## BILITY SECOND S

India's Cross-disability Magazine

success

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## 16 வகை

# அனைத்தும் சிறந்த சுவை

உங்கள் உணவை மேலும் சிறப்பாக்க, நாங்கள் ஆவக்காய், தொக்கு, எலுமிச்சம், பூண்டு, தக்காளி, இஞ்சி போன்ற 16 சிறந்த ஊறுகாய் வகைகள் தருகிறோம். அத்தனையும் ருசித்திடுங்கள்.



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Mahesh Kinth



Ubedull<mark>a Nave</mark>d Azmi









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#### From the Editor's Desk

#### Friends,

We seem to be forever on a discovery spree... relishing the minute nuances of life, every single day.

Such a day of discovery was the day when eleven bright and intense students came to meet us for admission to the various streams of study in Sathyabama University. These were the students we had shortlisted, as the more deserving ones, from among all those who had applied. It was elating that in the short time that the scheme – to throw open totally accessible university education with full scholarship, for ten students with disabilities – had been announced, there had been such tremendous response, countrywide.

They were so full of enthusiasm and zeal. Some of them had come to Chennai from places as far as Meghalaya, some with anxious parents in tow and others by themselves. The courses applied for were wide-ranging from Engineering to B. Ed to B. Com. Theirs for the choosing – their dreams to follow – their way – with every requirement attended to – from computers with the relevant software, to sensitised professors, to Braille/basic sign language facilities, physical access in the class rooms and in the hostel, and follow up tutoring by qualified mentors... and all this, on a full scholarship throughout.! I really do not know who are the most thrilled – we at Ability Foundation, or the students, or Sathyabama University! But what I do know is that, we each are eager to give our best and make this an example for others to emulate. And I am sure it is only a question of time before others follow our lead.

I do believe, that this is a very important stepping stone leading to a society in which every person has the space, the right, and the capability to be able to pursue one's own ends as an equal citizen of the country. The right to set out and follow one's own path in life is really the foundational concept that offers an absolutely level playing field and equitable opportunities to every individual – with or without disability. This is what makes society tick as a whole.

In this issue of "Success of ABILITY", we focus on the recipients of our CavinKare Ability Award 2014... people with wide ranging disabilities and seemingly insurmountable odds... but all of who, have fought for their own space and equal opportunities and rights as citizens, to make possible their high achievements that would render the whole nation aglow. I am therefore, as confident as ever, that the future holds great opportunities for us. Of course, it holds its difficulties as well. The requirement for us is to work very closely with the new government, such that, we are able to get through the difficulties and seize the opportunities, to reach where we want to reach, with the flame in our hearts still burning bright.



#### Beroz Vacha (1927 - 2014)



#### - a legend who will live on...

eroz, a much loved and respected pioneer and educationist who passed away on April 24th, 2014, leaves behind numerous admirers including children with disabilities and their families whom she loved dearly and whose lives she transformed through her vision and dedication.

From the time that Beroz was a little girl she was sensitive to children with disabilities. After her marriage, Beroz decided to teach deaf children and went to Manchester University in the UK to train. On her return to Mumbai, she started teaching at a leading oral school for the deaf. Within a year of teaching, the management recognized her commitment and dedication and appointed her Principal of the school.

Beroz believed 'No one is incapable of being taught and no one can do without education. It is the fundamental birthright of every child to be loved and to be educated. Hence when a leading industrialist approached her to teach his 13 year old daughter who was deaf and was also losing her vision rapidly, Beroz immediately rose upto the challenge. To update herself on the latest teaching techniques, she trained at Perkins School for the Blind and Gallaudet University, USA.

In 1977, Beroz founded The Helen Keller Institute for Deaf and Deafblind (HKIDB) in Mumbai thus pioneering the education of deafblind in India and South East Asia. The institute started in a small way with two teachers, three children and Rs.150 functioning from the home of one of the teachers. Under Beroz's leadership and guidance, the institute grew rapidly and thirty seven years later, offers a wide range of services for children and young adults with deafblindness. Over the years, HKIDB has offered direct services to approximately 200 deafblind students and hundreds of deaf students, and indirectly impacted the lives of innumerable more students.

She was the first to bring in the philosophy of Total Communication to India to teach the deaf, deaf with multiple handicaps and the deafblind. She also set up the first teacher-training institute for the deafblind in Asia at HKIDB.

Beroz's integrity, honesty, enthusiasm and selfless service were a source of inspiration to many teachers, including me. Several leading experts in the field of deafblindness in India today chose this field because of her. The visit of Rodney Clark, then CEO of Sense UK to HKIDB led to the setting up of Sense International India, which provides services to deafblind children across the country. Such was her charisma and ability to convince others to support her cause, that I have heard many a policy maker and funder say, "I cannot say no to Beroz"!

She took a personal interest in every student and loved him or her to a fault. She believed that high functioning deafblind young adults, needed more opportunities to achieve their potential. Thus she set up a Mini Computerised Braille Press.

She also believed that deafblind students should be allowed to sit for class ten exams like other students. With their computer expertise, four students passed the National Institute of Open Schooling exams. As a result of her faith in them and the opportunities provided, Pradip Sinha won the first CavinKare Ability Award for achievers with disability in 2003. Zamir Dhale, a CavinKare Ability awardee, joined Sense International India as their Advocacy Officer and continues to impress everyone with his leadership skills. Beroz was equally concerned about orphaned deafblind children and aging deafblind, and HKIDB is in the process of setting up a Group Home for them at Karjat.

Beroz was honoured for her outstanding contribution to the education of deafblind with several national and international awards, including the prestigious 'Rustom Merwanji Alpaiwala Memorial Award in 1990 and the 'Ann Sullivan Medal' in 1991.

Sanjay Leela Bhansali who made the films Khamoshi and Black, remembers Beroz thus: "After the three hours I spent with her, I knew I had found my Ann Sullivan. She may not have given birth to them, but she is her students' mother," he says.

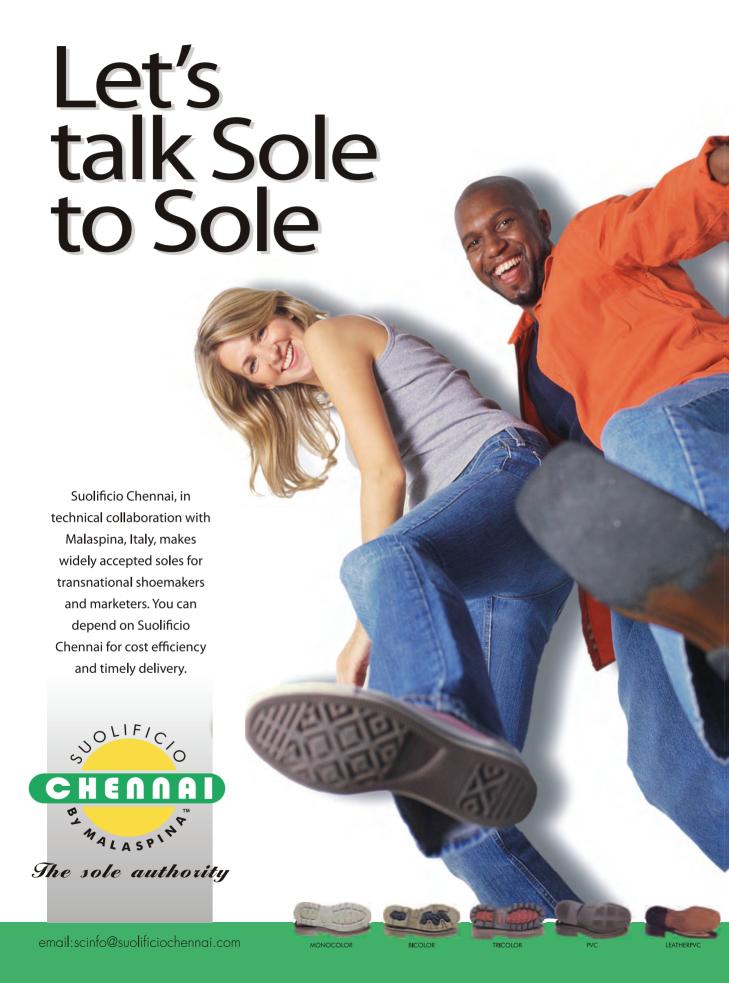
She strived to change perceptions about the deafblind and has left a legacy that will live through the continuing efforts of parents, policy makers and educators to provide equal opportunities for those with deafblindness to lead a life of dignity and quality.

In my mind's eye, I can still see Beroz teaching everyone the sign "I LOVE YOU." We love you too, Beroz! You will live forever in our minds and hearts and we will always strive to carry forward the work that you began.

Reena Bhandari pays tribute to Beroz Vacha, founder The Helen Keller Institute for Deaf and Deafblind, who was her mentor for thirty six years. Reena was principal of the Deaf and Deafblind sections at the Helen Keller Institute Mumbai and Director. Voice Vision India before turning consultant in 2011.



Reena Bhandari













At the initiative of Ability Foundation, over the last year **Ability Foundation and NIFT Chennai**, have together, worked on "Inclusive Fashion" - a project that aims to take forward sensitive and empathetic fashions suited to the physical limitations of persons with disabilities.

The project aims at creating awareness and sensitivity to disability issues in the context of design and fashions such that students of NIFT are sensitized in the need for accessible fashions that go a long way in promoting independence of living and lifestyles for disabled persons. As the future designers of the country, it is important that the idea be inculcated in them in terms of looking at clothes and accessories for persons with disabilities both from the point of view of style and functionality.

Thus the "Inclusive Fashion" project included sensitisation sessions as well as interactions with people with disabilities. The students, then, began to work with four persons with disabilities and have today, created a line of clothing for them. The resource persons and models were Malvika Iyer, Siddharth Jayakumar, Vijay Irudayaraj and Sundari Sivasubbu.

It was an exciting journey which culminated in the resource persons/models walking the ramp as part of the NIFT Graduation Show '14 Fashionova at Chennai Trade Centre.

#### The collection:

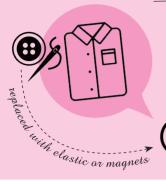
The collection was created by a group of passionate and creative design students of NIFT Chennai. As for the resource persons: Malvika Iyer, a PhD scholar and motivational speaker, needed clothes which combined creativity and functionality. Malvika's shirt incorporated elastic thread to make it an easy to wear everyday garment for people who use prosthetic hands. The contemporary sari gown that Malvika wore was specially designed for her wedding trousseau.

Siddharth Jayakumar, a banker and a frequent business traveller, needed formal wear that was easy for him to wear independently. The shirt that he wore thus had magnets replacing the buttons for ease of fastening and removing.

Sundari who works in CSR with an IT major loved to wear formal long skirts for work and for leisure, but had difficulty in finding something which did not get entangled in the wheelchair. The skirt that she modeled was the short at the back and long in front, combining both style and functionality. Her blouse was a cropped top with a longer back which did ride up when she sat on the wheelchair.

Vijay, an entrepreneur in the hospitality business, and needed smart, functional clothes that were easy to wear. His shirt was done with magnets. A waistcoat, which had long been on his wish list, was designed with additional pockets to hold his wallet and mobile phone.

#### INCLUSIVE FASHION











**Sundari** Sivasubbu

The green room was abuzz with stunning models brandishing dangerously high stilettoes and hourglass figures. Even in the ordinary tubelights of the green room, the models were shimmering. "How should I do your hair ma'am?" asked the hairstylist, holding a dryer. I just shrugged and asked him to just brush my hair and leave it loose. A make-up artist appeared from somewhere and offered to do my face. After some reluctance, I just let him do a quick touchup. Though I sported a nonchalant attitude as I waited in the room, watching the models and chatting with the chirpy student designers, I did feel faintly queasy. I was growing nervous by the hour before it was my turn to go on the ramp.

Being a communications professional who is required to do powerful presentations and speeches at various events and forums inside and outside the huge IT company where I work, I've always felt at home on the stage. But to walk... err...wheel on the ramp at a professional fashion show amidst professional models! Well... that was a definite first and altogether a completely different experience!

It all began when I got a call from Ability Foundation. It felt great to hear about their Inclusive Fashion Project with the students of NIFT. It was incredible news because, just a couple of years ago, I wrote a piece on the challenges faced by wheelchair users in finding the right outfit. That was a time, I was struggling to come to terms with the changes in my body posture

and gradual weight gain due to long hours of sitting on the wheelchair. My wardrobe during college had been mostly jeans, shirts and skirts, but these were becoming increasingly uncomfortable to wear from the wheelchair, with all my new challenges. I had long gotten used to wearing dresses that sort of fit me and the ones I could find in the small number of wheel-chair friendly stores in the city (the trial rooms are another story though!). Often they turn out to be clothes that I neither loved nor reflected my personal statement, but I've got used to the lack of choice.

Which is why, I was able to identify with the project right from the beginning and felt great to be part of it! The students were brimming with ideas to suit my clothing needs. Even taking the right measurements was a challenge but they did it with aplomb. They asked for a wish-list with my preferred colors and styles.

Finally, D-Day arrived and the girls surprised me with their creations. They had made a pretty mint green top, which is very comfortable to slip on, and a stylish dark brown skirt. The skirt was shorter at the back and straight in the front, so there are no awkward hanging hemlines while sitting. The top was loose and shorter in the front to avoid a paunch-like look, and longer in the back, so that, it doesn't ride while being helped into and out of the wheelchair. The girls had carefully taken into consideration all the specific needs I mentioned initially. The whole look was semi-formal and stylish and I loved it!







was on top of the world when I walked the ramp for Ability Foundation at the NIFT Fashion Show. I received compliments galore from the guests at the event. Some of them even asked me to consider modelling in future. But that wasn't all. I was honoured to be a part of an event, that promoted inclusion by featuring models with disability, which I feel, is an important step forward towards an inclusive society.

It was an amazing experience to work with Ability Foundation and the staff and students of NIFT.

I have always been attracted to fashion and taken a keen interest in designing clothes that are accessible yet stylish. A few months ago, I was approached by Ability Foundation to become a model for accessible clothing for their initiative with NIFT. It was wonderful sharing my stories and experiences with the students. We discussed some of the problems, that I faced with ready-made clothes with respect to my prosthetic hands. Very soon the students came up with innovative ideas to design clothes catering to my needs. One of them converted a ready-made shirt with buttons into a very accessible shirt by adding elastic to the buttons which I could wear it on my own.

> But the best part of the project were the gowns that were specially designed for me to walk the ramp. The two gowns had completely different designs, textures and colours. But there was one common feature: 'accessibility'. The students designed attractive shrugs to accommodate my prosthetic hands that would also complement the gowns. After one week of hard work, dress rehearsals and brainstorming ideas, we were ready with two stunningly gorgeous gowns for the big day.

I had always dreamt of wearing beautiful gowns like that and the team at NIFT and Ability Foundation helped me achieve that dream.

From personal experience, my research and interactions with others with disability, I know that the way we dress is important for selfconfidence and for claiming an identity in a society which often tries to tell us what we are. The considerations to be kept in mind when it comes to clothing when you are a person with disability are as diverse as disabilities themselves. Hence, functionality

as well as style is the need of the hour and I feel proud to be a part of this and would love to continue my association with it.

Malvika Iyer

Malvika lyer



#### AVINKARE

ome March and it's CavinKare Ability Awards time! Every year there is so much a mix of emotions for everyone of us at Ability Foundation. This year was no exception. That it was the 12th edition of the Awards was in itself an incredible feeling. That we had received as many as 185 nominations from so many states spreading far and wide across the country was extremely energizing. Finally, that the recipients were so amazing, each and every one of them, was truly inspiring.

Our recipients this year were CavinKare Ability Award for Eminence: Mahesh Kinth, Chhindwara, Madhya Pradesh. CavinKare Ability Mastery Award recipients Biju Varghese, Pathanamthitta, Kerala, Sangeeta Gala, Mumbai, Maharashtra and Ubedulla Naved Azmi, Rajnandgaon, Chhattisgarh.

Our illustrious jury - film maker, Gautham Vasudev Menon; renowned vocalist and composer, Bombay Jayashri; M Murali, Proprietor, Sri Krishna Sweets; **Dr Mariazeena Johnson**, Director, Sathyabama University; **G Dhananjayan**, Chief, South Business-Studios, Disney UTV.

Cut to the awards presentation itself. As is our norm, the event by itself, was high profile, glamorous and enjoyable evening for the city's select, discerning audience which was at once inspiring, invigorating and motivating everyone to spring to action.

When it comes to the CavinKare Ability Awards however, the 'why' of what we do, has always engaged us, sometimes more than the event itself. What is the message we are conveying this year? In what way will be the audience be impacted by what we say and what we showcase? To what extent does the event itself work to shift perception about disability and trigger thought in the process?



Therefore this year too was no exception. The disability sector in the country was at the crossroads; there was a sense of hope that the new disability rights bill would soon be passed by Parliament and that the rights based approach which disability activists had been advocating would become a reality. Keeping this in mind, we wanted our awards presentation this year to reflect this... as usual, unusually.

This we decided to do, with four of our country's well-known and celebrated persons with disabilities, giving away the citations to the awardees and thereby make a statement by their very presence on the dais. Thus when S.Ramakrishnan, Garimella Subramaniam, H.Ramakrishnan and Sandeep Kanabar, who exemplified achievement and empowerment, and reflected this through their own examples, the importance of rights in the lives of persons with disabilities was stringently evident throughout the auditorium. The impact was electrifying.

Something old, something new. This was certainly true of the music and dance offering this year. The uplifting Tamil song "Ulagam Ondru", specially written for Ability Foundation by lyricist Thamarai, and set to music by musician-composer Srinivas was performed again, on public demand, this time by celebrity singers. Added to this, the presentation of energetic folk dances of India, choreographed by John Britto, and presented by the students of the Tirupur School for the Deaf, the dancers from John Britto's Dance Company and actor Padmapriya, Truly a treat for the senses. We read more about this in Yashaswini's apt account of the evening and in the words / comments of our friends and viewers.



Until 2015 then.









"Oh, another awards ceremony!, said a dozen voices as I left for the CavinKare Ability Awards 2014. To the uninitiated, it might be just another awards ceremony. To those in the auditorium that evening, nothing could have been further from the truth.

Try as one might, the magic of the evening cannot be revisited in prose. Perhaps we are better off looking back at a series of memories, of images from an evening of celebration, felicitation and appreciation.

Jayshree Raveendran stands on stage, her eyes shining with happiness and her arms opened wide. The entire hall is silent and a creak can be heard as a pair of eyes leans in to get a closer look. Not one soul dares to look away from the lit up stage as Dr. Mariazeena Johnson of Satyabama University donates ten admissions from her university with full scholarship to Ability Foundation that tense yet placid silence that fills the air, that quiet excitement, that feeling of gratitude and hope. These few moments capture the essence and meaning of CavinKare Ability Awards better than the best poetry ever could. The enthralled representatives of Ability Foundation, the satisfied beam of Dr. Johnson and the awestruck gasp of hundreds in the audience – there it is,

The cool, calm composure of Sangeeta Gala, assistant director of various Bollywood movies, is unmistakable. The poise in her stride, her comfortable, chic look and her warm 'vanakkam' to the Chennai audience all reflect the same confidence with which she has met the camera, both in front of it in Barfi and Black as well as behind it as an assistant director. Sangeetha's short yet powerful acceptance speech hits many a chord for lessons in self confidence and determination. For our Image Number Two, there she is on the screen, speaking of hurdles crossed and peaks attained.

The other recipients of the CavinKare Ability Awards, Mahesh Kinth (Eminence), Biju Varghese and Ubedulla Naved Azmi (Mastery) are by no means to be left behind. Whether it is in battling an acquired disability (as in the case of Kinth and Varghese) or one from birth (Azmi), whether it is a case of fighting the battle as an individual (Varghese and Azmi) or through a structured institution (Kinth), these gentlemen are second to none. Image Number Three in our photo montage is composed of their grinning faces, unassuming and joyful, unmindful of the paparazzi-like camera flashes as they soak in thunderous applause.

After being called on stage to read and present one of the citations, Kanabar takes a moment to speak of the impact that Ability Foundation has had on his life. Standing in front of the audience in flesh and blood is one of Ability Foundation's numerous success stories, speaking of how Jayshree Raveendran's trust in him spurred him to expand his horizons, push his boundaries and chase his dreams. Image Number Four of the evening is Sandeep Kanabar, the personification of gratitude and hard work.

Singers file onto the stage, singing of shared rivers and seas. Dancers twirl on stage to beats of bhangra and other folk tunes. Song and dance, cheer and joy, skill and talent. Whether music or dance, the sheer delight of performing shines through and establishes an unmistakeable bond with every single member in the audience. Actress Padmapriya joins dancers from John Britto's Dance Company as well as the Tirupur School for the Deaf in a perfectly synchronised, coordinated, rhythmic masterpiece. The result? Magic on stage and an audience as enraptured as a five year old who has seen a rabbit being pulled out of a hat - the perfect Image Number Five.

The audience is on its feet, the strains of the national anthem run through the room, goosebumps on every arm – there can be no better ending to CavinKare Ability Awards 2014 than the sense of unity and togetherness that hang in the air. The fulfilment of purpose, quiet pride and unbridled amazement bind hundreds of individuals together. The final image of the evening is one of togetherness - people who had walked in as strangers are now bound by a shared sense of amazement and appreciation, determination and drive. The words of Jayshree Rayeendran strike a chord and one can almost hear them resonate in the room - "working towards contentment, satisfaction and changing mindspace."

"Learning to love, respect and seek happiness in everybody" Dr. Mariazeena Johnson

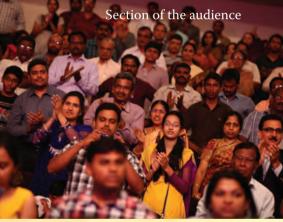
"I know what I am doing. I know what I can do." - Sangeetha Gala

"Let's remove barriers. Let's celebrate life." (Translated line from the theme song – Ulagam Ondru)

"Ability Foundation has only one thought - of being together" - Revathy









Yashasvini Rajeshwar



I do not know disabled. I do not even know differently abled. I only know ordinary and extraordinary.

Bas Ek Zaraa... Saath Ho Teraa...

This line from an old Hindi Song kept playing in my mind relentlessly as I watched the CavinKare Ability Awards ceremony with awe and amazement.

The best part about this award ceremony was the truly wonderful way in which the Achievers were honoured. They were treated with utmost respect and admiration and made to feel like minicelebrities themselves which they indeed ARE and deserve to be so:)

If the stupendous dance performances left me bedazzled, the stories of these super-spirited, inspiring souls succeeding against all the odds left me dumb-struck. It was such an honour for me to be on the stage presenting the citation to one of the awardees, who was an absolutely incredible person!

The awards ceremony gave me a feeling as if I was watching the Monks who sold their Ferraris! It re-affirmed my belief that there are only 2 kinds of people in this world - ordinary and EXTRA-ordinary and that the choice is entirely OURS. I felt that all a disabled person needs to soar high is just a gentle hand that says - You've all of us beside you!!

And that's what Ability Foundation and Cavinkare do in the Cavinkare Ability Awards Ceremony. Hence I couldn't help humming "Bas ek zaraa... Saath ho teraa..."

Sandeep Kanabar





#### a story of true fortitude and leadership

#### MAHESH KINTH

RECIPIENT OF THE CAVINKARE ABILITY EMINENCE AWARD 2014

Leader | Educator | Rehabilitator

he event that changed Mahesh Kinth's life was a road journey that he and his friend undertook in a place called Betul where he worked as a mechanical engineer. They were travelling on a motor cycle when a truck hit them. The memory of that day, 18 years ago, cannot even today, be erased, but Mahesh, the braveheart that heis, says, "If it hadn't been for that day, I wouldn't have had this." His extended, outstretched arms toward what is now his love, his life: Aadhar Foundation, a registered NGO in Poamain village in Chhindwara district, that focuses on rehab of children with physical as well as mental disabilities.

For Mahesh, the value of life became clear when he almost lost his life in that accident on that fateful day. With no one even stopping to help them, the two friends sat on the road, post the accident for hours waiting for someone to rescue them. In shock and pain, Mahesh surveyed the damage done and felt that

a large part of his right leg bone seemed powdered. "Yes, powder, like, dust," he says. "I saw just a tiny part of the bone in front of me," he adds. The delay in reaching the hospital (for the record, the accident took place at 7AM and they reached the hospital, the same day at 3PM) caused excessive bleeding and irreparable damage. He underwent numerous surgeries that resulted in his right leg being three inches shorter than his left leg. "The doctors gave up and said that they wouldn't be able to help me beyond this point. I would have to live with this disability, which would mean that I could no longer walk normally, run or drive ever again," he recalls.

Being on bed for five years, he began to live a life of compromises. He witnessed and understood the pain of other disabled people who were fighting for ramps in public places, for better facilities in the public transport system and for inclusion in schools, colleges and educational institutes. This gave Mahesh





a new perspective on life. "After years of living a 'normal' life, it was only after my accident that I was sensitised to understanding just how unprepared we are to include people with disabilities in our society. Where is the respect, appreciation and recognition for them? That's when I told myself that instead of brooding, I first had to get up and do something. I needed to make a difference," says Mahesh.

This change of perspective was the main reason that Mahesh didn't go back to doing a mechanical engineering job after his accident, despite having the option. "True, my life would have been easier, cushy, with the security of monthly pay cheques and medical bills that would have been reimbursed. But I wanted something different, I realised that I had been given a second lease of life to do something for this".

In year 2000, arming himself with B. Ed degree in special education, he began working with physically and mentally disabled children. Mahesh and his wife (who married him after his accident) provided special education, training and therapy for the children and even offered door-to-door counselling for the parents. In 2002, he founded the Prerna Institute of Rehabilitation and Research in Jammu and Kashmir. The institute, in partnership with Sahyog India, another NGO, started the J&K Chapter of Special Olympics.

Three years ago, Mahesh opened the Aadhar Foundation in Chhindwara, near his wife's village. "Our village sorely needed someone like Mahesh to start an institute here," says Rajendra J Mehta, a retired businessman from Chhindwara. "This is largely a tribal region, where people have little or no knowledge of hygiene, of how to look after themselves and their children. They need someone like Mahesh to handle their special needs' children with a gentle touch, sensitivity and professional care."

Aadhar Foundation currently works with 60 children with various disabilities: Cerebral Palsy, hearing impairment, visual impairment and Down's Syndrome. The foundation works purely on donations and all the money is put into buying equipment for the children, uniforms for the trainers and further, developing and improving the institute.

Mahesh's life is dedicated to the Aadhar Foundation, to the extent that his family, mother, wife, son, all live in the premises of this modest building that has a built up area of 1600 sq ft. "I want as many kids as possible to reach here," he says. "If they can't come to the foundation we go to them". He does experience pain in his right leg when he walks long distances but that hasn't stopped him from doing door-to-door surveys and counselling sessions in villages near Chhindwara.



The village folk find it difficult to trust anyone and therefore meeting everyone face to face, becomes vital. "We are able to reach at least 100 children with the weekly and monthly counselling sessions that we host in villages, visiting villagers and telling them about diet, nutrition, education, etc.," he says.

"All the children here are my own. To watch them grow is my biggest dream. That these children are included in society, that they get their rights and live their lives independently with dignity and respect is my vision and mission.



#### **CAVINKARE ABILITY AWARD FOR EMINENCE**

Overcoming relentless impediments of an acquired disability He realised the importance of rights, social inclusion and Equal Opportunities for all disabled persons.

He not only initiated the Prerna Institute of Rehabilitation & Research For the people of Jammu & Kashmir in the far away border areas, He also set in motion the Jammu & Kashmir Chapter of Special Olympics – to promote sports for Persons with intellectual disabilities. Triumphing over such overwhelming obstacles as Physical, financial, language and more...

Not stopping there... he went on to Take under his umbrella of support The requirements of children with every disability, Setting up an organisation of his own - 'Aadhar Foundation' In the remote village of Poama, Chhindwara Spurring on, not just education, but also equally, the promotion of Independence, rights, advocacy and outreach programs, Also providing doorstep education to children and guidance to parents Benefitting all and making it his life's mission to awaken society on The capabilities of persons with disabilities

> His story is one of true fortitude and leadership We can only ask... 'what next, Mr. Kinth?'





#### a story of true grit and determination

#### UBEDULLA NAVED AZMI

RECIPIENT OF THE CAVINKARE ABILITY MASTERY AWARD 2014

Educator | Web Designer | Programmer

ayera cradles him gently in her arms, smiling, before handing him to his father. Her son, whom she has just held so lovingly in her arms is 25 years old, 3 ft tall, weighs barely 18kgs, cannot walk, sports a hearing aid, wears glasses and is still dependent on his parents for his day to day matters. Once Naved is handed over to his father, he is carefully put into the front car seat of the family's newly acquired car, an i10, which was purchased after pumping in a substantial amount of the family's income.

The car was purchased because Naved narrowly escaped being hurt by a speed breaker when he was travelling in public transport. For most people getting jolted by a speed breaker wouldn't mean more than a minor bump on the head. However, for Ubedulla Naved Azmi - who is fighting Osteogenesis Imperfecta, and will continue to fight it till his last breath, it could, without any exaggeration, mean having a close brush with death. His bones,

due to the disorder he lives with, are brittle. So brittle that when he was a child, even a sneeze could result in a fracture.

When Sayera delivered Naved, the nurse asked the doctor horror-faced in the delivery room, "Does this child have no bones?". He was born with 20 per cent bone formation and more than 260 hair line fractures. It was obvious that there was something seriously wrong with the baby. When Sayera found out, she cried, cursed, wept, screamed and yelled at everyone around her and yet no one in particular.

Later, though shattered, Sayera and her husband Aziz accepted baby Naved with grace, dignity, hope and gratitude. The couple was ready to face anything, deal with whatever consequences that came their way. Their willingness to genuinely understand the "disorder" allowed them to introduce brand new vocabulary in their lives with terms like OI, brittle bones, genetic mutation and type one collagen gene.





Undeniably, Naved's life has been, and still is, one of extreme challenges - he has short stature, weak tissues, fragile skin, muscle weakness and loose joints. He is prone to bleeding, easy bruising and frequent nosebleeds. He has hearing loss, breathing problems, curvature of the spine and is prone to breaking his bones.

Today, Naved teaches at Simna Tech Institute, which offers certified diploma courses in computer studies, programming and technology. He holds a Masters degree in Computers Application (MCA) from Sikkim Manipal University and is planning to pursue a Ph.D. He is also a professional software developer and a guest faculty member in various institutions, schools and colleges in the neighbourhood areas.

He has developed a website (navedazmi.co.in) talking in detail about his condition in a bid to encourage others who may be like him. "I want people to know that nothing is impossible," he says. He has the reputation of being an outstanding teacher. Ritu, one of his students couldn't agree more. "I'll be honest. I was sceptical when I heard that a physically disabled person would teach me. I even complained to my family but somehow went to my class. The first time, he took our class, I was completely surprised. He is one of the best teachers I have ever found for computers. His class in engaging and fun".

Other than all these commitments, Naved helps students with their college projects during the evenings in his house. The students huddle around Naved's bed as he cannot sit without support. He lies down with the keyboard placed flat on his abdomen, having learnt the keys by heart. "This is the *mahaul* (atmosphere) when we come here: Aunty (Naved's mother) takes care of us, Naved sir teaches us, doesn't ask for money – we give whatever we feel like – sometimes we help aunty in the kitchen...

He makes everything perfect," says Priyanka Tiwari, a student at Naved's home.

Several people affected by OI, especially in India, are relegated to the dark corners of their homes, hardly encouraged to interact with the world outside and considered the result of all the "bad luck" that the parents have accumulated from the forefathers. In fact, a lone success story in India of an OI patient is that of Firdaus Kango, a Parsee playwright and author who is now settled in London. But Sayera and Azmi sa'ab were certain that as far as possible, they would try and make their son independent. Luckily for them, Naved's two older siblings were very accommodating, sensitive and warm to their brother.

Today, in fact, while his brother is an engineer in New Delhi, his sister, married in Nagpur is a qualified doctor. "Naved's condition inspired her to become a doctor," say the parents. Deeply fond of Naved, the three siblings share a healthy relationship. "We understand that we are getting old and he will require someone to pick him up carefully, with utmost caution because of his brittle bones," says his father. Noticing his intelligence and sharp intellect, Naved's parents encouraged him in his studies.

His "disabled" demeanour is his biggest strength, is what people say. "It's not that he doesn't get depressed. But whenever something upsets him, he dives deeper into learning more about the world of computers". Interestingly, some of his teachers have, in fact, ended up learning quite a lot about life through his eyes. Jhalam Singh Rathod, professor, commerce, RCCIT College, Rajnandgaon, who has known Naved for five years, observes that Naved's personality is such that he goes out and actually chooses anything challenging. "Easy is not for him. He always wants to do something new, learn something



new. And the way he has moved step after step, to secure his dreams, despite his disability is inspiring not just for me but for the whole of Rajnandgaon.

On his part, Naved agrees that pausing is not something that comes easy to him. He understands that being disabled is the truth that he has to live with. "All I will say is that, if I have managed to come so far, so can you. No one should feel dissuaded. Everyone has their own unique strengths and we need to celebrate life," he says. His dream, he tells us, is to open an educational institute for the underprivileged and for the people with physical and mental disabilities. "People like me have to grow within society." His mother, standing proudly besides him, says, "I want to be recognised by everyone in the world as Naved's mother. I want the world to know him, so they too can be motivated."

Naved's journey is one of incredible grit, strength, power. His journey is one that teaches how the human mind, once determined, can break barriers,



overcome boundaries of disabilities and create a difference in so many people's lives. He is not shy of his condition, not shy to meet people, not shy to meet anyone's gaze. He is happy to talk about his condition, explain how despite being 25 years old, he is still carried in the arms of his parents. But other than that, he is absolutely independent, earning for himself and dreaming his dreams.

#### CAVINKARE ABILITY MASTERY AWARD

Living with a condition called Osteogenesis Imperfecta That renders one's bones very brittle to the extent of Being confined to bed most of the time, *He chose not to be vanquished, but live a life of* Courage and cheer. Living his dream, surmounting tribulations Towards his pursuit of scholastic distinction, Battling widespread bias on account of disability, with a never-say-die attitude, he completed his Masters in Computer Science and soon aspires to do his Ph.D as well

He is a well known website developer, who is Also a person who has shaped many careers in the field of Computer science, by coaching students in computer programming.

His story is one of true grit and determination He is a source of inspiration to many - disabled and non-disabled.





#### a story of dreams come alive

#### SANGEETA GALA

RECIPIENT OF THE CAVINKARE ABILITY MASTERY AWARD 2014

Facilitator | Assistant Director | Teacher

angeeta Gala's eyes sparkle when she talks about cinema. Sangeeta, who was born with a severe hearing impairment, was enthralled by the worldof cinema from a young age. She felt a deep connection to the movies she watched, and often found that tears would well up in her eyes during films. "I would tell people that I'd even be a mimicry artiste just to be there (in the film industry). But I would be told that no one would bother with me because I am deaf," she recounts. Despite the discouraging remarks, Gala has indeed succeeded not only by being in the film industry, but in all the other aspects of her life. In a world where the However like every road to success, Sangeeta's was filled with obstacles and challenges which she had to overcome. Now, as a highly successful professional woman, she is able to give hope to countless others through her achievements.

Sangeeta was almost two when she was diagnosed as profoundly deaf. Her father, who was an uneducated

man from a poor Gujarati family, did not understand this and believed that she was "slow". It was her mother, Shantaben Maganlal Barot, who insisted that she be educated. "She was from a village but she ensured that I got the best education despite the family's dismal financial condition," says Gala. She studied at The Stephen High School for the Deaf and Aphasia in Dadar, Mumbai and later joined the Helen Keller Institute for the Deaf in Chowpatty. "Because of these institutions, I can speak today", she says. Following her elementary and high school education, Gala graduated from the Jai Hind College in Mumbai, where she studied Psychology.

Sangeeta's dream of joining the film industry did not come true until much later in life. After college, she began her career as an athlete. She came fifth in the long jump event at the Deaf Olympics in 1985. Though her time as an athlete was shortlived, Gala attributes her confidence and health to this period in her life and to the fitness regime



that she still continues to follow. She then pursued a career in social work. "...I then learned that [Sanjay Leela] Bhansali was looking for training for his actors," recounts Gala, "His assistant director came to the Helen Keller Institute and saw me training kids in non-verbal communication." After a meeting with Bhansali and his assistant director, Sangeeta was recruited to train actor Nana Patekar in the film Khamoshi.

Years later, the paths of Bhansali and Gala crossed again. Gala was asked to be Bhansali's assistant director and, upon accepting this position, helped train actors during the filming of Black. The task proved to be challenging, as Gala was often rebuffed by her colleagues, who believed Bhansali hired her as an act of charity. However, she worked hard to train the actors, whose performances were successful, realistic and universally acclaimed. Gala thus proceeded to training actors in Devdas, Sawaariya,

and Mani Ratnam's Ravaan. Gala currently works as Bhansali's associate director and trains actors preparing to play characters who are hearing or speech-impaired. The hit film, Barfi, was Gala's most successful project wherein she worked closely with Ranbir Kapoor to acquaint him with the mannerisms of a hearing and speech-impaired person.

At the peak of success, one might forget the importance of a cause and the reason why a goal was initially created. This was never the case with Gala. She chose to continue to be actively engaged in helping individuals with disabilities and is today creating a database of professionals to recruit into the film industry as trainers, photographers, actors, etc. Truly, achievements are worth celebrating for a number of reasons, although largely for the fact that she has provided people with a better understanding of the world of people with disabilities even while forging a career for herself in mainstream cinema.



#### CAVINKARE ABILITY MASTERY AWARD

*In a world where verbal communication is the norm* As a person with profound deafness, she is not just heard, but Widely respected and invited by the stalwarts of the Fiercely competitive world of mainstream film industry, no less To be part of their productions... as a sought after Assistant Director.

Overcoming all social, emotional and physical disadvantages of this *Invisible disability, she has brought it on herself* To communicate well, living a life of Great independence as a working professional.

Worldly-wise and articulate, she communicates Fluently and affably with everyone, overcoming the stress And demands of her profession with confidence and poise

And more... she includes in her ambit, Her concern for other deaf persons across the country By bringing them into the world of films in various capacities

> All of which reveal a courage and fortitude Seemingly oblivious to obstacles.



#### a story of independence and self-belief

#### BIJU VARGHESE

RECIPIENT OF THE CAVINKARE ABILITY MASTERY AWARD 2014

Inventor | Entrepreneur | Mobiliser

n 1997 Biju Varghese, an electrician, had an accident that changed the course of his life. He had completed his work for the day and was returning home, riding pillion on his friend's scooter. When scooter hit a median and both were thrown off. The next thing he remembered was waking up in a hospital, 20 days later, both legs paralysed. He was then 25 years old. Then followed a very frustrating year: in acute pain, in a wheel chair and constantly in and out of hospitals. He was physically, emotionally and financially at the lowest point of his life.

"As I lay in bed at the mercy of others to even get a glass of water, I decided that I had to somehow become independent. Lying in bed, I would place a board on my chest and repair electronic devices and even make stabilizers to earn enough for my medicines", Biju recalls. However, it was a program that he saw on the National Geographic channel that resulted in his independence – both physical and financial. This was a documentary on Air force One, the American President's airplane. He noticed that the pilot was using only his hands to work all the knobs to get this massive plane up into the air. He never used his legs at all. That's when the idea came to him to design a car, which could be driven by only using hands. He used the two lakh rupees compensation he received from the insurance company to buy a car and began to design a system to attach to the car to be able to drive it using his hands. It took five prototypes, fifty thousand rupees and five long years, to finally develop the system exactly the way he wanted it. He still remembers the exhiliration and the sense of freedom he felt, when he finally drove his family from Erumely where he lives, to the neighboring town of Mundakkayam. The processof getting a patent for his invention, getting a driving

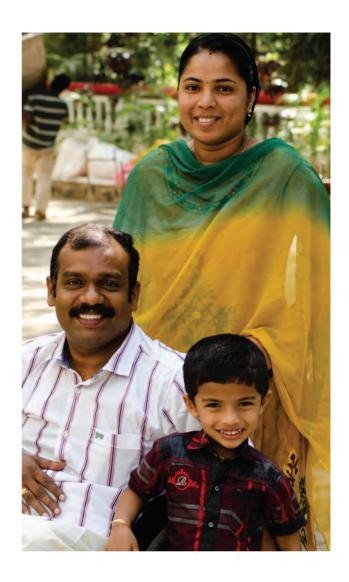


#### COVER FEATURE

license for a person with disability and getting his car approved by ARAI or the Automotive Research Association India took another grueling seven years. He is the first person in India with a disability to acquire a driving license.

Biju's passion is to give motivational talks in schools, colleges and work places. He believes everyone has the potential to overcome any disability whether born with it or developed later. Many people invite him to give talks that motivate their near and dear ones. And many-a-time, Biju takes them out for a drive while talking to them. He does all this for altruistic reasons, not monetary benefits.

Biju has taken it upon himself to share his invention and help others in the same situation as himself. People come with their cars to get the system fitted. The cost of making a system and fitting it into a car is Rs. 25,000/- . but when the customer is in no position to pay the money, Biju fits the system for free. In some cases, they just pay him whatever they can afford. But that does not seem to worry him in the least. He is happy just to see his customers driving on their own. Driving a car gives tremendous amount of self-confidence and dignity to one's life, in addition to making them mobile and independent. That is Biju's biggest gift.



#### CAVINKARE ABILITY MASTERY AWARD

Overcoming immense obstacles due to the loss of limbs As a result of an accident that left him paralysed Coming from an economically weak section of society as well. He nevertheless, chose not to be vanquished, But to live a life of courage and independence

Refusing to be dejected or yield to a life of Submissive acceptance, he realised the Importance of independence, individualism and mobility. At his own initiative, he engineered a hand operated car which, Not only made him self-reliant, but also spurred on Hundreds of others to independence Changing lives of countless others with mobility-impairment

> His story is one of true grit and determination And a source of inspiration to many.

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hey listen,

I am not born; I am being born if you know what i mean i am a verb not a noun

hey listen.

the cicadas are out again shrilling up the afternoons

hey listen.

all spirituality is really only just a yearning for the forest

hey listen.

the tv is on too loud

hey listen,

i love you like the moon loves the earth

hey listen.

an observer is part of the scene

hey listen,

i have really started enjoying this solitude it makes the whole place come alive

hey listen.

animals are better at being animal than humans are at being human

hey listen,

take off your clothes and tell me about angels, goddesses and other cosmic beings

hey listen,

inside the stunned oceans are echoing the sounds of terrifying liquid screams

hey listen,

they are using bulldozers to have a conversation with the mangroves

hey listen.

my favourite pastime is to lie in bed and listen to the sounds of afternoon birds or else to sit in the mornings radiating waves of pleasure out to the world or then closing my eyes at nights and thinking up interesting names for my pain

hey listen.

from where we are the centre of the atom is farther than the centre of our galaxy

hey listen.

do you ever get that nature-heart-stick-lollipop feeling?

hey listen,

i hope it doesn't come down to this for you but if it does i want you to know that you can completely trust the great emptiness

hey listen.

don't ever lose touch with your anger

hey listen,

your mind is out there constantly on display

hey listen.

it is the simple observation of the turning of the universe that is called enlightenment. The simpler your observation, the greater the yahaukufrookydookydoo enlightenment

hey listen,

let's do the best with what we have

hey listen,

you don't really know a place till you've seen it in moonlight

hey listen.

get out of the head

hey listen.

the ants have started building their nests in the trees

hey listen,

i'm on my way out but i'm also on my way in

hey listen.

the spoonbills have arrived

hey listen,

it's time to end this poem and return to the silence

hey listen,

listen

hev!



Salil Chaturvedi



#### Conference on



 $\dashv$  Inclusive technologies for an improved quality of life  $\vdash$ 

22nd August 2014, Taj Connemara, Chennai

amil Nadu Technology Development & Promotion Centre (TNTDPC) is a joint initiative of the Government of Tamil Nadu and Confederation of Indian Industry (CII). TNTDPC is incorporated as a Society. The centre is mainly focused towards providing a helping hand to the Small & Medium businesses and entrepreneurs in Tamil Nadu to reach and to compete in the global market place through technology innovation and meeting international standards.

With this background, TNTDPC of CII is organizing the one day conference on "Assistive and Rehabilitation Technologies" with the theme of 'Inclusive technologies for an improved quality of life' on 22nd August 2014, Hotel Taj Connemara, Chennai.

The objective of the conference is to bring together the industry researchers, clinicians, consumers, consumer led organizations, policy makers, technology developers and providers, NGOs, Academia and other relevant stakeholders who focus on improving and increasing access to technology and rehabilitation products and services with the goal of ensuring full inclusion and participation for differently abled people.

This conference will aim to cover the key areas in the following sessions:

**Assistive Ergonomic Technologies:** This session will discuss about how to incorporate the various technologies such as Product design, Hardware Interface design & Software interface design; how to enhance the efficiency and effectiveness with which work is carried out: how to enhance certain desirable human values at work, etc.

Assistive Medical Technologies: This session will discuss about early intervention and diagnosis of people with differently abled; Medical technologies and solutions available for them; various medical treatment available, etc.

Assistive Rehabilitation Technologies: This session will discuss about the various rehabilitation technologies and solutions available for Visually Impaired, Locomotor Disability, Mentally retarded, etc.

Assistive Software Technologies: This session will discuss about what are all the software technologies / solutions available for differently abled such as Internet Browsers for vision impairments, Braille Note, Magnify,

Around 200 participants from major Healthcare, Medical Equipment and device Manufacturers, ICT, electronics & service industries, government bodies, consulting group, Investors, NGO's, etc. are expected to attend the conference.

For more details on Participation / Sponsorship please Contact Mr. Sriram | 9003633779 | sriram.m@cii.in TAMIL NADU TECHNOLOGY DEVELOPMENT & PROMOTION CENTER

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Magazine Partner



### All for a helping hand

#### THE RIGHT TO LEGAL CAPACITY

It has been seen, that consistently, throughout legal systems, it is persons with disabilities who face the denial of legal capacity the most. Legal capacity is indispensable for the exercise of civil, political, economic, social and cultural rights.

ne of the great dilemmas faced by law makers in the implementation. of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) lies in the recognition of the right to legal capacity. There have been debates, right from the point of drafting of the convention, on the manner in which legal capacity is to be exercised and the limitations which may be necessary on the same.

In India, groups of Parent's Organizations (parents of children with intellectual and developmental disabilities) have been at loggerheads with persons with intellectual and developmental disabilities (who are considered to be high functioning) and users and survivors of psychiatry on issues concerning recognition of legal capacity, and the appointment of quardians.

Article 12 of the Convention affirms that all persons with disabilities have full legal capacity. Legal capacity has been denied to many groups throughout history – including women, the illiterate, and racial and ethnic minorities. It has been seen, however, that consistently, throughout legal systems, it is persons with disabilities who face the denial of legal capacity the most, especially when all discrimination against other groups have been gradually removed from most legal systems. Legal capacity

is indispensable for the exercise of civil, political, economic, social and cultural rights.

There is a distinction which has been carved out between "legal capacity" and "mental capacity". As clarified by the general comment on Article 12, dated 14th of April, 2014, "Legal capacity" is the right to be recognized as a person before the law (legal standing), and the right to exercise rights given under the law (legal agency). "Mental capacity", on the other hand, is different, and differs from individual to individual. and from situation to situation. In many legal systems, including India's, the difference between the two is conflated to the detriment of persons with disabilities.

Take, for example, the Mental Health Act of 1987, which has provisions allowing for a Court to declare a person to be of "unsound mind", and thereby leaving all decisions as regards their property to a guardian. The holding of someone to be of "unsound mind" deprives them of all legal capacity – Indian Law is replete with instances of being held to be of "unsound mind" as grounds to deny persons the right to marry, the right to vote, the right to independent living, and the right to enter into contracts. provisions of the Mental Health Act require to be amended,



Amba Salelkar

and cannot persist under a new legal regime for persons with disabilities. No person with disability can be branded as a person of "unsound mind", no matter how profoundly impaired their skills of comprehension may be, and stripped of all legal capacity.

Even under the National Trust Act, the concept of plenary quardianship, which is, in effect, a blanket certification for a need for quardianship for exercise of all legally binding decisions, denies a person this legal standing to be recognized for any decisions that they choose to exercise.

"Legal capacity" is the right to be recognized as a person before the law (legal standing), and the right to exercise rights aiven under the law What then? Are our friends and family with disabilities forced to adapt themselves to a world where admittedly, decision making is difficult even for persons who do not consider themselves in need of assistance? As explained above, the next step is recognition of their own individual mental capacity, and what kind of assistance may be required to assist them in decision making. Many persons with psychosocial, developmental, and intellectual disabilities will gain immensely from accessible information and space for decision making and communication, as their individual needs may require. There can never be a "one size fits all" for persons with disabilities and their requirements for access and reasonable accommodation. and this must be determined on the basis of their needs.

Along with this, comes the guestion of safeguards – how do we ensure that these enabling mechanisms are not misused by the service providers to suit their own needs? Guardianship is one of the proposed solutions to this situation, but has been in fact frowned upon by the UN. Guardianship is, in fact, perceived

as a "lazy" solution to the exercise of legal capacity – by placing the onus on the guardian, the State is washing its hands off its obligations to enable supported decision making under the UNCRPD. Secondly, quardianship as it exists under law does not take into account the problems faced by countless number of persons with disabilities who are abandoned or otherwise have no family members who can be trusted to take all decisions on their behalf. In some cases, it may be impossible to determine the will of a person, despite best efforts, perhaps in cases of profound disabilities.

The acts of persons acting in the nature of guardians are, in such cases, evaluated by Courts, and at present, guardians are mandated to act in the "best interests" of their wards. This test, while being very much part of Indian jurisprudence, undermines the will of the individual. The test which much emerge while evaluating a person who exercises decision making on behalf of another person must be the 'best interpretation of will and preference' of the person.

Discussions on legal capacity are complex, and hiding behind quick fix solutions is unhealthy and disrespectful of the rights of persons with any disability who may require some support in decision making. Where organizations and State bodies need to accommodate possible assisted decision making models -be they registrar offices, banks, election commissions or hospitals – this mandate needs to happen, and this will not be possible without effective participation from civil society. These discussions may be hard, but cannot be dismissed as a "waste of time" when compared to other essentials of the disabilities rights discourseafter all, it is all about "nothing about us, without all of us".



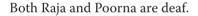


## GLES DA

SUCCESS BREEDS SUCCESS

Raja Kushalnagar and Dr. Poorna Kushalnagar are professors in Rochester Institute of Technology, one of the top universities in the United States. Both have Ph.D. degrees. Dr. Raja teaches Computer Science and Dr. Poorna - Psychology. Dr. Raja, in addition to his Ph.D. in Computer Science also has a Master's degree in Law. They have two young sons and live in a suburb in Rochester.

Sounds like a typical story about a successful Indian couple in the United States. Yes, but with a twist.



I am sure parents of deaf children and other professionals working with deaf children will benefit from learning about these young people. Nothing succeeds like success and instead of focusing on the problems deaf people face, let us stop a minute and look at what they can do.

Thanks to various disability laws that provided equal access to communication and educational opportunities, deaf people around the world have achieved success in personal and professional lives. I have the good fortune of meeting many of them. However, these two people stand out as the crème de la crème among them. Here are the excerpts from my email conversation with them.

You both have doctoral degrees (and Raja has a law degree too). What was the driving force behind your ongoing thrust for higher education?

Raja: Our families valued education highly. We also followed their example - our parents had advanced degrees, and so did many of our siblings. Initially, we worked after graduating from college, but reached a "glass ceiling" and opted to return to school and obtain terminal degrees.

Poorna: My parents are both professors. My eldest sister and brother have doctorates. Another sister has a medical degree. All of them served as role models, and were staunch supporters in my academic pursuit.

Now that you both have "terminal degrees", are you satisfied with your educational achievements or are still striving for higher education? Remember, we learn all our lives.



Dr Madan Vasishta

#### Author's Note:

The fact that the families of both Raja and Poorna are highly educated has helped them focus on getting higher education. However, this is not a requisite. Many people whose parents have little or no education are also motivated when their parents encourage them.

Raja: I am satisfied with my achievements, but continue to expand my horizons in my research endeavours as a professor.

Poorna: My curiosity and passion for learning never end. I enjoy attending scientific conferences and keeping up-to-date with cutting-edge research. The best part of this experience is that I get to network with other colleagues in the field, where continued and new collaborations form.

Did your higher education pay off in getting the jobs you had prepared for? Or do you feel you are underemployed?

Raja: It paid off in getting the job desired - professor.

Poorna: Not really. I am a research professor, which means I have to constantly seek for external funding to support my position. I have always known this, and accepted the challenge. The best part about being in this position is that I get to do research that interests me the most.

Raja, you are perhaps the only deaf person in the world who has a Ph.D. in Computer Science. This is unique achievement. However, you still went ahead and got the law degree? Why was it necessary?

Raja: The reason I got a law degree was to become a better advocate for myself in college and to write about policy and accessibility afterwards.

What specific support system helped you achieve your goals? Do you think if you were in India, you would have achieved here what you have in the US?

Raja: I am the third known self-identified deaf person to get a Ph.D. in Computer Science and the second self-identified deaf person to get both a Ph.D. and J.D./ILL., so it is not unprecedented. However, all of them including myself got their advanced degrees after the passage of the Americans with Disabilities Act(ADA). A Masters degree is less structured and requires more independent work than a Bachelors and one cannot learn solely from textbooks and tutors. Similarly, a Doctorate degree requires much more independent work, group discussion and reading, than a Master's. It is much easier to learn and excel under these learning requirements with appropriate accommodations (aural to visual: sign language interpreter or captioning).

The right to aural-to-visual accommodations guaranteed by ADA was most important. In India, as this was before the passage of the Disabilities Act, I did not have the chance to request direct accommodations. Instead my parents opted to put me in a small class cohort, with the same teachers and friends from 1st through 12th standard. When younger, my parents tutored me, and when older, I signed up for private tutoring. These arrangements worked well for school, but work less as education becomes less structured and requires more independent work.

Poorna: My parents moved to USA soon after they found out I was deaf. Although I would have loved to be raised around my people in India, I have to say that IDEA and ADA helped to advance my education and postdoctoral training in the USA, something I would not be able to get as easily in India.

I understand you have two young sons. How do they feel about their deaf parents being uniquely qualified?

Raja: Our sons are proud of our achievements and work and aspire to similar achievements. They wear shirts and caps with finger spelling and NTID logos on them; they also happily sign to us in public and love to mingle with other KODAs.

Author's Note: KODA stands for Kids of Deaf Adults. In the United States there are local and regional organizations of KODAs that have regular meetings and various camps. These help these children understand deafness and develop a positive attitude toward it. We need similar organization

in India.

Poorna: When I asked my sons this question, they stated that they feel proud. When my younger son was in preschool, both Raja and I were doctoral students. At that time, his preschool teacher asked him what he wanted to be when he grew up. He answered, "I want to be a Ph.D. student." Today, both our sons continue to state that they will pursue Ph.D.s. Both proudly wear Google shirts and caps that have finger spelling alphabet print. They are not embarrassed with using ASL in public, and have very strong connection with other peers who have deaf parents in the community.

#### What advice do you have to give for deaf people in India who do not have the American support system (the land of the opportunity)? How can they realize their dreams?

Raja: My advice to deaf students and employees is to maximize your learning/productivity, and to optimise communication - through texting or email. It is also very helpful to find "allies" who will learn some fingerspelling or signs and convey important information that you would otherwise miss. It is also important to educate authorities (university, company, politics), that deaf can do anything except hear. One way would be to write articles for local news or to give a speech, if necessary, jointly with a hearing person.

Poorna: Choose professions or jobs that provide the least barriers, yet bring them closer to their dreams. This might not be the most perfect job, which is okay.

At what age did you learn sign language? What role did sign language play in your education, employment and social lives?

Raja: I learned signs at age 25. Sign language was key in obtaining higher degrees, in work and in social life.

Poorna: I learned ASL when I was 3 years old. My best friend had a large deaf family. ASL has a calming effect on me. When I use ASL, I feel relaxed and non-fatigued. Knowing ASL helps me connect with other deaf adults in the community, both professionals and working class members. They provide wonderful support and a sense of belonging, which I find to be stimulating and healthy. This support gives me the strength and patience, as I interact with hearing colleagues who are less willing to accommodate my needs.

In India, the government is emphasizing "full inclusion" for all disabled children. This also means minimizing special schools for disabled children. Do you think deaf children can successfully participate in regular schools? Or do you think special schools with full access to communication are important?

Raja: Full inclusion in theory is a great goal. But in practice to date, it addresses only some of the issues that deaf children encounter; many issues are poorly handled, especially socialization and incidental learning.

First, deafness is low-incidence, so it is rare to have more than one deaf child in a neighbourhood or school. Second, current accommodations do not support direct communication (as it goes through an interpreter or captioner), so the deaf child misses out much social interaction; also the child misses out on relational learning. i.e., observation and modelling of others which can lead to delays in socialization and cognition.

#### Any message you might have for parents of disabled children and professionals working with them.

Raja: The goal is to envision a deaf adult who has the academic and social skills to be autonomous with skills to navigate both home and job environments. Development is holistic - along communication skills (aural, visual, both), academic skills, social skills and self-confidence. If anyone of these is neglected, the development is impacted.

Author's Note: There is a fallacy that oral skills are tied to intelligence. I have often heard comments like "that deaf person can lip-read because he is smart." It must be borne in mind that lip-reading skills and linguistic proficiency are different skills.

Author's Note: As the readers may have already concluded, the key to success is parental involvement, support for education and trust in their child. More than that is communication. Deafness is a communication disorder and once we provide equal access and a level playground, they thrive and do same as or even better than their siblings. Generally though communication develops first, so that has to be strong for other competencies to grow and thrive.

Poorna: Around 96 percent of children with hearing loss are born to parents with intact hearing, who may initially know little about deafness or sign language. Therefore, such parents will need information and support in making decisions about the medical, linguistic, and educational management of their child. Some of these decisions are time-sensitive and irreversible and come at a moment of emotional turmoil and vulnerability (when some parents grieve the loss of a normally hearing child). Clinical research indicates that a deaf child's poor communication skills can be made worse by increased level of parental depression. Given this, the importance of reliable and up-to-date support for parents' decisions is critical to the overall well-being of their child. In raising and educating a child, parents are often offered an exclusive choice between an oral environment (including assistive technology, speech reading, and voicing) and a signing environment. A heated controversy surrounds this choice, and has since at least the late 19th century, beginning with the International Congress on the Education of the Deaf in Milan, held in 1880. While families seek advice from many sources, including, increasingly, the internet, the primary care physician (PCP) is the professional medical figure the family interacts with repeatedly.

#### What role did your parents play in shaping your educational success?

Raja: My parents were key - they imagined a future for me being a successful adult and used that to consistently interact with me and encourage me to succeed. Though they did not know about aural-to-visual accommodations, they incorporated into their interaction -- pictures, diagrams and combine with text. Without parental involvement and interaction, it is much harder to develop skills. Also, they had the foresight to place me in a small class and ensure that I had the same friends and teachers throughout school.

Poorna: They accepted that I was deaf, and allowed me to use ASL and develop a healthy with network friends. This acceptance provided the foundation to shape my confidence for educational success.



The Kushalnagars bonding on holiday

# 



Family Of Disabled" (FOD) disbursed an assortment of gadgets to 48 people with disabilities at Agarwal Dharamshala, Saraswati Vihar, New Delhi, in a simple, impressive function. The event was jointly sponsored by Radha Mohan Charitable Trust (RMCT) and Chitrakoot Mahila Mandal (CMM).

Ms. Preeti Basra, COO, FOD, gave a brief description of the services offered to people with disabilities by the organization. She mentioned the FOD's pilot project that was introduced in March this year, of job-placement, commensurating with qualification and capabilities of applicants with disabilities. Mr. Rakesh Dhingra, founder of the RMCT said that his business Ruchika Industries had provided jobs to 10 visually impaired persons.

Mr. Ajay Amar of Prerna School Of Inspiration contributed to the cost of nine hearing aids which were distributed on the occasion. He also arranged for fresh audiometry for all the recipients of hearing aids, by ALPS International Private Limited. Master Mohit, a 13-year-old student of Class VIII in a Govt. School narrated his experiences at FOD. He has a total loss of vision in his right eye and partial vision in left eye since birth. He has been instrumental in getting many students with disabilities of his school helped through FOD, who were all provided with tricycles and bicycles.

On the occasion, two short films were also screened. A nine minute film - "A Life Relived", produced by Impulse Productions showcasing activities of FOD and its founder Rajinder Johar, and the second film, about the utilisation of funds received from the general public and Reliance Foundation after FOD had been featured in an episode of actor Aamir Khan's TV serial Satyamev Jayate. Currently with the money received, a rehab centre UNNATI is under construction in Najafgarh, New Delhi. To date, FOD has disbursed a variety of gadgets to 1128 individuals with disabilities.

### Free Mobile Apps

for people with hearing disability

Grey Group Singapore ("Grey") has developed two innovative mobile apps for smartphones that aim to improve the quality of life of people with hearing disabilities.



#### Say It With Signs

is an app that helps users with hearing disability to answer

and respond to phone calls. The app uses voice-to-sign technology to "translate" the audio messages during a phone call into digital hand signs that are displayed on the receiver's phone screen. The user with hearing disability can reply by texting. Using text-to-voice technology, this text is read out to the caller.

#### **Hearing Aide**

is an app designed help the hearing - impaired



by alerting them about emergencies or potential danger. The app recognises specific sounds in both indoor and outdoor environments and alerts the users through 20 - second vibrations and a message displayed on the phone screen.

Hearing Aide comes preloaded with 5 standard alarms for ambulance, fire brigade, police sirens, fire alarm and smoke detector. Users can record sounds and create their own alerts.

Source: http://globalaccessibilitynews.com/

## TAX BENEFITS

### for persons with disabilities in India

The government of India has recently provided various benefits, concessions and reservations to empower persons with disabilities and their families - section 80U, 80DD, 80DDB and 10(14) under Income Tax Act and Professional Tax Act. The benefits are explained below:

- Income Tax Act, Section 80U Deduction in case of person with disability
  - Who can claim the benefit: Individual who is resident during previous year and is certified by Medical Authority to be a person with Disability. Deduction allowed: In case of Person with Disability (at least 40%) Rs 50,000 /- is allowed. In case of Person with Severe Disability (80% of one or more disabilities) Rs. 1,00,000/- is allowed.
- Income Tax Act, Section 80DD Deduction in respect of maintenance including medical treatment of a dependant who is a person with disability

Who can claim the benefit: Individual or Hindu Undivided Family (HUF) who is resident during previous year, and has incurred expenditure in relation to maintenance or treatment of depended disable or has invested in a particular scheme of LIC for benefit of the depended disable.

#### **Deduction allowed:**

- A) Rs 50,000/- for the medical treatment (including nursing), training and rehabilitation of a dependant, being a person with disability. Or Rs 1,00,000/- for the medical treatment (including nursing), training and rehabilitation of a dependant, being a person with Severe disability having medical certificate granted by prescribed Medical Authority
- B) Any amount paid or deposited under a scheme framed by the Life Insurance Corporation or any other insurer or the Administrator or the specified company for the maintenance of a dependant, being a person with disability or person with Severe disability (subject to over all limit of Rs 50,000/- or 1,00,000/- as applicable)
- Income Tax Act Section 80DDB Deduction in respect of medical treatment, etc

Who can claim the benefit: Individual or Hindu Undivided Family (HUF) who is resident during previous year, and has paid any amount for the medical treatment of such disease or ailment, for himself or dependent in case of individual or any member of HUF in case of HUF

Deduction allowed: Rs 40,000/- deduction shall be allowed or amount actually paid, whichever is less, in case of senior citizens (Above 65 years), an

additional deduction of Rs. 20,000 shall be allowed towards payment of the senior citizen. i.e. in case of senior citizens the above limit of 40,000 shall be upgraded to Rs.60000.

For the purposes of section, the following shall be the eligible diseases or ailments:

- Neurological Diseases where the disability level has been certified to be of 40% and above,—
  - (a) Dementia
  - (b) Dystonia Musculorum Deformans
  - (c) Motor Neuron Disease
  - (d) Ataxia
  - (e) Chorea
  - (f) Hemiballismus
  - (g) Aphasia
  - (h) Parkinsons Disease
- 2. **Malignant Cancers**
- 3. Full Blown Acquired Immuno-Deficiency Syndrome (AIDS)
- 4. Chronic Renal failure
- Hematological disorders
  - (a) Hemophilia
  - (b) Thalassaemia

#### Income Tax Act Section 10(14) Rule 2BB Transport Allowance

Who can claim the benefit: Salaried Individual Deduction allowed: Rs 1600 Per Month **Important Points to be noted:** 

- Transport allowance is granted to an employee, to meet his expenditure for the purpose of commuting between the place of his residence and the place of his duty. Most of employers pay Rs 800/- per month as the same is exempted. However for employee, who is blind or orthopaedically handicapped with disability of lower extremities, the exempted amount is Rs 1600/- per month
- Employee can request employer to structure their pay in such a manner that they receive Rs 1600/as monthly transport allowance to claim the benefit.
- Tax Exempt is irrespective of actual expense. (No bills/receipts needed)

Information Courtesy:

Praful Vyas, Hon. Secretary, Andhjan Kalyan Trust, Gujarat

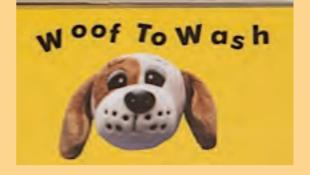
#### **CHENNAI EAGLES**

#### WHEELCHAIR BASKETBALL IN CHENNAI

**▼**he YWTC Charitable Trust, in partnership with Choice International, a UK based Non Profit Organisation, is trying to promote Wheelchair basketball in India. As a first step, they have started efforts in Chennai. This initiative is called "CHENNAI EAGLES". With the support of Sports Development Authority of Tamilnadu, YWTC are arranging weekly wheelchair basketball practice sessions for interested people.

One of the main objectives of the YWTC Charitable Trust is promoting sports for people with disabilities with an emphasis on swimming. Sport can be an effective stepping stone to empower disabled people within their communities and in society at large. It can also act as a gateway to employment, leadership development and promoting societal acceptance and inclusion, ultimately improving a disabled person's quality of life.





The world's first dog-assisted washing machine has been launched in the UK, making the everyday task of doing the laundry easier for persons with disabilities.

'Woof to Wash', a washing machine which is activated by a dog's bark, was created by laundry specialist JTM Service and functions with dogs trained by the charity "Support Dogs."

The assistance dogs are trained to tug on a rope which opens the machine door for loading. When ready, the dog nudges the door shut and barks to begin the washing cycle.

A voice-activated switch is turned on when the dog barks and the machine then automatically dispenses detergent and begins to wash at 40 degrees. Once washing has finished, the dog steps on a paw print shaped button at the bottom of the machine and the door opens.

The revolutionary machine is hoped to enhance the quality of life and independence for thousands of people with a range of disabilities across the UK.

Inventor John Middleton, MD of JTM, said: "We developed this machine because mainstream products with complex digital controls seldom meet the needs of the disabled user. "We had already created a single programme, one button machine, to make life easier for people with a range of different needs. When we heard about the amazing work "Support Dogs" does, the 'Woof to Wash' was an obvious next step."

Rita Howson, director of operations for "Support Dogs," added: "Doing your own laundry is something most of us take for granted. Support dogs of all sizes can load the machine, bark to turn it on and, with the push of paw, open the door and unload the washing."

John Middleton added: "A voice-activated washing machine, combined with a single 40 degree wash cycle and facility to automatically dispense the correct amount of detergent, could be invaluable to people who are visually impaired, have manual dexterity problems, autism or learning difficulties."

Eleanor Davis

# Mind controlled robotic suit



On June 12, 2014 at about 5pm local time, a paraplegic Brazilian man rose from his wheelchair, and took a kick that opened the 2014 World Cup in Sao Paulo, Brazil. This miraculous occurrence was the culmination of twelve years of intense research and work headed by Dr. Miguel Nicolelis, a neuroengineer at Duke University, and his team of scientists and engineers. The hundreds of millions of eager fans watching football's greatest tournament were stunned by a remarkable new demonstration of technology: the mind-controlled robotic exoskeleton.

Nicolelis envisioned the exoskeleton in 2002, while working on brain machine interfaces (BMI). Just four years earlier he, along with a group of colleagues, published a study stating that the brain of a rat could be used to control a robot device. He developed his studies and later demonstrated that the brain of a monkey could initiate movements in a robot using electrodes. This led him to the realization that humans could complete a similar task. He gathered an international team

to create the mind-controlled suit which would enable paraplegics to walk and move - in an operation known as the Walk Again Project. Among the coalition of scientists working on the humanoid robot was Dr. Gordon Cheng, the founder of the Institute for Cognitive Systems at the Technical University in Munich. "The main goal of the project is to demonstrate that a brain-machine interface can be the centre of rehabilitation," Nicolelis tells IB Times UK, "Walking is only the beginning. That is the most immediate objective, but the technology could also restore upper limb movements and functions to allow patients to be able to speak again, by establishing a direct link between the brain and machines."

So how does the machine operate? A paraplegic person is put into a suit and given a cap which is covered in electrodes to pick up brain waves. The brain wave signals are sent to a computer situated on a backpack, which is also worn by the operator, which decodes them and uses them to move hydraulic drivers in the suit. The person places their feet on plates with sensors which detect when contact is made with the ground. As the foot touches the ground, a signal is shot up to a small device on the sleeve of the operator's shirt. This device fools the brain into believing that the foot is moving, and in turn the people feel as if they are walking. A large part of the suit is covered with artificial skin and sensors that allow the wearer to feel a variety of sensations. "The movements are very smooth," said Nicolelis to the Guardian, "They are human movements, not robotic movements."

This innovative system has undergone a variety of safety checks. Nicolelis and his team attended a football match in Sao Paolo to check if phone signals and radiation would interfere with the working of the suit. Fortunately, they found that the chances of the exoskeleton malfunctioning are extremely narrow.

The implications of this project bring hope for those who are paraplegic, or have any other similar disability. All of the innovations we're putting together for this exoskeleton have in mind the goal of transforming it into something that can be used by patients who suffer from a variety of diseases and injuries that cause paralysis, says Nicolelis. Thanks to Nicolelis and his team, millions of people were able to witness a paraplegic man taking a step forward with the power of his own mind.

Uma Velamuri



Michael Rosenkrantz talks about his love for basketball and his experiences with coaching wheelchair basketball in Nepal and India. He is a freelance writer and VSO volunteer and currently lives in Nepal.

Typically I like to sleep late on weekends, but the mornings are when I play and coach basketball. From March 2009-Februrary 2012, I coached basketball on Saturday nights at the Delhi YMCA. But in Nepal, the basketball action seems to happen in the mornings. I came to Nepal as a VSO volunteer in June and most recently on Sundays I wake up at 6:30 AM, my friend Raj Kumar picks me up at 7 and by 7:30 we are on the courts at Arunodaya Academy in Swoyambhu, waiting for the team to roll in from their home about one kilometer away.

I see the smiles on the guys' faces as their attendants lift/roll them down the stairs to get to the courts, many of them with their urine bags attached to their wheelchairs. I see the amazement of the children at Arunodaya Academy as they watch the guys play basketball. This is no ordinary basketball team, but is an Army wheelchair basketball team, showing up with the same enthusiasm of any other athletic team, ready to take on all opponents. These guys are different as they can't jump for rebounds or shoot a jump shot, can't run up and down the court, although in their wheelchairs they can move fairly quickly, but not as efficiently as someone in a specialized sports wheelchair. These guys can set a pick, although sometimes their chairs get tangled up, can play defense, although sometimes their leg rests extend out too far and can shoot a basketball on a regulation hoop, although sometimes their shots are way off because they can't get the same lift as someone who can jump. The athletes on this team can even "run" plays, do a three person weave and make layups.

This team is full of young guys, who might have been injured in the Maoist conflict, injured by a land mine and spent years in a hospital rehabbing, or maybe they were injured in a car accident or fell and injured their spinal cord to the point where they could no longer use their legs to walk. Some of these guys are married, have children and want to be productive members of Nepali society. Those who are married, have incredible wives who have overcome prejudice and one of the wives even told me, "look beyond disability".



Michael J. Rosenkrantz



They are strong women in their own right, enduring sometimes years for a family not accepting their husband and his "fate".

The guys on this team and other persons with physical disabilities tell me that without sports they would be depressed, have bed sores, have little exposure to society and have problems such as urinary tract infections. These guys are artists, weight lifters, advocates for themselves and other persons with disability. These guys and their wives struggletolive

lives like other couples. But there are also the guys who can't find wive sbecausethey are in a wheelchair, can't find a job, which is most of these guys, because employers won't give them an opportunity, even though there is nothing wrong with their minds, their arms or their eye sight.

While in India, working for the National Trust, Ministry of Social Justice and Empowerment, Government of India, I learned a lot about persons with developmental disabilities. One of the popular words coined by our Joint Secretary was "Discoverabilities", i.e. looking beyond a person's disability to truly discover their abilities and is based on society being inclusive and providing opportunities. I saw a full range of persons with disability doing the same thing as anybody else in society, having the same aspirations, but needing more accessibility and opportunity in order to live out their dreams. But I also heard a lot about the myths as to why someone had a disability. At the National Trust we worked a lot on overcoming these myths through an all India discoverability awareness campaign known as Badhte Kadam. The fourth year of this campaign was completed in November 2012 by the National Trust throughout India.

I recently attended the first "Career Expo for Persons with Disability" in Nepal, a good start. Through my association with persons with disability I know that a lot more is needed for the athletes on "my team". I know that these guys need to be recognized for their talents, need to have opportunities to participate in sports on a regular basis, have a job to go to, in order, to earn for themselves and their families, for those not married they need opportunities to find a woman to marry, but mostly they need, like all of us, to have dreams, which society will help them to achieve.

The athletes on "my team" inspire me, just by being who they are and what they are trying to do. I complain to myself when I miss a shot or make a bad pass, but the reality is that even as I get older I can still jump a rebound or shoot a jump shot. Maybe I can't run as fast as or am not as quick as I once was, but for the guys on "my team" they just keep rolling on, and hopefully we can help them to find their discoverabilities.

I love basketball, a real passion of mine. Recently I had the opportunity to coach the Chennai Eagles, a new wheelchair basketball team. This came as a great opportunity as I had started my wheelchair basketball learnings in India in 2011, when I was a volunteer for the National Trust in New Delhi. My friends from Wheelchair Athletes Worldwide (WAW) had come to India in November 2011, did a few clinics and donated sports wheelchairs to Amar Jyoti School in Delhi and the Ability People in Visakhapatnam. Since this time I've become passionate about disability sports and creating opportunities for disabled people.

Coaching basketball is coaching basketball, no matter whether someone is able bodied or disabled. The major difference being that the person is in a wheelchair. The wheelchair becomes a part of the disabled person which then becomes part of the learning for them to be a good player. Wheelchair

basketball players can zoom up and down the court, maybe even faster than able bodied players. The skill level of wheelchair basketball players can be great, like any sport, this just takes time and practice.

I always enjoy facilitating and this is what I did with the start of the Chennai Eagles. It was wonderful for me to see the interest and the athletic ability of the athletes that I had the privilege of being with for three days. I saw tremendous promise and was very happy that my friends Troy Justice and especially Jayasankar Menon, the former captain of the Indian Men's National Team, were willing to provide continued coaching. This will be the real way that the players will improve, through Indian coaches.

I was honoured to be part of the three day training and hope to do more in future.

EVERY SUNDAY I go to a Nepal Army training base near Swayambhunath and coach the Army Wheelchair Basketball team. Whenever I walk on the base, I am a bit discombobulated, i.e. what is an American (especially one who is very anti-military, I mean look at all the "wasted" money, when there are so many people living in poverty throughout the world) and now-a-days, one on crutches, doing on a Nepal Army base? At times it is surreal, but this feeling disappears quickly, as I get into my coaching mode.

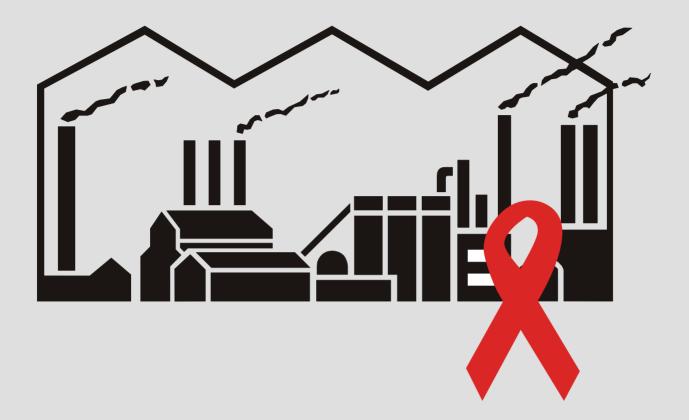
It's one thing to coach persons with disability to play basketball, which I do on a regular basis, but it's an entirely different experience to have to walk through a security gate, guarded by soldiers with guns (although they always smile at me and probably wonder what is this guy doing here again). On some level, I wonder what it is I am doing here every Sunday morning, but I do realize that it is really not about the confines of the Army base.

This is more about the excitement that I feel in teaching and refining skills, although I can't really play wheelchair basketball. I'm used to using my entire body to play basketball, but have a hard time sitting in a wheelchair and using only my upper body to pass, shoot and dribble. I get too tired pushing the wheelchair up and down the court, but yet Himal, Raju, Ram, Tilak, Narayan, Prem, Funey, and all of the other guys that make up this team, do everything that I and/or the other coaches ask, no matter how much it hurts. I'm amazed and inspired by these guys, who can no longer use their lower bodies but are athletes, people of indescribable passion for sports and more importantly life.

Because it's really not about basketball; some of the guys do weightlifting or swimming or table tennis or whatever they are enabled to do. Nor is it just about sports. No, it's more about the fact that these guys are active participants in life; most of them have families, lead full lives according to their capabilities, just like my other friends. They haven't given up, although, I would bet that after all of their mishaps they might have thoughts about this.

Even for me, temporarily on crutches, and with my really poor Nepali, I get through to the guys and they to me and we have a blast and they make me happy just watching. These guys want to succeed in whatever they do or in whatever they are involved. These guys give me another reason for living my life to its fullest. My hope is that these guys can feel how much they mean to me and how proud I am to watch them practice and play. These guys and the many other persons with disability who are participating in life are my personal heroes and they are all winners.





Industry has a special responsibility towards society. It has better resources and superior organizational strengths and managerial acumen. If we can help the world win the war on HIV/AIDS, we will be helping society in a very special way.

- A. M. Naik, Chairman & Managing Director

L&T offers the community HIV/AIDS prevention and detection services, counselling and treatment. L&T received an award from the Global Business Council (London) for Business Excellence in HIV/AIDS.





# Redefining Beauty

Vaishnavi Venkatesh on ALFAA's Fashion show featuring models with autism...

We've been given grey matter for a reason - to differentiate us from other species and make a difference in this world."

Ruby Singh, the director of ALFAA (Assisted Living For Autistic Adults) grew up believing this. While everyone shushed her dream of becoming a movie star, she continued to think that being in the limelight was not just about looking good. There was a life beyond the looks and that's what she saw. This got her thinking and the idea of having a fashion show featuring persons with autism was born.

When I first heard about a fashion show and autism, the concept felt like an oxymoron. Persons with autism do not like social gatherings, screamed all my textbooks. But one conversation with Ruby converted me. It isn't the social gathering that they are wary of, it is the hostile environment.

"When the atmosphere is positive and people are cheering them on, they feel good and are comfortable walking the ramp", she said. "But this also takes a lot of perseverance and practice. My son was very restless for an hour before the show, but when he finally did walk on the ramp, he enjoyed it thoroughly."

During his younger years, Ruby often felt that her son could give most child models a run for their money. That he was autistic didn't deter her from thinking that he could enter a profession only "normal" children would be welcome in.

"Child models are pulled out of school to shoot for advertisements. They look happy and carefree in the ads, no different from children with autism. There's also a mutual benefit when children with autism are used for modelling products or in still photography."



Vaishnavi Venkatesh

# Beauty is being redefined today. Mindsets are changing and we must leverage this to make our voices heard.

Indeed, there is. Brands take a bold step by choosing to advertise their products with children with special needs. This sensitizes the brand towards creating an inclusive society and also becomes a medium for creating awareness. People see the humane side to these brands and support their initiatives. A small footnote in the advertisement can go a long way in sensitizing society.

But there's more to this than making an appearance on advertisements. These options are a source of remuneration and for adults with autism, it's a great way of supplementing their income. Adults with autism are usually involved in routine jobs - such as making candles, greeting cards, bags, diyas etc. The income may be steady but there is a low profit margin to these. Having a modeling assignment every now and then can boost their savings to a great extent. They rely less on their caregivers and earn a living to sustain themselves.

Where does ALFAA fit into this picture? ALFAA will create a platform where profiles of persons with autism can be showcased. This will help them get assignments. They will continue to participate in fashion shows to create more awareness within society - another important factor for marketing this idea. Their most recent show was at Soul Santhe, an eclectic crafts market in Bangalore. Coordinated by Prasad Bidapa, one of India's premier fashion show coordinators, this was a success! Two children were walking on the ramp for the third time - so they were very comfortable. There were 6 children in all, and they were sponsored by three companies.

"We will hand over the cheques to the children and their parents at a separate ceremony", says Ruby. "These children deserve to receive their remuneration with the people who have supported them the most their parents." But this made me curious.

Modeling has not always been considered an ideal profession, even for persons without autism. How did the parents react to the idea that their children could model for brands? "Initially, there was hesitation - as there would be for most professions. But the idea soon caught on - our children could be the faces of sensitizing top brands and making society more inclusive. At the same time, they would be financially independent. This made them more confident of supporting their children."

If you're thinking (like I was, I admit rather guiltily) that these children are "trained" to be like normal models, then read on... the children who model are encouraged to be themselves. Their behaviour isn't trimmed or curbed, and they aren't packaged as the ideal models. "Our goal isn't for them to be accepted as normal - we want them to be accepted for what they are. Society needs to see these children and accept them, and modeling is a great platform to make this happen."

I watched my stereotypes and misconceptions getting busted one by one. My conversation with Ruby was immensely eye-opening and I was left with one very poignant thought that she gave me - "Beauty is being redefined today. Mindsets are changing and we must leverage this to make our voices heard".



## No looking back

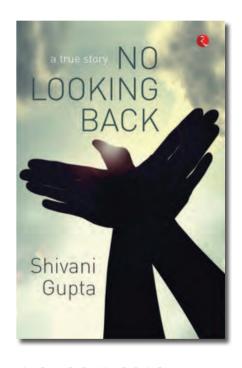
I have always felt lucky to be born disabled. No, it is not because of the privilege that I have been looked after by people from the time I was a baby till well into my forties as I haven't grown up, as some friends like to joke. But, it is because I have seen a few people (who are my friends now) becoming wheelchair-users in their prime, they all have been brave and somehow surmounted the ordeal. The latest addition in this list of friends is Shivani Gupta. I had heard a lot about her as an award-winning crusader for the disabled.

But, when I heard about a book on her life on the social media, I felt a little sceptical as we Indians are not good at saying it in writing. Yet, I got the book even though I was unsure that I would even finish reading it. And, to my surprise I was visualising the author's life and before I knew it, I began turning pages (though I was reading an ebook).

What happens when the dreams of a twenty-two year old girl crashes in a car accident? Obviously, the harsh fact would take its time to sink in, and, it would be a painfully slow process. The realisation that your life has gone topsy turvy and things would not be back to normal ever again, is hard hitting. You may find Shivani's life story familiar to some extent, as it covers medical negligence and the lack of knowledge of medical staff to deal with her case.

For me, the book really begins when Shivani starts describing things after the rehabilitation (meaning that she had accepted being a wheelchair user). She dwells on matters that we in India usually tend to brush under the carpet or gloss over. The family is believed to be sacrosanct here, especially if you are disabled they become your support system. Shivani tells us about the issues between her father and her helper about how to take best care of her that made her wish to get out of the protective umbrella of the family. She achieved this when she got a job as a peer counsellor at the Indian Spinal Injuries Centre (where she herself was treated) and she started living on the premises to avoid travelling from home to the centre on a daily basis. The space provided to her was far from comfortable,





NO LOOKING BACK Shivani Gupta Rupa Publications India Rs 295 | PP 272





Paresh Palicha

but, with dogged determination she survived there until she got an apartment of her own in the vicinity. There are more nuggets from her day to day life that endorse her determined outlook and her wish to make everything she went through worth its while.

The other thing that strikes you about Shivani is the audacity with which she talks about her relationship with Vikas, an occupational therapist whom she had met at her place of work. He was a much younger man, full of life and passion for his work. He saw a hero in her and their relationship developed into something that would be a taboo even in this day and age. They got romantically involved and their courtship continued for many years before his parents agreed to their marriage. In between, they did many interesting things like learning about accessibility and inclusion in foreign lands. Most importantly, they launched an accessibility consultancy and thus "AccessAbility", an audit firm (not a NGO), became pioneering thing in India.

But, as luck would have it Vikas lost his life just a few months after their marriage, in a car accident. And, this book is Shivani's tribute to him. In a way, writing this book helped her to come to terms with her loss. A word of caution to the people who read books to experience the flourish of language, this book is not for you as it is plain, simple and to the point.

As the final words, we can say that the book "No Looking Back" is more about the Art of Bouncing Back.

# Out of my mind



**Mallika** Velamuri

"Never in my life have I had a teacher tell me to be quiet because I was talking to somebody in class! It was the best feeling in the world! I felt like the rest of the kids!"

~ Melody

This was the phrase that struck me the most in the book "Out of My Mind" by Sharon Draper. The book, written in first person, chronicles the thoughts, anguish, confusion and struggles of 11 year-old Melody, who has cerebral palsy. She has a photographic memory and is very intelligent. However, she is always placed in the special education class because all of her teachers and doctors have labelled

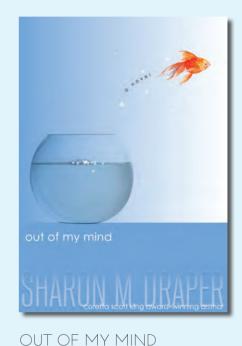
her as "retarded". But they don't understand that just because she could not speak or move, it did not mean she did not have a fully functioning mind. She understands things well, but is never able to show it. One of my other favourite quotes from the book is "It affects my body, not my mind." And I don't think there is any better representation of what a teenager in Melody's emotional and physical condition feels.

As a teenager, it brought to my mind that just because someone has a disability doesn't mean that they don't have the same emotions as any other teenager. She cares about having friends and how she looks and music and TV shows and everything else that all teenagers care about, disability or not. Just because other people didn't take the time to communicate with her, doesn't mean that she did not have anything to communicate.

Another of my favourite parts of the book, would have to be when Melody wants to try out for the Quiz Bowl team and in the preliminary round everyone is shocked to see her in the room, ready to take the test, and she gets one of the highest grades. My least favourite part however, comes right after that, when her teacher says "If Melody can get 100 % then the test is too easy, right?" because even after she studies and proves that she is a very bright student, people still don't give her the chance.

This book affected me in a big way. Melody has a teaching intern come and help her out at school called Catherine. I like the way she isn't condescending towards Melody and talks to her as a person rather than an incapable child. I realised how much someone like Catherine could help kids like Melody and make them feel confident and intelligent. Catherine could really make a difference in many people's lives and when I grow up I would like to do the kind of work that Catherine does.

It is a beautifully written book and I would recommend this to both students and adults for a broader perspective of the world we live in and the different kinds of people who live in it.



Sharon M Draper
Publisher SIMON & SCHUSTER
Rs 566 | PP 295



# ...visually yours!



Sannah Gulamani

Travelling has always been one of the loves of my life, and recently I was lucky enough to have the opportunity to travel around Nepal with a lovely friend. As much as there are hidden treasures in the UK that are waiting to be explored, the feeling of travelling abroad to absorb the culture and language of a foreign country is an experience that can never be matched. Travelling and learning about the world and socio-politics is not only incredibly enriching, but also an opportunity to reflect and continue to learn about one's self. People might assume that travelling would pose a threat for me as I am deaf, however I find it liberating. I had three unmapped weeks ahead of me: a week alone at a yoga retreat, and then relaxing, learning, chatting and trekking with a friend.

In most countries that I visit, although ▲ I find that access can be quite inadequate compared to British standards, I rarely feel like a foreigner. I have a good explanation for this. Although I am fluent in both British Sign Language (BSL) and spoken English, my first language is not English.

When I was diagnosed as deaf at 5, I did not have any English language development and this delayed the process of learning the language. However, BSL is neither dependant nor strongly related to spoken English. It has its own syntax and grammatical structure. Therefore, when visiting non-English speaking countries, or countries where English is the second language, I feel more of a connection to the people. There is more patience and respect between two individuals speaking different languages and often, gestures and use of visual aids are the main elements of communicating. I find that I can naturally build up a conversation and banter with the locals and, language is, generally, not a barrier, which really brings out the heart of travelling. Not being able to hear the unwanted calls of attention and the constant bother of haggling and selling at markets can prove to be a big advantage!

We planned the whole trip to Nepal online, including flights and initial meetings points.



I organised my stay at a yoga retreat which consisted of following a strict routine, waking up at 6:30am, going to sleep at 9pm and staying in a tent for 5 nights. The retreat was situated a few miles outside the city centre. However, with my experience of uneven, narrow, winding roads in developing countries, I knew it wasn't going to be a quick journey!

Upon my arrival, I was immediately blown away by the serenity of the place, and also by the fact that it was pitch black and no source of lighting was available. A wave of panic crossed over me; how would I communicate with people and understand the protocols? It was then that I was first introduced to Nepal's regular power shedding (blackouts).

Electric power in Nepal can be scarce and frequent blackouts occur for long periods of time. This was one of the hardest things I had to adapt to when travelling in Nepal. Light is an incredibly vital source for deaf people due to the fact that we communicate visually , whether it is through lip-reading or sign language, and without this, a common phrase stated by many deaf people is that they are faced with 'two disabilities': not being able to see and take in visual communication and not being able to hear. Candles were often used as a replacement for light, but this alone is not enough. I was really thankful to my yoga teacher, who, during his daily health talk, offered to write up everything that was spoken, on the board. The tricky bit was reading in the dark during our meditation talks in the evenings, but it was the best that could be done in that situation and it made the yoga retreat experience a lot more enjoyable.

Despite unfortunate this one circumstance, I felt fully relaxed and invigorated after a week of daily meditation, which included yoga practices and methods that were very traditional and which I had never experienced before. Within the physical yoga itself, the sessions were very focused on physical strength and relaxation on all parts of the body, especially around the face. Some exercises consisted of rotating eyes, pranayama (nose) through breathing in and out, physical movements of the abdomen and chest and so on.

In our meditation session, with scarce electricity, we had to do exercises focusing on a candle or a chosen point in the room. There was also physical chanting through using repetitive mantras, focusing on the clarity of our voice and volume of projection. One bizarre encounter I experienced was a morning routine of cleansing the sinuses which involves a teapot of warm water, tipping your head sideways, inserting the tip through one nostril and allowing the excess water to come out through the other.

After a few days of doing this, I noticed the benefits, and for the rest of the day I felt refreshed and cleansed. Whether or not I will take on this method and apply it to my daily life in England, remains to be seen!

The day of departure arrived and I moved on to Thamel, the touristy area of Kathmandu where I had arranged to meet my friend at our hostel. It was bliss to be back in a bed after a week in a tent and I eagerly waited for her to show up. It was only after several hours and several cups of masala tea, that I found out that her flight was badly delayed. As night set in, I sat in the hotel lobby, conversing with the locals and trying to arrange a



NEPAL



PRAYERS



KATHMANDU

taxi to pick her up, logging in and out of wireless for updates and mingling with the hotel staff. At one point I was even asked to man the reception desk! After a few hours of waiting at the airport, I finally greeted my friend Ellie after almost a year!

Both of us found Kathmandu completely overwhelming, with the flooded narrow streets of tourists, market stalls, peddle rickshaws and ancient temples. We attempted a city tour, guided by the Lonely Planet but eventually gave up and settled for a roof top terrace restaurant and huge plates of biryani!

On our adventures, we met a few deaf people, one of whom was a man I used to go to school with. I had been told that there was a large deaf community

in Kathmandu, and this was confirmed by a local deaf person we met on a bus journey, who got involved in our conversation on seeing us signing. He told us there were deaf clubs in and around Kathmandu. Hungry for communication, which he probably lacks in his own country, he was happy to meet us and stayed by our side for the next few hours. Although we are both deaf, we had communication problems as I am no expert in Nepalese sign language and he could not understand British Sign Language. We communicated using a mix of both with the help of some International Sign Language (mainly used for finger-spelling certain things) as well as general gestures. We actually managed to have a decent conversation.

My travel partner, Ellie, who is not deaf, began to notice the importance of visual communication, which was made difficult when we were forced to walk in single file to avoid traffic, and distracted by the



BIRIYANI!



ME & ELEANOR



EVEREST FLIGHT



MT EVEREST

honks, market cries and incessant. selling that was thrust at us... we decided to take to the mountains for some peace and quiet!

The next morning, a little blurry-eyed, we reached the top of Mt. Everest! All right, we took a plane, with a load of other tourists... but we still made

it up! This was the Everest flight pass which took us right along the mountain range with the most fantastic views of the snow covered, icv blue mountains with nothing but clear skies above and sparse land below. We got a taste of the mountains and wanted to take part in Nepal's famous trekking routes. We headed out to Kathmandu Valley the next morning, to undertake what our guide assured us was an 'easy' trek.

We started off with walking up some steps. What starting off as an exciting trek soon became a monotonous journey when we realized that the entire day's trek consisted of walking up those steps! Our poor guide had to deal with me constantly asking "are

we almost there yet?" and "how many more steps to go?" The trek as a whole was an amazing experience. We were in the heart of the Kathmandu Valley, walking through local villages and observing their everyday routines of farming, maintaining crops and collecting water for cooking. Often we would see elderly men and women as well as very young children, collecting their resources

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in a woven basket, placed on top of their heads and walking along a steep hill. Other groups who were doing longer treks had porters who carried an average of perhaps 25kg each. It was then that I realized that with the small backpack that I was carrying and frequent gulps of water, I couldn't complain!

We were fortunate that while we were trekking, it was also the Holi Festival (a Hindu religious festival of colours), so we had the opportunity to see this colourful display amongst the valleys of Nepal. We were also greeted by stunning views of the Himalayas, in particular the Annapurna region; carefully perfected arch shaped snowcapped mountains with sparkling glints reflected from the sun.

However, being deaf and travelling is not easy. I have experienced some unfortunate incidents being deaf is a risk to my own safety. I always make sure that I'm surrounded by people I know, especially to aid with communication, during those times. For example, in Nepal we were caught up in a protest that involved rioting between the police and the local community. We were meant to arrive at our destination at 2pm, but were held up on the mountain roads for 7 hours. Words and conversations were being flung about everywhere, and among all the chaos it was difficult to keep up with what was going on. decided to be assertive and approached people to ask what was happening; my travelling partner Ellie did a wonderful job of telling me what



VILLAGE DURING HOLI



VISITING TIBETAN REFUGEE SETTLEMENT



TIBETAN CARPET WEAVING

was going on. We were asked to get off the bus and walk a mile or so through the riots to another bus. It was getting dark, and although it was quite scary, the one thing that I was scared of, was being shut off from communication altogether. I didn't want to be left in a position where I was unable to fend for myself or access anything.

Eventually, through an exhilarating mountain bus ride in the dark, we made it to our destination in one piece! We were quite far from the town itself and at this point we were bombarded with hotel owners offering us rooms for the night. As it was pitch black, it was virtually impossible for me to negotiate or communicate any deals, so Ellie took on this job. Looking back now, I laugh at this situation and it will always be one of my exciting travel stories to tell, but on a serious note, it made me realise how much I rely on communication when situations like these occur.

Being deaf will never stop me from travelling. As they say, the loss of one sense is compensated by the heightened development of another; in my case my sight is often heightened due to my loss of hearing so I am able to appreciate the beauty that the world has to offer. And for that, I am thankful.

## JET STREAMS, SPONTANEITY, & THE PERFECT SPOT



Salil Chaturvedi

in a silver-foil sea a gateway to heaven 'no, it looks like a white smiling shark!' it doesn't really matteryou are always at the perfect spot

friend was staying over with us for a few days, and somewhere early along the way, it was decided that we would do things spontaneously. Spontaneity reminds me of combustibility. Anyway, we made sure that we made no plans.

As a result we 'found' ourselves at various places... beside a lake, spending time watching a slim Tamil lady picking white flowers which had fallen from a tree. She collected a large handful and then smelt them in her palm and went into the tourist bus she had come in and put them in it.

Then, because of some delay in a restaurant, we found ourselves watching a full moon coming up over a river and a little later, also by chance, saw it rising over a hill with no other soul in sight. We watched the outlines of trees on the ridgeline as the moon bathed everything in its light. (white is the light of the night).

One evening, we just landed up at a beach and saw the jet streams power their way over Goa. We happened to be on a beach that had thousands of seagulls. The highlight of the evening was to see a mammoth flock of seagulls rise up together, as if in answer to a mysterious call, and form this enormous circle, whipping the wind into a vortex. It was a wide circle of seagulls that narrowed out on top. The spontaneous dance (or ritual) lasted for about fifteen minutes and abruptly came to a stop.

'Will it rain?' I was asked, since I am prone to making weather predictions at the slightest hint of cirrus clouds. 'I'd say a ten percent chance,' I said nonchalantly. It rained late at night for precisely thirty seconds, but that sealed my reputation alright.

Somewhere during all that spontaneous bumbling, (I think during a late night drive on the up-and-down -left-and-right roads of Goa) all three of us agreed that when you are spontaneous, you are always at the perfect spot.



Looking Beyond Disabilities & Breaking Barriers Together

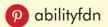
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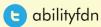
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