न करे। वो इस बात को स्वीकारना सीख जाते हैं, कि उनका बच्चा जा चुका है और वो कभी वापस नहीं आयेगा। उससे भी ज्यादा महत्वपूर्ण है उनका यह सीख जाना कि उन्हे अपने खोये हुए बच्चे के दुख



बिना सम्भव नहीं है। ऑटिज्म के साथ एक त्रासदी जरूर आती है पर हमारे कारण नहीं बल्कि इसलिए जो हमारे साथ हुआ है और आप इस बात पर दुखी हो अगर आपको किसी बात का दुख ही मानना है तो पर दुखी और शोकायुक्त होने से बेहतर है कि आप इस बात से इतने पागल हो जाए और इसके लिए कुछ सार्थक कर डालें। दुश्वान्तघटना हमारा ऑटिस्टिक होना नहीं है बल्कि इस दुनिया में हमारे लिए कोई जगह न होना है। और जगह हो भी कैसे सकती है जब हमें इस दुनिया में लाने वाले हमारे अपने माता पिता हमारे जीवन पर शोक बना रहे हैं। आप एक नजर अपने ऑटिस्टिक बच्चे पर डाले और एक मिनट खुद से बात करे कि वह बच्चा क्या नहीं है। खुद से सोंचे यह मेरा योजनाबद्ध व आशा किया हुआ बच्चा नहीं है। यह वो बच्चा नहीं है। जिसका मैंने अपनी कोख में 9 महीने इन्तजार किया और उसके पैदा होने में कितने घंटों की प्रसव पीड़ा सही। यह वो बच्चा नहीं है जिसके लिए मैंने कितनी योजनायें बनायी अपने तर्जुबे बांटने की। वो बच्चा तो आया ही नहीं। यह वो बच्चा है ही नहीं।

को अपने जीवित बच्चे पर हावी नहीं होने देना है। यह तब और भी जरूरी हो जाता है जब नया जीवन उस समय जन्मा हो जब हम अपने गुजरे हुए बच्चे का शोक मना रहे हैं।

आपने बच्चे को ऑटिज्म के तहत नहीं खोया है। आपने उसको इसलिए खोया है क्योंकि जिस बच्चे की आप को आशा व इन्तजार था वो तो आया ही नहीं इसमें उस ऑटिस्टिक बच्चे के जीवन का कोई दोष ही नहीं है। और आपके इस दुख का बोझ हमारे उपर नहीं होना चाहिए। हमें ऐसे परिवारों की जरूरत है और हम ऐसे परिवारों के योग्य हैं जो हमें देखें हमारी कद्र करें न कि ऐसे परिवार जिन की धुंधली दृष्टि ऐसी परछाई के लिये है जो कभी थी ही नहीं। आप शोक मनायें, पर अपने खोये हुए सपनों के लिए न कि हमारे लिए। हम जिन्दा है। अब जीती जागती असलियत है। और हम आपका इंतजार कर रहे हैं।

मेरे दृष्टिकोण से इन्हीं बातों पर गौर करने के लिए ऑटिज्म समाज होना चाहिए। न कि इस बात पर शोक मनाने के लिए जो है ही नहीं, पर उस चीज को अच्छे से समझने का जो असलियत है हमें उसकी जरूरत है। हमें आपकी मदद और हमें समझने की जरूरत है। आपकी दुनिया हमारे लिये बहुत खुली नहीं है और हमारा इसमें जीवनयापन करना आप की मदद के

फिर जाये और जो कुछ शोक मनाना है मनाये, अपने ऑटिस्टिक बच्चे से दूर जाकर और चीजों को उनके हाल पर छोड़ना सीखना शुरू करें।

जब आपने चीजों को स्वीकारना शुरू कर दिया हो वापस आये और आपने ऑटिस्टिक बच्चे को फिर से देखें और खुद से कहें यह मेरा आशा किया हुआ योजना बद्ध बच्चा नहीं है। यह एक दूसरे ग्रह का बच्चा है जो गलती से मेरी जिंदगी में अपने प्रकार के ख्याल रखने वाले मां बाप के बिना आ गया है। मुझे नहीं पता कि यह कौन है या इसका आगे क्या होगा। पर मुझे पता है यह एक अजनबी दुनिया में बिना मां बाप के भटकता हुआ बच्चा है। इसे पढ़ाये उसके लिए उसकी व्याख्या करने वाला और अभिवक्ता बनें। और क्योंकि यह दूसरे ग्रह का बच्चा मेरी जिन्दगी में आ गया है तो यह कार्य मेरा है अगर मुझे इस बच्चे का साथ चाहिए।

अगर यह सम्भावना आपको जागृत करती है तब आप हमारा साथ मजबूती और दृढ़ निश्चय में आशा और खुशी से दें।

पूरी जिन्दगी के साहासिक कार्य का बीड़ा उठाना आपके आगे है।



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