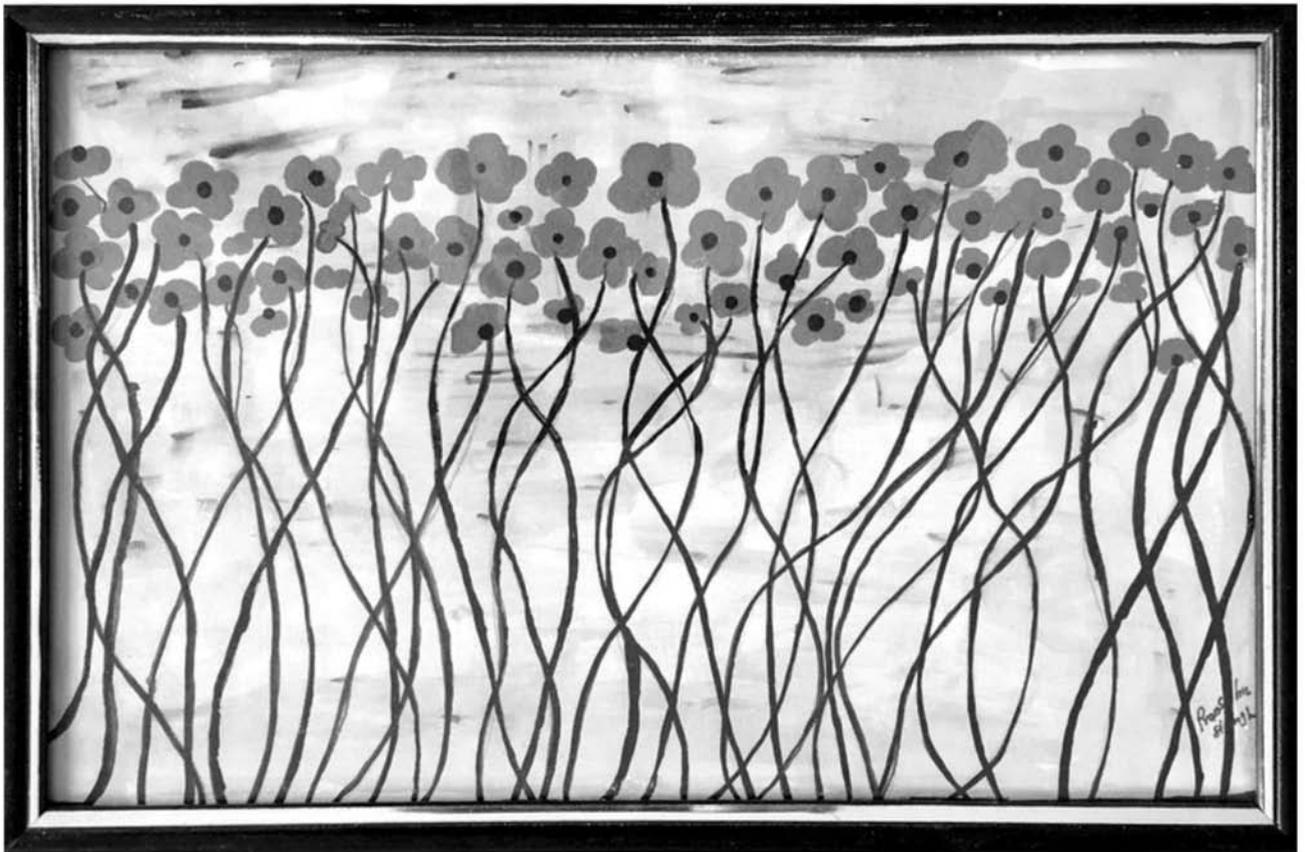


autism network

AUGUST 2016 VOL. 11 ISSUE 2



ACTION FOR AUTISM



autism network

AUGUST 2016

VOL 11 ISSUE 2

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.

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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YOUR CONTRIBUTIONS

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

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

Cover Illustration

'Field of Flowers'
by Pranshu Singh, 19 years.
Violet Class, Open Door School

WISHLIST !

- Apartment/House for Residence for people with Autism
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PAGE ONE

As Delhi waits for the monsoon to truly kick in, the ambitious Skill India Program appears to aggressively promote skilling for employment. The program ostensibly provides for employment training of persons with disabilities too; but of course persons with autism and developmental disabilities find no place there. Which is not surprising at all. Individuals with autism do not find employment, period. A few exceptions do, not because of but rather despite all efforts.

The elusive Rights of Persons with Disabilities Bill seems to have drowned in the depths of that potent mix of politics and bureaucracy. Periodically there are excited murmurs from 'Those Who Know' that "the bill will be tabled in the winter session of Parliament," or "the bill will be tabled in the monsoon session of Parliament". Woollens have been mothballed, shorts aired, saris and umbrellas hoisted, and in a couple of months Diwali spring cleaning and white washing will start. Seasons come and seasons go, but the bill remains snugly ensconced in the cold storage for the powerless, those groups that have no 'clout,' 'votes', or 'voice'.

To add to this static state of affairs there is a move to declare that special needs schools should ensure that students with developmental disabilities and specific needs finish their schooling in seven years and leave school. Schools should make them complete their learning, get them independent and fully equipped to face the world within these magic seven years. Hence any Government funding for education will be limited to those magic seven years. Those who had the privilege of participating in this discussion sought enlightenment, in vain, on this astounding new plan; after all, typical children need 12 years to complete their schooling!

But then, don't we get the decision makers we deserve? When parents say: "Any money I spend on my child with disability will give me no returns, unlike the money I spend on my 'normal' child", can we expect others to think any better, or care for the good, of our children?

On a happier note, as those who have been checking their website will know, the National Trust has come up

with some good schemes with sensible allocations. Something to truly cheer about.

So on to other cheerful things.

As Tony Attwood's much anticipated workshop draws near – just three months to go – we wait excitedly for two invigorating days of learning. For those of us who have been fortunate to have attended his workshops before, we cannot wait to share that experience with others. If autism in all its glorious spectrum is a poorly understood condition, Aspergers Syndrome in particular, is even less so. Yet a true understanding of Aspergers Syndrome is critical to successful education, employment and life for all those often exceptionally verbal individuals, whose physical demeanour suggests they blend into the crowd but their social behaviour makes them stand out!

Stims are something that we all indulge in, whether we have autism or we don't. For the most part they serve an important purpose as elucidated by Kirsten Lindsmith in the last issue of Autism Network. But not all stims are born equal. Not all stims are a healthy aspect of the autistic identity. Stims can sometimes be extremely harmful. In this issue Lindsmith writes about the dark side of stims and what we can do to help when they take over an individual's life.

"Many people require various forms of sensory input to regulate their systems... people with ADHD benefit from mild background music while working to keep up their dopamine levels ...Stimming can also be an outlet for overload — sensory or emotional — and provide a feeling of relief and reset from overwhelming feelings"

We are very pleased to carry in Hindi Jim Sinclair's seminal piece 'Don't Mourn for Us'. Autism Network had carried the original version more than 15 years ago. Reading 'Don't Mourn for Us' in those times had been a life changing experience for this writer. It needs to be read in as many languages as possible.

As the weather gets less hot but more humid we wish our readers happy reading in the rains.

• LEAD ARTICLE •

The Dark Side of the Stim: Self-injury and Destructive Habbits

Kirsten Lindsmith*

In my previous article, ‘Stimming 101’**, I wrote about autistic stimming as a normal and healthy aspect of autistic identity. While this is most often the case, I want to follow up with a slightly different article, because not all stims are created equal.

Sometimes stimming is unhealthy or even dangerous. Parents, caregivers, and autistic people all need tools to deal with these types of stims. We in the autistic advocacy community often paint all stimming as wonderful and healthy, leaving high and dry those who need help. So, let’s talk about the dark side of the stim.

The Dark Side

One of the most frequent questions I get from readers is what to do about unhealthy stimming. These requests come from both non-autistic caregivers and autistic people.

A few typical examples include children who bang their heads against walls, teenagers who bite their fingers and nails until they bleed, or adults addicted to self-harming behaviors like cutting or burning.

As I discussed in Stimming 101, stimming serves a variety of purposes.

Many people require various forms of sensory input to regulate their systems. For example, people with ADHD benefit from mild background music while working to keep up their dopamine levels and maintain focus.

Stimming can also be an outlet for overload—sensory or emotional—and provide a feeling of relief and reset from overwhelming feelings. Examples of this can even be seen in overexcited neurotypicals.

Related to the latter, but slightly more extreme: stimming can provide a safe haven from full overload and meltdown. Regular, strong stimulation provides a focus point for the body and mind, helping to shut out painful stimuli.

The stronger the overload, the stronger the stim has to be to provide the needed relief.

This last purpose is a primary source of unhealthy stimming, for this very reason.

Everything Louder than Everything Else

How do we respond to discomfort? To fear? Let’s look first to film and literary clichés for examples...

We grit our teeth and bear it. We ball our fists and dig our nails into our palms. We bite our tongues to keep from screaming. We pinch ourselves. We slap hysterical people to knock them out of it.

What do all these methods have in common? They all involve the distraction of pain as a coping mechanism.

Have you ever been so upset that you instinctively retreated to the distraction of overwhelming stimulation, even in a mild way? Perhaps you relished the burn of a pure shot of vodka, squeezed your hands together a bit too tightly, or jumped into a too hot shower.

There’s a reason pain is the universal distractor. Pain is the only form of stimulation that our nervous systems will not acclimate to.

All other sensory receptors, when continually stimulated, eventually stop firing.

If you walk into a house with too many cats, you may cringe at the strong scent of kitty litter, but if you stay and hang around you’ll stop noticing the smell. This isn’t about attention, this is a physiological reaction. You really do stop smelling the cat pee.

But if you’re in pain, you won’t acclimate to it. As long as the reason for the pain is still present, your nervous system will keep on sending you those signals. Not only that, but it will prioritize that sensation above others.

Pain is perhaps the strongest bodily sensation we have. It covers and blocks out all other sensations. This is what makes it so useful—it tells us when something is wrong. It keeps us safe when we are injured and need to tend to our wounds. But this is also what makes it so dangerous for those prone to sensory overload.

Most people have never felt sensory or emotional discomfort so strong they would injure themselves to cover it. But to a person with a sensory or emotional processing difference that threshold can be much easier to reach.

Types of Unhealthy Stimming

I'm going to focus here on the most common types of unhealthy stimming that readers bring to me. There are always going to be exceptions that don't fall into a neat label, but in an effort to be as practical as possible, I'll divide unhealthy stims into two major categories: Overload, and bad habits.

1. Overload

These are the stims that drown out everything else. Including:

- Hitting the head (against a hard surface or with objects)
- Biting or scratching the hands, arms, or other parts of the self
- Hitting oneself or throwing the self against hard surfaces
- Other extreme injurious behaviors that come on suddenly and forcefully

2. Bad Habits

These stims, while still unhealthy, are done in a more slow and controlled way. They may come on gradually and escalate, or may occur at low levels continually.

Including:

- Biting, picking, or scraping at the finger or toe nails to the point of injury
- Dermatillomania and trichotillomania (skin picking and hair plucking, respectively)
- Self-harm behaviors such as cutting, burning, stabbing, etc.
- Biting or scratching the self at a continuous, low-grade level (e.g., chewing on the hands)
- Pica (eating non-food items, such as paper or tinfoil)
- Other dangerous or injurious behaviors that are done relatively calmly, either continuously, in all or most contexts, or under stress

Addressing Overload Behaviors

There are two primary ways to interrupt dangerous overload stimming. The first is to remove the problem stimulus that's causing the overload. The second is to redirect the behavior while still addressing the need for stimulation. Usually, some combination of the two methods will be most effective.

Removing the Problem

This first method is most effective as preemptive intervention, or during the initial, ramp-up stages of meltdown.

Preemptive intervention requires the problem stimulus to be specific, predictable, and controllable.

For example, my mother once worked with an autistic little girl who had several triggers along these lines. If she heard a studio audience applauding on TV, or saw her sister's bellybutton, it would set off an intense self-injurious meltdown. These meltdowns could be averted preemptively, by turning off the kids' favorite show before it panned to the audience, and by bathing and dressing the girls separately.

Removing a problem stimulus can also be effective if you catch the meltdown during the early stages. I once worked with a little boy who would start pulling at his hair in the build up to a meltdown. If the build up continued, he would progress to hitting himself in the head with his fists. Hair pulling was the warning sign I watched for.

If you are the caregiver

Intervene with this method if you know a trigger is coming, see the problem behavior beginning, or notice warning signs that it is about to start.

If you are the autistic

If you struggle with dangerous overload behaviors, tracking your own meltdowns is similarly important. If possible, it's helpful to have a second person who can keep track of your meltdown patterns for you. If you don't have that luxury, then journaling during mild to moderate overload is one alternative (journaling during full meltdown is usually impossible).

One way to begin the process of tracking your warning signs is to use an app that will remind you at intervals to record how you feel. I recommend either default reminder apps (setting reminders at hourly intervals), or something like iMoodJournal for iOS.

Focus on physical sensations:

How does your stomach feel? How do the muscles in your face feel? Do you feel hot or cold? And if so, where? Do you feel numb or tingly anywhere? Keep track of what your body is doing at continuous intervals. Then, if you have a meltdown, you can later look back over your journal entries and check out how you were feeling in the hours leading up to it. Similarly, just setting continual reminders to check in with yourself can help you avoid meltdowns entirely. I'll write a future post on how to develop these types of meltdown coping skills.

The important element is learning to identify the signs that a meltdown is coming, and to interrupt it before it reaches the point of no return. Whether that means leaving a party, turning off the music, or moving to a quiet, dark room, this method is about removing a problem.

This method is NOT helpful if the problem is an emotional one. For anyone who struggles with emotional overload, I recommend seeking Dialectical Behavior Therapy (DBT) or Cognitive Behavioral Therapy (CBT) from a qualified provider with experience working with your particular diagnosis. If you don't know where to start, I recommend browsing the Psychology Today directories.

Redirecting the behavior

This method is the most practical, and the one you will probably need to make use of the most often.

What if the problem stimulus is schoolwork? Wearing clothes? A perceived slight from a stranger? An argument with a significant other? Puberty?

What if the stimulus can't be identified, can't be removed practically, or is too abstract to remove? Or what if the meltdown is already so intense that removing the stimulus doesn't help?

In situations like these, the dangerous stimulating needs to be redirected, and replaced with a safe stim that serves the same purpose.

If you are the caregiver

It is your job to find a way to provide intense, unignorable stimulation that will drown out the world and provide a focal point for the person having the meltdown. The type of input depends on the person.

For example, that little boy prone to hair-pulling and head-hitting I mentioned earlier favored auditory and vestibular input. Playing a favorite song very loud,

while picking him up and swinging him around, was the best way to help him through his meltdowns.

A few examples of safe, intense stimulation to provide are:

- deep pressure (squeezing up and down the arms, pinching the finger tips, a strong bear hug, or lying on top of the person)
- vibration in the chest area or around the mouth (a massager on the chin and mouth area, or rhythmically pounding on their back with your hand)
- loud music (playing a rhythmic, sensory oriented song, or singing right in their ear)
- strong vestibular input (spinning or pushing them in a swing, or, if size and strength allow, picking them up and spinning them around)

If you're not sure what kind of stimulation your charge likes best, pay attention to what they're seeking through their behavior.

- Is she hitting or biting herself? She needs deep pressure. Focus first on the areas she's hitting.
- Is he screaming? He needs auditory input. Play some loud music. Using your phone is best, since you can move it around. For added input, move the speaker back and forth, from one ear to the next, or move it forward and back, close to the ear and away again.
- Is she throwing objects, trashing the room, or throwing herself on the floor? She needs vestibular input. Put her in a swing, on a bouncer or trampoline, or pick her up and spin her around.

If you are the autistic

Start by compiling a list while you're calm of ideas for intense sensory input. Keep multiple copies scattered around, such as on your phone, on your computer, and posted up on your fridge. You need a bank of sensory options that you can keep adding to over time. Ideally, what you're looking for are different types of intense stimulation that can provide a sensory buffer or sensory reset to give you the input you need without resorting to hurting yourself.

A few of my favorites are:

- Hold ice cubes
- Have another person sit on you, or invest in a weighted blanket
- Keep a playlist of intense, sensory oriented music you can blare in headphones (feel free to contact me for recommendations)
- Squeeze your wrists, hands, and finger tips (push down on the nail) instead of biting or scratching

- Take a cold shower or bath
- Again, the goal is to keep adding to the list every time you think of or find a new idea.

Addressing Bad Habits

Bad habits are often more difficult to deal with than dangerous meltdowns. Where meltdowns come and go like hurricanes, bad habits are ever-present. But similar guidelines apply for handling these. You can try to remove the trigger, redirect the behavior, or both.

Removing the trigger

This one isn't always possible with bad habits, sadly. But for some habits, it can be.

For example, If your child eats glue, and you've tried and failed to redirect this, your next step is to lock up the glue.

One of the bad habits I have is biting my lips. For whatever reason, my lips chap very easily. This means I nearly always have little tears and flakes of skin on my lips. If and when I inevitably feel them (either with a finger or by rubbing my lips together), I compulsively bite at the flaps of skin and peel my lips to pieces. The more I bite, the more flaps and flakes appear. It's a self-propagating cycle. The only way I've found to interrupt this behavior in myself is to always have lip balm available. If I can smooth down the flaps and flakes with balm, I won't feel them as much, and then I can avoid the trigger (feeling the rough texture) that causes the behavior.

I was able to quit biting my nails much the same way. But because this process was more involved than simply applying lip balm preemptively, I'll include it under redirection.

A Note About Root Causes

I recently received a message that reminded me of something I had earlier forgotten to address here. Many "bad habits" or self-destructive stims can come from root causes that need to be addressed. For example, the message I got was a story about a root cause I've heard happen to more than one person: An autistic teen suddenly developed a new, very violent stim of banging his head against the wall. He was brought to doctor after doctor, and no one could figure out the problem.

One professional even went so far as to dismiss the issue, telling the boy's parents that this was "just something autistic people do," and they would have to get used to it. Eventually, they noticed something. His wisdom teeth were coming in impacted, pressing into a

nerve! He was in horrible pain, and banging his head against the wall was his only coping mechanism.

Often if there's some underlying medical issue it may go unchecked because an autistic person can't speak to effectively explain the problem. These issues may also go overlooked in more verbal autistics, if due to alexithymia, they either don't understand the problem themselves, or can't articulate it well.

Some examples of common medical issues that can cause self-injurious behavior are:

- Inflammation (allergies, autoimmune disorders, food intolerances, bad drug reactions)
- Dental issues (cavities, new teeth budding, broken teeth, mouth injuries)
- Gut issues (IBS, celiac, injuries, menstrual cramps or PMS, UTIs)
- Headaches (migraines, low blood sugar, low blood pressure, TMJ/jaw cramps)

Redirecting the behavior

Redirection involves identifying the sensory need that's creating the stim, and filling it another way.

Besides lip balm, another thing that keeps me from biting my lips is having chew toys on hand. My favorite stim toy supplier, Stimtastic, sells adult-friendly "chewelry" that looks nice to wear while still serving its purpose. Chew toys can also help with pica, though I would advise getting only the strongest toys, or else the toy itself can become the dangerous object.

I once worked with a teenage boy who chewed at his fingers and scraped them with his teeth nearly constantly. This would create ever-present wounds small and large on his hands. The only way I found to redirect this behavior was to give him something to hold with a rough texture. The more texture, the better. He could then rub the thing he was holding instead of rubbing his fingers against his teeth.

While I never had issues with chewing or scraping my fingers, I did bite my nails compulsively and unconsciously for over 10 years. I would bite them down so far that my fingers were constantly in pain. The process for overcoming this habit was long, and very methodical. I'll share the details, because I've found that the steps I used to break this habit have been essential in breaking others.

How I stopped nail biting

Because I was biting unconsciously, I couldn't simply

decide to stop. I first had to identify the warning signs. For this, I enlisted the help of a second person.

I told my boyfriend at the time to watch me, without interrupting the biting, and tell me what the process looked like.

He told me that before I started biting, I would begin touching my fingernails. I would feel along my nails with the tips of my fingers, and rub my nails against my lips. I was feeling for rough patches. Then, when I inevitably found some irregularity, I would bite. This was the point of no return, because if I found a rough patch, I had to get rid of it. I couldn't choose not to. It became a compulsion.

At first I tried to stop feeling for rough patches. But this ignore simply wasn't practical. I couldn't avoid touching my fingers in my everyday life, let alone break the habit of feeling for rough spots.

So I found a way to redirect, to choose a healthy alternative.

I started carrying a nail kit with me.

I kept a nail kit in my bag. And if I didn't have a bag, I made sure to have a nail file in my pocket.

From that point on, whenever I felt a rough spot on a nail, I could file it down. I could get rid of the rough patch without biting. And filing away a rough patch always removed less nail and skin than if I had tried biting it away, because biting only created more rough spots.

Eventually, as time went on, my nails grew long enough that I could fully redirect the habit into something no longer destructive. Now, I have a new stim to do with my fingers. Something I do constantly, unless I'm holding something. Now, I clean under my fingernails, whether there's something under them or not. It looks either snobby or slobby, depending on context. But at least I'm not biting!

To summarize, the best methods for redirecting bad habits involve finding a similar stimulus. If the habit involves the mouth, use gum, or a chew toy. If it involves the hands, find a fidget toy.

Some bad habits are more difficult to redirect, such as self-harm.

A few quick examples of ways to redirect self-harm behaviors and distract yourself from these thoughts are:

- scribbling on a piece of paper until the entire page is black
 - drawing pictures on your skin
 - following other painful-but-safe coping strategies, like those listed above in the overload section (holding ice cubes, cold shower, loud music, and so on).
- If you're struggling to break a habit or addiction to self-harm, feel free to contact me via email and I can help you design a more personalized coping plan. Stimming is amazing, healthy, and necessary, yes, but sometimes it can be horrible and dangerous. I hope this post helps anyone struggling with unhealthy stimming. And to all my readers, please contact me if you have questions about anything I talked about here, or about anything I've left out. I'm here to help, if I can!

This article was first published on <https://kirstenlindsmith.wordpress.com/2016/02/05/the-dark-side-of-the-stim-self-injury-and-destructive-habits/> and has been reprinted with the permission of the author.

**Kirsten Lindsmith is an author, artist, consultant, and autism advocate. After receiving an ASD diagnosis at the age of 19, she began co-hosting the online television show Autism Talk TV, and speaking about her experience as a young woman on the spectrum. Kirsten has written columns for WrongPlanet.net and AutismAfter16.com, and was profiled in The New York Times in a feature titled Navigating Love and Autism. She is a member of the board of advisors for the Yale Child Study Center's Initiative for Girls and Women with Autism Spectrum Disorder. Kirsten currently works as a special needs nanny in partnership with Melody of Autism, and as a consultant for parents, professionals, and individuals on the spectrum. She maintains a blog at: KirstenLindsmith.Wordpress.com where she writes articles about ASD.*

***Lead Article Autism Network April 2016*

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Cheers for PEERS

Andre Velho*

Karl is a 17 year old young man with autism who goes to mainstream college. He is a good student and does well in his exams. His biggest challenge is that his college-mates bully him into doing their homework for him and he feels that he should help his ‘friends’ no matter what! Ravi is a 13 year old boy with autism who also goes to mainstream school. Shyam has a couple of friends in school and he loves to talk to them about his action figures. He often reports that his friends walk away in the middle of his conversation with them and he struggles to figure out why! Aliya, a 15 year old girl with autism complains to her mum that her friends make funny faces when she tries to join their conversations.

Autism or ASD is a spectrum condition that affects different people differently. It is sometimes easy to detect, especially when the symptoms are quite obvious. However, there are many individuals with ‘higher functioning autism’ or as I prefer to refer to them – individuals that are less impacted by the condition, who can function within the typical range with regard to language and intelligence and sometimes their autism even goes undetected. Most often they have great difficulties in social skills – in making friends and keeping them so. During adolescence, the demands of peer relationships increase and the individuals who are less impacted by autism tend to be self conscious of their difficulties in socialization. This can lead to depression and anxiety, isolation, teasing, bullying, rejection, low self-esteem, school drop-out and unemployment.

While the momentum of early intervention services in autism in India is gaining, there is lack of social skills training programs to work with less impacted individuals with ASD. The result is that their poor ability to socialize precludes them from having meaningful social relationships. It is not the lack of desire to make friends – they desperately want to do so but fail miserably when trying. This failure is due to the lack of effective programs and inadequate resources to teach social skills. For most neurotypical children, basic social skills like turn taking and initiating a conversation can be acquired easily but for those with autism, the process can be tough. While many neurotypicals learn these skills simply by being exposed to different social

situations, the neurodiverse children need specific teaching to help improve their socialization skills.

In February 2015, Action for Autism organized a workshop on social skills training called PEERS (Program for the Education and Enrichment of Relational Skills) that was conducted by Dr. Elizabeth Laugeson, clinical psychologist and an Assistant Clinical Professor in the Department of Psychiatry and Biobehavioral Sciences at UCLA and co-author of the PEERS Program. PEERS incorporates and builds on many elements that are integral to successfully teaching social skills. This program is evidence based on a large sample in the US and the great thing about it, is that it is manualised - which means it can be adapted and replicated. The intervention has had positive effects on the social skills of many adolescents with autism in the US and this could be a life changing program for thousands of adolescents with autism in India too.

The PEERS Program is a 14-week training that covers topics right from how to exchange information when having a conversation and what to do when you invite a friend over to your house, to how to use appropriate humour and how to handle bullying in school. It requires participation of the child as well as one of his/her parents so that whatever skills are taught can be practiced and generalized to real world situations.

I attended the PEERS training program in February 2015 with the aim of introducing social skills training for adolescents in with autism in Goa. Goa does not have any sort of socialization program for people with autism at all, and this was a great opportunity to change the lives of so many individuals with ASD and their families. Sethu, being Goa’s premier organization for child development services has a large number of clients with autism that could benefit from social skills training. It could change the lives of so many children in Goa and Sethu’s services in autism intervention could be strengthened. However, I was apprehensive that convincing parents that their children could use this training and hoping they would be able to take time out of their busy schedules to participate in it would be a difficult task.

As soon as I returned from Delhi, I conducted a small training for the professionals at Sethu who were

convinced that this program could be a success. Since it requires 2 trainers - one for the adolescents and one for the parents, Sethu's director, Dr. Nandita de Souza voluntarily and enthusiastically partnered with me to implement PEERS in Goa. Dr. de Souza had already previously created a list of children she had seen over 10 years who she thought would benefit from some sort of social skills instruction, and this was a great opportunity for these now adolescents to get the training they needed.

We adapted and tweaked the program as minimally as possible to make it appropriate to the Goan situation. Because of the pressures of school and examinations, we decided to reduce the duration of the program from 14 to 10 weeks so increase the likelihood of participation. Some modules were combined and conducted together instead of separately. We had to leave out one module due to time constraints and we chose to exclude what we taught was the least applicable out of all the modules.

Using the best of our convincing skills and we contacted 10 families to participate in PEERS. A few of the adolescents were in the 10th standard and could not attend it this year. Many parents lived far from Sethu and worked full time outside the home and could not commit to 10 continuous weeks. Finally, four of them agreed to participate. One mother desperately wanted her daughter to participate but her daughter refused take part. Since PEERS is totally voluntary and both – parent and child should *want* to participate, we could not force the matter. Four was finally our magic number.

In September 2015 we kick started the program – I worked with the adolescents and Dr. de Souza worked with the parents at the same time but in separate sessions. It was imperative for the parents to wholeheartedly participate in the program since they would act as their children's social coaches at home and in real social situations. Over 10 weeks, the families came to Sethu with the hope and enthusiasm that this program was going to significantly change the way the adolescents interacted with their friends. They were between the ages of 13 and 18 and took time out of the homework, extra-curricular activities and free time to come to Sethu once a week. They all knew the importance of what they were learning and week by week their improvements were clearly visible.

Each session began with a homework review of the assignment from the previous week (each week the

family was given a social skills assignment which basically was practicing what they had learned at home/at school/at different social situations). This usually took about 15 minutes and any troubleshooting of problems was discussed. The main lesson for the day was presented didactically and was enhanced by video-demonstrations since people with autism are extremely good visual learners. Role-plays were also used in the session so that they could practice what they learned at that time itself. Dr. de Souza and the parent-group would go over the same lesson as their children but in a separate session. Parents were instructed on ways in which they could help their children overcome difficulties through weekly socialization homework assignments. The sessions concluded with parents and adolescents reunited in the same room where the assignment for the day was discussed.

The role of the parents was to coach their children and monitor them when practicing different social skills and in doing their homework – they were asked not to do the homework for them! This team approach that PEERS encourages was what got the homework done each week. It gave us great joy and satisfaction to hear about hard work that the families put in each week to complete their assignments. Every participant had different issues each week that they needed help with and were very open to discuss the same. Whether the challenge was not knowing who was in charge of choosing a game when they invited a friend over, or not accepting that humour is appropriate and it is OK to tell jokes, the participants with ASD themselves most often provided valid solutions to the others' difficulties!

The greatest quality of this program is that it is totally voluntary - no parent or child was forced to attend it. The parents could not force their children to attend either. As a result, we hardly encountered any behavioural challenges or disciplinary issues. Any minor ones that did come up could be easily resolved by simply presenting rules of expected and unexpected behaviours and going over the same. Further, there was not a single day of absenteeism among the parents which was truly remarkable.

It was important for us to understand whether and how much the program was helping the families and so we used two outcome measures to test this. One of them was the Test of Adolescent Social Skills Knowledge (TASSK) which is a self-administered questionnaire completed by the adolescents. It assessed their knowledge about specific social skills taught during the intervention. The scores of the TASSK range from 0-26, with higher scores reflecting greater knowledge of the taught social skills. The average

score before starting PEERS was 12 out of a maximum of 26 points. When they were reassessed after completing the 10 weeks, their average score went up from 12 to 22 points – a difference of 10 points!

We also wanted to assess the adolescents' core autistic symptomatology and so the Social Responsiveness Scale (SRS) was used to measure this. The SRS assesses the severity of autism symptoms as they occur in natural social settings and it is a questionnaire filled in by the parents. Higher the score – more is the impact of autism in the adolescents' social life. Before starting, the average SRS score was 74 but after attending PEERS it dropped 9 points to 65!

These outcome measures showed no doubt that PEERS was effective in improving the knowledge of various crucial social skills and helped reduce the symptoms of autism that were hampering these participants from having meaningful and social relationships with their friends.

The 10 weeks of PEERS at Sethu was a learning experience for everyone involved. Sure there were hiccups along the way – whether it was videos not loading, homework not done, family reaching late or too many snacks to focus on the lesson, it was a fantastically fulfilling rocky road journey. We had lovely feedback from the parents and here is what a couple of the parents had to say –

“PEERS was a great guidance program for my son. He now wants to organize frequent barbecue get-togethers with his friends. He has joined a new school and on a recent visit, a couple of his friends asked me to tell him not to tease them. After enquiring further, I found out that he was using the ‘tease-the-tease’ approach to being teased himself by them! This made me overjoyed and we both did a victory dance! I feel this program should also be adapted for younger children since they have a chance to learn social skills and how to defend themselves right from a young age.”

“We had a good opportunity to be part of PEERS. It was with a group of parents and the teens together doing their exercises successfully. It was well laid out and we had lots of guidance in creating a friendly environment for our teens. It also provided a chance for us parents to discuss our teens' social skills. Overall it was a great experience. Our son has since been attending his music classes happily with other students. He has also attended a local summer camp which he enjoyed.”

Although it would be easy to rest on our laurels, it is urgent that we continue this program and reach out to many more families across Goa. We are looking to start the second batch of PEERS this coming September and we hope that it will be as or more successful than before.

**Andre Velho is an autism interventionist at Sethu Child Development and Family Guidance Centre in Goa. After obtaining a master of arts degree in Autism in the UK, Andre felt the need to come back to Goa, use his knowledge and expertise and give back to the place he calls home. He loves music and cars and plays in a band part time!*

Game Review by Maithri Sivaraman*

Learn Through Play

Pajama Party (INR 299)

From Chalk and Chuckles

There is no question that play is an integral part of child development and we know that children with autism often find it very hard to play in a manner that is beneficial to their development. The best way to foster growth in this area is to target it during early intervention. Here is a review of a game that could aid families, therapists and educators initiate their students into the world of play.

Game

Pajama Party

Age Level

Preschool and kindergarten

Description

Pajama Party is a very well-designed game by Chalk and Chuckles and has been a huge hit with my young learners with autism. It allows me to help them practice identifying colours, scanning arrays, visual discrimination and picture descriptions. Marvin, the cow, throws a Pajama Party to all his cow friends who come dressed in a mixture of colours. They bring cake, presents, gifts, balloons and more. The game comes with a pair of dice, 21 double-sided cards of cows and 21 thinking cards.

Skills and Modifications

The game has two parts and is designed to suit both

preschool learners as well as those in kindergarten and elementary school. You can remove the thinking cards and only use the dice and cow cards for the preschool kids.

Colour Identification and Matching

The game is originally designed to identify two colours at a time. Some kids might find that very hard to do. With my very young players I only use one dice at a time and pick out the cards that have cows wearing the same coloured shirt and pant. That way the objective of the game is to roll the dice and pick out the cow whose clothes match the colour on the dice – there's only one colour that needs to be matched and identified. Once they are familiar with this I introduce the second dice. In the initial stage I fix the second dice to a particular colour (say, yellow). Now they roll the other dice and pick out the cows that are wearing clothes that match the colour on their dice + yellow. Gradually they learn to roll two dice and find the cow that matches the colours on both dice.

Attending to stimuli

The game can be played in such a way that no matter who rolls the dice, the person who is the fastest to identify the cow gets to keep the card. It helps kids who tend to zone out during other's turns to stay focused on the game. Also, turns are decided based on who 'moos' the loudest and fastest after the previous round has ended.

My kids find it incredibly funny and I see them trying to engage in a 'Who Moos Louder' contest with their neuro-typical play partners!

Scanning

Any version of the game requires good scanning skills. For example, the dice might show yellow and red. The learner must scan all the 21 cow cards (at least at the beginning) to find the matching card. If your child finds this too hard, you can start with one dice and six cards.

Shadow Matching

The thinking cards have a set of shadows which match with the cow cards. It provides good practice for the kindergarten kids to pick out the correct card and can be quite challenging.

Two-step Listener Responding

Some of the thinking cards have visual instructions to find a particular cow – for example, red + cake. So an adult or an older peer can read out the instruction and

the learner finds the cow that's wearing red and holding a cake. If the learner is motivated by the game, they are more likely to engage in the listening activity.

One of my advanced language students also helped me develop a variation to this game without using dice. You could take turns describing a cow card (for example, "the next person for the party is wearing blue and holding a guitar") and wait for the other player to find the picture.

Picture Description

Some of my kindergarten and early elementary students love to talk about the cow card that they pick up. The cows are usually holding an object for the party or striking a funny pose. It is a great idea to include picture description as part of the game for kids with intermediate or advanced language skills. You may also get to see them imitate the funny pose!

Peer Play

This game is a great option for peer play or play with a sibling or older peer.

Pros

The different versions of the game make it possible to retain interest in the game for long. It is a great tool to facilitate generalization of colour matching, scanning and listener responding.

What I love best about this game is that it can be used with students with varying skill levels – all the way from single colour identification and matching to picture description.

Cons

The cow cards are a little too small. Had they been the size of the thinking cards, it would have been great. The purple and blue colours look similar and can be hard to distinguish between, but I must say some of my students do it with great ease!

Cost

INR 299.

You should invest in the game if there is an older sibling or peer who can play with the child with autism or if you are looking for motivating ways to generalize colour matching and scanning skills.

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हमारे लिए शोक न करें

जिम मिनकलैर

अनुवाद – पूजा खन्ना

इस लेख का प्रकाशन हमारी आवाज, ऑटिस्म नेटवर्क इंटरनेशनल कांफ्रेंस टोरान्टों 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 हूं 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 हूं।

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 देखे 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। अर्थात 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 सम्बंध 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 कुंठित 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 मुमकिन 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 अन्जाने 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 सकें।

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 उन्हें अपने खोये हुए बच्चे के दुख 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 आपको 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 जिनकी 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 हैं। 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 आपकी मदद के 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। दुश्वान्त घटना 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।

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।

HELPLINE



ACTION FOR AUTISM

Q My daughter, H, is twelve years old. I am having a lot of difficulties with her toilet training. She doesn't indicate at all when she wants to go to the toilet. Even if I take her to the toilet at regular intervals, for most of the times, she doesn't do her job there. Sometimes she stands up from the pot and does it standing within seconds just over there. Sometimes she comes out of the toilet and does her job after a few minutes. I have kept a record of her timings for a month and tried to take her as per those timings. But her schedule varies. Sometimes she does it more frequently whereas on other days there are long gaps. Sometimes she cooperates for the whole day. For the past two weeks I am noticing that she starts jumping and laughing before doing her job, but I am not sure if it she is using this to communicate her toileting needs. Please help.

A Thank you for sharing your concern about H. We appreciate your desire to teach H to relieve herself in only the toilet and also to indicate her need to urinate and defecate well in advance, to avoid accidents. As with any other skill, toileting too needs to be taught gradually in steps. Independence in this very complex self help skill involves control over physical, physiological, cognitive and sensory processing and generalise the same in different situations.

When teaching a child to void oneself at the appropriate place i.e. the toilet, it is first important for the child to have the ability to recognize the sensation of needing to relieve oneself, an area of difficulty for a large number of children with autism (almost 98%, according to an American study). Just like one associates that 'hollow feeling' in the stomach with hunger, we also recognize that the heavy feeling of discomfort in the lower part of the stomach, indicates the need to urinate or defecate depending on the particular sensation. Our body has the interoceptors which help us to recognize this sensation and since these receptors (sensation recognizing connections) are present internally in our body, teaching the child how to recognize these messages may be a bit difficult and may involve actually creating the sensation within the body. For instance, one can give the child plenty of fluids, in an effort to replicate the heaviness in the lower abdomen signalling a full bladder and hence 'feel' the need to urinate.

From your description, it seems that H does recognize the sensation to relieve herself occasionally and also has the physical skill to perform the job. This means we need to use strategies to teach her to consistently recognize this sensation and also learn to relieve herself in the appropriate place.

When doing so, schedule training or taking the child to the toilet at regular pre determined intervals, is very effective. But taking the child to the washroom too frequently may not be a good idea, because that would come in the way of the building the capacity of bladder muscles to retain urine which in turn leads to better control. Taking her at too short a duration will reduce chances of accidents but will not help her to build the control or to learn to control the need to void until taken to toilet. Instead finding the optimal time to her to the toilet would be more effective.

You are already taking H to the toilet at regular intervals based on the data that you have collected for a month observing the times at which she relieves herself. However, you have also mentioned that to her toilet schedule tends to vary. Have you noticed anything different about those days? For instance, on the days she urinates more frequently, has she drunk more fluids, is it less warm/ cooler than other days? Or on the days that she is urinating at longer gaps, has she been sweating more? These may help you vary the times at which you take H to the toilet, varying her toilet schedule as per her needs.

Keeping this in mind, you could start taking H to the toilet and help her sit on the toilet seat every 60 to 90 minutes, so that she learns that she can relieve herself only at a specific place, ie in the toilet, when she sitting on the pot. When she is sitting on the pot, you may want to talk to her, praise her for sitting well, so that the sitting on the pot, per se, becomes a positive experience.

You can give her something to hold on to or a toy to play with when she is sitting on the pot to help her sit better, unless you feel that this may distract her from doing the job. And when she has relieved herself, remember to praise her BIG and praise her specifically

'Good doing your job in the pot!' You can also give H something that she likes a lot - a toy, an edible, music, anything that will help her remain motivated to relieve herself in the toilet.

On the occasions that she does not void, instead of coercing her to sit on the toilet seat for a long duration and insist that she urinates, it may be more advisable to let her go after she has been sitting for a couple of minutes and then bring her back to the toilet after a short while. This would ensure that the experience of sitting on the pot remains positive. Praising her specifically- 'Good sitting on the pot' will also help keep this experience positive. Do remain focussed at this point of time to avoid accidents and take H to the toilet frequently till she relieves herself. And when she does eventually void, as mentioned earlier, do remember to praise her specifically, as well as give her something that she likes. And once she voids, you can once again revert back to the 60/ 90 minute schedule.

In the event that an accident does happen, please do not get disheartened. Instead clean her up without giving the behaviour any attention and staying emotionally neutral.

You have mentioned that sometimes H has started laughing and screaming and you are not sure if she is trying to indicate her need to go to toilet through this behaviour. We would suggest that you do not take her to toilet ONLY at the times when she shows this behaviour because by doing this, you will in effect be teaching her that she can indicate/ communicate for her toileting needs by laughing and screaming. Taking her to the toilet consistently and regularly, even when she is not exhibiting challenging behaviours like jumping and laughing will increase the chance of success of relieving herself in the toilet.

When you say that 'sometimes she does it in standing', have you noticed anything different at these times? Does this happen when she is not going into her usual toilet or when the toilet is wet or she has to go bare feet or if she is doing with a specific person/s like only with you (which could be her way of getting attention)? For sensory challenges, try simple strategies like placing a stool under her feet (if you feel her feet are dangling) and/or letting her support herself against the wall (if you feel additional support would add to comfort) and/or wear slippers while entering the toilet (if a wet floor/ cold feel of the toilet floor may cause discomfort). Also prepare her beforehand if, at home, she has to use a toilet different from the one that she usually uses or

when she may have to use a toilet when she is not at home. Should you notice that she is doing this with a specific person/s, it is very important that she gets no attention for the accident, but, instead at all other times when she is doing something appropriately, including relieving herself in the toilet, she gets a LOT of attention.

When teaching H to recognise the 'discomfort' associated with the need to defecate or register the sensation, you can make her sit on the toilet seat every day at fixed time, preferably after meals when her stomach is full and passing stools is easier. You could do the same when you notice a sign of discomfort or a gesture suggesting that she needs to defecate.

We need to remember that oftentimes children with autism suffer from constipation and infrequent bowel movements. Limited diets due to food preferences, as well as sensory issues may further aggravate the problem. Introducing healthy food with enough fiber in small portions is a good idea. Getting a child used to a new diet will take time, but consistency is the key to success. We need to remember that changing the child's food habits also means changing the food habits of the entire household, which though difficult, is not impossible! And to also remember that such adaptations for the entire family need not be for a lifetime, but, only till the child has got used to a somewhat balanced diet and has a more regular bowel movement.

Giving visuals as reminders, as well as social stories to help the child understand where it is appropriate to relieve oneself is always advisable. Also do ensure that H has free access to the toilet whenever possible and that in new places you always show her where the toilet is. Further, help H perform the task in a 'socially appropriate manner', with teaching her to close the door of the toilet when she is using it and undressing or dressing ONLY inside the toilet. Slowly start working on generalization by encouraging H to use the bathroom in different settings like the school, relatives' house, malls etc. And, most importantly, as when teaching any skill, do remember to reinforce every small effort that H makes.

Once H has achieved a degree of success in relieving herself in the toilet and there are far fewer accidents, it would be important for you to start teaching her to

(...cont on Pg 18)

UPCOMING WORKSHOPS

Know Me Teach Me Annual Training Workshop

Date: 21-23 September, 9 am – 5 pm • Venue: The National Centre For Autism, New Delhi

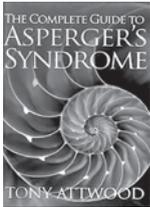
*“Is he really autistic ?
“Can he really study?”*

“Why does he not learn like other kids? Why doesn’t he play with other kids?”

*“Why is he so rude?!”
“Can he get married?”*

If you have any such questions, this workshop is for YOU!

Early Bird Registration ends on 3 September 2016



Asperger’s Syndrome & High Functioning Autism Training by Tony Attwood

Dates: 25-26 November 2016 Venue: India International Centre, New Delhi

Action For Autism brings you the rare opportunity to learn with **Professor Tony Attwood**.

Prof Attwood is recognised internationally as one of the leading specialists in Autism Spectrum Disorders, especially the high functioning end. He has authored several books including *Asperger’s Syndrome – A Guide for Parents and Professionals* which has sold over 350,000 copies and has been translated into over 25 languages. His subsequent book, *The Complete Guide to Asperger’s Syndrome*, is one of the primary textbooks on Asperger’s syndrome.

Prof Attwood is regularly invited as a keynote speaker at International Conferences. He presents workshops and runs training courses for parents, professionals and individuals with Asperger’s and High Functioning Autism all over the world. He has worked with many thousands of individuals of all ages. He is adjunct professor at Griffith University, Queensland and senior consultant at the Minds and Hearts clinic in Brisbane.

Over the course of two days, the **training will focus** on issues across the lifespan, especially strategies to:

- Make friends
- Improve social understanding and relationships
- Reduce being bullied and teased
- Build upon cognitive abilities
- Manage feelings and facilitate emotion management
- Sustain employment



Who Should Attend?

Parents, family members, relatives, educators, clinicians - anyone wanting to understand more about Autism Spectrum Disorder and how to support children and adults with an ASD.

Early Bird Registration ends on 26 September 2016

For more information, Email: <anvay.trainings@gmail.com> or Call us on <+91 99531 13208; +91 11 4054 0991-92> or visit our website:<www.autism-india.org>

(...cont from Pg 16)

indicate her need to go to the toilet using the mode that she uses to request/ communicate for her other needs. You can teach her to use a sign or exchange an object/ photograph/ picture card or say the word (if she has vocals) consistently before you take her to the toilet.

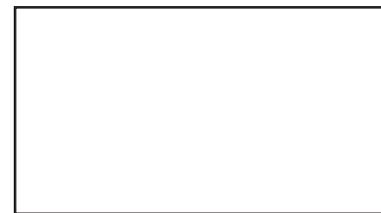
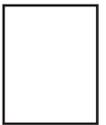
We hope that you will find some of these strategies useful. Please remember not to turn this into 'battle of wills' and that H does not use the toilet training task as a way to control you and the other caregivers. We wish you the best in your journey ahead.

This helpline question has been answered in conjunction with Dr Anjali Joshi. Dr Anjali Joshi is a practising occupational therapist, trained in S. I. and you can contact her anjali Joshi.ot@gmail.com

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