

India's Cross-disability Magazine

May 2019

Savant Social skills Repetitive behaviour Non-verbal communications Sensory sensitivities Anxiety Depression Emotions Patience Social situations Acceptance Conversation Eye contact Love Michelangelo Wolfgang Amadeus Mozart Steve Jobs Albert Einstein Children of the Stars Silent Fall Cries from the Heart Savant Social skills Repetitive behaviour Non-verbal communications Sensor Jensi' Ities Anxiety epression Emotions Jocialsituations Accer Inc. Conversation Eye le e l'ir elc elc P Nr J? **Jbert** contar LOV 15 nr/ Einst 2 etitive behaviour Non-verbal communications Sensory sensitivities Anxiety Depression Em Units Social Situation nadeus ersatic cor olfo ldr Mozart nste Heart All Silent he Sa var vities ve t our /ert ۱m C/ Anxie tuat ٥n ence Mic JOL ilent ozart-

Fall Cries from the Heart Savant Social skills Repetitive behaviour Non-verbal communications Sensory sensitivities Anxiety Depression Emotions Social situations Conversation Eye contact Love Acceptance Patience Michelangelo Anxiety Silent Fall Wolfgang Amadeus Mozart Albert Einstein Steve Jobs Children of the Stars Cries from the Heart Savant Social skills Repetitive behaviour Non-verbal ommunications Sensory sensitivities Anxiety Depression Eye contact Social situations Conversation Acceptance Michelangelo Patience Wolfgang Amadeus Mozart Steve Jobs Silent Fall Love Savant Social skills Repetitive behaviour Non-verbal communications Sensory sensitivities Anxiety Depression Eye contact Social situations Acceptance Michelangelo Patience Social situations Acceptance Conversation Eye contact Michelangelo Wolfgang Amadeus Mozart Steve Jobs Albert Einstein Children of the Stars Silent Fall Cries from the Heart Savant Social skills Repetitive behaviour Non-verbal communications Sensory sensitivities Anxiety Depression Emotions Patience Social situations Acceptance Conversation Eye contact Michelangelo Wolfgang Amadeus Mozart Steve Jobs Albert Einstein Children of the Stars Silent Fall Cries from the Heart Savant Social skills Repetitive behaviour Non-verbal communications Sensory sensitivities Anxiety Depression Emotions Social situations Acceptance Michelangelo Conversation Children of the Stars Eye contact Love Acceptance Patience Michelangelo Wolfgang Amadeus Mozart Steve Jobs Albert Einstein Children of the Stars Silent Fall Cries from the Heart Wolfgang Amadeus Mozart Albert Einstein Children of the Stars Silent Fall Cries from the Heart Wolfgang Amadeus Mozart Albert Einstein Children of the Stars Silent Fall Cries from the Heart Savant Social skills Repetitive behaviour Non-verbal communications Sensory sensitivities Love

CONTENTS

4

NEWS & NOTES

Robotic arm for self-feeding, online course for 3D printing assistive devices, revolutionary hands-free wheelchair, Soundscape app, and ELIA, the promising new alternative to Braille.

COVER FEATURE

LAST WORD

How poised are we to respond to the autism conundrum? Get enriched by three essential, unique and nuanced perspectives on autism – a child's, parent's and a professional's.



SPOTLIGHT

What is the way forward in hemophilia care and management? Mukesh Garodia, Vice President (Development), Hemophilia Federation (India), lays out a roadmap.

Who is really disabled? Dr. Madan Vasishta gives you a peek into some of the hilarious situations he has been in, courtesy misconceptions about disability.

WE'D REALLY LIKE TO HEAR FROM YOU

Whether you are a person with disability, or a parent or a friend or just someone who cares, we look forward to getting to know you and your concerns. You are just a click away!

Editor	JAYSHREE RAVEENDRAN
Managing Editor	JANAKI PILLAI
Deputy Editors	HEMA VIJAY SUCHITRA IYAPPA
Assistant Editor	Sruthi s raghavan
Design	Shwetha ramani
Hindi Translation	MALINI K

CORRESPONDENTS

ANANTNAG: Javed Ahmad Tak +911936 211363 HYDERABAD: Sai Prasad Viswanathan +91810685503 BHUBANESHWAR: Dr. Sruti Mohapatra +91 6742313311 DURGAPUR: Angshu Jajodia +919775876431 GURUGRAM: Sidharth Taneja +919654329466 PUNE: Saaz Aggarwal +919823144189 Sandeep Kanabar +919790924905 BANGALORE: Gayatri Kiran +919844525045 Dr. Ali Khwaja +9180 23330200 NEW DELHI: Abhilasha Ojha +919810557946 USA: Dr. Madan Vasishta +1(443)764-9006

PUBLISHERS: Ability Foundation | Editorial Office: New #4, Old #23, 3rd Cross Street, Radhakrishnan Nagar, Thiruvanmiyur, Chennai 600 041. India. Ph: 91 44 2452 0016 / 2452 3013. Published by Jayshree Raveendran on behalf of Ability Foundation. Email: magazine@abilityfoundation.org

Rights and permissions: No part of this work may be reproduced or transmitted in any form or by any means, without the prior written permission of Ability Foundation. Ability Foundation reserves the right to make any changes or corrections without changing the meaning, to submitted articles, as it sees fit and in order to uphold the standard of the magazine. The views expressed are, however, solely those of the authors.

ABILITY FOUNDATION & SATHYABAMA INSTITUTE OF SCIENCE AND TECHNOLOGY

AN INITIATIVE TOWARDS INCLUSIVE UNIVERSITY EDUCATION FOR PERSONS WITH DISABILITIES

Ability Foundation and Sathyabama Institute of Science and Technology come together to offer 50 seats for students with disabilities for the year 2019-2020 in the following programmes.

- Engineering (B.E., B.Tech., M.E., M.Tech.)
- Arts & Science (B.A., M.A., B.Sc., M.Sc., B.Com., B.B.A.)
- Management (M.B.A.)

This unique offer opens up immense possibilities for bright students with disabilities to get the best of university education.

The selected students will also be offered complete scholarship throughout the study period, in a totally accessible and inclusive environment.

For details and application forms, log on to www.abilityfoundation.org

Completed forms must reach Ability Foundation on or before May 15, 2019

For more details, contact +91 9962386773 / varsity@abilityfoundation.org





News &Notes

ROBOTIC ARM FOR SELF-FEEDING



ere is a robotic invention that could usher in a large degree of independence for people who have lost the function of their hands or arms. Researchers at Washington University have developed a robotic arm, ADA (Assistive Dexterous Arm) that may be attached to a motorised wheelchair. Once activated, the ADA can pick up the 3D printed fork docked on the side of the

wheelchair, while ADA's camera scans the plate, identifies the type of food placed on the plate and tells the ADA how to pick it up, guided by special algorithms. After picking up the food, the ADA brings the food close to the user's mouth so that the user can bite it. ADA can also adjust to suit the head movement of the user, relying on information it picks up through its arm mounted camera. Similarly, if the plate is empty or if the user indicates that he or she has eaten enough, ADA moves away and puts the fork back into its dock. To see how ADA operates, log on to http://www.washington.edu/news/2019/03/11/how-to-train-your-robot-to-feed-you-dinner/

LEARN TO 3D PRINT ASSISTIVE DEVICES

ere is how you can 3D print your own assistive devices. PrintLab, a UK based developer of 3D printing curriculum and global distributor, has released a free online course that allows users to learn 3D printing on their own and custom make assistive devices, rather than rely on expensive assistive devices available in the market. This has been made possible through PrintLab's Assistive Device Academy, the firm's human-centred design project where students create a range of assistive devices for people with disabilities. This creative project was developed in collaboration with Makers Making Change, a community-based initiative that connects makers to people with disabilities. This online course includes case studies, tutorial videos, activities, development of design, and manufacture of the 3D prototype. The design process is hinged on identification of the individual user, and thereupon concepts are developed to solve the daily challenges of the user. For more, check out https://classroom.weareprintlab.com/

HANDS-FREE WHEELCHAIR



Image courtesy: Omeo Technology

his hands-free wheelchair lets a user pursue any activity he or she chooses while moving on the wheelchair, be it catching a ball or watering plants! With the Omeo wheelchair, users don't have to turn the wheels with their hands. What makes this possible is that one can lean forward to accelerate the wheelchair, lean back to brake, and lean sidewise to navigate. This is achieved by Omeo's patented Active Seat Control system. The wheelchair's powerful two-wheeled self-balancing platform allows the user to travel over uneven terrain, scale inclines and navigate troughs. Another advantage of the wheelchair is that it has no bulky steering column, so, transferring from and to this wheelchair is easy. The Omeo wheelchair was developed by Kevin Halsall

based on Segway technology, inspired by the desire to help his friend engage in sports. The wheelchair's design has been constantly upgraded over the past seven years and is now available for the world market.

SOUNDSCAPE APP FOR COMMUTING INDEPENDENTLY

oundscape, an app developed by Microsoft's artificial intelligence and research development team can come in very handy for blind and low vision users in commuting independently. While there are many other apps that inform users of what is around them, this app allows the user to set up markers or beacons. Thus, when a marker is set up by the user for a particular intersection or bus stop, the app gives out a sound alert when the bus reaches that particular location, and the user can then ask the bus driver to stop and let him or her get off the bus, doing away with dependence on fellow commuters or the bus driver for such guidance. The soundscape app is an outcome of Microsoft's AI for Accessibility global initiative.

Soundscape provides information on the user's surroundings with synthesised binaural audio, creating the effect of 3D sound. This app can run in the background in conjunction with navigation or other applications to provide additional context about the environment. Soundscape runs on iPhone 5S or later and is compatible with most wired or bluetooth stereo headsets.

AN ALTERNATIVE TO BRAILLE?

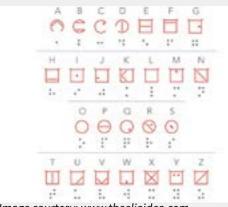


Image courtesy: www.theeliaidea.com

hile braille is an effective language for printed documents for blind users, people who lose sight later in life struggle in learning and using braille. ELIA (Education, Literacy, Independence for All), a new system/font for blind people, created by Andrew Chepaitis, can offset this challenge. The advantage of ELIA is that it looks very similar to letters of the English alphabet, and it is expected that a person can learn the ELIA font in just a few hours. The two basic components of the ELIA font are an outer frame that consists of a circle, semi-circle, square and the figure of

a house, and an inner frame with fonts similar to English alphabets. ELIA Life Technology, the company that offers ELIA, is currently developing an affordable tactile printer that will enable users to produce ELIA Frames[™] or braille for individualised applications. The company will also be developing a tactile tablet in the future. For downloading ELIA font and knowing more, log on to http://www.elialife.com/ ■

COVER FEATURE

DIFFERENT STROKES The Autism Conundrum

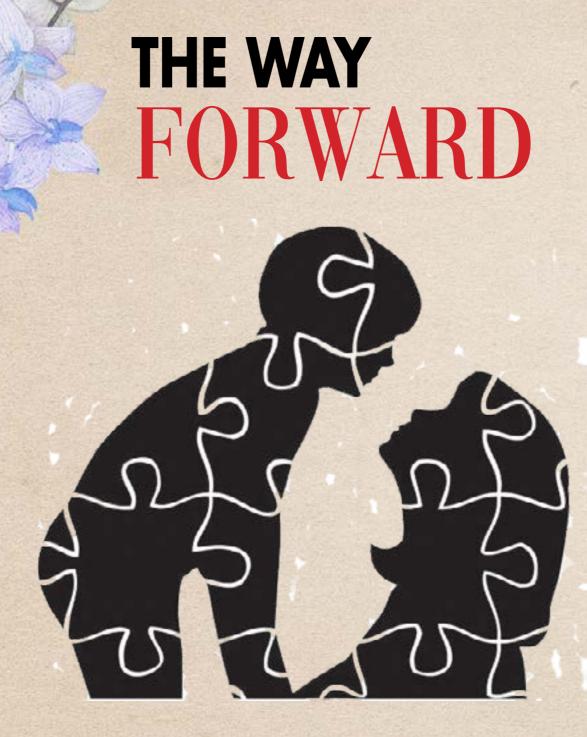
utism awareness is at a high in India, and around the world. Not without reason. Autism has emerged as the fastest rising developmental disorder across the world. While accurate statistics in India are hard to come by, the United States' National Survey of Children's Health's recent study on autism spectrum disorder (ASD) informs that 1 in 40 children in the US have a diagnosis of autism spectrum disorder. That's quite massive. Meanwhile, according to the World Health Organisation, one in every 160 children is living with autism; WHO mentions that the figures may be even higher. Compelling numbers, this, and the ado being made about autism seems richly deserved and needed.

How well are we in India, as a society and as a country, poised to respond to the challenge of autism? Is our public health system equipped to provide children with autism needed measures – from diagnostics, medication and psychological services, behavioural and occupational therapy to special education and much more? Do we have a system of integrating children with autism into mainstream society? These are issues that need to be addressed comprehensively.

Nevertheless, often, we fail to register the diverse flashpoints embedded in autism. Not just with respect to the spectrum that autism encompasses, but also in terms of the individuals involved. Only in understanding the diverse do we understand the whole, and in our cover feature this time around, we bring to you three essential, unique and divergent perspectives – that of a child with autism, a parent and a professional resource person. Read on. Get empowered. Get enriched.



COVER FEATURE



While early intervention has been unequivocally accepted as a means of addressing autism, the path begins to blur subsequently. What then is the need of the hour? GITA SRIKANTH, Founder Director, BCBA, WE CAN Resource Centre for Autism and CEO, ProACT Behavioral Services, explores the intricacies of the issue.



t is that time of the year again when the spotlight shifts to Autism. As a condition, autism has always intrigued parents and professionals and continues to hold its mystical sway in our minds. From being hailed as the precursor to what humans are increasingly going to be, to being individuals with unique gifts and abilities, autism continues to be interpreted in so many ways.

The numbers of people with autism are on the rise, and the Center for Disease Control and Prevention (CDC), USA's state health protection agency, puts the current estimate of people with autism to be 1 in every 59 persons. Autism is four times more likely to impact boys than girls. Individuals with autism are known to face challenges in social communication, relationships and in understanding societal cues and norms. While these are commonly known facts about autism, other aspects of the condition are not spoken about as much.

Recent research has shown that girls with autism remain unidentified till late adolescence or early adulthood, and sometimes even later. It is often mislabeled or not recognised, and only when they show more severe autistic symptoms and behavioural challenges do they receive diagnosis and support (Bargiela, Steward, & Mandy, 2016). Women who may be in the spectrum also tend to camouflage their difficulties better and often learn to imitate others in social settings, in a bid to belong. (https://www.autismspeaks.org/ blog/things-i-hear-woman-autism-you-dontseem-autistic-me). "A very relevant aspect of intervention for autism is the focus on play and leisure skills. In the chase for maximising inputs, these very critical skills are often overlooked."

Many studies have shown that about 40% of youth with autism spectrum disorders have high levels of anxiety. This presents often as specific phobias, obsessive compulsive disorders, social anxiety or separation anxiety. Assessing anxiety in this population is challenging, given that it is difficult to understand if these behaviours are caused by anxiety, social avoidance, or rigidities and the need to adhere to routines. Their outward behaviours are the same and it is clinically hard to differentiate the underlying cause. Less verbal individuals may show their anxiety through disruptive behaviours. Early identification of co-morbid anxiety can ensure that the individual receives the right intervention to prevent possible emergence of allied mental health conditions such as depression, social withdrawal and attempts at self-injurious behaviour.

There is also very little literature on what adulthood is like for individuals with autism. Apart from having no numbers in India, we also know very little about their living arrangements, skill levels, employability and mental health. There is an increase in the incidence of autism, "Adolescence, privacy, sexuality, safety and life skills – these are topics we shy away from addressing... Are we really fulfilling our roles as educators, parents and responsible stakeholders?"

and so, a large number of young adults on the spectrum will enter the community in the next few years, a community that does not have enough resources of any kind, to support them.

So, what is the way forward then?

By now, early intervention is a path that is fairly clear. The path starts to blur once the child is about six years of age; it is a haze once the individual crosses age 18, and then it's a black hole.

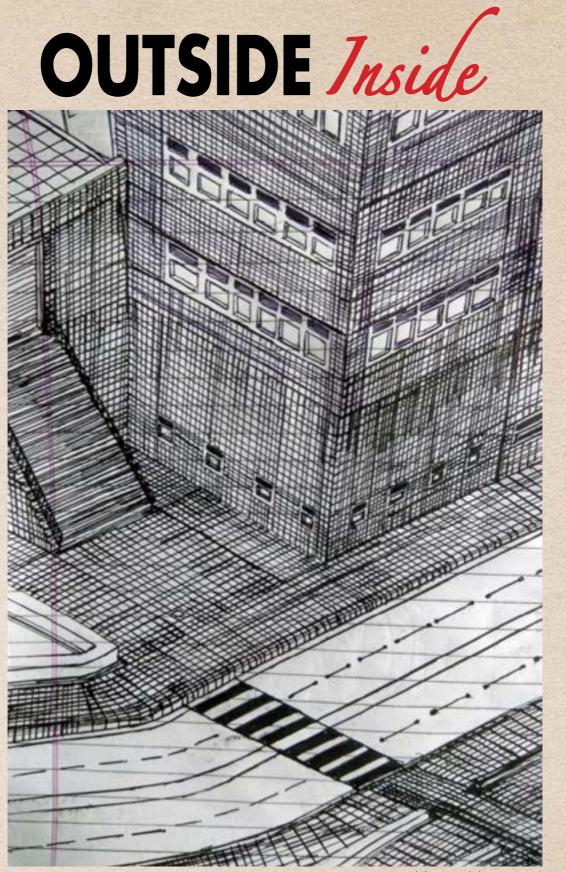
What then is the need of the hour? What should autism awareness be all about? Are we ready for the life-span approach for individuals with autism and their families?

Right at the beginning when the family receives a diagnosis of autism, providing them with accurate details about the condition, its implications for them and the child and possible ways forward would be step one. Giving them a realistic picture and options for intervention would help the family make an informed decision regarding services for the child. Apart from this, counselling services to help the family deal with the diagnosis would make the process of acceptance quicker and easier. Providing them weblinks to authentic, curated online information will help them sieve facts from speculation and myths. Creating relevant reading material in local languages for those who are most comfortable with reading in their own dialects is an urgent need. This would also help disseminate information to grandparents and extended family members, and thus the family would receive whole-hearted support.

Families and children need clear educational assessments that can help determine what the educational path for every child should be, so that these decisions are backed by scientific evidence rather than hopes, wishes and dreams. A very relevant aspect of intervention for autism is the focus on play and leisure skills. In the chase for maximising inputs, these very critical skills are often overlooked. The child gets so used to being kept 'occupied' all day, that he has no skills to just be and do things for fun. And the environment often forgets that he is a child first, and then a child with autism.

Then there is adolescence, privacy, sexuality, safety, and life skills. Many of these are topics we choose to shy away from, especially addressing sexual needs – the what, where and how of handling sexual urges, handling interactions with people of either sex safely, and appropriately. And let's not forget equipping them with skills for productive engagement, keeping in mind that there is a whole life ahead of them!

Are we ready for this? Are we really fulfilling our roles as educators, parents and responsible stakeholders?



Artwork by Kaushik, 14 years

COVER FEATURE

The Kochi Biennale 2018 ushered in a paradigm shift in the country, by giving a mainstream platform to artists on the autism spectrum to showcase their perspectives to the world, writes AJAI VADAKKATH, parent of a wonderful 17-year-old on the spectrum, and someone who has been associated with the Kochi Biennale Foundation since its inception in 2012.



he idea for an Outsider Art exhibition to be held during the Biennale was conceived in July 2018 when Priti and I chanced upon some exceptional works of art by a few young artists in Bangalore. These were artists with Autism Spectrum Disorders and had not gone through the regular mainstream school curriculum. Their ability in art was outstanding but they were constantly being defined by their disabilities.

Artists who are on the outside of traditional art practices and almost always marginalised from the social mainstream too have something to say, and with the talent we saw, we were convinced that they needed a larger and more befitting platform to say it from. The idea was to take that art – whose display and exhibition is largely restricted to the disabled community – and display it alongside larger exhibitions being hosted by big galleries or mainstream art platforms.

Both of us, Priti and I, thought we were perfectly positioned to make this project a reality since we were parents of a 17-year-old son on the Spectrum, and Priti being an artist herself, the impetus to execute this project was there. I had worked with Bose Krishnamachari, Founder of the Kochi Biennale Foundation, almost since its inception and I approached him with this idea. Seeing few of these artworks, he was intrigued and said that they surely deserved a larger audience and at once promised to extend



Artwork by Sakshi, 18 years

"Those artists who are almost always marginalised from the social mainstream too have something to say, and they need a large and befitting platform to say it from."



Artwork by Pranav, 18 years

help and support from the Kochi Biennale Foundation in hosting such a show before Biennale 2018 concluded.

Being members of many large groups of parents of persons with autism on WhatsApp and YahooGroups, we made an Open Call to Autism organisations across the country for entries for the show. There were 230 entries from all over India that went through rounds of selections by the biennale team, overseen by Krishnamachari himself. Seeing the quality of these artworks, Bose said that he was going to look at them objectively and not consider the age or extent of disability of the artist and treat it just like any other art selection process. Finally, 66 entries by 38 artists were selected. The ages of the artists varied from 11 years to 33 years.

'Outsider Art' constitutes an internationally recognised category of self-taught or naïve art

and often refers to original work produced by talented creators outside of the mainstream, whose expressions convey a strong sense of individuality.

Outsider Art in this context is used to denote the art practice of persons with autism who are not specifically trained in formal art schools, have neurodevelopmental disabilities and often deal with social exclusion. The art they produce may be outcomes of their non-linear thinking, obsessive-compulsive nature, stimulus over-selectivity, and other attributes peculiar to autism.

This exhibition sought to give a platform to artists on the autism spectrum to showcase their perspectives and expression to the world and create awareness about forms of creativity that exist outside of art institutes and accepted norms.

COVER FEATURE

APPLAUDING AUTISM

"My life is entwined between genius and idiocy."

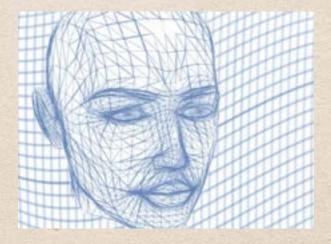
Join VISHAL ANAND a 'savant' 13-year-old with autism as he explores the exciting universe of his own mind and his interplay with the world around him.



eridians and equators are the imaginary lines passing through the globe, but there is seldom a possibility for a line that passes through the human mind. On the contrary, there is one such line miraculously drawn between the astral body and physical body. This is the reason I would give to explain why I was born autistic. Nature and man are always conjoined in their existence as esteemed rivals bathing in their own pride. Nature always gives and never expects whereas man always gets and rarely gives. If autism is nature pre-defined, we give the world immense knowledge, prayers and innovation. Our existence is met with millions of expectations.

Indeed, my life is entwined between genius and idiocy. Mood swings and flat tones in my mind are the morons that exist in my brain as a cancer or tumour forever. There are tidal waves that keep oscillating between these two stages. A genius brain is intrinsic to my thoughts, but autism is very much extrinsic. It is obvious that extreme behaviour is much more visible than extreme intelligence. These numerous incidents make up my life as a boy, a student, and a genius too.

I earn the tag of dyslexic, a person with dysgraphia, multiple disabled and so on, it is clear my illiteracy is very strong. However, my value is my intelligence and intuitive creativity. My hieroglyphic artistic brain has the potential and depth of contemporary and modern art, but this silly boy can't draw a hut with trees. That is



"When I move from this hemisphere to the other, making every paradigm shift, can I expect that shift from you too? Please do come closer to us, as much as we reach out to hold your hands."

the oxymoron in my condition, a unique identity called Savant – "so-called learned idiot".

Have you ever wondered what's the distance between normal and abnormal people? Of course, autistic people are always abnormal. Deep research is needed to enumerate facts to ascertain the space that exists in this territory. I constantly thrive to move towards the normalcy curve in my behaviour and appearance in society. It is an effort to be a bit more normal and acceptable among conditioned minds.

When I move from this hemisphere to the other, making every paradigm shift, can I expect that shift from you too? Please do come closer to us as much as we attempt to hold your hands. That region may be grey and vague, but remember, it takes black and white to bring about grey. Hence, blend of the known and unknown is the culmination of knowledge and wisdom.

In this primrose moment, autism and no-autism is the best coalition for the millennials to vote strongly for progress, success and innovation on this planet, Earth.

Away from reach I see the horizon, yet My path to tread is the next road to go for now.

Time for a **PARADIGM SHIFT**

Preventing secondary disabilities, freeing children from pain, providing treatment for all – can this be made a reality? Mukesh Garodia, Vice President (Development), Hemophilia Federation (India), outlines the way forward in hemophilia care and management.



uch has changed on the ground, and much hasn't as well... as far as hemophilia is concerned. To those of us who don't know, hemophilia is a genetic disorder in which the person tends to bleed excessively and internally, rendering an immediate first aid difficult as a result of its invisibility. An inherited blood disorder, which if unmanaged, can be fatal, hemophilia should therefore be taken very seriously and constantly attended to. Hemophilia can be life threatening as the internal bleeding in intracranial, gastrointestinal and the throat regions could get fatal. Frequent bleeds into joints and muscles could make this a disabling condition as well.

Statistics say that about 1 in every 10,000 people are born with hemophilia. This is a condition that affects only males. However, the carriers happen to be the mothers. Effective management is hence crucial in dealing with hemophilia as the condition is not curable.

However, the good news is that, with proper care, most people with hemophilia lead relatively normal lives as long as they manage the condition well. This is managed by the infusion of manufactured clotting factors as well as certain lifestyle changes, such as avoiding contact sports and heavy physical activities.

Thirty years ago, an immediate response to a bleed was Rest, Ice Compression and Elevation (RISE). The infusion of factors began much later. Recollects Mahesh, a person with this condition, "Those days, I can hardly remember the numerous times I had to take a week off from school and rest in bed. I was able to spend just 45 minutes writing the exam, in order to avoid a bleed".

Today, Mahesh, like many others like him, leads an active and

productive life. Times today are such that, as and when Mahesh has a bleed, he simply injects himself with an infusion and wraps up his arm in a bandage and goes about his routine. Of course, the dosage of the factor concentrate must be based on the body weight and type of bleed.

There was a time when full blood transfusion was the norm. Now, the norm is the infusion of just the missing clotting factor/protein called Anti Hemophilia Factor concentrate injection, a far less cumbersome ritual. This, along with physiotherapy is crucial to managing hemophilia.



There continues to be a marked lack of awareness on hemophilia across the board. There is even less awareness that it is now a recognised disability.

SPOTLIGHT

Across the country, every district government hospital is now well equipped to extend medical care to people with hemophilia, reasonably well stocked with infusion factors, concur experts working in the field.

At the non-governmental level, the Hemophilia Federation (India), established in 1983 by Ashok Bahadur Verma, a Delhi-based businessman born with severe Hemophilia A, now has chapters across the country, and serves as nodal points for physiotherapy, counselling, and all kinds of assistance.

HFI represents India as a National Member Organisation at the World Federation of Hemophilia based in Canada. HFI serves about 22,000 hemophiliacs registered under the National Hemophilia Registry through its 90 chapters across India.



The last 30 years have seen phenomenal progress in managing hemophilia in terms of treatment. Yet, there continues to be a marked lack of awareness on hemophilia across the board – be it with admission panels, certifying bodies, railway authorities, administrative officials and even physicians themselves. There is even less awareness that hemophilia is now a recognised disability,

A neglected aspect in managing hemophilia is counselling, essential for those with the conditions, the carriers for this condition, mothers, and the family in general. following the Rights of Persons with Disabilities Act 2016 that included hemophilia as a disability.

Hemophilia continues to remain an under-recognised condition. More than 1,00,000 patients with hemophilia will get identified only if the laboratory facilities in rural areas and government hospitals across India are improved. In a sense, hemophilia also carries the challenges of being an invisible disability. Until the bleed happens and is visible, people with hemophilia are not seen as people with disabilities at all.

Even today, one of the most neglected aspects in managing hemophilia is counselling, which is so essential for those with

the condition, the carriers for the condition, mothers, and the family in general. Children with hemophilia are forced to stay away from vigorous impact games and other such activities and end up feeling isolated.

What could now revolutionise the management of hemophilia is the assumption of a prophylactic approach, rather than the therapeutic mode of treatment. For this, at the organisational level, what

might now be targeted is the stocking of every Primary Health Centre in the country with infusion factors. With this, the loss of time and productivity, and risk of secondary injuries or disabilities on account of bleeds will be greatly addressed.

Also necessary is the engagement of local pharmaceutical manufacturers to ensure the manufacture of factor concentrates locally in adherence to strict international safety, efficacy and protocols. This is a vision of our Hon'ble PM's "Make in India" initiative. Additionally, there is an imminent requirement for Hemophilia Treatment Centres (HTCs) and Coagulation Laboratories in all government-run medical colleges equipped to identify new children/persons with hemophilia. The World Health



Organization has named India among those countries having the highest number of maternal deaths from postpartum haemorrhage. Early detection of vulnerable women could save many lives, but this is possible only if the centres have the capability to monitor such cases. For those who are employed, benefits from the Employees State Insurance Corporation (ESI) should be expanded to cover medical treatments arising from bleeding.

As a person with Hemophilia Severe A, born in the 1970s with basically no treatment available, to losing two younger siblings, to working for the hemophilia community, and starting a society in Guwahati and becoming the Vice President of the Hemophilia Federation (India), I am hopeful that with continued sensitisation of relevant government agencies, the general public, and hemophilia stakeholders, we shall soon see the reality of hemophilia without disability and children with hemophilia free from pain.

SYMPTOMS OF HEMOPHILIA

- Unexplained and excessive bleeding from cuts or injuries, or after surgery or dental work.
- Many large or deep bruises.
- Unusual bleeding after vaccinations.
- Spontaneous internal bleeds into joints and muscles.
- Pain, swelling or tightness in the joints.
- Blood in urine or stool.
- Nosebleeds without a known cause.
- In infants, unexplained irritability.

Who is **REALLY** "*handicapped* "?



Tongue in cheek, DR. MADAN VASISHTA brings to life some of the hilarious situations he has been in, courtesy the many misconceptions that people without disabilities harbour about disability.



have been deaf for over 65 years and do not consider myself a handicapped person. I am not. I am satisfied with myself. Well, almost. I wish I could have done more, but as a friend pointed out to me, I have achieved more than 99% of so-called "normal" people. That friend is "normal", by the way.

The real handicapped people, based on my vast experience in dealing with them are the so-called

non-handicapped or normal people. They are so wrapped up in their perceived "normalcy" that they cannot see farther than their noses. No. I am not insulting them. I am just stating a fact. I will make my case until I can end it with the "quod erat demonstrandum" or Q.E.D. as we write after a geometrical theorem is proved.

First, we need to take care of nomenclature. What do we call people who have no visible disability?

"Normal" does not sit well with me, as it is hard to define what is normal, and it is usually subjective. "Hearing" can work from deaf people's angle, but blind and wheelchair folks can hear too.

"Non-handicapped" might work, but it is too long and has a hyphen in it. The same goes for "disability-impaired". To make it simple, I will call them DI for now.

The DI folks do not understand us. The reason? They suffer from "minority phobia". This phobia forces them to not learn anything about us and develop all kinds of half-baked notions about us. Let me give you some examples. These are real. I do not usually go to restaurants but am often forced to, by my son who thinks restaurant food is good. (Did I mention he is DI?)

I remember going with him once to a really nice restaurant in New York. While the hostess was seating us, she saw my son signing to me and asked him what he was doing. He told her that his father was deaf and that he was communicating with him using signs. She smiled at me in the

> usual patronising way and then held out a finger asking my son to wait and went away. We sat down and wondered what was going on. She reappeared and gave me a menu. I looked at it. It was in Braille. All problems related to my deafness were resolved! We sat stone faced and after the lady left, I looked wide-eyed at my son who was trying to hide his laughter. He

signed to me, I do not have to interpret for you now, use the Braille menu! I threw the menu at him.

The other incident was when I was travelling from New Mexico to Oregon for a meeting. I had to change planes in Denver. When I boarded the plane, I told the stewardess that I was deaf. She became very helpful and led me to my seat and even helped to put my carryon in the bin above. When we arrived in Denver, I retrieved my bag and was ready to run to the connecting flight gate, as there was very little time for the flight to leave. As I arrived at the door of the plane, the stewardess stopped me and told me to stand in there. I told her I was in a hurry. She assured me not to worry. So, I waited. About ten minutes later, an orderly

The so-called normal people are so wrapped up in their perceived "normalcy" that they cannot see farther than their noses.



What do we call people who have no visible disability? "Normal" does not sit well with me, as it is hard to define what is normal, and it is usually subjective.



came with a wheelchair and the stewardess proudly pointed it to me asking me to sit down on it. I did not know whether to laugh or cry and just shook my head vigorously and pointed to my two legs. "I can walk", I told her and demonstrated my ability first by walking and then running to catch my plane. I do not know if she had called out to me asking me to wait. I did not have the interest or the time to find out.

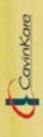
A deaf friend of mine, who had had the same experience, told me that he had not objected to it and had just quietly sat down on the wheelchair and let them push him to the connecting flight gate. He thought I was dumb to have declined the nice offer and hurt the lady's feelings.

The last interesting experience happened in a plane too. Qatar Airline is known for its great service. As I entered the plane, I told the stewardess about my deafness, telling her to write to me whenever she needed to communicate. She was very helpful and followed up by stopping by my seat every 15 minutes and asking me if I needed anything. I did not and wanted to tell her that all I needed was to be left alone. When the time for dinner came, she passed out menus to all passengers. She told me to select from the menu what I wished to eat and drink. I checked out the entrée and other items and included in my request whiskey and beer before dinner and wine during dinner.

A few minutes later, she showed up with my whiskey, beer and wine, all at the same time, and neatly arranged them on the tray in front of my seat. My fellow passengers looked at me with wondering eyes. They must have thought I had a drinking problem. No food, just a lot of liquor!

There are more incidents to show that the DI are the real handicapped people. But these should suffice. After all, some of these DIs are my best friends.

Do I need to add Q.E.D. here?



16 வகை அனைத்தும் சிறந்த சுவை

உங்கள் உணவை மேலும் நிறப்பாக்க, நாங்கள் ஆவக்காய். தொக்கு, எலுமிச்சம், பூண்டு, தக்காவி, இஞ்சி போன்ற 16 சிறந்த ஊறுகாய் வகைகள் தருகிறோம். அத்தனையும் குசித்திடுங்கள்.



N CHILLI PICKE

GARLIC PICKUE

T MANGO PICKLE

MANGO THOKKU PICKLE

•

MANCO AVARKAI PICKI

COCINCER PIC

Ruchi

Puchi

LIME PICKLE

Puchi

•

Ruchi