

autism network

APRIL 2019 VOL.14 ISSUE 1



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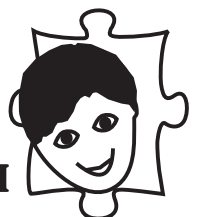
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ACTION FOR AUTISM



autism network

April 2019

VOL 14 ISSUE 1

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

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YOUR CONTRIBUTIONS

Do you have any comments, suggestions to offer? Information and experience to share? We look forward to our readers' participation. Send letters, articles, illustrations to: The Editor, Autism Network at the above given address or E-mail: actionforautism@gmail.com

Editor: Merry Barua

Associate Editor: Indrani Basu

Editorial Board: Dr Nidhi Singhal, Preeti Siwach, Sudhanshu Grover, Dr Vibha Krishnamurthy, Shubhangi Vaidya

Design & Production: Bindu Badshah, Sudhir Pillai

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

'The Family'

by Shravya Gahlot, 10 years old, from Gurgaon

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Website: <http://www.autism-india.org>

Helpline Email: helpline.afa@gmail.com

PAGE ONE

On this the 25th year of the official existence of Action For Autism (unofficially we are closer to 30, shhh!), as we ready to go to press, one of the largest chains of hypermarkets in India has decided to embrace autism awareness. Named 'Quiet Hour', the event is planned to launch on 1 April, when 22 of their stores across India, are set to go autism-friendly.

The effort will include sensitising over a thousand of their stores' team members across India, making aware other shoppers who will not just get to see many more individuals with autism shopping or accompanying their families, but also be exposed to the hypermarket staff's positive interaction with autistic visitors.

There are a staggering number of other events planned for the month of April which has now come to be observed as Autism month the world over. Across the country there are shows, walks, marathons, culinary events, art exhibitions, performances, seminars, conferences and workshops to just name a few. In years to come as more centres offering specialised services come up and more people come together to form organisations, the number of events will increase and multiply. And indeed, they must. It will require very many more years of very many more events and knocking on very many more doors for awareness of the condition to reach acceptable levels. Though what can be termed as acceptable is a moot point!

More people have heard of autism, though they may not know what that means. So, there is indeed much to be thankful for. And yet, after many years of efforts by multiple entities, there appears to merely be a dent in the stigma and myths and misinformation surrounding autism. Certainly, myths and misinformation do not disappear with a 'poof' after 'x' number of awareness events. But their persistence serves to remind us that awareness is a long hard haul.

There has been much posting and reposting on social media of the UN theme for World Autism Awareness Day 2019 '**Assistive Technologies, Active Participation.**' Yet all of those same people do not give access to assistive tools and strategies to their children and wards with autism.

After all, there is awareness, and there is awareness! There is positive awareness. And there is the kind of

awareness one can do without. As long as there is stigma, awareness will be about autism as a 'life-threatening' 'disease' that is 'tragic', 'soul-destroying', about people with autism who are 'violent' and 'aggressive', and about 'suffering', 'saint-like', 'warrior' parents who are 'martyrs' in the 'war' 'against' autism.

No amount of people-first language can make a difference when the premise is one of negativity and othering. Neither, one must add, does the pedestaling of people with autism, calling them saints, special children of God, advanced evolutionary beings, etc help in dispelling stigma. And the greater the stigma, the more the inclination towards woolly 'research' findings promoted by uninformed media hacks, and the desire to chase after 'professionals' selling therapies that promise to cure autism.

The more we create awareness, the more we find that it is acceptance that is the key. One may or may not be deeply aware of autism, but if one is accepting of differences, if one is willing to make place in society for those who are different, without attempting to fix them to fit a chimeric ideal of 'normal', then awareness can even take a backseat. That is when the 'label' of autism will become irrelevant not because the label is discriminatory, but because the environment is no longer discriminatory. Then can we truly say "Aaleej well".

Wishing everyone success in our efforts during World Autism Acceptance Month.

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• LEAD ARTICLE •

Five Ways to Damage an Autistic Child Without Even Knowing

By Chris Bonello

Yep, uncomfortable title. But sadly, these are subjects that I feel we have a responsibility to talk about. Today, I'm going to share some habits that I've seen in a wide variety of contexts: some of them in my career in education (mainstream and special), some of them from people dealing with me as a man with Asperger Syndrome, some of them I've seen in the form of internet comments, and so on. Although often done unknowingly- hence the article title- these habits have the potential to do harm.

This is a tricky subject, I know, but these are five mistakes that need discussing. You'd be surprised how easy it is to make them.

Rather importantly, this is not specifically a guide for parents. (Not being a parent myself, I don't claim to have any insight specific to parenting.) It is a guide for anyone who has any contact with a young and/or vulnerable autistic person, whether they are parents, teachers, teaching assistants, family friends, and so on.

Ok, deep breath....

1) Talk about them like they're not in the room.

It really is surprising how many people I've seen doing this. The assumption is made, often without the speaker realising, that since the autistic person is looking away in silence, they must not be listening.

Which, of course, is quite a harsh assumption to make about people who simply communicate differently.



Partly because it would be disrespectful to talk about any non-autistic person as if they weren't in the room (and therefore, why on Earth would it be different for autistic people?), and partly because of the

things that can end up being said if you think they're not listening. I'll let this badly-drawn picture do the talking. *For the record, people do this with babies and very*

young children too. I would say the same applies. Even if they're not talking to you, always make the assumption that they're listening.

When I worked in special education, on principle I always talked to the nonverbal students. I never expected any kind of communication in response, because that wasn't the point. The point was to give them the experience of social communication.

For example, one lunchtime I was sat outside with a twelve-year-old lad who I'm going to pretend was called James. I was talking to him, mainly about how much the weather sucked (being an Aspie I'd much rather talk about dinosaurs or Sonic the Hedgehog than endure small talk, but I'm British so the weather is our typical go-to conversation.). I was also quite sad that day for reasons I won't go into, but I carried on talking to him despite not being in a talking mood. After all, his needs took priority over mine.

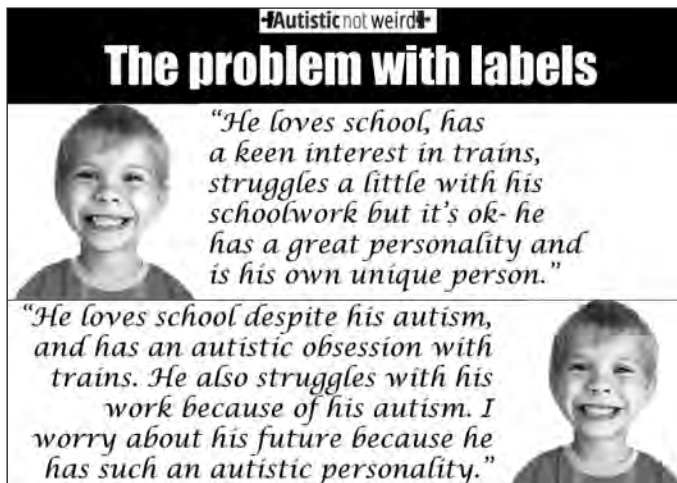
As I talked, he said nothing, did not look at me, and gave me no indication that he was listening. Nonetheless, at one point I simply said, *"I like you, James. You're a nice lad."*

I didn't expect him to go from staring-into-space mode to suddenly looking me straight in the eyes, grabbing my shoulder and laughing really really loud, but that's what he did. Because guess what? *He was listening!*

Everyone communicates, some just in their own way. And listening is part of communication too.

2) Assume that most of their identity is down to autism rather than personality choices.

The phrase "yeah, that's his autism" is one I have heard far too many times. Even in professional circles. Yes, our autism influences us. Yes, it often gives us particular habits or interests unique to us. But to say it's "just his/her autism" is implying that we don't get any say in the matter.



I remember when I was running a chess tournament in a special school (it was amazing- the students got more from that one tournament than in any of the sixteen I'd run in mainstream). One crucial match was scheduled for a day when the school was doing a special event. Throughout the day there was only one opportunity for this game to be played... and ten minutes before the start, one of the students got a migraine and had to go home.

This stressed me out because I was relying on that match's result so I could drive straight to the trophy centre after work and have the prizes engraved (and therefore get them handed out before the end of term). And I'm fairly transparent, so people could tell I was bothered by something.

When I told one of my colleagues I was feeling stressed, she immediately asked me "oh dear- is it because today's been a break from routine?" No, it wasn't. (And speaking as a former primary school teacher, you should only be in the classroom if you can adapt reasonably well to unexpected change.)

Some other examples:

- I'm good at maths because I put the effort into learning. It's not "just my autism".
- I dislike small talk because there are more useful, funny, important or heartfelt things to talk about. It's not "just my autism".
- I'm honest with people because it's the right way to be. It's not "just my autism".
- I love chess because... well, I've written a whole article about it (<https://autisticnotweird.com/10-reasons-for-chess>). It's not "just my autism".
- **I run a sizeable Facebook community** because I'm driven to guide others who are affected by the issue.

And there are a hundred parts of my personality that drive me to do that - not just my autism.

- And you know what, even my anxiety isn't autism-related. It was done to me.

That said, there is a balance. Like I said, autism does have an impact on us. I used to watch *Independence Day* on video over and over and over and over again when I was twelve, and you could validly say that this habit was influenced by my Asperger's. But the main reason it happened was because *Independence Day* was an awesome movie! (At least, to me at twelve it was.)

Moral of the story? Regardless of how strongly autism influences the child in question, don't forget that they have a personality too.

3) Assume their perspectives are skewed and unreliable.

This is Morgan. Brilliant lad, and I promise I'm not just saying that because his brain's so similar to mine. You may know him from the Facebook page: Planet Morgan Aspie Superhero.



Disclaimer: I showed this section to Morgan whilst seeking his permission to publish it, and I asked him for no-holds-barred honest feedback about what he was comfortable with me writing.

His only demand was that I change the picture at the bottom to something cooler.

Morgan's Asperger Syndrome is, in my opinion, not a significant problem for him. In fact (although I may be biased here), I think his Asperger's actually just makes him awesome.

Sadly, it's his severe anxiety that presents him with his biggest challenge. He no longer attends school because the word alone makes him afraid. And, in a story all too familiar to parents of autistic children, the source of this anxiety was a devastating amount of bullying throughout life at one of his previous schools. Unfortunately, this bullying was allegedly not addressed effectively. (And yes, I used the word "allegedly". This is no indication of my personal beliefs, but simply mindful of the fact that having a website as well-read as *Autistic Not Weird* - I have a duty to write responsibly.)

According to those closest to him, the bullying continued because each incident was seen as Morgan having a skewed perspective. After all, he had an autistic spectrum disorder and didn't see social situations like the rest of the children. Therefore, the attitude was allegedly taken that if all the other children in the class were ok and Morgan was not, it was likely to be his 'faulty' perspective at play.

Let's leave aside the little fact that children with special needs are significantly more likely to suffer from bullying by their peers. (And that combining this with repeated disbelief has caused untold damage in the past - damage that makes even Morgan's experiences seem tame.)

And you know what, let's pretend for a moment that people are correct in saying that autistic people are less reliable. (Spoiler alert: they're not. When a crime happens, you *want* a witness with an Aspie memory close by! But let's just pretend otherwise.)

Even then, the autistic person's anxieties are *still* real, and they *still* need to be addressed.

Oh, and **if bullying or abuse is reported by a distressed child - autistic or not - it *must* be taken seriously.**

Britain is still dealing with the fallout of a whole generation of abused children who grew up being ignored: literally thousands of victims who had to wait until the twenty-first century to be believed. Things are a lot better now than they used to be, but disbelieving a child simply because of their neurological differences is not only damaging to their self-esteem: it's putting them at very serious risk.



(Morgan *is* safe now, by the way, and he has been for a while. In fact, given time to grow up and the right opportunities to

learn, he'll be the perfect person to help and guide vulnerable people - and I've made sure to tell him so.) *I'm aware that point #3 may be better made if I didn't have such happy pictures of him here. But I won't have him looking sad here. Not a chance.*

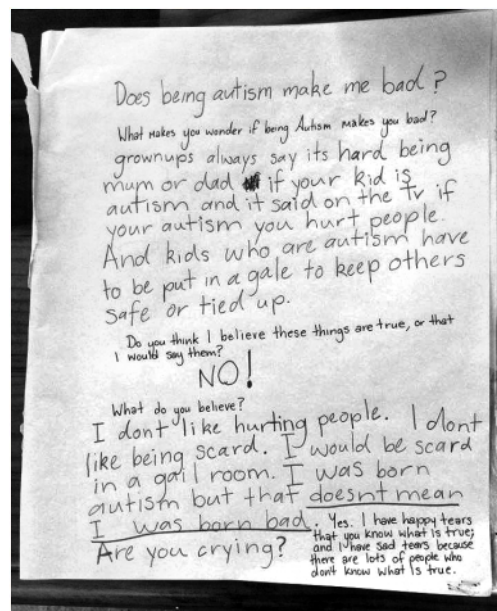
4) Allow the world to teach them that autism is A Bad Thing.

Right from the moment we hear about it, we're instructed to believe that autism is A Bad Thing. That's

why people like me get so many messages from worried parents, asking what they're supposed to do post-diagnosis because they don't know anything about autism. But their worries reveal that they *do* know one thing about it: **it's supposed to be bad.**

Speaking as an autistic man, my opinions differ somewhat. But I understand their panic completely. The unknown can be very scary if you feel something's bad but you don't know why. (For example, everyone feels a chill in their spine when their boss asks "Can I have a word with you?")

Now, non-autistic people seeing only the negatives is counter productive enough. But imagine the damage that gets done when *autistic people themselves* are led to believe that their autism makes them deficient. Heck, combine this point with #1 and talk about how terrible autism is right in front of them, and watch what happens to their self-esteem! I'll give two examples that struck me greatly. First of all, there's Cadence. Cadence's family has their own Facebook page (<https://www.facebook.com/I-am-Cadence-1032108113468280>) and this picture below went sort-of-viral not long ago.



You may have already spotted the most tragic sentence (in my opinion), but I'll quote it anyway:

Grownups always say its hard being mum or dad if your kid is autism.

Looking at their page, it becomes obvious that Mum and Dad are doing a sterling job as parents. But other people - the TV, and perhaps even society itself - have led

Cadence to believe that a large part of her personality is *A Bad Thing*. Which is absolutely not fair.

Secondly there's the story *about a six-year-old Californian boy being comforted by Santa, after asking whether he'll be on the naughty list because of his autism* (<http://6abc.com/news/boy-afraid-hell-be-on-naughty-list-because-of-his-autism/1114282/>). Given Santa's reaction, most people thought of this as a sweet story when they read this. But me personally - despite my reputed positivity about pretty much everything - I shuddered.

I dream of the day when six-year-old children won't have to live with the baseless assumption that being autistic is enough to land them on the naughty list. (Actually, wait - that assumption isn't baseless at all. It's based on what they're made to feel by non-autistic people.)

And finally... a point which may rub a couple of people the wrong way, but it *has* to be said.

5) Let them find out that you “love them but hate their autism”.

This point is a step up from #4, only far more personal. And yes, I am well aware that lots of people feel this way, parents in particular. Some have even written articles and blog posts entitled “why I love my child but hate his/her autism”. And I get it - watching vulnerable children struggle is a dreadful experience, and even more so if they're your own. Hating the condition that holds them back is quite a natural response.

But bloody hell, it can be damaging.

Why? Well, imagine that a child's mother makes the mistake of saying the sentence “I love my child but hate their autism” in a place where the child can overhear her. The child will take one very significant message from that, and one which will *definitely* stick with them: “Wow... *a part of me is so dreadful that even my mother can't love it.*”

Everyone struggles with their personal demons. Everyone. And some people only cope with their demons based on how well other people *let* them cope.

When someone knows you hate their autism, you are bringing those demons to life. You are giving their demons a name, and you are giving those demons authority.

More than anything, you are saying that the child is *right* to be fearful and hateful towards a large part of themselves.

Again, I get it. I've watched so many struggling children that I've had to learn how to steamroll over the physical hurt I feel for them (not that it always works, of course). And if there's a stand-out factor that is causing them harm or lost potential, of course I want to address it. But I refuse to *hate* part of a child.

If you've reached the end of this and still “love the child but hate their autism”, that's your right to do so. But please, for the child's sake, *please* never let them find out.

So to summarise:

Instead of talking about them as if they're not in the room:

- Remember that they can hear you, and always assume they are listening.

Instead of assuming a person's autism defines their character:

- Remember that they get to make personality choices just like non-autistic people.

Instead of believing that their perspective makes them less reliable:

- Remember that you're actually skewing your *own* perspective on autism by making this assumption.

Instead of allowing the world to teach them their autism is *A Bad Thing*:

- Tackle the problem head-on and remind them how awesome they are.

Instead of loving the child but hating their autism:

- Love the child.

Hope this helps some readers. Like I said, some of these mistakes are surprisingly easy to make - but then again, plenty of them are easy to avoid.

Since I wrote this article, it's become by far the most read on Autistic Not Weird....*And finally, there's an extension to this article containing points 6-10!*

Additional ways to damage autistic children without even knowing:

Footnote: People have offered other suggestions too, which are also good enough to share. I'll list them all here.

- 6) Repress their special interests, since they often use these to communicate and cope with stress.** *(Stephanie Keyes)*
- 7) Only focus on bad behaviour whilst ignoring good behaviour.** *(Stephanie Keyes)*
- 8) Fighting all their battles for them, with the automatic assumption that they can't do anything independently.** *(Adapted from a suggestion by Eric Van Gucht)*
- 9) Leaving your child undiagnosed and refusing to get him the proper help he needs because of the stigma an autistic child will bring you.** *(Adapted from a suggestion by Kristin Pedigo)*
- 10) Treat your child as if their autism-specific struggles are no different to what everyone else faces in life, which means that if they find their issues difficult it's inferiority rather than difference.** *(Adapted from Audre C- Yes, autistic and non-autistic children have several struggles in common - more than we often think - but it's so important to recognise when their issues need individualised help.)*
- 11) Talk about a "cure" for it, implying that it needs to be cured, and because it needs to be cured, it is bad.** *(Pieter Dykhuis, age 14)*

• This article was first published in <http://autisticnotweird.com/five-ways-to-damage/> and has been reprinted with the permission of the author

Chris Bonnello is a former primary school teacher with Asperger Syndrome who has also worked in special education, now an award-winning writer and international speaker.

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



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Demystifying Budgeting for NGOs – A Step by Step Guide

By Nina Munshi

‘A budget is telling your money where to go instead of wondering where it went.’

Most people with little or no experience in finance or accounting tend to get overwhelmed at the thought of working on a budget either for their program, department or organization. They think it is the finance team’s responsibility, but the best person to make a budget is the person who plans to spend the money.

Budgeting is nothing more than deciding the strategy for your program or organization; how many more beneficiaries you want to reach, which geographies you want to expand to, new programs you want to launch etc. All these cannot be achieved without planning for the right financial resources.

Why Do You Need a Budget?

- To help the organization or program set strategic direction and meet its goals. Budgets help clearly define the short term (1 year) and long term (3-5 years) plan and can be used to articulate organizational goals e.g. set targets to achieve a surplus, plan for expansion of regional offices, etc.
- To define plans for various programs and identify ways to make them sustainable. Program Heads can decide on the expansion of their programs, number of beneficiaries they would like to reach, additional benefits they would like to roll out to the communities, etc.
- To recruit the right set of employees to support the organization/program. The success of an organization/program is dependent on recruiting the right number and profile of people.

Budgeting helps you decide how many people to hire of what profile and at what cost to ensure program success

- To raise the funds required to achieve desired outcomes. Fundraisers can plan their fundraising strategy based on the funds required by the programs and

the organization. A budget helps identify how much money is required by which program and by when.

- It gives clarity of thinking; a budget provides structure to how financial information is presented and reviewed within and outside the organization.

This structure can be replicated in reporting to donors, providing the transparency that most donors love.

BENEFITS OF BUDGETING

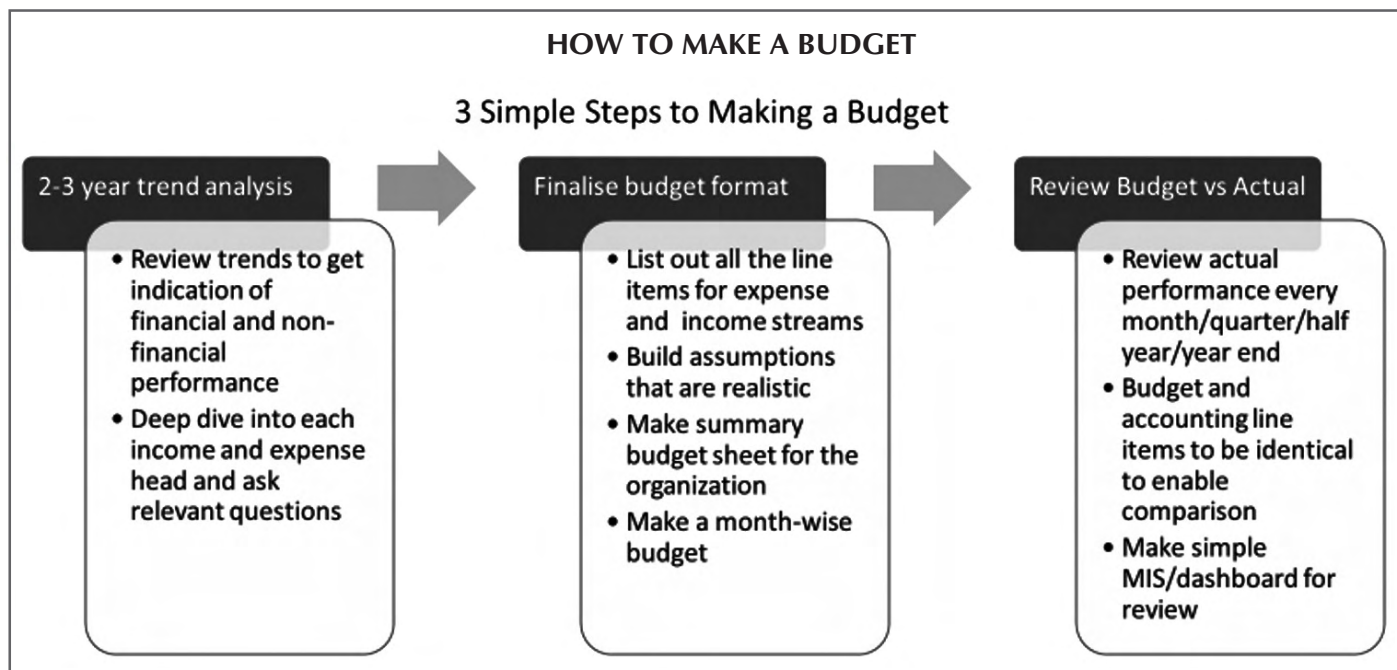
- Enable organizations to set strategic direction
 - Define plans for programs to make them sustainable
 - Plan recruitment of employees
 - Raise funds required to achieve desired outcomes
- Provide structure to review and present financial information**

Who To Involve in the Budgeting Exercise?

- Making a budget is not just the job of the finance team. The people who will spend the money should be involved in drafting the budget. Program Heads and Department Heads should be responsible for their budget as they know their work best. Hence, they should decide what expenses they most definitely need to incur and what they can do without.

Similarly, the fundraising team should budget for the income they plan to generate. In fact, all the members of the organization should be involved in the drafting stage of the budget process.

- While program and department heads are responsible for drafting their budget, it is the Management Committee and Board’s responsibility to review the budget for the entire organization. They should decide the targets for the organization, review plans for each program and region before signing off on the final budget.



STEP 1 - Review 2-3 Year Trends

- Before you begin budgeting for a new year, review past trends over a period of 2-3 years. It will give you a clear indication of how each of the programs, regions and the organisation is performing.
- A trend analysis would throw light on things like - is your expense increasing over the years, which specific heads account for the highest share of expense, is income increasing in line with expense, how many beneficiaries reached year on year. The trend will showcase not just financial performance but also outcomes achieved viz a vis financial performance.

This analysis helps deep dive into each expense or income head and ask relevant questions.

STEP 2 – Finalise the Budget Format

- Based on the trend analysis, list out the line items for direct, indirect expense as well as income streams for each of the programs and profit centres. The 3-year analysis will also help identify past trends which in turn will help build assumptions which are realistic and achievable for current year's budget
- Make a summary budget sheet for the entire organization, which is a collation of numbers from each of the programs/departments/profit centres. This will help define the entire organization's performance (i.e., will there be an overall surplus or deficit)

- The budget should be made for each month of the fiscal year and should not just be a total number for the year.

STEP 3 – Review of Budget vs Actual

- It's not- just make it, file it, forget it! Actual performance needs to be reviewed against the budget every month, quarter and half year. This allows for any course correction if required mid-year
- Accounting line items have to be identical to the budget line items, only then can you compare actual performance vs the budget

- Make a simple dash board/Management Information System (MIS) format that gives summary of the income, expense, surplus/deficit numbers of each program/region and of the entire organisation.

This dashboard should be accessible to the Management Committee and should be updated at the end of every month

TIPS

- Once the short-term plan or budget (1-year) has been completed and the team is comfortable with the budgeting exercise the next step is to create in a long-term plan (i.e., a 3-year plan). This will allow the team to have a long-term view of the program and organization.

- Always write the assumptions in detail for each income/expense line item. The test is for another person to read it and understand what it means.
- Account for all expenses; direct and indirect.
- Research prices and costs and base them on previous year's levels, don't guess or make up expenses.
- Give yourself at least two full months to complete the budgeting exercise, so start well in time to be ready before the start of the new year.
- Check calculations twice to ensure there are no errors in formulas or calculations.

Restructuring the Budgeting Process - A Case Study

Action for Autism (AFA) a Delhi based NGO working with autistic individuals, wanted to adopt a rigorous and structured approach to the organisation's financial planning and review process.

They reached out to Theia Impact for help in designing and piloting a restructured budgeting process. All the heads of programs and departments were an integral part this initiative. After going through a rigorous process of trend analysis and restructuring the budgeting process, AFA are happy that the entire team talks the language of numbers and sustainability.

Merry Barua CEO of AFA said "At AFA we were restructuring our budgeting processes and had Theia Impact consult with us on this. We went through a rigorous budgeting exercise that included in particular all the program heads. We are extremely satisfied with the outcome. The exercise gave us much-needed clarity of how each of our programs was performing financially. The exercise is helping us tighten programs, decide on staff requirements, bring about changes to make the programs financially viable including planning our fund raising. This has given direction to the entire team and we are all pulling together to move ahead."

Nina Munshi has been a supporter of social causes for over a decade. She is the founder of Theia Impact helps develop strategy, build capacity and increase outreach of NGOs and social enterprises. This results in acceleration of their pace of work with impactful outcomes. Before this she was responsible for setting up CRY in UK. Nina is a marketing and advertising professional having worked with organisations like Grey Worldwide, Lowe Lintas, HSBC and Hutch Telecom. You can contact Theia Impact at nina.munshi@theia-impact.com

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Causes of Autism

An Excerpt from:

Understanding Autism: A Guide for Parents and Teachers

By Onita Nakra

“Don’t think that there’s different, better child ‘hiding behind the autism. This is your child. Love the child in front of you. Encourage his strength, celebrate his quirks and improve his weaknesses, the way you would with any child”

- Claire ScovellLaZebnik, author,
Growing up on the Spectrum

Introduction

It is easy to deal with a medical condition when the cause is known and established, but in autism, there is no specific cause that one can confidently point to. This makes it very difficult for parents as they ‘shoot in the dark’ trying to use different treatments that may help their child. Every parent and educator would like to know that causes autism at least to stop the feelings of guilt and confusion.

...It is something I did wrong when I was pregnant?

...Should we have had another child?

...Was my baby lonely when I started working?

These are just some of questions that haunt parents. We definitely know that autism is not caused by poor parenting or by an emotionally traumatic event such as witnessing a car accident. Unfortunately, till date, there is still no *confirmed* causal factor, unlike other conditions such as Down’s syndrome where we know for certain that is caused by an extra chromosome. The literature on autism is replete with articles about ‘possible causes,’ but parents should look for objective, scientific supporting data. What we do know for certain is that autism spectrum disorders are most probably caused by multiple factors interacting in complex ways, i.e., genes, environment and factors impacting brain development.

The Role of Genetics

Research in the area of genetics is an ongoing process and holds some promise. We still don’t know whether a single gene causes autism or a group of genes. No single gene has been identified as responsible for autism, and most genetic researchers believe that multiple genes are involved (International Molecular Genetics Study of Autism Consortium, 1998). Scientists have discovered the presence of a gene called FMR1 that result in the developmental disorder quite similar to autism – fragile X syndrome. However, fragile X syndrome causes intellectual delays unlike children with

autism who have normal intellectual ability for the most part.

A few studies have begun to find some cases of autism linked to maternal exposure to certain viruses (measles, mumps, rubella, herpes, syphilis, cytomegalovirus and toxoplasmosis) and chemicals (thalidomide and valproic acid) . However, these account is very small proportion of all cases. Some large-scale studies have been set up to begin to understand the contribution of environmental factors to the etiology of autism, for instance, the CHARGE(Childhood Autism Risk From Genetics and Environment) studies at university of California- Davis, but research is still in the initial stages.

Brain Research

It is widely accepted that atypical brain development underlies the development of the observable symptoms of autism. How genes and the environment interact to cause the brain to begin developing differently is still being debated. What is clear is that these differences in the brain development can be traced to either before birth or very soon after birth even though the behavioral and social signs of autism tend to be unobservable until after 18 months of life. The exact nature of the brain differences is not clear either.

Studies have shown differential development in many brain areas including the frontal and temporal lobes, the cerebellum and the sub- cortical amygdala and hippocampus. The scarcity of evidence , methodological challenges and conflicting findings have not yet allowed precise conclusions to be drawn about either the specific brain regions affected or the mechanism of development that lead to observed brain differences. Other studies point to the patterns of connectivity between and within brain areas as the issue (e.g., Courchesne and Pierce, 2005) rather than specific loci while other researchers focus on specific types of neurons (e.g., mirror neurons) or paterens of neuronal activation (Bernier et al., 2007)

Attwood points out: “Research studies have clearly established that Asperger’s syndrome is due to a dysfunction of specific structures and systems in the brain.” Research studies have used brain-imaging technology to confirm that Asperger’s syndrome is associated with a dysfunction of ‘the social brain’ there is ‘weak connectivity’ between certain components of the brain (such as the amygdala, basal ganglia, cerebellum, etc.). Some structures are wired differently causing the social deficits seen in poor social reasoning, empathy, communication and thinking.

What is the reason for this different neurological wiring? The reason for this difference is probably again due to genetic factors, Asperger noticed a shadow of the syndrome in the parents (particularly fathers) of the children he saw and proposed the condition could be inherited. Research after that has indicated that using strict diagnostic criteria for Asperger’s syndrome, about 20 percent of fathers and 5 percent of mothers of a child with Asperger’s syndrome have the syndrome themselves (Volkmar et al., 1998.). Most of them have not been formally diagnosed themselves. Looking further into the genetic pool of extended families (second and third-degree relatives), more than two-thirds of children with Asperger’s syndrome have a relative with similar characteristics, which again suggests there is a strong genetic factors.

Parents frequently wonder whether a difficult pregnancy or birth could have caused their child to have autism. This is difficult to determine. Cedarlund and Gillberg (2004) point out that pregnancy complication have been identified in 31 percent of children with Asperger’s syndrome, peri- natal or birth complications in about 60 percent. However, no single factor has been identified to link complication in pregnancy with signs of autism.

The Role of the Environment

Pollutants and chemicals in the environment cause Autism

Toxic pollution of water, food and the air is a reality of the 21st century. Many scientists believe that chemicals (preservatives and pesticides) added to food can damage brain tissue. The immune system, especially of newborn babies and babies in the womb, is delicate and easily impacted by harmful chemicals. Toxic chemicals likely cause injury to the developing human brain either through direct toxicity or interactions with the genome. The significance of early chemical exposures for children’s health is not yet fully understood, and we still

don’t know why *all* children exposed to environmental pollutants don’t get autism.

I have summarized below some popular (but unproven) theories about other possible cause of autism.

Some Common Theories with Little Scientific Evidence

Vaccinations cause Autism

In the last decade or so, a lot of press has been directed against the use of vaccinations in infants. There were several reasons for this. Parents believed that the regression they witnessed in their children between the ages 12- 24 months was somehow linked to their child receiving the MMR (measles, mumps, and rubella) vaccination around the age of one year or later. The MMR vaccine is believed to inject live viruses into the muscles and then causing inflammation in the gut and brain. Vaccination companies were accused of being hand in glove with doctors to hide the truth. Scientists say autism symptoms that arise around the same time are an unrelated chance occurrence. A study from Great Britain in 2008 trying to prove this ‘link between autism and the MMR’ was discovered to have been falsified by the lead author, who has subsequently lost his license to practice medicine.

The decision not to vaccinate a child is controversial. Many parents choose not to vaccinate their child against measles, mumps and rubella, especially if their first child was diagnosed with autism. This can lead to more serious health consequences both for the individual child and his peers, should he enter school unvaccinated. Some parents ‘space out’ the vaccine so that their child receives immunization spread over intervals. Doctors generally recommend that the child should be healthy before receiving any vaccinations – parents should ensure their child is not running a fever or a cold. There has also been a lot of discussion and debate about the mercury contained in vaccinations. Between the last 1980s and 2002, babies received many combined doses of vaccinations containing large quantities of mercury. Parents in the USA protested and demanded that mercury is removed from vaccines.

This process took time, and it is safe to say that since 2001, no new vaccine licensed by FDA (USA) for use in children has contained thimerosal as a preservative and all vaccines routinely recommended by CDC (Center for Disease Control, USA) for children younger than 6 years of age have been thimerosal- free, or contain only trace

amounts of thimerosal , except for some formulations of influenza vaccine.

It is important to note that:

- Most children are not affected after they receive the MMR vaccine.
- Some children show signs of autism in very early infancy before they have been exposed to antibiotics or vaccines.

Food Allergies and Leaky Guts Syndrome cause Autism
Sears and other biomedical doctors (Sears, 2010) make a strong argument that food allergies and use of antibiotics irritate the guts and immune systems of infants. Antibiotics kill the healthy probiotic bacteria, which help to increase children's resistance to diseases and increase irritation in the intestinal tract. Intestinal irritations create a situation called leaky gut. According to this theory, the gut stops secreting the digestive enzymes that are supposed to be secreted. The lining of the gut becomes leaky- its filtering ability is reduced, so food toxins and other proteins are absorbed easily, destroying the child's immune system. Another result of this intestinal dysfunction is that the body can become deficient in vitamin B and D, minerals (zinc and calcium) and certain amino acids.

Sears and other biomedical doctors believe that children with autism lack certain intestinal enzymes, which makes it difficult for them to digest milk, gluten and wheat. They recommend removal of all dairy, wheat and gluten products from the diet. On the other hand, there is little research to support that such a nutritional approach is helpful.

In addition, the following points must be noted:

- Not all children with autism have intestinal problems.
- Treatments such as withdrawing milk, dairy, wheat, gluten do not reduce the autistic features.
- Children with autism tend to have picky eating habits, so any withdrawal of essential nutrients from their diet must be carefully monitored by a nutritionist.

It is important for parents to understand that it may take years before science can identify the exact cause of autism. There is a multitude of theories, difficult to unravel. It is far better to focus on early identification and seek interventions than worry about the exact cause. Undoubtedly, as a parent, one wishes to know more about what caused the condition, but until we have more clarity and empirical evidence, it's best not to jump to hasty conclusions.

Quick Summary

There is increasing suspicion among researchers that autism does not have a single cause but is probably caused by multiple factors interacting in complex ways, i.e., genes, environment and factors impacting brain development. The genetics of autism are complex, as more than one gene may be involved. Several theories based on environmental factors have been proposed.

Some of these theories focus on prenatal environmental factors, such as agents that cause birth defects; other focus on the post- natal factors include gastrointestinal or immune system abnormalities , allergies and exposure of children to drugs, vaccines, infection, certain foods or heavy metals.the evidence for these risk factors is anecdotal and has not been confirmed by reliable studies. Brain-imaging technology and neuropsychological studies show that there is some dysfunction of specific structure in the brain.

REFERENCE

1. Courchesne E, and Pierce K. (2005). Why the frontal cortex in autism might be talking only to itself: local over-connectivity but long- distance disconnection. *Current opinion in neurobiology*. 15(2):225-30
2. R. Bernier, G. Dawson, S. Webb, M. Murias (2007). EEG mu rhythm and imitation impairments in individuals with autism spectrum disorder .In *brain and cognition*,64(3) 228-237
3. Attwood , T. (2015). The complete guide to Asperger's syndrome. London: Jessica Kingsley
4. Volkmar, F., Klin, A., and Pauls, D. (1998). Nosological and genetic aspects of Asperger syndrome. *Journal of autism and development disorder* 28, 457-463
5. Cedarlund,M. and Gillberg, C., (2004). 'one hundred males with asperger syndrome: a clinical study of background and associated factors .' *development medicine and child neurology* 46,652-661
6. Sears, R.W. (2010). The Autism book. Little, Brown & Company: New York

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सिटिमिंग 101, अथवा :

मैंने कैसे चिन्ता करना बन्द किया और सिटिम से प्यार किया

कस्टन लीन्डस्मिथ

अनुवाद – पूजा खन्ना

यह पूरी तरह से सामान्य है, परन्तु अधिकतर शर्मनाक ऐसी चीज जिसको दबाने के लिए हम अपने बच्चों को प्रोत्साहन देते हैं, अथवा निजी (प्राइवेट) में करने की सलाह। एक निरंतरता पर मौजूदा स्वास्थ्य से बुरी आदतों से, निंदा से, सिटिमिंग उतना ही विविध है जैसे कि मानवता है।

सिटिमिंग क्या है ?

सिटिमिंग – खुद को उत्तेजित करने का संक्षिप्त नाम – यह एक ऐसी परिभाषा है जिसे अभी तक शब्दकोष में जगह नहीं मिली है, हालांकि यह ऑटिज्म समुदाय में सबसे ज्यादा आमतौर पर समझी हुई परिभाषा है। मनोचिकित्सकों द्वारा स्टीरियोटाइप (रूढ़िबद्ध धारणा) बुलाया गया, सिटिमिंग “एक बार-बार दोहराने वाला शारीरिक संचार है जो एक अथवा अनेक चेतना को (सेन्सेस) विनियमित तरीके से उत्तेजित करता है” (मेरी पसन्दीदा परिभाषा, ऑटिज्म विकी से)

मैं पहले यह साफ करना चाहूंगी कि ‘सिटिम’ और ‘टिक’ एक जैसे/समान नहीं है। जहाँ सिटिम लयबद्ध और नियमित होती है, टिक्स गैर लयबद्ध और अचानक होती है। ऐसा कहे जाने के बाद मैंने तौरतेस (tourette's syndrome) वाले कई लोगों के साथ उपाख्यानों और घटना का विवरण बाँटा है और हमारी (गैर पेशेवर) सर्वसम्मति यह थी कि टिक्स और सिटिमस में बहुत कुछ समान दिखता है। दोनों को (कभी-कभी) रोका जा सकता है, यद्यपि उनको रोककर रखना बहुत कष्टप्रद महसूस होता है। जबकि ‘टिक’ को रोक कर रखना, छींक को रोक कर रखने के पास है, मैं कहूंगी कि सिटिम को रोककर रखने की तुलना एक खुजली को खरोचने से की जा सकती है

(अगर वह खुजली कभी जाये ही न और समय के साथ बढ़ती जाये जैसे एक मच्छर की नाक हमारे सांस में हो और वहां से छोड़ने का नाम ही न ले) जबकि सब लोग कभी-कभी सिटिम करते हैं, ऑटिस्टिक लोग अपने सामान्य जोड़ी दारों के मुकाबले अधिक ज्यादा बार करते हैं। चीजों को और दिलचस्प बनाने के लिए, ऑटिस्टिक लोग विशिष्ट व अनोखी तरह की सिटिमिंग पेश करते हैं।

सबसे प्रसिद्ध ऑटिज्म सिटिमिंग के प्रमानांकन को तीन मुख्य वर्ग में विभाजित किया जा सकता है।

- हाथ की सिटिमिंग

जिसमें हाथ को हल्के से लहराना, उँगली हिलाना और उंगली को कुलबुलाना शामिल है।

- शरीर की सिटिमिंग

जिसमें शरीर को आगे-पीछे हिलाना, गोलाई में घूमना और सर को झटकना शामिल है।

- आवाज की सिटिमिंग

जिसमें कराहना, चीखना और अलग-अलग तरीके का इकोलेलिया (शब्दों को वापस दोहराना) शामिल है।

जहाँ यह सब कुछ सबसे जाने-माने ऑटिस्टिक सिटिम है (और सबसे अधिक ध्यान हथियाने वाले भी)

सिटिमिंग एक विशेष व्यक्ति अथवा परिसिथित के अनुसार अविश्वसनीय रूप से विविध और अधिकतर अनोखी होती है और तरीकों के सिटिमस में यह शामिल है।

परन्तु यह सीमित नहीं है :

किसी लुप-झुप अथवा गोल घूमते हुए सामान को

घूरना, अलग-अलग बनावट की सतहों को मलना या छूना, वस्तुओं को चाटना अथवा चबाना, बालों को उँगली से घुमाना अथवा दुलारना, जोड़ों को चटकाना, पैरों से ठक-ठक करना और कोई किसी भी तरह की बार बार करने वाली, उत्तेजित करने वाली क्रियाएं।

सामान्य लोग भी सिटिम करते हैं। कुछ दर्शनीय सामान्य सिटिमस में संगीत की लय पर उंगली अथवा पैरों को ठक-ठक करना, चेहरे को तनाव में सहलाना रॉकिंग वाली कुर्सी में बैठ कर शरीर आगे-पीछे करना शामिल है।

जब मैं छोटी थी, मेरी सबसे पहले की और ध्यान देने योग्य सिटिम अंगूठा चूसना था (ज्यादातर मेरे मूल्यवान कंबल के खुरदरे कोनों को अपने उपरी होठों पर घिसना) और अपनी आँखों को मलना या दबाना।

मैं एक बार अपनी प्राथमिक विद्यालय की सुबह की मीटिंग में पूरे समय अपनी आँखें अपने घुटनों में कसकर दबाकर बैठी रही। अंधेरा मुझे शान्त करता था और दबाव बड़ा कड़क व आरामदायक महसूस हो रहा था। बाकी बच्चे, आलथी-पालथी मारकर बैठे हुए टीचर को देख रहे थे और जब तक पहले लेसन की छुट्टी नहीं हुए उन्होंने ध्यान नहीं दिया।

“कस्टर्न रो रही है” एक सहपाठी चिल्लाया। मैंने उपर देखा, जैसे यह सूचना पूरी कक्षा में फैल गयी और मेरे सहपाठियों के होठों से दोहरायी जाने लगी।

“नहीं मैं नहीं” मैंने विरोध किया। परन्तु दबाव ने मेरी आँखों को लाल कर दिया था और “मैं अपने घुटनों को अपनी आँखों में दबा रही थी” यह कहना एक टीचर के सामने जो मुझे उस समय पर शर्मिंदगी में आराम दिलाने की कोशिश कर रही थी। एक बचकानी व बुरी तरह से की योजना सुनाई दे रही थी।

ऑटिस्टिक लोग सिटिम क्यों करते हैं ?

मुझे यह सवाल बहुत बार ऑटिज्म वाले बच्चों के साथ काम करने वाली टीचरों से आता है। वो मुझसे मिलने को बहुत उत्साहित रहती है, एक ऑटिस्टिक व्यक्ति जो ऑटिस्टिक मानसिकता को समझने के काबिल है और वे जानना चाहते हैं कि यह विशिष्ट ऑटिस्टिक व्यवहार जो वो अपने छात्रों में देखते हैं क्यों है

और वो अधिकतर अचमभित हो जाते हैं कि इस सवाल का जवाब देना कितना आसान है।

मैं एक बार Maryland, Rockville में स्थित The Ivymount School के ए एस डी प्रोग्राम में गयी, हर तरह के अनुपयुक्त बच्चों के लिए एक शानदार जगह थी। कक्षाओं के बीच में चलते हुए मुझे याद है बच्चों का तमीज से तीन मिनट की ब्रेक के लिए मांगना, जब भी वो व्याकुल महसूस करते थे, अपनी मेज छोड़कर लचीली दबाव वाली वास्केट को पहनना अथवा किसी सिटिम वाले खिलौने के साथ खेलना अथवा वजन वाले कम्बल या तकिये के नीचे लेटना। मैंने सोचा, मैंने बचपन में ऐसी समझ वाला वातावरण पाने के लिए क्या क्या न दे दिया होता।

कुछ कक्षाओं का चक्कर लगाने के बाद, मैंने खुद को एक कम उम्र की शिक्षिकाओं के समूह के बीच उनके कई विद्यार्थियों के निराले किस्से सुनते हुए पाया। वे खासकर एक प्यारी सी छोटी सी बच्ची के बारे में बात कर रही थी जो उन सबकी बड़ी पसन्दीदा लग रही थी। टीचरें उसकी मासूमियत के किस्से याद करते हुए चीची करने वाली आवाज से बोल रही थी। उस बच्ची के गुलाबी गाल, उसकी चमकदार आँखें, उसके वो पीप जैसे घुँघरैले बाल और छोटी सी ची: ची: करती आवाज।

“हर बार मैं जब भी उसे देखती हूँ मैं उसे बाहों में भर कर हमेशा के लिए भींचना चाहती हूँ”! एक टीचर

अपने हाथों से अपने सीने से दबाते हुए और अपने पैरों के गेंदों पर आगे पीछे घूमते हुए बोली।

“ओह, मुझे पता है, मुझे पता है! वो सबसे प्यारी छोटी सी चीज है, ” अपनी आँखें भींच कर बन्द करते हुए अपनी मुड़ी हुई बाहों को अपने शरीर के विरुद्ध खींचती हुई, अपनी टुडडी को मुक्के पर रखकर और कमर को जल्दी-जल्दी मोड़कर और वापस सीधी करते हुए एक दूसरी टीचर बोली “मैं तो उसे सम्भाल ही नहीं सकती इतनी प्यारी है वो!”

अपने हाथों को मोड़ते हुए और अपने कन्धों को आगे-पीछे सरकते हुए तीसरी टीचर बोली। यह सवाद अन्त में एक बड़े विद्यार्थी की ओर बढ़ा एक माध्यमिक विद्यालय का लड़का – जिसको anime एक खास Shoyo Romance Show पसन्द था।

“उसको इस कार्यक्रम में डूबते हुए देखना इतना अधिक चित्त आकर्षण करने वाला है” उस लड़के की कक्षा की एक टीचर बोली, “मैं कभी-कभी उसके साथ देखती हूँ और सारी कहानियाँ इस G-rated (नियत किया हुआ) यौन तनाव की है और जो कहीं आगे नहीं जाता, जब तक बिल्कुल अन्त में दोनों मुख्य पात्र एक दूसरे के लिये अपना प्रेम स्वीकार कर लेते हैं और एक साथ हो जाते हैं। यह पूरा निर्माण उसे उन्मादी तरीके से सिटिम कराता है। वो अपने हाथ फेंकते हुए बोली “ वो पागलों की तरह कूबड़ निकाल कर अपनी उंगली को हिलाता डुलाता है जब भी रिश्ते में किसी प्रकार का खास बढ़ाव होता है मैं इसे बिल्कुल भी समझ नहीं पाती हूँ।”

हाँ, मेरे पास भी एक ऐसा विद्यार्थी है एक दूसरी टीचर ने कहा।

हो सकता है यह प्रश्न कुछ अटपटा लगे। पर क्या आप बता सकते हैं कि ऑटिस्टिक व्यक्ति ऐसा क्यों करते हैं ?

मैंने उन्हें समझाया कि वो खुद ‘पागलों’ की तरह सिटिम कर रहे थे जब वो कुछ मिनट पहले अपनी प्यारी छोटी सी प्यारे घुंघरूले बालों वाली विद्यार्थी के बारे में बोल रहे थे। शायद उनके सिटिमस इतने चरम नहीं थे जैसे उस पीटीन लड़के कैरोमानी कोमेडी देखते हुए थे, परन्तु उनका मूल कारण एक जैसा ही था।

भावनाओं का निर्माण, भावनाओं या शारीरिक तनाव को निकालने या निवारण करने की जरूरत (मासूमियत, चिन्ता, घबराहट, अन्य कोई चीज) इन सबके अधिभार के कारण, ऐसी चीज है जिसे सबने किसी न किसी समय पर महसूस किया है।

ऑटिस्टिक में अधिभार बहुत जल्दी हो जाता है। और मात्र इसे निकालने की जरूरत ज्यादा जल्दी होती है। जब मैं सिटिम करती हूँ, मुझे एक पुराने तरीके के boiler जैसा महसूस होता है जो अपनी भाप निकाल रहा है – कभी – कभी छोटे विस्फोटों में और कभी-कभी बड़े बड़े भाप के गोलों को डकार लेकर उगलने जैसा।

कभी-कभी सिटिमिंग दबाव को निकाल देती है – खासकर अच्छे प्रकार की सिटिमिंग। कभी-कभी एक सिटिम हमें आक्रमणशील और भारी संवेदी निवेश (Sensory Input) को रोक देने में ध्यान केंद्रित करने में मदद करती है, और एक अनिवार्य रूप से मुकाबला करने में सहयोगी बनती है।

यह एक प्रकार से खुद को शीतलता प्रदान करता है, चाहे किसी को शीतलता की जरूरत है क्योंकि कोई चीज बहुत प्यारी है या एक एम्बुलेंस का सायरन बहुत तेज है। मूल कारण अनिवार्य रूप से एक ही है। मेरे विचार से सवाल यह नहीं होना चाहिए कि ऑटिस्टिक लोग सिटिम क्यों करते हैं, यह होना चाहिये कि ऑटिस्टिक लोग एक खास तरीके से सिटिम क्यों करते हैं। हर कोई ऑटिस्टिक सिटिम

नहीं करता है और न ही सारे ऑटिस्टिक लोगों के सिटिम एक जैसे होते हैं। मैं उंगली हिलाती हूँ, परन्तु अपने हाथ आगे-पीछे नहीं करती। मेरे बहुत सारे आवाज वाले सिटिम हैं परन्तु मैं रॉकिंग अथवा सर नहीं झटकती हूँ। मैं बालों को मरोड़ने जो आगे-पीछे राक करते हैं को जानती हूँ। मैं उंगली चटकाने और पैरों से ठक ठक करने वालों को जानती हूँ, जो उंगली नहीं हिलाते व हाथ फ्लैप नहीं करते। हर अपने खास निजी सिटिमिंग शब्दकोष की तरह ही खास और अनोखा है।

जनता से सिटिमिंग

जब मैं छोटी थी एक विशाल सिटिमस के प्रदर्शन की सूची का दावा करती थी, हालांकि उनमें अधिकतर को एक खास, संयोग से निजी वातावरण की जरूरत होती थी और इस प्रकार मैं शर्मिन्दगी से बख्श दी जाती थी।

जब मैं बहुत छोटी थी, जब भी मैं अपने छोटे से शरीर को टायलेट के ऊपर अपने बचपन वाले घर में उठाती थी मैं पूरा पोटी का समय मेढ़क की तरह टर्-टर् लम्बी, खिंची हुई आवाज, उन भिनभिनी कंपन वाली टाइलस के विपरीत उनकी गूँज के मजे लेती हुई बिताती थी। जब भी मैं flush करती थी मैं जल्दी जल्दी अपनी उंगलियों से कान को बार-बार बन्द करती थी, उस टायलेट में पलश की खतरनाक आवाज को सागर के 'हुश-हुश-हुश' आवाज में एक असम्भव सी 300 बी पी एम की गति में तबदील करती थी – एक छल जो मैंने अपनी पूर्वी स्कूल टीचर से बड़े बच्चों का बाथरूम का इस्तेमाल आसान बनाने के लिए सीखा था और मैं हर बार यही करती हूँ जब भी मैं टायलेट पलश करती हूँ। ऐसी सिटिमस से मुझे कभी परेशानी नहीं हुई क्योंकि इन्हें निजी परिस्थिती की जरूरत रहती थी।

परन्तु जैसे मैं बड़ी हुई मेरी एक बाथरूम क्रिया ने पब्लिक जिन्दगी में रास्ता बना लिया। मेढ़क की तरह

टर्-टर् करने के अलावा (खासकर बहुत उर्जावान महसूस करती थी)। मैं अपनी उंगली को अपनी आँखों के सामने लचीला कर बाथरूम की सफेद पृष्ठभूमि में रखती थी। यह गति न सिर्फ मुझे मन में दबी उर्जा से राहत की अतुलनीय हद प्रदान करती थी। बल्कि बार-बार इस इमेज को देखकर (Stimulus हटाने के बाद) मेरी उंगली द्वारा बनाये दो गुलाबी आँखे एक दृष्टि वाला सिटिमि जो मुझे बहुत खुशी देता था जिसके कारण को मैं कोई नाम नहीं दे सकती।

एक सफेद पृष्ठभूमि के सामने इस प्रकार सिटिम करना मुझे एक सरासर अवर्णनीय प्रकार की सन्तुष्टि देता था – और हां सतह सफेद ही अथवा हल्के रंग की ही होनी चाहिये थी। उन गुलाबी पंखों को ठीक से काम करने के लिए। क्योंकि अब मैं यह लोगों के बीच कर रही थी खासकर जब मैं तनाव में होती थी, मैं इसको अपने सबसे ज्यादा तनावपूर्ण वातावरण : मेरे स्कूल में भी करने लगी।

जब तक मैं छठी कक्षा में पहुँची मैं इसे हर एक घन्टे में कई बार कर रही थी। जैसे कि आप कल्पना कर सकते हैं कि मेरा काफी मजाक उड़ता था। अन्त में मेरी टीचर ने मेरी मां से यह चिन्ता जताते हुए कि बाकी बच्चे मुझे बड़ा कठिन समय दे रहे हैं और उनकी खुद की निजी चिन्ता कि मैं सचमुच इसे नियन्त्रण में नहीं रख पा रही थी, सम्पर्क किया। मैंने अपनी मां से कहा कि बेशक मैं नियन्त्रण कर सकती हूँ।

परन्तु मुझे खुद भी यह समझ नहीं आया कि मैं इतनी सिटिम की जरूरत क्यों महसूस करती थी। यह सारा कोलाहल मुझे शीशे के सामने इसको कोशिश करने के यकीन दिलाने के लिए बहुत था। और मुझे जल्दी ही समझ आ गया कि यह मेरे सहपाठियों के लिए इतना विवादास्पद क्यों था। और उसके बाद मैंने यह सबके सामने कभी नहीं किया।

मैं अभी भी इसे अपनी कार में, बाथरूम में और अन्य

समय जब मैं अकेली होती थी करती थी। और बेशक हमेशा एक सफेद सतह के सामने (और मेरे कम्प्यूटर का मानिटर उसके लिए बिल्कुल उचित था, जैसे कि) कभी-कभी जब मेरा दिन अच्छा, आसान और आरामदायक और मैं शान्त और जुड़ी हुई महसूस करती थी। मैं खुद से सोचना शुरू कर देती थी “ क्या मैं शायद ‘सच में’ आटिस्टिक नहीं हूँ ? आज मैं काफी सामान्य महसूस कर रही हूँ।”

तब मैं बाथरूम की तरफ बढ़ती थी और उंगली हिलाने के एक बाध्यकारी दौरे में घुल जाती थी अथवा लोगों से मिल कर वापस गाड़ी चलाते हुए अपने पर फटी व कर्कश आवाज में चिल्लाती थी और सोचती थी ओह सच है मुझे नहीं लगता सामान्य लोग ऐसा करते हैं।”

पर अब जो सिटिमस मैं लोगों के बीच करती हूँ छोटे और अपेक्षाकृत काफी सामान्य होते हैं। मैं अपनी उंगली चटकाती हूँ होंठ काटती हूँ। गुनगुनाती हूँ और सीटी बजाती हूँ। अपनी उंगली। पैरों से ठक-ठक करती हूँ और अपने नाखून साफ करती हूँ (काटने के बदले) मैं अपनी गम्भीर वाली सिटिमिंग को निजी जगहों के लिये रखती हूँ।

जाहिर है जब तक मेरा कोई बहुत खराब दिन न हो और तब मैं सबवे पर चलती हुई अपना माथा मलती हुई, जोड़ों की मालिश करती हुई, चेहरे के सामने अपनी मुट्ठी भींचती व खोलती हुई वाली लड़की होती हूँ। हाय! मेरा बुरा न मानना, आज कुछ ज्यादा ही भीड़-भाड़ है!

पर हर ऑटिस्टिक अपने गम्भीर वाले सिटिम को बाथरूम के लिए रोककर नहीं रख सकती और ‘गम्भीर’ से मेरा मतलब ‘सामाजिक रूप से अनुचित’ है।

(...to be continued in the August issue of Autism Network)

<UPCOMING WORKSHOPS>

Mainstreaming Students with Autism

12 - 13 April 2019

Venue: The National Centre for Autism, New Delhi

The workshop will help you prepare young ones for mainstreaming. Parents & Professionals have an opportunity to develop an understanding of fine nuances of the difficulties that the child with ASD faces in the classroom and the accommodations required to facilitate an inclusive learning environment.

Indrani Basu, Founder & Director of Autism Society, West Bengal conducts workshops on inclusion at mainstream schools, creating awareness and understanding for children with Asperger's Syndrome and is a resource person for a number of organizations in India and Bangladesh. She is also a mother of two children with ASD; her elder son has Asperger's Syndrome.

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Workshop by Dr Brenda Smith Myles

29 - 30 September 2019

Venue: India International Centre, New Delhi

Dr Myles hailing all the way from US will be in India to talk about Practical Solutions for Understanding Rules in Social Situations, Behavior Interventions for Individuals with ASD, Self-Regulation, Meltdowns, Sensory Issues and more.

Dr Brenda Smith Myles has made over 1000 presentations all over the world and written more than 250 articles and books on ASD.

Formerly, a professor in the Department of Special Education at the University of Kansas, Dr Myles is the president of AAPC Publishing – a company that publishes books on autism spectrum disorder.

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This is a tentative events calendar and the dates and events are subject to change. Please stay in touch with us to get regular updates and let us know if you wish to be added to our mailing list to get updated information about AFA and our events.

For more information contact our Coordinator:
011-40540991/92 email <anvay.trainings@gmail.com>

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

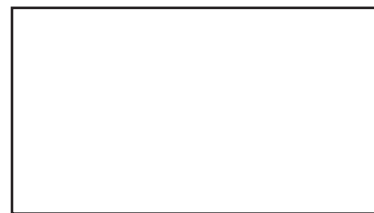
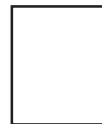
Savings A/C No:

Within India Transactions: 600501010009008

Oversees Registrations: 600501550010210

All contributions are tax exempt under Section 80 G of Income Tax Act.

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