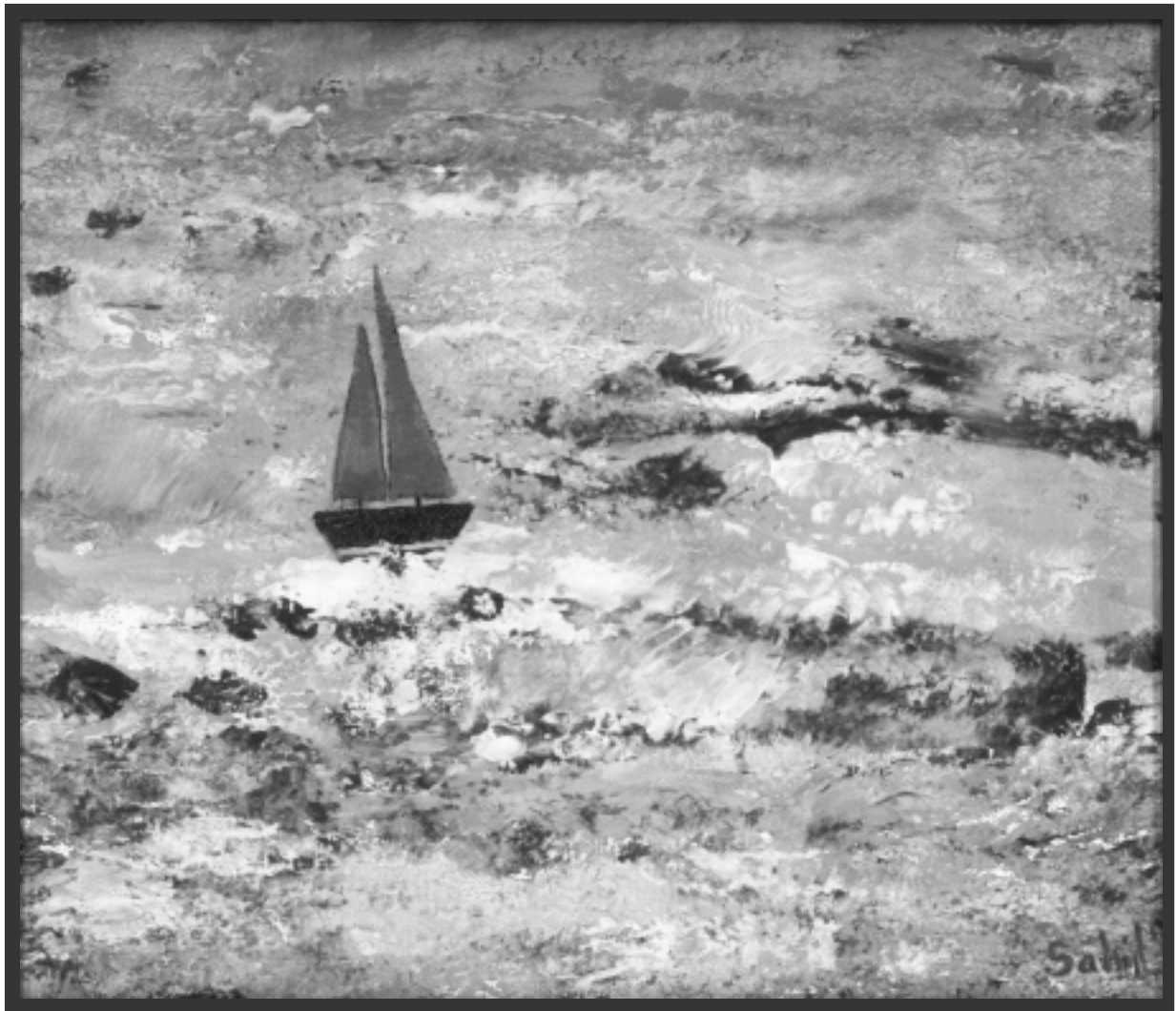
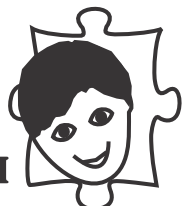


autism network

VOLUME 21, APRIL 2024



ACTION FOR AUTISM



autism network

2024

VOLUME 21

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

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

Autism Network does not accept advertisements. Expenses are met through memberships, donations and sponsorships, from our readers, friends and well wishers. The journal is for free distribution.

INFORMATION

For information on receiving the Autism Network write to:
Action For Autism, Pocket 7 & 8, Jasola Vihar, Behind Sai Niketan,
New Delhi - 110025. Tel: 40540991/2

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 a 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 Boat in the Sea by Sahil Baghdadi

Sahil Baghdadi, 30, has a passion for painting. He enjoys making copies of pictures using different mediums and bright colors. Sahil enjoys people and music and works in a sheltered workplace.

WISH LIST !

- Computers and computer accessories: keyboard speakers, mouse, hard drives, extension cords
- Computer games, X Box Konect
- Music systems: head phones, bluetooth speakers
- Washing machine, mixer grinder, induction plate, electric kettle, table mats, door curtains, waterproof aprons, hand towels, bean bags, ball chairs
- Trampoline, bean bags, indoor plastic slide, see saw, handyman kit: hammers, pliers, screw drivers, small drilling machine, nails, puzzles, bubbles, balloons, timers, beading boxes, squishy balls, pop-its
- Playdoh, pull along toys, light & sound making toys, Lego, pretend play toys: dolls, doll house, doctor's sets, furniture sets, grooming sets, kitchen/tea sets
- Classroom stationery: markers, A-4 sheets, A-3 sheets, acrylic paints (250 ml bottles), enamel paints, primers, paint brushes, old newspapers, glossy magazines, acrylic paints, clipboards, batteries (AAA & AA)
- Plastic baskets/jars, containers with lids, ziplock bags
- Volunteers: For yoga, art & craft

If you want to help, write to AFA or call:
AFA: 40540991/2, Reeta: 9811103702

Website: www.autism-india.org
Helpline Email: helpline.afa@gmail.com

C O N T E N T S

Page One	1
An Interview with Author Aditi Sowmyanarayan	2
Facilitating Independence for Autistic Children in Self-Care Routines	5
Going on a Holiday!	12
Learning with my Autistic Child	14
Hindi Article	18

PAGE ONE

Hello readers!

Our discussions when planning the April issue took into cognizance a number of earlier issues that carried a greater number of accounts of and by individuals who are typically viewed as 'high functioning' and 'independent'. For this issue, we wanted the focus on the lives and experiences of autistic people with higher support requirements, people who are typically, and inappropriately, labelled 'severe', while also being mindful of the importance of supporting early learning for future independence.

In a world that increasingly prioritizes conventional notions of independence, productivity, and success, those who may require higher levels of support are frequently overlooked, misunderstood, and marginalized. They face unique challenges that impact nearly every facet of their daily lives, from communication and self-care to navigating a society that too often dismisses them as incompetent. In recent times the media and much of mainstream discourse around autism too has tended to focus on those who are able to articulate their experiences, advocate for themselves, and live independently or semi-independently. While these perspectives are valuable and necessary, they do not tell the whole story.

Autistic individuals with 'high support needs' may require significant assistance with daily activities and may not communicate in ways that are easily understood by the broader population. This does not mean they lack voices or agency. Rather, it reflects a different way of being, one that demands recognition, understanding, and respect; in a world that is often unforgiving of diversity.

We front this issue with an insightful interview with autistic self-advocate Aditi Sowmyanarayan. Aditi happens to also be non-speaking. Non-speaking autistic persons as a group typically invite dismissal as having limited capacity. Readers will recall early literature on autism that stated that if a child does not develop speech by age five, it was an indication of brain damage with little scope for learning. Aditi's interview illustrates the strides we have taken in our

understanding of disability, and shines a light on the importance of presuming competence. Just because someone communicates differently or requires significant support does not mean they are incapable of complex thought or meaningful participation in their communities. Aditi, and the many other non-speaking autistic self-advocates remind us that everyone deserves the opportunity to be seen, heard, and understood. It is also worthwhile to remind ourselves that independence is not absolute. No one is fully independent. We are all co-dependant.

Autistic people are individuals regardless of whether they are speaking or non-speaking, and regardless of their perceived levels of independence - which are judged solely from a neurotypical perspective. And like everyone else every autistic person also has dreams, preferences, relationships, and rights. They are sons, daughters, friends, writers, readers, siblings, travellers, partners, job-holders, and members of our communities.

This issue is also a small vignette of the realities of this community, their lives, challenges and triumphs, moments of joy and connection, through accounts of the autistic community. While autistic people are taking the lead as advocate, these caregivers and family members too frequently serve as advocates and interpreters, navigating inflexible systems and societal barriers to ensure that their loved ones receive the opportunities and dignity they deserve.

It bears saying here that being more independent does not equal need for no support or that navigating the neurotypical environment is a breeze for such individuals. Truth is that they too have their challenges as much as those with high support needs and buying into the binary of 'severe' and 'high functioning' does damage to the autistic community.

It is through efforts of autistic people and their allies that we can create inclusive environments that presume competence and capacity of all, and where the needs of individuals across the spectrum can be prioritized.
Happy reading

An Interview with Author Aditi Sowmyanarayan

Aditi Sowmyanarayan, 18, is an award-winning writer, avid blogger and a non-speaking autistic advocate. Her fiction novella, 'With You Right Through', won the Best Manuscript award at JK AutHer Awards. Aditi presented at the United Nations World Autism Awareness Day event, 2023. She is also a member of the steering committee of the India Chapter of Institute of Neurodiversity, a Europe based not-for-profit. Aditi is passionate about raising awareness about non-speaking autism and alternative modes of communication and regularly blogs on www.smallstepbighthought.blogspot.com.

1. You are an amazing writer. Can you share what inspired you to start writing and share your journey as an author?

Thank you! I have always enjoyed reading. I picked up the ability to read when I was three. I also began building these colourful tales in my head, which soon became a favourite pastime since I didn't have too many friends to go out and play with. I, however, did not have a reliable mode to put these tales to paper until I was introduced to technology and typing on a laptop. I was introduced to typing on the laptop when I was 14. What started off as small creative writing exercises in class gave me the impetus to start my own blog page. The response that I got for my blogs, coupled with motivation from my educators encouraged me to get my short stories published. Small Stories Big Thoughts was launched on February 11, 2023 and is now in its third imprint, with a revised foreword. In the meantime, I had self-published my novella, *With You Right Through* on Kindle. My parents happened to chance upon the newspaper advertisement calling entries for AutHer awards 2022 and decided to enter my novella in the

best manuscript category. Winning the award was a watershed moment and the novella, published by JK Paper, in association with Readomania, as *Gobble Thy Prejudice*, is available on Amazon and in a few bookstores as well.

2. What is your favourite thing about writing?

The fact that as a writer I literally get to be the protagonist I create, while I am writing. I get to think, perceive and express like the protagonist and that's my favourite part of being a writer.

3. Who are some of your favourite authors and what do you like about them?

Ruskin Bond, P G Wodehouse and Salman Rushdie are my favourite authors. Their writing is so beautifully descriptive that you picture the setting, characters and events in your mind, kind of like a movie playing out.

P G Wodehouse was what other writers writing humour can only aspire to be.

I aspire to write like Ruskin Bond; capture the charm in everyday living. I want to write about the girl or boy next door who are superheroes in their own way and I want to write about the inherent goodness that most of us possess even to this day.

Writing fantasy fiction to highlight a few harsh realities and unpleasant truths; no one does it better than Salman Rushdie.

4. Your writing revolves around the theme of capacity and strength of human spirit. Is it a conscious effort? What drives your belief in human spirit and character?

I love to observe people and I write about the kind of people we see around us every day. And that is the crux of it all. We fight multiple battles every day and obviously don't emerge victorious in every single one of them. But what many of us do is learn from our experience and try to think outside the box, do things differently and grow in the true sense of the word. The evolution of humanity is a testimony to human spirit. If you think about it, many discoveries have occurred in ordinary everyday life settings. Would Newton have discovered and understood gravity had an apple not fallen on his head?

Everyday life and the quintessential boy or girl next door, I believe, make for great subject for writing fiction that embodies the human spirit.

5. We couldn't help but notice how many of your stories involve characters who are either chefs or starting their cooking journeys. Are you a foodie? Do you enjoy cooking? How is your relationship with food?

I have a love-love relationship with food and a hate-hate relationship with cooking. I am a foodie with a massive sweet tooth, so that's a double whammy. I don't enjoy cooking as I find it sensorially triggering. So, I am a bit like Kusum, the main protagonist of my novella *Gobble Thy Prejudice*, except I avoid cooking for a very different reason.

6. What do you hope to achieve with your writing endeavours?

I write because I want to and because I enjoy it thoroughly. My work is a labour of love. If my stories engage and entertain my readers and leave them with some food for thought, it makes me happy and motivates me to write more and write better. I also write blogs regularly for Avaz, India

Autism Center and advocacy pieces for Institute of Neurodiversity (ION). The aim of these blogs is to raise awareness about various aspects of living with autism, especially non-speaking autism and the impact of AAC (Augmentative and Alternative Communication) in helping many of us autistics find our voice.

7. When did you learn about your autism diagnosis and how?

Growing up, I realised that I am very different from most people my age in my neighbourhood and school. I was probably five when I first realised it and I had heard the word 'autism' at home and at school. I figured it probably had something to do with my being so 'different'. I was eight when my parents spoke to me about my diagnosis.

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

I have had different accommodation and support needs at different points of time, but what has helped is that I have been fortunate to have been in learning centres that were open to providing these supports. But the most important reason why I am a self-confident adult, for most part, is my family, who love me for who I am, my mother who never for once stopped believing in my abilities.

9. What helped you find your voice as a young adult and self-advocate?

Technology! Avaz helps me have conversations with people around me, I write on Pages in MacBook Pro, which has the feature of predictive text that makes the process of writing more seamless and I use social media like WhatsApp and LinkedIn to stay connected and use Instagram extensively as well.

10. What are some common myths about non speakers that you wish to dispel through your advocacy and writing?

I want to get across the message that we are as human as anyone else, which means we have our own set of interests, likes, dislikes, strengths, challenges, perspectives etc. Just like no two neurotypicals are the same, no two non-speakers are the same either. But in order to understand this and understand us as people, we need to have a voice and a reliable mode of expression. We need AAC.

11. How do you feel societal perceptions of non-speaking autistic people have changed over time and what further changes do you think are needed?

I think technology has not only given us non speakers a voice, but has also opened up ways and means for our narratives to reach far and wide. But what hasn't changed much, sadly, are the basics. Access to meaningful quality education, opportunities for work, acknowledging our autonomy and unique identity and access to supports that we require to lead our lives to the best of our ability – we have barely taken baby steps in these spaces.

12. In what ways do you incorporate your personal interests and passions into your advocacy work and writing?

Writing is my passion; more specifically writing fiction. I love to read, travel and observe people. I incorporate my observations into my stories and that is probably the reason why I am able to create protagonists that my readers can relate to.

The motivation behind my advocacy work is to use my voice to herald a positive change, in whatever

little ways that I can. Having said that, autism is a wide spectrum with a very wide range of strengths, challenges and experiences. I do put in a lot of research before writing advocacy blogs.

13. We really enjoyed reading your works. Any future works we should be on the lookout for?

Thank you! I have completed writing the manuscript of my next novel. It is tentatively titled 'Thus She Rose'. It is a story about courage, grit and standing by your convictions, even if that entails turning against your own family. It is set against the backdrop of Kashmir.

I have submitted it to a publisher and hope it gets published soon.

Facilitating Independence for Autistic Children in Self-Care Routines

Indrani Basu

1. INTRODUCTION

Being independent in daily self-care routines such as washing hands, toileting, bathing, dressing, undressing, hold tremendous value in our lives.

Independence in such activities in autistic individuals is often equated with the ability to lead dignified and self-reliant lives as adults. Mastering self-care routines is a major leap toward functional independence, giving the child a sense of control over the environment and works wonders for a sense of achievement and self-esteem. Independence in self-care routines need to be an essential goal in the educational plan of most autistic people from very early on, along with the many other skills to enhance well-being and fullest participation including communication - receptive and expressive language skills, social understating to enable easier and fruitful navigation of relationships and the social world; cognitive and academic skills; play and leisure skills for enjoyable occupation in free time and much more.

We know that autistic people have a different neurobiology, a different way of experiencing the world, a different way of learning. They often have laser-sharp focus that makes them concentrate on particular details to the exclusion of others, so that they may miss the context in which an activity takes place. So, some autistic people do pick up self-care routines much like non-autistic people but many need planned teaching.

2. IMPACT OF THE UNIQUE AUTISTIC LEARNING STYLE AND EXPERIENCES ON SELF- CARE ROUTINES

Understanding the specific learning styles, strengths and differences of autistic people help guide all

teaching. It is useful to look at these from the lens of independence in self-care routines for better learning outcomes.

I. Sensory Experiences

We understand the world through the information received from our senses. We receive information from the environment through our senses, process and integrate the information received to make 'sense' of what is happening around us.

Sensory processing and integration are a major area of difference in autistic people. Sensory information is perceived differently, processed differently and this has a pervasive impact across almost all facets of functioning, including in self-care routines. Each autistic individual has unique sensory experiences and thereby the challenges they may face would differ, too. An individual may have an overly sensitive scalp leading to difficulties in learning to shampoo hair, or a highly sensitive sense of smell or touch, throwing up challenges in using the soap available. Differences in proprioception may affect the sense of awareness of one's body in space. So, while shampooing hair, a person may apply shampoo on just the front of the head instead of moving the hands to cover the entire surface of the skull. Proprioceptive differences also impact understanding exact how much pressure needs to be exerted across varied situations such as squeezing out the precise amount of toothpaste or tapping the keys on a computer keyboard.

Some individuals may find it difficult to sit and balance themselves on the toilet seat because of vestibular issues. There may be yet others who find

an Indian style squat toilet very overwhelming because of distorted depth perception that could be linked with both visual and vestibular issues. These sensory difficulties could come in the way of using the toilet independently.

II. Interoception

One sense germane across most self-care routines is interoception. Interoception is the ability to be aware of internal sensations in our body. It is that which enables us to answer the question, 'How do I Feel?' at any given moment. It helps us be aware if we are feeling hunger, thirst, hot or cold, heart rate, temperature, pain, fatigue, a full bladder as well as emotions.

For example, when we notice that our lower abdomen is feeling very full and exerting a pressure, that feeling provides us with a clue that our bladder may be full, which leads us to take action and use the washroom. Or at a mealtime perhaps we notice a tight or heavy stomach which lets us know that we are full and that is when we may stop eating. We are also aware that this feeling is very different from the heaviness we feel when we need to use the washroom. Similarly, on a very humid day, when we have been sweating a lot, we may feel very 'grimy' and that is the day when we may use soap more generously or scrub ourselves better when taking a bath.

Interoception is often dysregulated in autistic people, making it hard for them to both perceive and interpret these internal feelings thus making it very hard for them to take action to mitigate these feelings, impacting the ability to initiate and be independent in self-care routines.

III. Monotropism

It is said that autistic people are more likely to be monotropic (Garau et al., 2023), ie have an interest based nervous system. They focus more of their attention resources on fewer things at any one time,

often the primary task at hand, compared to other people who may be polytropic. The focus on this primary task is very intense, often compared to 'tunnel vision', which makes switching attention to other tasks hard, especially when shifting attention from a task of high interest.

Hence, when engaged in a task, especially of high interest, other things may drop out of awareness and these things that get dropped, tend to stay dropped. This may lead to the person being less likely to recognize that they may need to use the washroom or eat or drink water to restore energy and may need reminders or some kind of system to do so.

IV. Motivation

Drawing on the preceding we can see that self-awareness, ie recognising personal needs is often a leading motivator for self-care routines. The differences in self-awareness arising out of both a dysregulated interoception, as well as monotropism may well account for the difficulties in achieving independence in self-care routines in autistic people.

In addition, most non autistic people crave social motivation. They are driven by what other people think and believe of them, and would go to great lengths to appear 'good' in other people's eyes. A little two or three-year-old, making an effort to wash her mouth neatly after a meal, or go to the toilet instead of relieving in her diaper, may be doing so less from a place of self-awareness, but more from the awareness that her effort is going to make her parents happy and that she is being 'smart' when doing this. While autistic people enjoy people and social motivation, they may not contextualise their actions with the responses from people. In addition, their sensory challenges may come in the way of their enjoying social approbation.

However, they are highly intrinsically motivated. If tasks or activities are connected to a special interest,

most would be motivated for the same. A child who enjoys the visual and auditory stimulus of water rushing down a commode after using the flush, may be motivated to relive himself in the toilet, as that would lead to the flush being used. However, even when the activity is not related to a special interest, if these are made meaningful, predictable, and routine oriented, most can learn to be motivated to complete these tasks.

It is also important for teaching strategies to mesh with the autistic learning style. When that does not happen many face failure which leads to lowered motivation levels. As we know, success breeds success, and failure breeds failure.

It is important to keep all these factors that impact motivation in mind when teaching self-care routines to autistic people. In fact, it is an important factor to keep in mind whilst teaching them any skill, since no learning can happen without motivation!

V. Imitation

Young children learn skills, including self-care skills by observation and imitation. They watch their parents and want to imitate them: comb their hair, eat and dress themselves accordingly. Given the differences in attention and motivation, many autistic children may not learn intuitively through imitation.

VI. Motor skills

They may also face difficulties in performing self-care routines due to delay in acquisition of motor milestones such as grasping objects or manipulating objects. So a child who is not yet fluent in grasping linear objects will have difficulties in holding a spoon, a toothbrush or a comb. The child who is not yet using a pincer grip (the ability to hold something between the thumb and first finger, a skill that usually develops in babies around 9 to 10 months old), will have trouble manipulating buttons and fasteners while dressing and undressing.

Difficulties in motor coordination and balance can lead to challenges in activities that require coordination between different body parts, such as tying shoelaces or washing one's bottom after defecation.

VII. Executive Function

Executive Function is the set of cognitive skills that include concentration, memory, planning, organizing, self-control, and planning, among other things that help us reach a goal. Autistic people may face difficulty with holding and organising information in their minds. Self-care routines require an effort in remembering the different steps in any routine and the sequence in which they have to be carried out. For instance, while bathing, if we intend to shampoo our hair we have to remember to shampoo as well as soap ourselves, and then rinse off both the shampoo and the soap. Difficulty in holding these steps in our mind may lead to missing a step.

VIII. Routines

Autistic people are natural routine followers. They thrive in predictable, routine oriented environments and these predictable patterns make it easier to navigate the world with autonomy and self-confidence. This, of course, applies to many non-autistic people too. Once having learnt a routine or skill most follow them with absolute fidelity. For example, Shaila had learnt as a child that she must chew every morsel of her food for a count of five before swallowing. As an adult she continues to do so ensuring that her food is never gulped down, leading to a healthy eating habit. Similarly, Robin learnt to hang his towel on the towel rack in the bathroom after a bath. The rest of his family members, including his neurotypical sibling, often has to be reminded to hang up their towels, but Robin never needs any such reminders.

It is important to capitalise on this wonderful strength of autistic people who having learnt a skill or a routine in a particular way, will perform that routine with precision.

Their fidelity to learnt routines can however lead to difficulties. Should they be interrupted in the middle of a well-set routine they may want to go back and restart the routine to enable them recall the sequence of steps required to complete the activity. After putting on one of her socks Dina got distracted by her mother. When she resumed, she had to take off her sock and restart the 'wearing socks and shoes' routine right from the beginning. Likewise, Nimesh put on his vest and shirt and as he was buttoning his shirt, he noticed that his shirt was on inside-out. He had to remove both his shirt and vest and put them back on again. This need to restart interrupted routines can make self-care routines extremely cumbersome and challenging.

Their wonderful ability to learn routines can also make it hard for them to unlearn a routine and learn it afresh in a different way. Hence, it is critical to teach the right routines from the word go, using appropriate teaching strategies and supports, ensuring that no wrong routines are inadvertently taught and that the learning is 'errorless'. Given the impact that independence in self-care routines have on general wellbeing, it is also important to start as early as possible, so that these become part of the person's natural routines.

Keeping these unique learning styles in mind, the following suggests a few strategies that can support autistic people (as well as those with other developmental disabilities) be independent in self-care routines.

3. STRATEGIES TO TEACH INDEPENDENCE IN SELF-CARE ROUTINES:

I. Identify the target self-care routine/s

Having a clear understanding of precisely which self-care routine/s will be taught currently, will help identify clear goals and guide the learning better.

We may want to factor in the person's age and what other non-autistic people at that age do, when

deciding the same. For instance, most children at the age of three have already begun being toilet trained. So, if working with a three year of autistic child, toilet training could be a goal. Similarly, many typical three-year-olds can take off elasticized lowers on their own while undressing, and hence taking off elasticized lowers independently, could be a target skill when working with the autistic three-year-old. However, most three-year-olds are supported completely when bathing, and learn to bathe independently at a later age, maybe, when they around 6 or 7 years old. Bathing, hence may not be a target self-care routine for the three-year-old. We may want to start teaching this skill a little before we would with the non-autistic child, giving the autistic child a little more time to master the skill (compared to a non-autistic peer), should s/he need it.

II. Sensory challenges

Sensory challenges are a significant guiding factor. Should the person have a lot of sensory difficulties around a particular self-care routine, we may look at easing the same, before putting in the additional demand of completing the routine independently. For example, should a child have severe oral sensitivities, we may want to first work on desensitization through oral massages with different textures, provide with textures that soothe etc., And, when there is a degree of tolerance, we start teaching to brush teeth by self. We need to remember that we may need to continue to accommodate for sensory difficulties, when we are actually teaching a skill to independence or even when the person is completely fluent in the skill. So, when teaching the child with oral sensitivities to brush teeth, we may need experiment with the least aversive toothbrush/ tooth paste. Or for the person who finds labels on clothes aversive, may always need the labels to be taken off his garments even when absolutely proficient in dressing by self.

It is important to note, that a few people may actually prefer to be 'in charge' of the self-care

routine around which they have a sensory challenge, as this may give them the control and enable them to self-regulate to the extent to which they can tolerate the sensation/s when there are completing the routine.

As with sensory challenges, readiness with regard **motor skills** may be yet another aspect to consider. For a child who has not learnt to use a pincer grip, we may want to teach and strengthen this skill first across varied activities. Once the child has a degree of proficiency in using the pincer grip, per se, we then teach to use fasteners and buttons. In addition to this, we will of course continue to strengthen any component motor skills required when teaching a particular self-care routine, as explained later.

Any current targeted skill, will hence need to be highly individualized based on an understanding of each person's needs and challenges. The degree of the challenges will help us decide if these difficulties should first be addressed on a global level before teaching the self-care routine or if we need to provide additional support for the same while concurrently teaching the self-care routine.

III. Do a 'task analysis'

All self-care routines are comprised of a 'chain' or series of several steps, each of which we carry out to complete the task. For instance, the routine of washing hands with soap comprises of opening the tap, wetting our hands, taking the soap, rubbing soap on the hands, keeping the soap by, rinsing our hands under water and then closing the tap.

A task analysis refers to noting each such step and the exact sequence that the steps occur in to lead to the completion of the self-care routine. When writing the task analysis, we may ideally want to perform the task ourselves to note the sequence of steps necessary to complete the task. A task analysis helps us with an understanding the discrete goals involved in teaching any self-care routine.

IV. Assess the person's current level of strengths and needs in the targeted routine/s

The next step would be to understand the child's current level of performance in the targeted routine/s.

Take notes; collect information for a few days. Which sections and how much of the skill does the person have mastery over?

If already fluent in the discrete skills in the chain and needs reminders to 'link' the steps to achieve independence, then one can start teaching to follow the steps in order so as to complete the task by himself.

If the task presents any steps that the person does not currently have mastery over, then it may be premature to expect the child to perform the entire task. In that case the person may first need to learn the missing skills, step by step, in order to eventually carry out that self-care routine independently.

If the person needs support in all the steps in the routine, that too will need to be noted.

This assessment provides the baseline. We will see a pattern emerge of what steps we will need to focus on teaching the targeted routine.

This information will also help understand other areas of difficulties and accommodations required. Are there difficulties in specific gross or fine motor skills? Are there specific sensorial issues? Do the necessary tools required for a particular self-care skill need adaptation? Or any other aspect/s that may help frame precise goals for more successful outcomes.

V. Identify motivators, embed special interests

Given that special interests can be highly effective in motivating autistic people, embedding such

interests in the routine itself is very powerful. A child who seeks 'visual stimulation' may find learning how to soap himself more motivating using transparent soaps like Pears glycerin that he can 'look through'. Similarly using specially flavoured toothpaste or toothbrushes that vibrate or light up could motivate a child brush their teeth. Or encouraging the person to pick out his favourite clothes to wear prior to teaching the dressing sequence, may enhance independence in learning this routine.

Providing with favoured toys, activities, food could also enhance motivation. For instance, when teaching a child to eat independently, the child who likes pickles could be offered a tiny amount of pickle after each morsel that is eaten independently. The frequency of offering the pickle would be gradually decreased as the child gains proficiency in the target skill. Or when teaching a child to sit on a WC while defecating, should s/he keep running away, s/he could be given a favoured toy to hold on to, to keep him motivated to continue sitting.

Remember, no learning can continue to be successful without appropriate motivation and hence enhancing motivation is imperative in any teaching process.

VI. Desensitise and/or trouble-shoot sensory issues.

As mentioned earlier, sensory processing difficulties often impact independence in self-care routines and these must be identified and addressed for the child to be able to learn. So, if a child resists washing hair because of an over sensitive scalp, we need to find ways of reducing the discomfort for eg use a soapy washcloth, pouring water gently over the head instead of using a shower to rinse; or try to desensitize the scalp by applying deep pressure on the scalp before showering and washing hair. If the smell or taste of the toothpaste is a concern, then we want to shop for new products (with the child if

possible) and experiment with different toothpastes. If the texture of a thick terry towel is aversive, we may want to use a thin towel or a 'gamcha'. If sitting and balancing self on a WC is difficult, we may provide a stool for the child to rest his feet on, to support him in feeling 'grounded'.

VII. Adapt tools and equipment

When the person is in the learning stage, it is ideal to ensure that the items required for the particular routines maximizes the chance of success in learning.

A common adaptation for many young children is providing with a baby seat (Fig 1.1) on the adult seat of the WC to help them sit comfortably.



Fig 1.1: Baby toilet seat

Such supports can be provided across varied self-care routines to encourage success.

When teaching a person to eat rice and dal with a spoon, it may be better initially to give a plate or thali with raised edges (Fig 1.2). This makes it easier to scoop the rice and dal when eating. Or, provide a spoon or fork with a 'grip' (Fig 1.3), to make gripping easier. Cutlery may also be needed for a child who has a sensory aversion to the feel of soft wet food – like rice and dal – on their fingers.



Fig 1.2: Thali with raised edges



Fig 1.3: Fork, spoon with a grip

When teaching a child to wear a T-shirt start with loose-fitting T-shirts that slip on easier. And as they get adept at wearing T-shirts by themselves, they could move to more fitted clothes.

VIII. Teach ONE STEP at a time, using backward chaining

An extremely effective and successful way of teaching self-care routine is through 'backward chaining'. Chaining refers to the process of teaching a sequence of steps, one step at a time, to complete an activity. As mentioned in the preceding, this chain can be arrived at by a task analysis of the specific activity.

There are two types of 'chaining' that can be used to teach: forward chaining and backward chaining. In forward chaining one begins with teaching the first step in the 'chain' or sequence and progressing to the last step. In backward chaining one begins with teaching the last step in the 'chain' or sequence first, and moving backwards to the first step in the chain.

• **Forward Chaining**

In the routine of washing hands the 'chain' that is arrived at through a task analysis could comprise of the following steps:

- Step 1. Open the tap
- Step 2. Wet hands
- Step 3. Take the soap
- Step 4. Rub soap on the hands
- Step 5. Keep the soap by
- Step 6. Rinse hands under water
- Step 7. Close the tap

In using forward chaining, the child first learns Step 1, i.e. Open the tap and the facilitator completes steps 2 to 7 for the child. When the child has learnt Step 1 we then proceed with teaching the Step 2, and the Step 3, and so on with successive steps till the last step i.e. Close tap is learnt to independence.

• **Backward Chaining**

In backward chaining the sequence for teaching will be reversed, as follows:

- Step 7. Close the tap
- Step 6. Rinse hands under water
- Step 5. Keep the soap by
- Step 4. Rub soap on the hands
- Step 3. Take the soap
- Step 2. Wet hands
- Step 1. Opening the tap

The person starts with learning to perform the last step first, i.e. Close the tap (Step 7) while we do steps 1 to 6 for the child with all the support required, without any specific teaching goals for these steps. When the child is fluent in Step 7 and is able to close the tap independently, we help him learn Step 6 i.e. Rinse hands under water, while we continue to do steps 1 to 5 for him with all the support required. Once the child is fluent in Step 6 and 7, we then teach him Step 5 i.e. Rinse hands. We keep teaching each previous step till the child has learnt the first step i.e. Open the tap to independence.

To be continued in the next issue of Autism Network...

Going on a Holiday!

By Chitra Iyer

As our recent holiday in Amsterdam and Paris drew to a close, I found myself reflecting what travelling with my autistic son entails and how with growing awareness and understanding, the experience has evolved over the years.

The preparation for the journey began a day before our departure. Knowing the challenges we might face at the airport I reached out to the Central Industrial Security Force (CISF), a crucial component of airport security. Thanks to multiple workshops organized for the CISF by Forum for Autism, a parent support group, we had heard about the many families who have benefited from their help when travelling. Armed with this knowledge, I called the CISF to notify them of our travel plans. They requested that I inform them five minutes before our arrival at the airport.

My 24-year-old Shravan is a happy go lucky five-foot-seven and has no concept of fear. He has autism, cerebral palsy, epilepsy and is non-speaking. Shravan has depth perception issues and so needs support when going anywhere. He loves to travel and given a chance would spend the whole day in a vehicle.

When we just got off the cab at the airport, there was a friendly officer waving at us who accompanied us to the Air India counter where I had pre-booked a wheelchair. As an aside, we had recently learnt about the Sunflower Lanyard adopted by airports around the world. It is a discreet indication that the wearer of the lanyard has a hidden disability and may need additional support. Wish this comes to our cities too or we can start a project ourselves in India so that in very noisy crowded places like the airport, people with invisible disabilities get the support they need.

With the support of the CISF officer, we proceeded through security, bypassing the long queues and heading straight to the priority line. Disabled individuals may if they want avoid the regular queue and head straight to the queue marked Priority/Business Class/Disability. This is a big help as waiting can be hard for our individuals. Shravan can walk independently, but he tries to shake hands with strangers, wants to be friendly, smiling at them and standing too close for their comfort; and the wheelchair helps in this respect too during the two and a half hour wait before boarding. We were given priority boarding which allowed us to take our seats before the other passengers. Shravan was seated with his parents on each side and with everything he needed to stay comfortable and entertained during the flight at hand.

Arriving at our destination, we were greeted by friendly wheelchair attendants who facilitated our exit from the aircraft and immigration and provided assistance as we made our way through the airport. Whether in Amsterdam or other countries we have visited, interactions with airport staff have always been positive, and we usually strike interesting conversations with them taking the time to inquire about our travel plans, previous experiences, and Shravan's needs.

During a short trip to Paris by train from Amsterdam, we had to help our son navigate a noticeable gap between the train and the platform's height. We each had to hold one of his legs to guide him to step onto the train. Despite the delay everyone waited patiently and helped make our journey much smoother.

Every country we had visited my son has been prioritised whether on hop-on-hop-off buses, at

theme parks – Universal studios, Disneyworld in the US and the Singapore zoo. This time too we experienced the same at the Amsterdam zoo. Priority also included a discount on the tickets at the latter.

When catching the flight back from Amsterdam we experienced five harrowing minutes when the cab dropped us at the wrong departure gate. We made the mistake of not pressing the assistance button at any of the gates and waiting for someone to approach us with a wheelchair – which is the accepted practice. Instead, as we rushed with our luggage trying to find and reach the correct counter in time, our son got agitated, reaching out his hand to those around him. Though apprehensive of the tall agitated man, no one flinched. Instead they simply kept themselves out of his reach and remained patient and understanding.

Back in Delhi, while de-boarding we encountered an oblivious and not too pleasant gentleman who obstructed the wheelchair's path with his bag and gave way reluctantly after much polite request. But then we got a very helpful young wheelchair attendant who facilitated us through customs and immigration with ease. The attendant then ushered us to the front of the queue for the onward flight to Mumbai. We were joined by a young mother with a bawling hungry infant who urgently needed to be fed. Seeing their need we asked them to move ahead of us. We were now joined by the same gentleman (he had a business class ticket), who elbowed his way to the top of the priority boarding queue ahead of the distraught young mother.

I could not help wonder at his behaviour. Was it his business class status that made him feel entitled to precedence over young children in need and individuals with disabilities? It was a moment of reflection on the true meaning of priority and the importance of empathy in our interactions with others. The concept of priority embodies inclusivity and empathy. When will priority become applicable in public places and queues in our country, at restaurants, at doctors, in a general hospital, in

grocery stores. In a society where we navigate traffic lanes with little regard for others, do we truly understand the needs of those with visible and invisible disabilities, senior citizens, infants, and others who require priority?

I share this to encourage families of individuals with disabilities to travel, only then will the world get educated on priority. It is our children's right which you must demand and make use of. Take advantage of what is available and demand for where it is not.

Chitra Iyer is an advocate for autism awareness, serves as Trustee and Treasurer of Forum for Autism, and as a Cost Accountant and Certified Financial Planner is deeply involved in supporting families of children with special needs. Chitra is the mother of 20-year-old Shravan who has autism and cerebral palsy.

ACTION FOR AUTISM
National Centre for Autism India

#HASH HACK CODE?

CODING FOR ALL

FREE CODING CAMP

AFA in collaboration with HashHackCode is organizing a free coding camp

Sessions: 2 (online)
Duration: 90 minutes per session

Topics of the session:

1. Early Logic.
Age 5 and above.
For developing logical and critical thinking
2. Creative coding.
Age 12 and above.
Basics of coding and primitive level know how

Mode: Web based application with the help of facilitators

Pre-requisites: Computer literacy and access to laptop or PC

Participants type:
Neurodivergent (any age) and Neurotypical students

✉ aailaan.afa@gmail.com ☎ +011 40540991/92

Learning with my Autistic Child

S Kalpana

The birth of Dravid, the first grandchild in my family, on the 25th of May, 2007, was a moment of immense joy for me. Like many expecting mothers, I had hoped for a girl, but my happiness was boundless regardless. As any proud mother would, I envisioned a future filled with dreams and aspirations for Dravid. I imagined teaching him multiple languages, encouraging him in sports, introducing him to musical instruments, instilling discipline, and guiding him to become a responsible individual. The anticipation of sharing these experiences with him filled my heart with excitement and love.

For the first year and a half, Dravid met all his developmental milestones on time. He called me and everyone else "mummy," a term of endearment that warmed my heart. However, I longed for him to call me "Amma," a word that held significant emotional power for me. He was a lively child who loved standing on our balcony, loudly speaking in his unique baby language that no one could quite understand. During this time, we were living in Kashmir, nestled in a mountainous area with our house situated in the middle row near the parking lot. Dravid's charming antics made him quite famous in our locality, and his habit of throwing things down from the balcony became a source of amusement for many. Because of him, I made numerous friends among our neighbors. Dravid was a happy child, and his presence was a solution to many of my problems.

However, I began to notice some concerns about Dravid's imitation skills. While I saw other children mimic behaviors and actions, Dravid seemed different. My husband, ever the voice of reason, advised me not to compare Dravid with other

children. His words, though comforting, didn't completely quell my worries.

Exactly at one and a half years old, Dravid received his MMR (measles, mumps, and rubella) vaccination. Like many children, he became mildly ill afterward, but this time something was different. He stopped talking. Around the same time, the washbasin in our house broke down in front of him, and I thought this might also be a reason for his silence. As a mother, my concern grew, especially as I was preparing for the birth of my second child. I had to travel to my native place for the delivery, and during this period, I consulted a renowned pediatrician, Dr. Sengutuvan, in Trichirapalli. Fortunately, he had knowledge about autism and referred us to a special education center for a diagnosis. On that very day, Dravid was diagnosed with autism. Before that, I met my aunt, who asked me a question that struck me deeply: "Dravid is not speaking, but does he follow instructions and directions?" Now I wondered if she was diagnosing his condition just by observing his communication difficulties.

The word 'autism' was entirely new to us, and the therapist explained that it was an incurable condition, with therapy being the primary mode of support. At the time, I was pregnant and found it incredibly challenging to accept the diagnosis. I cried a lot, feeling a deep sense of helplessness. Returning home, I faced the daunting task of explaining Dravid's condition to my in-laws and parents. Their responses varied from suggesting that we were inadequate parents to recommending religious rituals, Ayurvedic treatments, and dietary changes like the CFGF (casein-free, gluten-free) diet. I followed everything.

Dravid was just 18 months old, not yet toilet trained, a picky eater, and struggled with separation anxiety. Despite these challenges, I had to take him to a therapy center 45 kilometers away from home, even as I neared my delivery date. After the birth of my second child, life felt overwhelming, almost as if I had twins. Three months later, we moved to Delhi. At that time, I felt like my life had come to an end. The future seemed like a dark, endless tunnel with no way out.

On the 15th of September, 2009, I visited Action For Autism for counseling and began therapy sessions for Dravid. By January 2010, I had enrolled in the Mother and Child program (now known as the Parent and Child program). This program was a turning point, empowering me with knowledge about Dravid and autism. I learned how to train Dravid in essential skills like toilet training, nail cutting, and hair cutting. Although it took a lot of time and effort, I eventually succeeded.

What I learned was that the first thing we need to do is accept the child. Don't ask "Why me?" Embrace your child in social situations. People will talk behind my back and I know what they are talking about. I just need to ignore them. In public places don't think about what others think about me. Think about what I can do so my child will be comfortable in this situation.

Dravid initially didn't even want to walk near a salon. He used to scream and resist haircuts vehemently. However, with patience and the support of a kind hairdresser who used the same language I did with Dravid, he gradually became more comfortable. One day, Dravid surprised me by communicating his need for a haircut. He took me to the shop himself, and I felt on top of the world. Similarly, nail cutting was initially a two-person job, with Dravid resisting every attempt. But after months of persistence, he began to offer his fingers willingly for nail cutting. Achieving these

milestones raised my self-esteem significantly. Dravid started communicating his needs for toilet use, food items, and attention. Each small victory felt monumental. One day when Dravid suddenly called me "Amma" I was overjoyed.

Dravid began attending Open Door school at Action For Autism in 2011. At this time he had challenges with toilet training. Dravid liked cello tape on his hand so whenever he used the toilet I would give him a piece of cello tape and he quickly understood that if he used the toilet he would get something. For potty training, he liked bubbles. I used to blow bubbles when he sat on the toilet, and it helped a lot. For food, he didn't eat any single fruit but started eating fruits with his caregivers. They used to eat fruit, and he just tried it once and then started eating almost all fruits. I was surprised.

Anger management was a challenge, and I tried many techniques, but the school provided tremendous support to both of us. Each class teacher formed a unique bond with Dravid, which was incredibly heartwarming.

During the COVID-19 pandemic, I spent a lot of time with Dravid and gained a deeper understanding of his difficulties. I worked diligently to address them. This period also made me realize how much Dravid had contributed to my growth. He had made me a better cook, a makeshift barber, a more patient teacher, and an organized individual.

Dravid loves to travel, and our trips home are always filled with excitement. We usually start our journey early in the morning, taking a 4 a.m. flight followed by a 2.5-hour bus ride. Despite the long hours, Dravid enjoys every moment. On our recent 12-day trip, we travelled daily for various reasons, and Dravid was thrilled throughout.

At the age of five, Dravid started experiencing seizures and has been on medication ever since,

dealing with their side effects bravely. Now, Dravid has graduated from school and is set to join the Aadhaar vocational center soon. I couldn't be prouder of him.

Looking back, what I once perceived as a dead-end due to Dravid's diagnosis turned out to be a tunnel leading to a new world filled with opportunities and growth. I am immensely proud of being Dravid's mother and cherish the journey we've had together.

Reflecting further on our journey, I realize how crucial the support from various sources has been. The initial shock and confusion of Dravid's diagnosis were softened by the guidance and expertise of professionals at Action For Autism. Their detailed explanations and patient counseling sessions helped me navigate the complex world of autism, transforming my fear into a proactive approach to Dravid's development. The Mother and Child program, now known as the Parent and Child program, was particularly pivotal. The program was meticulously designed to address not just the child's needs but also the parents' emotional and psychological journey. It provided a holistic approach to understanding and managing autism, emphasizing practical skills and emotional resilience.

In the early days, each trip to the therapy center felt like an arduous journey. The 45-kilometer drive was physically and emotionally exhausting, especially with a newborn and Dravid's separation anxiety. But every session brought a glimmer of hope. The therapists were not just professionals; they became a part of our extended family, offering unwavering support and encouragement. They celebrated Dravid's smallest achievements with as much joy as I did, making the process less daunting.

One of the most profound lessons I learned was the power of acceptance. The initial denial and the 'why me?' questions only added to my stress. Accepting

Dravid for who he is, embracing his unique needs, and focusing on his strengths transformed our lives. It was a shift from constantly trying to fit him into societal norms to creating an environment where he could thrive. This acceptance extended to social situations. Initially, I was overly concerned about what others would think. The whispers, the stares, and the unsolicited advice were overwhelming. But gradually, I learned to block out the noise. I realized that my priority was Dravid's comfort and happiness, not societal approval.

Building a supportive community was another critical aspect of our journey. Our neighbors in Kashmir played an unexpected but significant role. Dravid's antics, such as throwing things from the balcony, became a source of amusement and connection. These interactions helped me build a network of friends who were empathetic and supportive. Similarly, the relationships formed at AFA's Open Door School were invaluable. The teachers and staff were not just educators; they became mentors and friends. They understood Dravid's challenges and worked with me to create strategies that catered to his unique needs. Their dedication and genuine care made a world of difference.

As Dravid grew, so did my understanding of autism. Initially, I was overwhelmed by the plethora of advice and treatment options. From dietary changes to alternative therapies, I tried everything in the hope of seeing improvement. While some methods were beneficial, others were less effective. It was a learning process, and over time, I became more discerning. The key was finding a balance between structured therapy and understanding Dravid's natural inclinations and interests.

Toilet training, for instance, was a significant milestone. Using incentives like cello tape and bubbles made the process engaging and less stressful for Dravid. These small victories built his

confidence and mine. Similarly, integrating his interests into daily activities made learning more enjoyable. Dravid's love for travel was leveraged to teach him about different environments and social settings. Each journey was an opportunity for learning and growth, both for him and for me.

The onset of seizures at the age of five was another challenging phase. Managing his medication and dealing with the side effects required a new level of vigilance and care. Yet, through it all, Dravid's resilience shone through. His ability to cope with the seizures and continue with his daily activities was inspiring. It reminded me of his inherent strength and the importance of supporting him through every challenge.

The COVID-19 pandemic, despite its global impact, brought unexpected positives for us. The extended time at home allowed me to observe and understand Dravid's needs more closely. I identified areas that required more attention and worked on them diligently. This period also highlighted Dravid's adaptability. Despite the disruptions in routine, he adjusted remarkably well, showcasing his ability to cope with change.

As Dravid transitions to the Aadhaar vocational center, I reflect on how far we've come. The initial diagnosis, which seemed like the end of the world, was actually the beginning of a transformative journey. Dravid has not only grown and learned but has also taught me invaluable lessons. He has made me a more patient, resilient, and compassionate person. The journey has been filled with challenges, but each one has strengthened our bond and deepened my appreciation for Dravid's unique spirit.

In conclusion, Dravid's journey has been a testament to the power of love, acceptance, and resilience. From the initial shock of his autism diagnosis to the numerous milestones we've

achieved, every step has been a learning experience. The support from professionals, the bond with caregivers, and the strength of our community have been instrumental in our journey. Most importantly, Dravid's unwavering spirit and determination have been the guiding light. As we look forward to the future, I am filled with hope and pride. Dravid's journey is a celebration of his achievements and a reminder of the boundless potential that lies within him. I am immensely proud to be Dravid's mother and cherish every moment of our shared journey.

S Kalpana is an educator at Action For Autism with over 12 years of experience in classrooms and sheltered workshops for autistic children and adults. In addition to being a professional, Kalpana has two sons who are both autistic.



REGISTER NOW

ACTION FOR AUTISM
National Centre for Autism India

Employment READINESS PROGRAMME

July 2024 | via ZOOM
For All Neurodiverse Individuals

TOPICS COVERED

- Conversational and Social Skills
- Money Management and Budgeting
- Problem Solving
- Time Management
- Health and Hygiene
- Understanding relationships and concept of privacy
- Emotion Regulation
- Formal Written Communication (like emails)
- Resume Building
- Interview Handling
- Concept of self and identity

BOOK YOUR SEAT NOW!
wne.afa@gmail.com
011 40540991/ 92

बिना जाने एक ऑटिस्टिक बच्चे को नुकसान पहुँचाने के पाँच तरीके

क्रिस बोनलो

स्रोत: ऑटिस्टिक नॉट वीर्ड (<http://autisticnotweird.com>)

हाँ, ये एक थोड़ा असहज विषय है, लेकिन ऐसे मुद्दों पर बात करना हमारी ज़िम्मेदारी है।

आज, मैं कुछ आदतों के बारे में बात करने वाला हूँ जो मैंने अलग-अलग जगहों पर देखी हैं। कुछ मेरी पढ़ाई के दौरान (सामान्य और विशेष शिक्षा दोनों में), कुछ ऐसे लोगों से जो मेरे जैसे अस्पेर्गेर सिंड्रोम वाले व्यक्ति के साथ रहते हैं और कुछ इंटरनेट पर की गई टिप्पणियों में। ये आदतें, चाहे अनजाने में की जाएं, नुकसान पहुंचा सकती हैं, और इसी वजह से इस लेख का शीर्षक ऐसा है।

मुझे पता है कि ये एक कठिन विषय है, लेकिन पाँच ऐसी गलतियाँ हैं जिनके बारे में बात करना ज़रूरी है। आपको ये जानकर हैरानी होगी कि इन गलतियों को करना कितना आसान है।

खास बात ये है कि ये मार्गदर्शिका सिर्फ माता-पिता के लिए नहीं है। (मैं खुद माता-पिता नहीं हूँ, तो मैं पालन-पोषण के बारे में कोई खास जानकारी का दावा नहीं कर सकता।) ये उन सभी लोगों के लिए है जो किसी युवा और/या कमजोर ऑटिस्टिक व्यक्ति के संपर्क में आते हैं, चाहे वो माता-पिता हों, शिक्षक हों, सहायक हों, परिवार के दोस्त हों, या कोई और।

ठीक है, एक गहरी सांस लें...

1. उनके बारे में ऐसे बात करें जैसे वे कमरे में नहीं हैं।

यह जानकर आपको हैरानी होगी कि मैंने कितने लोगों को ऐसा करते देखा है। लोग अक्सर सोचते हैं कि ऑटिस्टिक व्यक्ति चुपचाप कहीं और देख रहा है, तो वे सुन नहीं रहे होंगे। लेकिन यह एक गलत धारणा है। ऐसा सोचना उनके बारे में अनुचित है, क्योंकि वे बस अलग तरीके से संवाद करते हैं।

आप कभी किसी गैर-ऑटिस्टिक व्यक्ति के बारे में ये नहीं मानेंगे कि वे कमरे में नहीं हैं, तो ऑटिस्टिक व्यक्ति के बारे में ऐसा क्यों मानें? और अगर आप मानते हैं कि वे सुन नहीं रहे हैं, तो आप कुछ भी कह सकते हैं, जो गलत है।

जब मैं विशेष शिक्षा में काम करता था, तो मैं हमेशा गैर-मौखिक छात्रों से बात करता था, क्योंकि मुद्दा ये नहीं था कि वे जवाब देंगे या नहीं। मुद्दा ये था कि उन्हें सामाजिक बातचीत का अनुभव मिले।

एक बार की बात है, मैं बाहर 12 साल के एक लड़के के साथ बैठा था, जिसे हम जेम्स कहेंगे। मैं उससे बात कर रहा था, ज्यादातर मौसम के बारे में। (हालांकि, सच कहूँ तो, मैं एस्पेर्गर सिंड्रोम के कारण छोटे-मोटे बात करने के बजाय डायनासोर या 'सोनिक द हेजहोग' के बारे में बात करना पसंद करता, लेकिन मैं ब्रिटिश हूँ, तो मौसम हमारी सामान्य बातचीत का हिस्सा है।) उस दिन मैं थोड़ा उदास था, लेकिन फिर भी उससे बात करता रहा, क्योंकि उसकी ज़रूरतें मेरी भावनाओं से ज़्यादा महत्वपूर्ण थीं।

जब मैं उससे बात कर रहा था, उसने न तो मेरी तरफ देखा, न कुछ कहा, और न ही कोई संकेत दिया कि वह सुन रहा था। लेकिन, एक समय पर मैंने बस कहा, "मुझे तुम पसंद हो, जेम्स। तुम अच्छे लड़के हो।" मैंने सोचा भी नहीं था कि वह अचानक मुझे देखेगा, मेरा कंधा पकड़ेगा और जोर से हँसेगा। लेकिन उसने ऐसा ही किया! क्योंकि वह सुन रहा था! हर कोई अपनी तरह से संवाद करता है। और सुनना भी बातचीत का एक हिस्सा है।

2. यह मान लेना कि उनकी ज्यादातर पहचान उनके ऑटिज्म से है, न कि उनके अपने व्यक्तित्व से।

मैंने कई बार यह सुना है, "हाँ, ये उसका ऑटिज्म है," यहाँ तक कि पेशेवर लोगों से भी। हाँ, हमारा ऑटिज्म हमें प्रभावित करता है। यह हमें कुछ खास आदतें या रुचियाँ देता है। लेकिन ये कहना कि "यह सिर्फ उनका ऑटिज्म है" ऐसा लगता है जैसे हमारे पास कोई विकल्प ही नहीं है।

एक बार की बात है, जब मैं एक विशेष स्कूल में शतरंज टूर्नामेंट करवा रहा था। उस टूर्नामेंट से छात्रों ने बहुत कुछ सीखा। एक महत्वपूर्ण मैच उसी दिन था जब स्कूल में एक खास कार्यक्रम हो रहा था। पूरे दिन में केवल एक ही मौका था जब वह मैच हो सकता था। खेल शुरू होने से ठीक 10 मिनट पहले, एक छात्र को माइग्रेन हो गया और उसे घर जाना पड़ा।

मैं बहुत तनाव में आ गया क्योंकि मुझे उसी दिन मैच के नतीजे चाहिए थे, ताकि मैं ट्रॉफी लेने के लिए जा सकूँ और छात्रों को समय से पुरस्कार दे सकूँ। मैंने अपने एक सहयोगी से कहा कि मैं परेशान हूँ, तो उसने मुझसे पूछा, "क्या तुम इसलिए परेशान हो क्योंकि आज दिनचर्या में बदलाव हुआ?" नहीं, ऐसा नहीं था। (और एक पूर्व प्राथमिक शिक्षक के तौर पर, मुझे लगता है कि अगर आप कक्षा में हैं,

तो आपको अनपेक्षित बदलावों के लिए तैयार होना चाहिए।)

कुछ और उदाहरण:

- मैं गणित में अच्छा हूँ क्योंकि मैंने इसे सीखने में मेहनत की है। यह "सिर्फ मेरा ऑटिज्म" नहीं है।
- मुझे छोटी-मोटी बातें करना पसंद नहीं है क्योंकि और भी मज़ेदार या महत्वपूर्ण बातें होती हैं। यह "सिर्फ मेरा ऑटिज्म" नहीं है।
- मैं लोगों से ईमानदारी से बात करता हूँ क्योंकि ये सही तरीका है। यह "सिर्फ मेरा ऑटिज्म" नहीं है।
- मुझे शतरंज पसंद है क्योंकि... (मैंने इसके बारे में पूरा लेख लिखा है)। यह "सिर्फ मेरा ऑटिज्म" नहीं है।
- मैं एक बड़ा फेसबुक समुदाय चलाता हूँ क्योंकि मुझे लोगों की मदद करने की प्रेरणा मिलती है। इसमें मेरा व्यक्तित्व भी शामिल है, सिर्फ ऑटिज्म नहीं।
- और मेरी चिंता का कारण भी ऑटिज्म नहीं है, बल्कि यह मुझ पर थोपी गई है।

इसका मतलब यह नहीं है कि ऑटिज्म का कोई असर नहीं होता। जैसा मैंने कहा, ऑटिज्म हमें प्रभावित करता है। जब मैं 12 साल का था, तो मैं बार-बार 'इंडिपेंडेंस डे' फिल्म देखता था। आप कह सकते हैं कि ये आदत मेरे एस्परगर के कारण थी, लेकिन असल कारण ये था कि मुझे वह फिल्म बहुत पसंद थी।

इस कहानी से क्या सिखने को मिलता है? चाहे ऑटिज्म बच्चे को कितना भी प्रभावित करे, यह मत भूलिए कि उनके पास एक अलग व्यक्तित्व भी है।

3. यह मान लेना कि उनके दृष्टिकोण गलत या अविश्वसनीय हैं। यह है मॉर्गन। बहुत ही शानदार लड़का, और मैं ये सिर्फ इसलिए नहीं कह रहा क्योंकि उसका दिमाग मेरे जैसा है। आप उसे फेसबुक पेज "प्लैनेट मॉर्गन एस्पी सुपरहीरो" से जानते होंगे।

मॉर्गन का एस्परगर सिंड्रोम, मेरी नजर में, उसके लिए कोई बड़ी समस्या नहीं है। असल में, (हालाँकि मैं पक्षपाती हो सकता हूँ) मुझे लगता है कि उसका एस्परगर उसे और भी खास बनाता है।

लेकिन उसकी असली चुनौती उसकी गंभीर चिंता है। वह अब स्कूल नहीं जाता क्योंकि "स्कूल" शब्द ही उसे डरा देता है। और, ऑटिस्टिक बच्चों के माता-पिता के लिए यह कोई नई बात नहीं है कि उसकी चिंता का कारण स्कूल में उसे मिली बार-बार की धमकियाँ हैं।

दुर्भाग्य से, स्कूल की तरफ से यह धमकियाँ सही तरीके से नहीं संभाली गईं। (और हाँ, मैंने "कथित रूप से" शब्द का इस्तेमाल किया, और मैं यह पूरी ज़िम्मेदारी से लिख रहा हूँ।)

मॉर्गन के करीबी लोगों के मुताबिक, उसकी चिंता को गंभीरता से नहीं लिया गया क्योंकि लोगों ने इसे उसकी "गलत" समझ माना।

आखिरकार, मॉर्गन ऑटिस्टिक था और दूसरे बच्चों की तरह सामाजिक स्थितियों को नहीं देखता था। तो, जब क्लास में बाकी बच्चे ठीक थे और मॉर्गन नहीं, तो लोग यही मानते थे कि समस्या उसकी 'गलत' दृष्टि में है।

यह भूलकर कि विशेष जरूरतों वाले बच्चों को उनके साथियों द्वारा धमकाने की संभावना ज्यादा होती है। और जब बार-बार उनकी बातों पर भरोसा न किया जाए, तो इससे उनके मनोबल और आत्म-सम्मान को गहरा नुकसान हो सकता है।

अब, अगर हम मान भी लें कि कुछ लोग सही हैं जब वे कहते हैं कि ऑटिस्टिक लोग कम विश्वसनीय होते हैं (स्पॉइलर अलर्ट: ऐसा नहीं है)। असल में, अगर कोई घटना हो, तो आप चाहेंगे कि एक एस्पी मेमोरी वाला गवाह वहाँ हो! लेकिन चलिए, मान भी लेते हैं कि ऐसा नहीं है।

फिर भी, ऑटिस्टिक व्यक्ति की चिंताएँ असली होती हैं, और उन्हें नजरअंदाज नहीं किया जाना चाहिए।

और अगर कोई चिंतित बच्चा, चाहे वह ऑटिस्टिक हो या न हो, धमकाने या बुरा व्यवहार होने की शिकायत करता है, तो उसे हमेशा गंभीरता से लिया जाना चाहिए।

ब्रिटेन अब भी उन बच्चों की एक पीढ़ी से निपट रहा है जिन्हें दुर्व्यवहार का सामना करना पड़ा और जिनकी बातों को लंबे समय तक नजरअंदाज किया गया। अब हालात पहले से बेहतर हैं, लेकिन सिर्फ उनके न्यूरोलॉजिकल अंतर के कारण किसी बच्चे की बात पर भरोसा न करना, न सिर्फ उनके आत्म-सम्मान को चोट पहुँचाता है, बल्कि उन्हें गंभीर खतरे में भी डालता है।

(वैसे, मॉर्गन अब सुरक्षित है और काफी समय से है। सही अवसर मिलने पर, वह भविष्य में कमजोर लोगों की मदद करने और मार्गदर्शन करने के लिए एक बेहतरीन इंसान बनेगा - और मैंने उसे ये बताया है।)

4. उन्हें यह न सिखाएँ कि ऑटिज्म एक बुरी चीज है।

जब हम पहली बार ऑटिज्म के बारे में सुनते हैं, तो अक्सर यह सिखाया जाता है कि यह एक बुरी चीज है। यही कारण है कि मेरे जैसे लोगों को कई चिंतित माता-पिता के संदेश मिलते हैं, जो यह पूछते हैं कि ऑटिज्म का निदान होने के बाद उन्हें क्या करना चाहिए, क्योंकि उन्हें इस बारे में कुछ भी पता नहीं होता।

लेकिन उनकी चिंता यह जाहिर करती है कि वे एक बात तो मानते हैं: कि ऑटिज्म बुरा है।

एक ऑटिस्टिक व्यक्ति के रूप में मेरी सोच थोड़ी अलग है, लेकिन मैं उनकी दहशत को समझ सकता हूँ। जब हमें कुछ समझ नहीं आता, तो वह चीज डरावनी लग सकती है, खासकर अगर हमें लगता है कि वह बुरी है। (जैसे कि जब आपका बॉस कहता है, "क्या मैं आपसे एक बात कर सकता हूँ?" तो आपके शरीर में अचानक ठंडक सी महसूस होती है।)

अब, अगर गैर-ऑटिस्टिक लोग केवल ऑटिज्म के नकारात्मक पहलू देखते हैं, तो यह बहुत नुकसानदायक हो सकता है। लेकिन सोचिए, जब खुद ऑटिस्टिक लोग यह मानने लगते हैं कि उनका ऑटिज्म उन्हें खराब या दोषपूर्ण बनाता है, तब कितना नुकसान होता होगा।

अगर आप उनके सामने ऑटिज्म के बारे में नकारात्मक बातें करेंगे, तो उनका आत्म-सम्मान कैसे प्रभावित होगा, इसका अंदाजा लगाइए!

मैं आपको दो उदाहरण दूँगा जो मुझे बहुत प्रभावित करते हैं। पहला है कैडेन्स की कहानी। कैडेन्स के परिवार का एक फेसबुक पेज है (<https://www.facebook.com/I-am-Cadence-1032108113468280>), जहाँ एक तस्वीर वायरल हुई थी।

उस तस्वीर में सबसे दुखद वाक्य (मेरी नजर में) यह था: "बड़े लोग हमेशा कहते हैं कि अगर आपके बच्चे को ऑटिज्म है, तो माता-पिता होना मुश्किल है।"

कैडेन्स के पेज पर जाकर देखिए, उसकी माँ और पिताजी उसे शानदार तरीके से बड़ा कर रहे हैं। लेकिन बाकी लोग - टीवी, समाज - उसे यह मानने पर मजबूर कर रहे हैं कि उसका ऑटिज्म, उसकी पहचान का एक बड़ा हिस्सा, कुछ बुरा है। जो कि बिल्कुल भी सही नहीं है।

दूसरा उदाहरण एक 6 साल के कैलिफोर्निया के लड़के का है, जिसने सांता से पूछा कि क्या उसे उसके ऑटिज्म के कारण "शरारती सूची" में डाल दिया जाएगा। (<http://6abc.com/news/boy-afraid-hell-be-on-naughty-list-because-of-his-autism/1114282/>) सांता ने उसे सांत्वना दी, और लोगों ने इसे एक प्यारी कह।

मैं उस दिन का इंतजार करता हूँ जब छोटे बच्चों को यह नहीं सोचना पड़ेगा कि सिर्फ ऑटिस्टिक होने की वजह से उन्हें "शरारती सूची" में रखा जाएगा।

(असल में, यह धारणा पूरी तरह से बिनावजह नहीं है। यह इस बात पर आधारित है कि गैर-ऑटिस्टिक लोग उन्हें कैसा महसूस कराते हैं।)

और आखिर में... एक बात जो कुछ लोगों को बुरा लग सकती है, लेकिन इसे कहना जरूरी है।ानी समझा। लेकिन सच कहूँ, मुझे यह जानकर बहुत दुख हुआ।

5. उन्हें यह न सिखाएँ कि आप "उन्हें प्यार करते हैं लेकिन उनके ऑटिज्म से नफरत करते हैं।"

यह पिछली बात से एक कदम आगे है, और यह अधिक व्यक्तिगत है। मैं समझता हूँ कि कई लोग, खासकर माता-पिता, ऐसा महसूस करते हैं। कुछ तो ब्लॉग और लेख भी लिखते हैं जिसका शीर्षक होता है "मैं अपने बच्चे से प्यार करता हूँ, लेकिन उसके ऑटिज्म से नफरत करता हूँ।" और मैं इसे समझ सकता हूँ—जब हम किसी प्यारे बच्चे को मुश्किलों से गुजरते हुए देखते हैं, तो यह बहुत दर्दनाक होता है, और अगर वह बच्चा आपका अपना हो, तो यह और भी ज्यादा तकलीफदेह होता है।

इस स्थिति से नफरत करना स्वाभाविक है, क्योंकि आप नहीं चाहते कि आपका बच्चा पीछे रहे। लेकिन सोचिए, यह बच्चे के लिए कितना नुकसानदायक हो सकता है।

क्यों? क्योंकि मान लीजिए कि किसी दिन एक माँ गलती से यह कह देती है, "मैं अपने बच्चे से प्यार करती हूँ लेकिन उसके ऑटिज्म से नफरत करती हूँ," और बच्चा उसे सुन लेता है। बच्चा इससे एक बहुत ही महत्वपूर्ण बात सीखेगा, जो शायद हमेशा उसके साथ रहेगी: "मेरे अंदर एक ऐसा हिस्सा है जिसे मेरी माँ भी प्यार नहीं कर सकती।"

हर कोई अपने जीवन में किसी न किसी मुश्किल से लड़ता है। और कई बार, हम उन मुश्किलों का सामना तभी कर पाते हैं जब दूसरे लोग हमारा साथ देते हैं।

जब किसी को यह एहसास होता है कि आप उनके ऑटिज्म से नफरत करते हैं, तो आप उनकी मुश्किलों को और बढ़ा रहे होते हैं। आप उनके डर को और मजबूत कर रहे होते हैं।

सबसे बड़ी बात, आप उन्हें यह बता रहे होते हैं कि उनके डर और नफरत सही हैं, और उन्हें अपने अस्तित्व के एक बड़े हिस्से से डरना और नफरत करना चाहिए।

फिर से कहता हूँ, मैं समझता हूँ। मैंने कई बच्चों को मुश्किलों से जूझते हुए देखा है, और मुझे भी इन चीज़ों से भावनात्मक रूप से निपटना सीखना पड़ा है (हालाँकि यह हमेशा आसान नहीं होता)। और अगर कोई चीज़ बच्चे को तकलीफ दे रही है या उसकी तरक्की में रुकावट डाल रही है, तो स्वाभाविक है कि मैं उस पर ध्यान देना चाहूँगा।

लेकिन मैं किसी बच्चे के किसी हिस्से से नफरत करने के लिए तैयार नहीं हूँ।

अगर आपने इस लेख को यहाँ तक पढ़ा है और अब भी महसूस करते हैं कि "आप अपने बच्चे से प्यार करते हैं लेकिन उसके ऑटिज्म से नफरत करते हैं," तो यह आपकी सोच है।

लेकिन मेरी आपसे गुजारिश है—कृपया, अपने बच्चे की खातिर, कभी उन्हें यह महसूस मत होने दें।

तो संक्षेप में:

- उनके बारे में ऐसे बात करने के बजाय जैसे वे कमरे में नहीं हैं:
 - याद रखें कि वे आपको सुन सकते हैं, और मानें कि वे सुन रहे हैं।
- यह मानने के बजाय कि उनका ऑटिज्म ही उनके पूरे व्यक्तित्व को परिभाषित करता है:
 - ध्यान रखें कि उनके पास भी व्यक्तित्व चुनने का हक है, जैसे कि गैर-ऑटिस्टिक लोगों के पास होता है।
- यह सोचने के बजाय कि उनके दृष्टिकोण कम विश्वसनीय हैं:
 - याद रखें कि ऐसा सोचकर आप खुद का नज़रिया गलत बना रहे हैं।
- समाज को यह सिखाने के बजाय कि ऑटिज्म एक बुरी चीज़ है:
 - उनसे कहें कि वे कितने खास और अद्भुत हैं, और उनका हौसला बढ़ाएँ।
- बच्चे से प्यार करने के बावजूद उसके ऑटिज्म से नफरत करने के बजाय:
 - पूरे दिल से बच्चे से प्यार करें, बिना किसी शर्त के।

उम्मीद है कि यह कुछ लोगों के लिए मददगार होगा। जैसा मैंने कहा, इन गलतियों को करना बहुत आसान है, लेकिन अच्छी बात यह है कि इनमें से कई गलतियों से आसानी से बचा जा सकता है।

ऑटिस्टिक बच्चों को अनजाने में नुकसान पहुँचाने के और भी तरीके हो सकते हैं:

फुटनोट: लोगों ने कुछ और सुझाव दिए हैं, जो यहाँ साझा किए जा सकते हैं।

- उनकी खास रुचियों को दबाने की कोशिश न करें, क्योंकि वे अक्सर इन्हीं का इस्तेमाल बात करने और तनाव से निपटने के लिए करते हैं। (स्टेफ़नी कीज़)
- सिर्फ उनके बुरे व्यवहार पर ध्यान देने के बजाय, उनके अच्छे व्यवहार को भी सराहें। (स्टेफ़नी कीज़)

- हर बार उनकी हर लड़ाई खुद न लड़ें, और यह न मानें कि वे कुछ भी अपने दम पर नहीं कर सकते। (एरिक वैन गुच के सुझाव से अनुकूलित)

- अपने बच्चे का निदान न कराना और सही मदद न देना सिर्फ इसलिए कि आप ऑटिज्म के कारण होने वाले समाज के नकारात्मक रवैये से बचना चाहते हैं। (क्रिस्टिन पेडिगो के सुझाव से अनुकूलित)

- अपने बच्चे के ऑटिज्म-संबंधी संघर्षों को आम जीवन के संघर्षों से अलग न मानना, और अगर वे अपने मुद्दों को कठिन पाते हैं तो इसे कमजोरी न समझें। (ऑड्रे सी से अनुकूलित - हाँ, ऑटिस्टिक और गैर-ऑटिस्टिक बच्चों के बहुत से संघर्ष एक जैसे हो सकते हैं, लेकिन जब उन्हें व्यक्तिगत मदद की जरूरत हो, तो यह पहचानना जरूरी है।)

- ऑटिज्म के "इलाज" की बात करना और यह संकेत देना कि इसे ठीक करने की जरूरत है, और क्योंकि इसे ठीक करना है, इसलिए यह बुरा है। (पीटर डाइकहुइस, उम्र 14)

यह लेख पहली बार <http://autisticnotweird.com/five-ways-to-damage/> में प्रकाशित हुआ था और इसे लेखक की अनुमति से पुनः प्रकाशित किया गया है।

क्रिस बोनलो एक पूर्व प्राथमिक स्कूल शिक्षक हैं, जिन्हें एस्परगर सिंड्रोम है, और उन्होंने विशेष शिक्षा के क्षेत्र में भी काम किया है। अब वह एक पुरस्कार विजेता लेखक और अंतरराष्ट्रीय वक्ता हैं। 2015 में उन्होंने "ऑटिस्टिक नॉट वीर्ड" नाम से एक वेबसाइट शुरू की, ताकि वे अपने व्यक्तिगत और पेशेवर अनुभव साझा कर सकें। इस पहल से उन्हें 101,000 से ज्यादा फेसबुक फॉलोअर्स और उनकी वेबसाइट (autisticnotweird.com) पर 1.9 मिलियन से ज्यादा पेज हिट्स मिले हैं।

उनकी पहली पुस्तक "व्हाट वी लव मोस्ट अबाउट लाइफ" एक प्रेरणादायक किताब थी, जो ऑटिस्टिक बच्चों और युवाओं को कम अकेलापन महसूस कराने के लिए लिखी गई थी। उनका पहला उपन्यास "अंडरडॉग्स", जो विशेष आवश्यकताओं वाले नायकों की कहानी है, मई 2019 में प्रकाशित होगा। क्रिस को 2017 के नेशनल डाइवर्सिटी अवार्ड्स (डिसएबिलिटी के लिए सकारात्मक रोल मॉडल) के लिए नामांकित किया गया था और उन्होंने ऑटिज्म हीरो अवार्ड्स में दो बार जीत हासिल की है (टॉप जर्नलिस्ट 2017, ऑनलाइन सोशल कम्युनिटी 2018)।

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.

BOOK POST



ACTION FOR AUTISM

If undelivered, please return to:

The Editor, Autism Network
Pocket 7 & 8, Jasola Vihar, New Delhi - 110025

Published & printed by Merry Barua
on behalf of Action For Autism (AFA)
from Pocket 7 & 8, Jasola Vihar, New Delhi - 110025

Tel: 91 11 40540991, 91 11 40540992
Email: actionforautism@gmail.com
Website: www.autism-india.org

Printed at:

Naveen Printers
F-11/B, Okhla Industrial Area, Phase I, New Delhi - 110020

Editor: Merry Barua