Success & ABILITY

India's Cross-disability Magazine

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EQUITABLE EMPLOYMENT OPPORTUNITIES:

Emerging trends

CavinKare

16 வகை
அனைத்தும் சிறந்த சுவை

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

Contents

Vol 17 No 1

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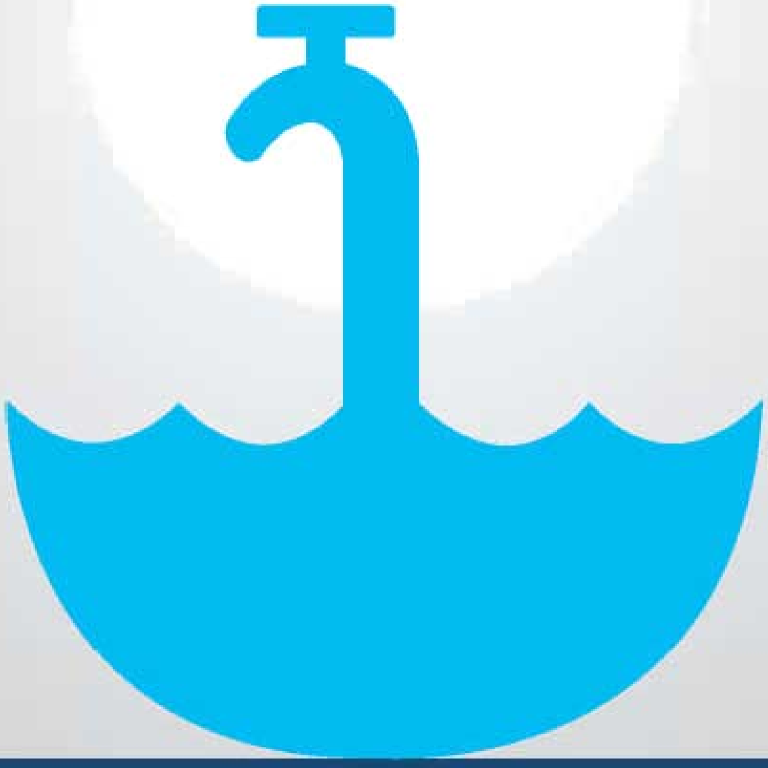

From The Editor's Desk

Friends,

Rahul Cherian. Lawyer, co-founder 'Inclusive Planet Centre for Disability and Policy'. Policy activist in disability law. The man who'd taken India's disability sector in entirety under his ambit, harnessing everyone to work collectively towards inclusive policy for all persons with disabilities, in all areas. Alive & vibrant. I now stare at the torrent of blogs, messages, poems, articles, commentaries that flooded my inbox, in honour of Rahul. Driving in the painful realisation that he is no longer alive. At age 39! In a matter of just a few days! And I had met him just the week before! What a huge impact he had made in people's lives! How beautifully so many people had captured in their writing, the essence of what he had meant to them. Why had I been unable to do likewise? Why had I choked over words every time I tried? I did try, believe me... but all I could see was that nonchalant, laid-back smile of his, every time he sat opposite to me across my office table and the incessant number of smileys he'd send every time we chatted online. The sheer unfairness of it all... the mute anger at the powers that be... the disbelief that something like this could really happen... that he who had grown to become the most sought after figure for the entire country's disability sector in so short a time, had been abruptly snatched away from us... yes, the unfairness of it all... the anger and the pain silenced me every time I tried. I am still trying to make sense of it all and really, truly failing in the attempt. He used to tell everybody that I was the first person he'd met in the disability sector when he decided to make his foray into it. Alongside here we reproduce the article he wrote for us, way back in 2002, which is still relevant today. *To live in the hearts of those you leave behind, is not to die* goes the popular adage... we therefore derive comfort that Rahul lives on amongst us, perhaps prodding us on, from wherever he is, with that same nonchalant smile of his, to learn the lessons he taught us... veritable wise lessons from young shoulders.

What is the magical ingredient that can wipe out unemployment and underemployment among disabled persons? What can help? This was a question put to me by a journalist friend recently. Well, I do sincerely believe that this 'magical ingredient' has already begun to make its presence felt. Slowly, but surely. We have attempted to bring out this flavour of this important ingredient in our cover feature in this issue – the 'was', the 'is' and the 'ought to be' of equal opportunity employment – for you to comment upon and as always, wait for you to give us your valuable responses.

Jayshree Raveendran
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LAW?

Rahul Cherian's first article for Success & ABILITY, published in the Jan-March 2002 issue

Law? Surely this is a strange topic for an article. But to me, it conveys everything. It clearly shows the mysticism that is associated with the legal institution. The frustration faced by all and sundry when dealing with courts and elaborate legal procedures, the "oh-come-off-it-no-law-is-so-unfair" expression on people's faces when they are at the receiving end of the legal machinery, and the feeling I sometimes get when I reflect my own choice of career. In this article I have tried to give the reader a bird's eye view of how 'law' is made and also some information that the reader may (hopefully) find interesting.

In India, law draws its 'inspiration' from the Constitution, the document that, 'We the people of India' have given ourselves. The Constitution some say, is the bones and marrow to which the Legislative, Executive and Judicial arms of the State add flesh and skin to finally make 'living law'. In essence, the Legislative, based on the guiding principles laid down in the Constitution, enacts or passes an Act.

To give you an idea of how this process works: the Constitution requires that the State (a 'technical' term used to denote all bodies and authorities making up the government) must treat all persons as equal under law and to provide equal opportunity for public employment to all citizens. Based on this constitutional objective, parliament enacted the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act in 1996. The objectives of this Act include the creation of a barrier free environment for persons with disabilities and the making of special provisions for the integration of persons with disabilities into the social mainstream. This Act requires the Union of India to appoint a Chief Commissioner and various committees to ensure that the objectives of the Act are fulfilled. The Executive then makes rules and procedures as to how the Act is to be actually implemented on ground zero. Lastly, the Judiciary interprets the Act and rules with respect to questions as to whether the obligations of the government under the Act are fulfilled and as to whether the Act is in accordance with constitutional objectives.

One of the most fascinating and consequently, frustrating, characteristics of law is that interpretation is king, The entire essence of a law hinges on its interpretation. The framers of a law while legislating (the process of framing a law) have to keep in mind the various permutations and combinations that a particular sentence or expression could entail, and the attempt should be to minimise ambiguity in the framed law. While the advocates on both sides interpret the law in favour of their client's case, the final interpretation is left to the Judiciary. Great weightage is given to judicial precedents (judgments laid down in the past) in trying to understand what law is applicable to a particular matter and what interpretation should be adopted. Some of the most important laws have evolved through the various judgments laid down by the courts over the ages. This body of law, termed 'Common Law' is essentially uncodified, (law which is not made by Legislature) and is based on common practices that have existed and evolved over the time.

The new modes in which business is conducted today (over the internet and otherwise), has led to the requirement of lawyers who can think out-of-the-box and who can apply existing law to the peculiarities of a situation that never existed before. A good example of this would be in the ability to determine whether the existing law relating to contracts is applicable to the contracts made in cyber world, such as over email or on websites, such as amazon.com This I believe, is the most exciting part of law since you are in a sense creating your own law and testing it to see whether your application of law will stand up in court.

Lawyers are knows to use jargon and also for rambling on endlessly. I am not about to argue on this matter either way, so let me conclude by saying "Res Ipsa Loquiter" – "the facts speak for themselves!!"

CREATING CHAMPS - RIPPLES Chennai 2012,

The National Swimming Competition for Persons with Disabilities

There comes a prompt "Hi!" from Moin Junnedi, the youngest swimmer with a locomotive disability to have clinched five gold medals and one silver at the 12th National Paralympic Swimming and Water Polo Championships held at the SDAT Aquatic Stadium, Chennai from 7th-9th December. Moin, the 13-year-old 'wonder boy', from Belgaum, with over 100 fractures in his body has mastered freestyle, backstroke, butterfly and breast stroke. For his part, Moin has already started dreaming big – to represent his country at the International Paralympic swimming competitions.

Nearly 350 swimmers from 18 states with various disabilities participated in almost 150 water events titled 'Ripples 2012', which was hosted by the Paralympic Swimming Association of Tamil Nadu (PSATN) under the aegis of the Paralympic Swimming Association of India. There were nearly 75 participants from Maharashtra, 60 from West Bengal, 19 from Karnataka and a substantial amount from other parts of India. The championships were held in three categories: seniors (19 years & above), juniors (15-18 years), and sub-juniors (below 15 years). The swimmers were classified into seven disability classes: S1 to S5, SD — locomotive (physical impairment such as polio, amputation, Down's syndrome, Cerebral Palsy); S11- visually impaired (partially and fully).

West Bengal bagged the overall championship with Maharashtra in the second position. "The reason behind taking up such an event in Chennai was to create awareness among the people here about the importance of sports in the lives of people with disabilities and also to bring the attention of government and society towards the importance of sports in the lives of people who are disabled", says Madhavi Latha, General Secretary, PSATN. With a considerable increase in the rate of women participants this time, Madhavi points out that the current national paralympic swimming meet could succeed to a great extent in this direction.

MUSIC KNOWS NO BOUNDARIES

The Skoog – a tactile cube-shaped instrument, when connected to a computer, produces the sound of over 1,000 traditional instruments. Invented by Dr. Ben Schögler and Dr. David Skulina, the Skoog is played by touch, from the slightest tap to a firm press of one of its brightly coloured buttons. Dynamic sensors react to movement and create a personal experience for each musician, using any part of the body to interact with the instrument and produce sound. This interactive

courtesy of Skoogmusic.com

instrument makes not just playing but also composing music viable for those with low mobility, intellectual and developmental disabilities.

From its birthplace in Scotland, the Skoog has now reached the homeland of Carnatic and Hindustani music, with two Skoogs currently in the country. It was in Vidya Sagar, a Chennai-based organisation working with children and adults with cerebral palsy and other neurological diseases, that the first live performance of the Skoog took place.

'The Elements', a composition created solely by the students at Vidya Sagar, marked the end of a seven day music workshop with 'The Opera Circus', a UK based classical music group facilitating musical therapy workshops for children with disabilities. Opened by Professor Nigel Owen, composer, inventor and specialist in neuroscience and music, the students took us through a beautiful composition of earth, water, fire, air and aether using the sounds of the Skoog. By tapping, squeezing and pressing on the Skoog, each performed their composition, varying the instrument and pitch depending on the way it was touched. Percussion instruments, soft vocals and atmospheric lighting created a melodic fusion of classical Indian music with western influences.

This inclusive instrument has proven results in improving communication, coordination and creativity as well as developing motor skills amongst those with a variety of disabilities. "Children who are completely non-verbal have started using musical communication", said Priyanka Devani, trombone and piano musician and member of The Opera Circus, catching her breath after the performance. The team has noted that the structure of a piece of music: a calm start, a building crescendo, falling to an end of absolute silence, has a calming effect on the body whilst aiding concentration and sparking new ways of self-expression.

Witnessing the positive effect that alternative forms of music has had on the children at Vidya Sagar, Professor Osbourne and his team hopes that the introduction of the Skoog as a way to learn and compose music, will support the sustainable use of musical therapy for those with intellectual disabilities, including autism and Down's syndrome. "I can't think of anywhere with more potential to take this forward than here", Osbourne told the audience, including the Disability Commissioner and NGO representatives, referring to the emotionally rich ragas that make Indian music so apt for music therapy.

MIND-CONTROLLED ROBOTIC ARM A TURNING POINT FOR QUADRIPLEGIA

The prosthetic arm, designed by the John Hopkins University's Applied Physics Laboratory (JHU/APL) and funded by the U.S. Department of Defense's Defense Advanced Research Projects Agency (DARPA). Photo credit: DARPA and JHU/APL.

A team of researchers from the University of Pittsburgh School of Medicine and UPMC have successfully trialed a human-like robot arm, which can be controlled by the mind to perform motions of everyday life. Designed for persons with quadriplegia, the robotic arm is seven dimensional and was tested by Jan Scheuermann, who used brain-computer interface (BCI) technology and training programmes to move her arm, turn and bend her wrist, and close her hand for the first time in nine years.

"This is a spectacular leap toward greater function and independence for people who are unable to move their own arms," said senior investigator Andrew B. Schwartz. "This technology, which interprets brain signals to guide a robot arm, has enormous potential that we are continuing to explore. Our study has shown us that it is technically feasible to restore ability; the participants have told us that BCI gives them hope for the future."

It was in 1998 that Scheuermann was diagnosed with spinocerebellar degeneration, which causes the connections between the brain and muscles to slowly deteriorate. "Now I can't move my arms and legs at all. I can't even shrug my shoulders", she said.

After screening tests to confirm that she was eligible for the study, two quarter-inch square electrode grids with 96 tiny contact points were each placed in the regions of Scheuermann's brain that would normally control right arm and hand movement.

Two days after the operation, the two terminals that protruded from Scheuermann's skull were hooked up to the computer. "We could actually see the neurons fire on the computer screen when she thought about closing her hand," Jennifer Collinger, assistant professor, Department of Physical Medicine and Rehabilitation said. "When she stopped, they stopped firing. So we thought, 'This is really going to work.'"

Within a week, Scheuermann could reach in and out, left and right, and up and down with the arm, giving her three dimensional control. Before three months had passed, she also could flex the wrist back and forth, move it from side to side and rotate it clockwise and counter-clockwise, as well as gripping objects, adding up to what scientists call 7D control.

The successful results of the trial hold exciting possibilities for the future, explained senior investigator Dr. Michael Boninger, "As this technology progresses it could readily have applications related to walking and therefore be applicable to people with paraplegia. Understanding brain signals related movement can have application in a number of neurologic disorders."

Boninger predicts that in the next 5 to 10 years the BCI technology will be actively used by persons with disabilities. "As this technology progresses it could readily have applications related to walking and therefore be applicable to people with paraplegia. Understanding brain signals related movement can have application in a number of neurologic disorders," he said. "For this to happen we need continued funding and continued volunteers like Jan."

TREATY FOR THE BLIND TO CONCLUDE IN 2013

After four years of negotiations, 2013 is set to be the year that a treaty to import and export accessible books for the visually impaired will be passed, opening up inclusive works worldwide.

According to the World Health Organization, there are more than 314 million blind and visually impaired persons in the world, 90 per cent of whom live in developing countries and the largest percent of which live in India. At present, international copyright law prevents making accessible copies of books and sending them to other countries which speak the same language. Although the Berne Convention, the first international copyright treaty, includes exemptions in copyright law (short quotations, news reporting and illustrative use for teaching purposes), it has generally been left to national governments to set their regulations.

In 2006 the World Intellectual Property Organisation (WIPO), discovered in a survey that fewer than 60 countries make special provisions for persons with visual impairments, including publication in Braille, large print of digital audio versions of texts. On 18th December, 2012 the WIPO General Assembly took the decision to hold a diplomatic conference in Morocco in June 2013, to complete the negotiations and improve access to texts for those with visual impairments worldwide. The late Rahul Cherian, who headed the Inclusive Planet Centre for Disability Law and Policy, and helped draft the treaty had commented: "This is an incredible development, and after a four year struggle we are looking forward to the treaty being concluded next year. This Treaty will revolutionise access to reading materials for persons with print disabilities around the world and we in India will hugely benefit from being able to import books in accessible formats from countries with large libraries such as the United Kingdom and the United States."

Currently around 1-7% of accessible books are produced by small charities, whilst less than 1% of books are published as accessible in developing countries. The passing of this treaty would change all this, opening up libraries with accessible texts to persons with visual impairments to access books in all the signatory countries.

US DISABILITY ADVOCATE AWARDED TOP HONORS

RICHARD ECKE

Susan Gjolmesli poses with her third Seeing Eye dog, 11-year-old Inez, a flat-coated golden retriever. "We're a team," she said. "I wouldn't be nearly as independent without her." / Courtesy of The Seeing Eye.

In 1966, the unemployment rate for disabled Americans, was higher than 70 percent.

Nearly a half-century later, the jobless rate for disabled people today is "a little better" at 67 percent, said Susan Moe Gjolmesli, longtime director of the Belluvue College Disability Resource Center in Bellevue, Wash. However, that's still two out of every three disabled job seekers who cannot find work.

"They're like everybody else; they want to get a job and pay taxes," the former Great Falls, Montana, woman said in an interview.

Gjolmesli said she could not get a classroom teaching job herself in the 1980s because of poor eyesight, and she has a friend, a talented violinist and math teacher, who applied for jobs to teach in public schools but was turned down because of severely impaired eyesight.

"He's really talented," she said. He makes a living teaching music privately, but she said employers often assume blind people cannot teach or maintain control of a class.

"It is frustrating," Gjolmesli said.

Gjolmesli herself has held a variety of jobs over the years, the last 18 at Bellevue College, where she advocates for the disabled, combining a firm resolve with a blistering typing speed of 90 words per minute. She uses computer software that reads back the words to her so she can edit her documents.

At age 64, Gjolmelsi continues to make history.

In Great Falls, she took part in the historic first graduation ceremonies for C.M. Russell High School.

Back then, Gjolmesli could still see well enough to recognise her friends and relatives. Since she had a hereditary, degenerative eye disorder called retinitis pigmentosa, her eyesight became progressively worse and she lost her remaining residual sight about a decade ago, following a severe bout with influenza.

Higher education for her was part of a plan.

"My grandfather insisted that I was going to college," she said.

A graduate of Gonzaga University in Spokane in 1970, Gjolmelsi recently received the highest award a disabled person can gain from the state of Washington, the Governor's Trophy in Memory of Carolyn Blair Brown. "It's a big honor," Gjolmesli said. "This is really the granddaddy (of awards) a citizen with a disability can receive in the state of Washington."

Her trophy is part of the Governor's Employer Awards Program, although most of the awards go to employers. This award goes directly to Gjolmesli, described in a Washington state news release as "a bold, fierce advocate who can articulate current research and represent the disability community with grace and poise."

Gjolmesli, who argues that people with disabilities provide the country with a welcome diversity, has plenty of admirers.

"Susan has simply refused to see herself or any of the people for whom she advocates as being unqualified to live a full life," said Michael McDermott, a friend and colleague, in the news release. "It has been this single-minded focus on what each human being has to offer that has made her one of the premier advocates for persons living with differences in the state of Washington."

Recognition Gjolmesli has received over the years includes Nordstrom's Community Leader of the Year award in 1993 and being named a "Living Treasure" at Bellevue College for her work to retain students with disabilities.

Richard Ecke writes a weekly column on city life. Email him at recke@greatfallstribune.com. Follow him on Twitter at @GFTrib_REcke.

This article was originally printed in the Great Falls Tribune

NASA LAUNCHES PROGRAMME TO MENTOR STUDENTS WITH DISABILITIES

NASA mentor John Gagosian and his mentee Jaylen

NASA's Office of Education has partnered with the District of Columbia Public Schools (DCPS) to boost science, technology, engineering and math educational opportunities among high school students with disabilities.

This career-focused Competitive Employment Opportunities Programme connects high school students with disabilities in DCPS, with professional mentors. "Our mission is to ensure that every DCPS student with a disability is able to experience the world of competitive employment, prepared to join the workforce and inspired to strive for excellence", said Raymond Hutchinson, Washington DC Public School Office of Special Education Specialist.

Although the Individuals with Disabilities Education Act, requires school districts in the United States to provide 'transition services that will reasonably enable children to meet their post-secondary goals', "there is a persistent achievement gap that exists between students with disabilities and their non-disabled peers, particularly when it comes to post-secondary outcomes", Raymond says.

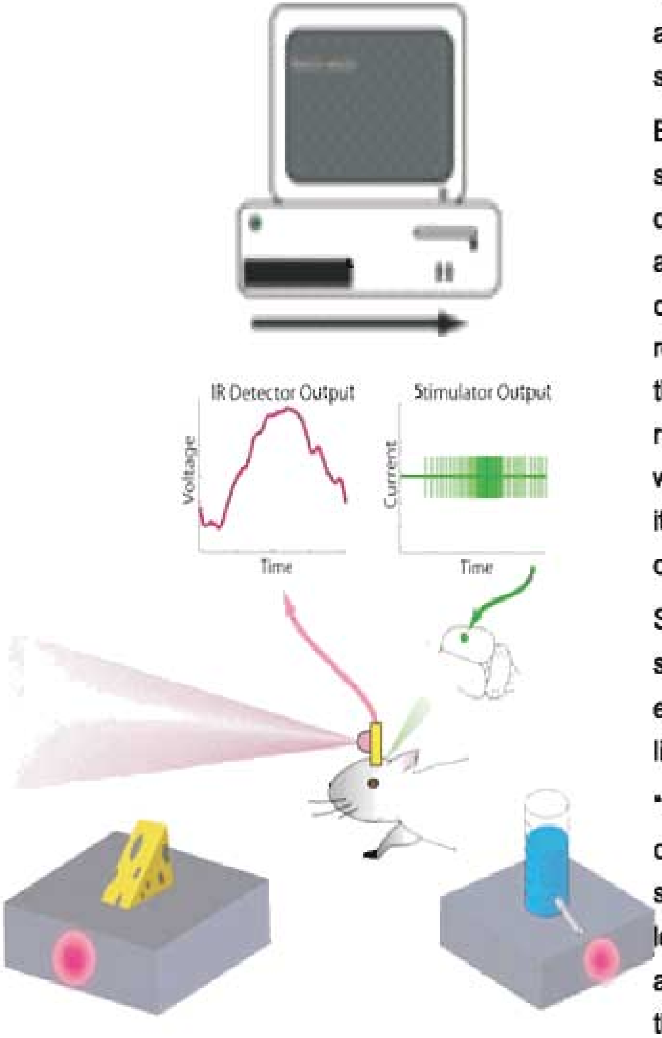
Working to close this gap, the programme is designed to increase confidence in students, the ability to perform soft skills, and result in a higher rate of student employment. Starting in the first half of 2013, roughly 20 students will participate, with hopes to take on more next year.

NASA, leading the world in the study of the solar system, has more than 18,000 employees, including those with disabilities. "NASA hires a wide range of people with different skills, perspectives, and expertise which allows us to build a strong workforce", said Dr. Mamta Patel Nagaraja, Women@NASA Project Manager and Engineer. After meeting with DCPS "it was immediately apparent to NASA that the programme held much promise and was targeting a great group of students", she added.

NASA's Office of Diversity and Equal Opportunity, works to ensure that all employees have an equitable work environment and also provides for reasonable accommodations, stating on its website: 'we must view our commitment to equal employment opportunity as a matter of personal integrity and accountability.'

Dr. Diane Clayton, Program Associate for Valador, a contract company supporting NASA's Office of Education added, "NASA needs professionals with wide ranging areas of expertise in both technical and non-technical fields to do all the incredible things that it does."

ONE STEP CLOSER TO MIND CONTROLLED MOVEMENT



Miguel Nicolelis, a neurobiologist at Duke University in North Carolina has led a research study into the use of sensory neuro prostheses - implanted devices to substitute a motor, cognitive or sensory role that has been damaged.

The study, which was published in the online journal, Nature Communications, examined whether adult rats could learn to distinguish infrared light through the use of a sensory prosthetic device. The researchers implanted microelectrodes in the cortical region of their brains, the area that processes touch information from the animals' facial whiskers.

The results showed that after training with the device, the adult rats acquired a new sense, to 'feel' infrared light and were able to navigate themselves with this new sensory function.

Beyond restoring normal neurological functions, the study suggests that through the use of sensory neuro prostheses, different parts of the brain can be trained to expand beyond a person's natural sensory capabilities, so that the brain's cortex takes over other roles, whilst retaining its original role. "When we recorded signals from the touch cortex of these animals, we found that although the cells had begun responding to infrared light, they continued to respond to whisker touch. It was almost like the cortex was dividing itself evenly so that the neurons could process both types of information", said Nicolelis.

Scientists hope that such findings will contribute to the successful building of an exoskeleton, a body suit that will enable a person who has been paralysed, to move their limbs with their thoughts.

"Expanding sensory abilities could also enable a new type of feedback loop to improve the speed and accuracy of such exoskeletons", said Nicolelis. The Walk Again Project, led by the Duke Center for Neuroengineering, is developing a high performance brain-controlled prosthetic device that they hope will enable persons with orthopedic disabilities to leave the wheelchair behind. The Project has received a $20 million grant from FINEP, a Brazilian research funding agency, to allow the development of the first brain-controlled whole body exoskeleton.

A first demonstration of this technology is expected to happen in the opening game of the 2014 Soccer World Cup in Brazil.

Editor's note: In 'Sencity', published in Success & ABILITY Oct-Dec 2012, the name of the photographer, Tim Leguijt was inadvertenty omitted.

Sign6 Conference –
An international Conference of Sign Language Users

An international conference was co-organised by the Indian Sign Language research and Training Centre [ISLRTC] and the International Institute for Sign Languages and Deaf Studies [ISLanDS]. The Academic partner for the conference was Indira Gandhi National Open University and Ability Foundation supported the event by working as the media partner. The conference venue was Neelams The Grand, Goa. 121 National and 39 International delegates from all over participated in the conference including delegates from Germany, China, Japan, Nepal, Czech Republic, Netherlands, UK, Iran, France, Saudi Arabia, and Prague.

Most of the presentations were made by eminent Deaf professionals in the field of research, linguistics, and Deaf education. Christian Rathmann from Germany and Soya Mori from Japan are well known researchers and had some impressive presentations to share. Some hearing professionals from the field were also present to share their expertise and knowledge.

The conference was a 5 day affair with 2 days for a preconference workshop . This was to prepare the delegates for the signed communication during SIGN6. This included teaching International as well as Indian Sign Language to the delegates .

Discussions took place on: deaf empowerment, the building of a corpus for Indian Sign Language under the Central Institute of Indian Languages, Sign language research ethics, and Deaf Peer Education: using deaf peer tutors to support deaf people with English literature,

The presentations included:

Comparing Japanese Sign Language, Chinese Sign Language and British Sign Language by Keiko Sagara.

How to find a sign in a Sign Language ontology without using written language? by Cedric Moreau and Anee Vanbrugghe.

Age- related sociolinguistic variation in sign languages, with particular reference to Nepali Sign Language by Upendra Khanal.

How far can developments in online sign language learning and teaching resources support sign language education and interpreting in isolated areas? By Linda Day & Tessa Padden, Director Signworld.

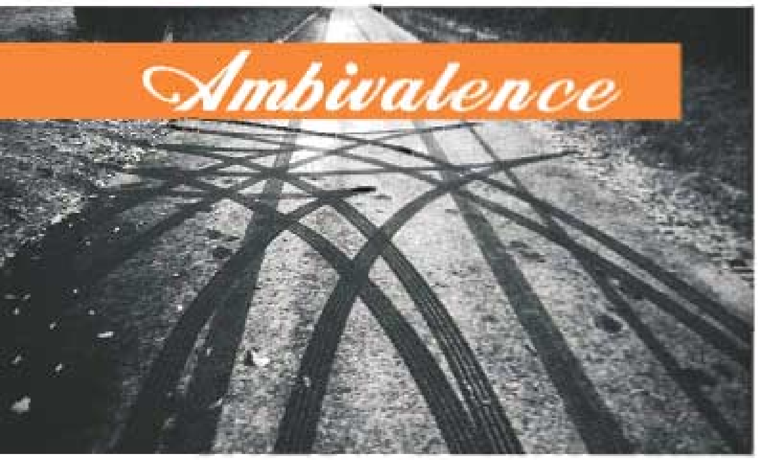
Processes of Deaf Empowerment and Deafhood in Mumbai and India by Sujit Sahasrabudhe.

Code switching in bilingual deaf signers using Burundi Sign Language and Indian Sign Language by Charles Njejimana, Sibaji Panda & Ulrike Zeshan.

This kind of conference is a new experience in India. The greatest benefit is exposure about deafness and sign language to the general public. People around were puzzled at all the waving hands and deaf people in one place. Seeing deaf people from many other countries also was enlightening.

Ms. Atiya Hajee & Ms Merrin George
ISLRTC / BAASLS
IGNOU

Stanzas



Ambivalence

SRIVIDYA SURYANARAYANAN

Stolen moments taken from life
Shaped in two state of ambivalence
While both exists side by side
Causing thoughts to churn and mix
Grief stricken in ambivalent stance
Spanned the divergent feelings.

Heart, a human vital of emotions
Seeks two opposing state
As love and hate at once gain
Entry within the boundless heart
Thoughts churn and mix
In a torrential fix.

Two decision stands affront
When both direction valid sound
Expectation towards both of them bent
To form the mutual round
Thoughts churn and mix
In a torrential fix.

Like a precious stone
Values added to the bones
Firming in beliefs contrary
Takes side of the opposing values
Thoughts churn and mix
In a torrential fix.

Philanthropic hands shake in tremor
To sign checks in favour
Of causes divergent types
Seeking attention eternally
Thoughts churn and mix
In a torrential fix.

Ambivalent moment molten found
Making thoughts to churn and mix
Ambling in the stolen ground
Two stark sides burn to fix
When in balance most unsound
All decision in uncertainty bound.

Brand Blackholes

In the whirl of brands
Ad films made grand
Displaying products' virtues
Hiding the vice from view

Engulfed within this blackhole
Of attractive offers for soul
Eager to be encaptured
Within a state of rapture

Stark reality covered in illusion
Creating imaginary feel good vision
To box of mesmerisation pricked
The mind of sleeping public tricked.

Pricked into illusion of vision
The public dwell in reason
Broadcast by brand owners
Replaced by visual lies sooner.

Adverted thoughts speak
Of hidden human desire peaks
When the magicians make
Visual for commercial sake.

Cast in a cask so old
Reeking of authenticity cold
Rules the brand Blackholes
Grabbing audience's souls.

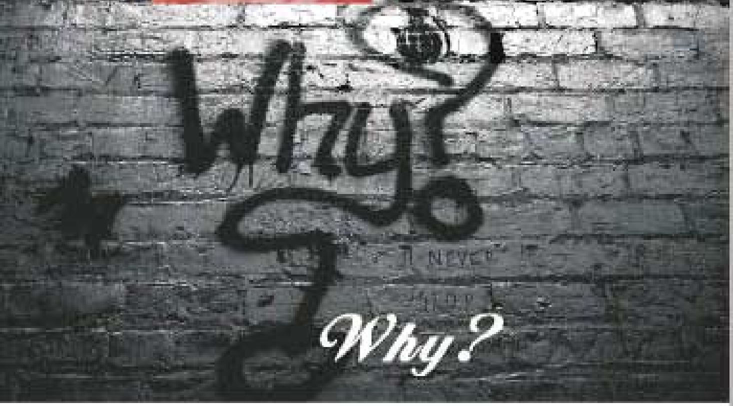
Brand that I sport makes me
A kind of person the world sees,
Making waves in false illusion
Carries the mind in delusion.

Engulfed in the brand blackhole
Losing identity and soul
Lives the majority populace
In a mazy entwined lace.

Survival

The cold winter night
Cloaks the environ in white
Twilight moment caught
In moment's splendour
Hunter and the hunted
Chase among the snow
Who is to win
In the survival race
Is yet to be known
Captured in a motion
Of real moments' terror
The rat's eyes shine
In gripped fear
The owl's eyes brighten
In carnivorous pleasure
The scene a gripping action
Caught amidst the vast snow
Anything could happen
The rat caught in claws
Or escaped from the predator
Life in these moments
Speak of unusualness
That surrounds survival
In general sense
My life like the chase
Is cast on uncertain terms
Creaking here and there
Of notions unknown
Wondering all the while
As to where it shall end
In a pleasing note
Or one of distress
While in frozen seconds
The mind wanders
In the labyrinth of pain
Seeking to find solace
In unusual games
While life is just like that.

DR SRUTI MOHAPATRA



Why?

I often wonder
Why do people
look at me with sympathy in their
eyes?
Why do they
subtly make me feel mangled?
Why do my needs, my helplessness
reach to them instantly?
But my laughter makes them cry?
Why my achievements are stared
at or glorified?
Why my wheelchair
arouses more interest than
the small trophy in my hand?
Why my accomplishments fall
far behind
My physical inability,
my imperfections ..?
Why am I not accepted as just one
more human being?
Why am I either glorified or
agonised?

Wanderer

As a wanderer, I forever walk the earth
From today to yesterday to the day before
From memories to musings
From dreams to fantasy
Drifting in light and shadow
I keep searching
I walk upon endless stretches of time
I look up to the sky and envision happiness
Gazing at the rainbow above
The agony relieved
I am a nomad, wanderer
In a world that was built from love ..

Reflections of the Setting Sun

Reflections of the setting sun
Playing over slick tinted glass
The orange hue shivers
As the rippling waves pass
The coconut trees sway
In the bosom of the water and wait
For the twinkling stars to
Arrive and shine till late
Sitting in my room
Looking across the window
I see the changing colours of a day
On the panes of a glass window

It still hurts

A kiss
A hug
Promises galore.
A dream
A world
That was ours alone.
Then you walked
Away from me; us all.
Too far to touch
Too far to call.
You went your way
Off to a new start.
The trauma you left behind
Ripped me apart.
The betrayal
The anguish
The fear, the hurt;
I can still feel you
Tormenting my heart.

Magic in my terrace

It is a place
I call my own
Amidst the crowd
Yet blissfully alone
When you are tired or sad
Or forlorn
Climb up the stairs
And all tension is gone
Watch the clouds
Wafting up there
Or the coconut trees
Swaying in the air
If you want to see
The rising sunGet up early
And it's your own dawn
As enchanting is
The sun getting ready to rest
A kaleidoscopic sky
Emerges on the west
As night sets in
Romance sets in the air
The twinkling stars adding
Magic precious to moments rare


MONOCOLOR
BICOLOR
TRICOLOR
PVC
LEATHERPVC

INCLUSION MATTERS

It seems a very long time ago, 1997 in fact, that Ability Foundation took its first tentative steps into the field of employment of persons with disabilities. Our first job seekers – a group of hearing impaired persons trained by us in basic computer skills and English communication. Our first employers: family and friends! Even then, just two years into our existence, it was clear to us that for an 'inclusive society' to become a reality, employment was critical and that it had to be on equal terms. Elsewhere in the country, there was the now legendary example of the Titan watch plant at Hosur, which hired persons with visual impairment. That apart, the idea of disabled persons and equal opportunity employment, by public perception, appeared to be an incongruous one.

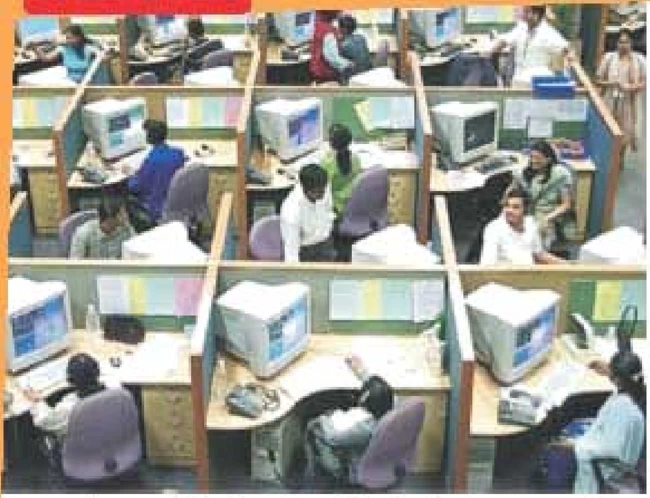
Cut to the year 2004 and the first edition of EmployAbility: the first job opportunities fair for qualified persons with disability. Organised by Ability Foundation, where placement and inclusive employment had been included to its spectrum of other activities much ahead of the times, the Foundation had been realising its vision to train and enable qualified people with disabilities find jobs in various industries. "That event," says Founder & Honorary Executive Director Jayshree Raveendran, "kick-started a journey in the evolution of attitudes of companies towards disabled people who were qualified but had lesser opportunities for interviews and truly opened the eyes of the corporate world. We were really only facilitators... but our intention was, and continues to be, to drive home the initiative of inclusion in the true sense of the word." Ever since, year after year, EmployAbility has been flooded by hundreds of eager job seekers from across the country who had travelled great distances to participate, as did the several recruiting employers. As the Foundation's team visited one prospective employer after another, the initial recurring question was: are there qualified people with disabilities? "This was the attitude that we needed to change. This was the reason for our existence. As resumes poured in however and we were able to meet every company's requirement, we were reassured ourselves! We were on the right track", adds Jayshree.

> While it's heartening to see the corporate sector wake up to the potential of hiring persons with disability in their respective companies. India still needs to face many challenges before we can boast of the country as being 'inclusive' in its approach.

Over the succeeding years and seven editions of EmployAbility later, the last – at Hyderabad in 2012 – there were remarkable and perceptible changes that occurred. Several organisations across the country are now set up to be actively engaged in promoting and facilitating training and employment for persons with disabilities. Aspiring job seekers from across the country are now presenting themselves more confidently, so too, are employers representing virtually every segment of industry aware and are willing to take this forward. Diversity and inclusion are today, the flavours of the season, and qualified, competent people with disabilities are keenly sought out by employers everywhere.

While it's heartening to see the corporate sector wake up to the potential of hiring persons with disability in their respective companies, India still needs to face many challenges before we can boast of the country as being 'inclusive' in its approach.

Sensitising employers to look at hiring people with disabilities as a human resource initiative, and not as part of corporate social responsibility, has been necessary to ensure a rights view rather than a charity view of disability. Convincing employers that it makes business sense to hire people with disabilities has been an important factor in ensuring



employment. On the other side of the fence, ensuring a steady supply of trained persons with disabilities, ready, confident and skilled to take on mainstream work, has presented a continuing challenge.

Aiding the growth and driving the path for inclusion in professional sectors, Ability Foundation's career wing, for instance, works towards promoting equitable employment opportunities for persons with disabilities with end-to-end solutions for companies and organisations. What's more, the employment wing looks at educating and sensitising the companies in not just hiring but also what to expect from persons with disabilities who are equally qualified, hard-working and talented.

Across the country, there are today a handful of organisations and groups, busy acting as facilitators, creating awareness on the potential of people with disabilities and simultaneously, empowering disabled persons themselves, to a greater extent, to meet the growing, albeit measured demand.

In April 2010, just as summer was arriving in Bangalore, Suresh Reddy walked into Wipro's campus at Electronic City. His supervisor was at the gate to receive him and the HR in-charge was both well-prepared and willing to take Suresh through the formalities associated with joining an organisation. That evening, Suresh went home with a sense of fulfilment, "I was not only happy that I had made it to Wipro (Technologies) as an instructional designer but more importantly, I felt, finally, here was an organisation that seemed aware and ready to handle a person with a lesser capacity", Suresh says. At Wipro, Suresh not only scaled up significantly in terms of his work as an instructional designer, he was also part of the diversity group and actively involved in the organisation's initiative towards creating an environment that is conducive for disabled persons.

Playing an integral role in Suresh's foray into Wipro has been Ability Foundation's placement wing that facilitated the process and the possibility of an interview. "Of course, once you make it to an organisation, it is up to you", Suresh clarifies, "to prove to everyone that despite being a person with disability, you are a valuable resource." Yet the journey to gaining employment is not easy for a person with disability, as Suresh experienced first hand. "You are not going to believe this," he says, "despite getting this far, the moment interviewers get to know I have low vision, the tone of the interview changes. They are either surprised or curious or apprehensive. Even though the concept of diversity in the work environment has been around for a while now, and is being touted as important and almost imperative, the truth is, we have a very long way to go. A hundred years perhaps to create awareness and then gain acceptance..."

In Mumbai, Ritika Sahni, founder of Trinayani, Mumbai, who has been in the sector for nearly 20 years, is more positive than Suresh. "You see, you cannot blame non-disabled people," she points out, "there's a certain helplessness that comes in the way of understanding a disabled person and more often than not, if effort is made, it is possible to reach a platform of understanding. If inclusion is not happening in some or many organisations, it is perhaps because of ignorance. That is exactly what organisations like ours are attempting to do; dispel ignorance in aspects of disabilities, create awareness and sensitise both the corporate and the academic community on the possibility and potential of the alternate talent pool that is just waiting to be tapped."

Ritika Sahni

In the context of Trinayani, placement was the direct result of an acute and intense sensitisation process towards people with a range of disabilities. "I remember the time," Ritika says, "during one of our advocacy programmes at a mall in Mumbai, we had two or three corporate professionals walking up to us and giving us their visiting cards. Less than a month later, we managed to place intellectually impaired adults. Today, nearly ten of them have been employed across auto stations across various departments."

It's a slow process, no doubt, but superbly rewarding, says Meera Shenoy, Founder, Youth4jobs, Hyderabad, which helps companies build an inclusive workforce, acknowledging that her work in enabling the rural disabled in Andhra Pradesh, has been one of the most transformational experiences in her life.

Shanti Raghavan

That pride in facilitating an inclusive environment is slowly but steadily becoming a matter of aspiration among organisations across sectors and industries. "There is a perceptible attitudinal shift that is taking place", notes Shanti Raghavan whose not-for-profit initiative Enable India, Bangalore, lists its core activities as the 'employment of people with disabilities, pre-employment services, supplemental education, counselling and support services, consultancy and training for other institutions and NGOs and technology services.' "It's amazing but it's true", Shanti says, recounting the story of a Bangalore-based girl who is severely disabled without the movement of her hands, and today works for an outsourcing firm based in Delhi. Among the first persons that redBus hired, the online bus ticketing website, was a youngster with a visual impairment and that too, to handle its Management Information Systems. How was this brought about? "Well", says Shanti, "the training is so researched and detailed that by the end of it, the trainees feel so charged up that they, in turn, become agents of change. The good thing is our candidates are buying into the vision that if you work better, it could motivate others too, and therefore we could all work towards being better Indians."

> That pride in facilitating an inclusive environment is slowly but steadily becoming a matter of aspiration among organisations across sectors and industries.

Arman Ali

All this is still work-in-progress. Today, quite a few organisations across corners of the country have taken up employment seriously and are waiting to make a lasting difference. In Guwahati, Arman Ali, Executive Director of Shishu Sarothi, recognises the problems that exist and yet is dogged about his pursuit. "What also needs to change is the attitude of people with disabilities themselves", he says. "They need to stop looking at their jobs as something that needs to come right up to them on grounds of compassion or sympathy. As far as corporates are concerned, it's time they woke up to the idea of employing people with disabilities but not only as a CSR initiative of sorts."

As everyone involved in employment in the disability sector acknowledges: companies need to understand and appreciate the fact that those set-ups that have absorbed disabled persons in their workforce, are most definitely more well-knit. The Employment Engagement Index, so to speak, is certainly higher today, although there are still miles to go. It's high time everyone realises that the sooner they become more accepting, the sooner they are on the way to becoming inclusive and adaptive leaders of the country.

According to Smt. Stuti Narain Kacker, Secretary, Department of Disability Affairs, the need of the hour is a "genuine sensitising of people towards the inclusion of persons with disabilities, in every walk of life, including professional." While she says that the department is absolutely serious about forging ahead with more partnerships with stakeholders, it is also expected that the 'willing parties' step forward to create more goodwill, more effort to move ahead in the right direction.


Ramakrishnan

Some companies, to be fair, are already marching ahead: Cafe Coffee Day for instance. According to K Ramakrishnan, President, Marketing, Café Coffee Day, the company is proud of its 'silent brewmasters'. According to him, their disabled workforce, "have a sense of smell that is so heightened that they genuinely are fantastic brew masters, they make very good coffee. We have identified that strength", he says. Café Coffee Day's vocational training college at Chikmagalur, Karnataka, trains youth and is more than willing to bring in candidates with disabilities within the fold of the company. "We definitely have the requirement to hire more people with disabilities. I do believe companies need to identify the strength and NGOs need to step forward to forge ties with corporates too", adds Ramakrishnan.


Debasis Das

Ask experts in the industry and they will tell you that the most critical requirement is the synergy between both corporates and NGOs. It is a two-way process.. If persons with disabilities need to walk that extra mile, so too do corporates have to take their own baby steps, at the very least. This was something that Debasis Das learnt when he was put in charge of the Costa Coffee branch in the Green Park area of New Delhi. Besides this, Das also made concerted efforts to learn sign language and then went on to head a team of six – all hearing impaired persons. Today, Das recruits and trains hearing impaired people for Costa Coffee's franchises across Mumbai, NCR and Bangalore.

A quick scan of the sectors and organisations employing persons with physical and intellectual disabilities makes way for a reassuring picture. Aegis Ltd, Euro Able (a Eureka Forbes initiative), Lemon Tree Hotels Ltd, Sun ITES Consulting, Wipro, Accenture, are just some companies that have been noted for their respective work in the area and felicitated at various award functions. Aegis Ltd, for instance, has an inclusive recruitment policy and employs 378 persons with disabilities or 1.37 percent of its workforce in the country. EuroAble is staffed entirely by people with disabilities. Lemon Tree Hotels Ltd has more than 100 employees with speech and hearing impairment, working in areas like housekeeping, kitchen stewarding and food and beverage service.


Ritheesh V Shetty

Bangalore-based Sun ITES Consulting Pvt. Ltd with 60 percent of its employees being disabled also trains them to become entrepreneurs who can, in turn, hire more disabled persons. According to its Managing Director, Ritheesh V Shetty, the company is trying to become a corporate entity to facilitate employment of the largest number of disabled persons in India, and in the world by 2020. "We aim to employ 2,000 people, of whom more than 1,000 would be persons with disabilities through our different branches in semi-urban and rural India, where there is a high concentration of disabled people", he said.

Forget the token CSR policies that allow disabled people to be included in organisations, research has shown just how companies do benefit by hiring those with physical or intellectual disabilities. In an excellent write-up on the prestigious Harvard Business Review blog, authors Prasad Kaipa (senior fellow in the centre for leadership, innovation and change at the Indian School of Business, Hyderabad) and Meera Shenoy, have storied a case study of Gitanjali Gems and found that the company, through its 'inclusion policy' has not only got a workforce of loyal employees, but also less attrition and a higher productivity compared to other firms. Today, 280 of the 2,500 workforce at Gitanjali Gems are disabled youth. According to Deepan Shah, Senior Vice President - Operations, the plan is to hire 5,000 people in the next two years of whom at least 1,000 are people with disabilities. Not surprisingly then, at Gitanjali Gems, the attrition rate of disabled youth is 1% compared to the 10% - 15% of others. Productivity is also high. So, in an 8-hour shift, there are 7-plus hours of productivity from the

Meera Shenoy

disabled employees, as compared to 5.5 plus hours from the non-disabled. The 1.5 hour loss per employee per day increases cost by roughly 10%. According to the study, the motivation and will power of disabled youth is high; they are eager to prove that their disability is not a deterrent to their performance. Most months, the productivity award is also won by a disabled employee even though they comprise only 12% of the employees.

Yet gaining employment isn't the be all and end all; in an equitable workplace the opportunities for career growth, training and promotions for persons with disabilities must be common practice. Similarly, for the employee to fulfil his/her potential, reasonable accommodations must be considered and implemented. Without these, employment becomes more of a challenge. A Delhi-based hypnotherapist at one of the city's leading hospitals mentioned to me how many of her patients with mental disabilities have struggled to find jobs, given that companies were wary. "They are talented but do have some challenges to face especially the people who suffer from mental illnesses. I have so many of such people coming to me complaining of how unsettling their offices and organisations can be", she says, adding that some have come back to her for continued counselling sessions within weeks of having found and subsequently lost their jobs.

On the government's part, even though concerted efforts are being made (by the Department of Disability Affairs, which is now a separate entity under the Ministry of Social Justice & Empowerment; for starters), barely 2% of persons with disabilities are educated. Many of those who are educated are struggling to find decent government jobs or move up the ladder. "How long will I serve just coffee? What is the growth plan that the company has in mind for me?" wonders a young man when I met him at one of the popular coffee outlets in South Delhi. To be sure, the government's efforts at providing job and social security for people with disabilities needs to have more power. Under the Eleventh Five-Year Plan, it targeted the creation of 100,000 jobs for persons with disabilities every year in the private sector, for which it was willing to pay the employer's contribution to the Employees Provident Fund and Employees State Insurance for the first three years for disabled persons who had earnings below Rs 25,000 a month. This however, has had no corresponding interest shown by the private sector, something that is a challenge for NGOs.

EmployAbility waiting area

EmployABILITY 2012

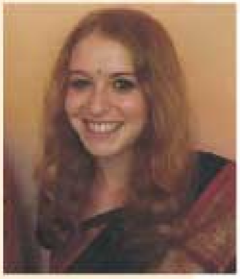
Waiting in line for an interview with Spencer's Retail, Ilaiah shuffles from one foot to the other, balancing on his crutches. His big brown eyes radiate expectation, "This is all about improving myself", he smiles, grasping the opportunity to be among 21 corporate hiring teams, all looking to hire the right persons with disabilities into their workplace.

Having lost the use of both legs to polio at the age of eight months, Ilaiah is amid the 770 strong qualified candidates with disabilities at Ability Foundation's EmployAbility 2012, the annual job fair which brings together qualified job seekers and corporates, from across India. Held in Hyderabad on 2nd and 3rd November 2012, this time the hiring teams represented almost all sectors, from pharmaceutical to consultancy, finance and IT. This was Ability Foundation's seventh EmployAbility, spanning two days of motivational seminars, aptitude tests and interviews.

"Being here gives me the added benefit of training in interview techniques", Ilaiah says, with eleven interviews in tow, "there are so many corporates here, I am able to ask questions and get answers – if I go on to further interviews, I will be prepared."

For many like Ilaiah, who has been in education for the past 18 years and remain unemployed, EmployAbility opens doors to the private sector looking to hire on the basis of merit. The acknowledgment that persons with disabilities are a competent workforce, strengthening and adding expertise to personnel, was unmistakable among the corporate representatives who conducted the interviews.

"Hiring persons with disabilities goes beyond corporate social responsibility", said Anil Kumar Singh, Associate Director at Capgemini, Mumbai, "we are very serious that we want to drive change internally." Attending their first EmployAbility, the Capgemini hiring team interviewed around 100 candidates and short listed 25 candidates for further evaluation. "For us, the question is why not hire someone with disability? You are anyway hiring people; there is a demand for jobs, so we want to fulfil that demand", added Anil.



ELEANOR DAVIS

At Capgemimi, a consultancy, technology and outsourcing firm that recruits 40,000 people in India alone, every recruiter has undergone a sensitisation programme. To ensure that reasonable accommodations are provided for employees with disabilities, external consultants have been hired to make recommendations on infrastructure and communication support in the workplace. Anil and his team want to take this initiative across the entire organisation.

The importance given to diversity in the workplace was evident, with companies returning for the 4th or 5th time to EmployAbility. "We have been pursuing this inclusive workplace for quite some time" said Prajwal, HR Manager at Wipro, Mysore. Wipro's pioneering efforts include an exclusive programme on inclusivity and diversity for all new employees, and a mandatory certificated course in the same, which has been running over the last six months. More recently, a sign language interpreter has been hired at Wipro to support those with hearing impairments, and so to assistive technologies for those with low vision have been installed.

"The more diverse the work group is, we have inevitably found heterogeneity in our thinking", said Prajwal, "this has spurred a lot of things in the organisation in terms of disruptive technologies and break through solutions. Over and above this, it is more about collaborating and seeing how people can be mainstreamed."

Not all were so sure that hiring persons with disabilities was for them. The hiring team at Mahindra Satyam, a global information, communication and ICT company, were wary that on paper, the candidate's profiles did not match their work requirements. Yet upon meeting face to face, perceptions began to change when the team realised the capabilities, qualifications and skills of the candidates in front of them. For others, EmployAbility was an eye opener to the talent pool available to recruiters. "We came in with absolutely no expectations", said Gayatri Kuppa, Staffing Manager at Novartis, Hyderabad, "we wanted to see what it was like and we really got a very good turnaround of people who are interested in the opportunities we have. It's been a very fruitful day for us."

The competency of candidates was indeed shining, with a plethora of freshers, professionals and those striving for further career growth. "I've been working as a customer service executive for the last one and a half years", said Jasper Singh, waiting in the registration, at what was his second EmployAbility. Having attended EmployAbility 2010, Jasper was placed at Standard Chartered Bank, and has been impressed by the positive attitude of his employers, "I have faced no difficulties, there is a good working culture and they are co-operative, professional and sensitised employers." With his left leg disabled, Jasper stressed on the importance of having a range of companies under one roof, with openings across the country, making it easier for those who might not be able to travel to attend interviews.

The challenge yet remains for freshers, with years of education under their belts, to get on the employment ladder and to secure that first job opportunity. Sapna Lalwani explains, "It's not easy to get interviews, employers do not consider a disabled person is good enough for the job, or to do the work" she says, having just completed six interviews at EmployAbility 2012.

With no large companies in her native Chattishgarh, M.P, Sapna has dreams to become a software developer, andis pleased to have met with so many equal opportunity employers who are opening their doors. "In the metros, survival is hard", she says. With both legs affected by polio from the age of one and a half years, Sapna uses a mobility aid, and is awaiting her transport as she speaks. "I've been looking for work for the last two years via the internet, but it is very difficult to move here and there" she adds, stating that the lack of ramps, access to bus stops and public spaces make seeking work and attending interviews extremely difficult.

For commerce graduate, Laxmi Narayan, moving to Hyderabad, away from his family in Medak District, A.P, was in the hope of finding employment. Laxmi believes that his disability is the main player in preventing him gaining work. "I feel that companies will reject me due to my disability" he says, having lost the use of both of his legs, "they don't see the capacity or talent of the person" he says, adding that despite clearing his chartered accountant exam, followed by a separate bank exam, he has remained unemployed.

Prospective employers have told Laxmi he needs to improve his communication skills. "There needs to be more skill and technical training", he says, unaware of any government schemes in this area. For those, like Laxmi, whose perceived disability is ranked above his capability to do the job, what needs to change? "Much change is needed", he says, eyes searching the ground for answers. After a long pause he tells the story of a journey he took via bus to his home town. Crawling, with the use of flip flops to protect his feet, Laxmi boarded the bus and headed to the seats at the front reserved for persons with disabilities. Finding them occupied by a non-disabled passenger, he asked them to move and allow him to sit. Undeterred, the passenger refused to move when asked a second time, leaving Laxmi to crawl to the back of the crowded bus. "The attitude of society is like this", he says, "this needs to change."

An understanding of the capabilities of a person with disability is intrinsic to ensuring that their human right to work and equality are met. Neeraja Padma, a process developer with an MBA in finance, who also has cerebral palsy, finds that ill-informed assumptions, and her inability to gain equal access to work and services, are interrelated. "I applied for a loan under a government scheme, but when they saw me they immediately told me I was not suitable, assuming that I could not handle the loan", she says. Such stereotypes filter into the work place, and not only prevent persons with disabilities from obtaining employment, but quell a company's chances of hiring a skilled and valuable worker. "Communication is very important", Neeraja says, slowly but clearly. "I can speak like any other person, but they will not consider me. I have knowledge, I have work experience, I have qualifications; they are least bit bothered about these."

Such is the need for employment fairs for persons with disabilities, like EmployAbility. As each year passes, we see an ocean of talent flooding the venue and lapping at each employer's stand. We also see the slow but steady increase in equal opportunity employers, who have recognised and endorsed diversity in their workspaces – not as a 'give back to society' initiative, but as a drive to take society forward, with benefits for all. "All of us talk about these issues, but it's another thing to take it up", says Prajwal, as a passing candidate interrupts to hand over his resume. "EmployAbility is one platform where we can get everyone together, see what suits us the best, and take home the best talent."

Nevertheless, slowly but surely, wheels are in motion. We believe this a good time for disability and employment. More than ever, employers are looking to hire people with diverse disabilities. The aspiration levels of disabled people themselves have never been higher, so too their awareness of market needs and demands.

Sure... much still remains to be done. If one looks at statistics, they are still dismal. But we believe that employment in the context of disability cannot be looked at by numbers alone. It's the qualitative dimension that is significant. A shift in perception... small ripples making way for bigger waves... inspiring stories paving the way for countless more... best practices being documented for others to follow.

Importantly, there is one key differentiator today. The disability sector itself has tended to, thus far, work largely in isolation. Consequently, the efforts made, laudable though they may have been, appear to be sporadic and there is duplication of efforts as well. Scaling employment up to the next level has thus been fraught with challenges.

Significantly however, today there is a clear understanding that reinventing the wheel is an expensive waste of time and effort. Therefore, networking seems to be the norm with discussions taking place at various levels and organisations in the disability sector across the country are joining hands to take employment forward. This coming together augurs well. Working together, we do believe, we are poised for a great leap forward in the near future.

AKHILA KRISHNAMURTHY, ABHILASHA OJHA
& THE ABILITY TEAM

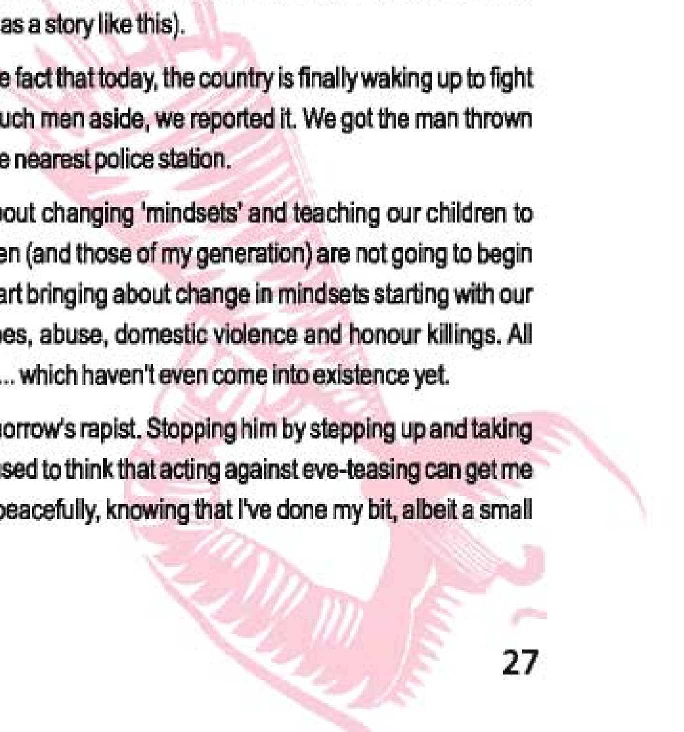
Shattering The Passivity

I've always been a massive propagator of the ignoring atrocities movement. If someone were to call out "Hey baaayebee" at me, I ignore and walk. If a random man waves at me from a car, I look at him as if he were invisible and move on. My theory in life has been that these men are not worthy of my attention, effort, resources or cognitive reasoning and hence, I ignore.

VAISHNAVI VENKATESH

A small, but significant incident has shattered the passivity within me and proven if my society needs to change, I need to be the one to start doing it.

My friend and I were followed by a man in his car today. The distance was barely a kilometre, the locality was one of the fanciest in the city and it was a scorching and crowded afternoon. I hate the fact that I need to justify the wheres/whats/whys of the incident, because I know questions like, Was it late in the evening? Were you out in a secluded area? Were you both girls? Was it a shady locality? crop up every time someone mentions a story like this (and I know, everyone has a story like this).



We could have ignored it. We would have ignored it, had it not been for the fact that today, the country is finally waking up to fight against such antics. Keeping the arrogance of not wanting to deal with such men aside, we reported it. We got the man thrown out of the restaurant and ensured that his car details were submitted to the nearest police station.

How is this helping change anything? We have lengthy discussions about changing 'mindsets' and teaching our children to respect women and inculcate equality in society. I'm sorry, but my children (and those of my generation) are not going to begin respecting women for at least another fifteen years. If we are going to start bringing about change in mindsets starting with our children, we are going to skip an entire generation. A generation of rapes, abuse, domestic violence and honour killings. All because we think we can only bring about the change in our own families... which haven't even come into existence yet.

If I want a safer society, I need to build it myself. Today's eve-teaser is tomorrow's rapist. Stopping him by stepping up and taking action might prevent many other girls from being followed in the future. I used to think that acting against eve-teasing can get me into trouble, giving me sleepless nights. On the contrary, today I'll sleep peacefully, knowing that I've done my bit, albeit a small one, in trying to change my own society.

TOP GEAR

SEENA RAVEENDRAN

A drive from the snow storms of Kashmir to the rough riders of Kerala; a strong punch of excitement, exploration and experience of a lifetime; sleepless nights, unpredictable climate changes, tangle of winding mountain roads that lead to and fro, sometimes a driver's rapture, but more often, a challenge…

Harish Kumar loves adventure, speed and cars; in any spare time, he vrooms in his Tata Safari through the busy streets of Ahmedabad. At 41, this telecom professional has successfully completed the latest All India Motor Expedition in 29 days covering 16,000km in May 2012, and set the record for being the longest distance ever covered by a person with disability in the country.

Born with an amputated arm below the elbow, quite early in life, Harish accepted the fact, but was never disheartened. "My parents were very supportive of everything I did. They never stopped me from doing anything; be it learning to cycle,

Seena Raveendran

tying shoe laces on my own, getting ready for school on my own, tying the knot of my tie or boarding the bus or train. I used to devise a way of doing things, and they would support by encouraging me to do things on my own." When he was rather young, Harish displayed a fascination for toy cars. "I had a passion to be fiercely independent since my childhood days, though owning a car was beyond our reach in the 80s. With my family encouraging me to take up sports, I was drawn to a variety of them. However, the adrenalin rush I derived from driving overshadowed the excitement of playing anything", recalls Harish.

The trip involved a drive through 28 state capitals and 7 union territories covering hundreds of towns and cities on the way.

> Ever since my childhood,
> my passion has
> been driving and
> my endeavour has
> been to be able
> to do all that a 'normal'
> person could do.
> This expedition was my
> way of telling the world that
> I'm no less than anyone.

"The journey was not just an expedition to seal some records. It was the fulfillment of a long cherished passion. Ever since my childhood, my passion has been driving and my endeavor has been to be able to do all that a 'normal' person could do. This expedition was my way of telling the world that I'm no less than anyone." For most part of the trip, Harish had to curb his instinct for speed and drive cautiously. He also had his set of bottlenecks on the way. "It was a test of endurance and resilience sometimes, when I had to cover the most rugged terrains of the country, driving with one hand." from the heavy rain falls in the terrorist afflicted Srinagar to the rash drivers of the Kerala highway, Harish has experienced true India.

Harish had taken up the all-India driving expedition, laid out by Limca Book of Records for the aspirants wanting to set or break national records. So what's the catch? The Tata Safari, and earlier the SUV that he has driven, have not been specially modified for him. "In the initial years I tried to explore the option of a modified vehicle, I was not able to track the proper person. When I started learning to drive I realised that I could drive any car without any modifications. This increased my confidence levels, provided me the flexibility to drive any car and also fulfilled my endeavor to be able to do any work which other people can do", Harish says.

Harish got trained in driving much later in life, though not from any driving school. "A local taxi driver in Rajasthan taught me the basics of driving during my tenure with a telecom company there, executing a project for the Indian Army in 1997 to '99", during which, Harish recalls one of the funniest moments from his driving classes, "when I was learning to drive I used to honk a lot. To my embarrassment my tutor once commented, 'Can you see that approaching train near the railway crossing?' I said yes. 'You don't need to blow the horn at it,' he replied", chuckles Harish.

For Harish, life should always move, though not at the speed of his Safari. "My next target is to take up Ahmedabad to London drive by road. This will be a very tough expedition covering 15 countries, and the expenses will cost a great deal", he says. Harish hopes to keep wracking up miles 'single-handedly'.

Harish's expedition has been recorded as a National Record 2013, in the Limca Book of Records for completing a solo-all India motor expedition in 29 days 6 hours and 20 minutes, making it the fastest expedition by a person with orthopedic disability.

London-bound

Mahesh Chandrasekar, currently an International Policy and Campaigns Manager with Leonard Cheshire Disability, finds London to be an accessible city in all respects. A strong advocate of the rights of persons with disabilities, and an avid traveller, Mahesh, with his years of experience as a disability activist in India, comments on his present job and the provisions made available for him at work and the quality of accessible living available in the city of London.

The numerous twists and turns in life's journey lead us to the most unexpected destinations and experiences. Are these one's personal choices or destiny? Whatever it be, the uncertainty of it all, is what makes life an adventure and an opportunity that needs to be explored.

A life considered 'normal' is what I was used to, until my youth. My life was made 'interesting' by a virus that crept in and chewed at the covering of my nerves, leaving me partially paralysed and weak. From then on, I started using a wheelchair.

I have lived and worked in various parts of India and, in the recent past, relocated to London for work. One of the most striking features of this city is access to public spaces and services. I use local buses to commute. Travelling by bus is free for all persons with disabilities, children below 16 years and persons who are above the age of 60. This makes it more attractive to travel and to go on adventures, in an otherwise expensive city.

For convenience, all the bus stops are on the same level as the pavement and there are pedestrian crossings and kerbs to the pavement. Each bus stop has shelters to protect against rain and sunshine. Some of the bus stops also have a small digital sign board that continuously updates the time of arrival of the buses.

Buses with ramps

A passenger on a wheelchair can just wave his/her hand to the driver as the bus approaches the stand, or when the bus halts, press the 'ramp request' button that is next to the middle door. The driver then activates the automatic ramp that flits out from the middle door on to the pavement. I can then roll into the bus and position myself in the designated place reserved for people in wheelchairs. This place provides a safe and comfortable position to travel. When you approach your stop to dismount, all you need to do is press the button with a wheelchair symbol and the driver opens up the ramp once again.

All the metered cabs in London have been fitted with a ramp too; therefore there is no need to book for a special cab with a ramp. There is no extra fee charged if you are a wheelchair user.

All persons living in the UK are registered at the local NHS (National Health Service) and the health services are free. As part of this service, assistive devices and any of the consumables that would be needed on a regular basis, such as urinary incontinence devices, are provided too.

Crossing the road independently- the kerbs on the pedestrian crossing

Education for all children up to the age of 18 is free in state schools, and all schools have arrangements in place to enroll children with disabilities, as well as to recruit staff with disabilities.

As part of 'Access to Work', a programme run by the government, the employer is legally bound to create an environment in which persons with disabilities can work and make use of all facilities in the office safely and independently. As part of this programme, an assessment of my requirements at the office, and my commute from home to my office was done. Initially I did not have a proper wheelchair, so the cost of my commute to work by a local metered cab was covered. Following this, they provided me with a customised powered wheelchair, free of cost. With this I am able to commute to work independently. When I need to travel out of office on work, the cost of my personal assistant is reimbursed. Similarly, appropriate support is provided to persons with different impairments such as hearing, vision and so on.

> “The aim of this article is not to paint a rosy picture, but to attempt to communicate the proactive steps taken by duty bearers that help me to seamlessly blend and be part of everyday life and live with dignity.”

While accessing any of the public services, I find that there are specific provisions made for persons with disabilities. These include questions on services, such as getting a driver's license, a parking permit or paying for utilities such as electricity and water.

Information on the percentage of a person's disability, or a medical certificate from a specialist doctor in a government hospital is not asked for. The system operates transparently and in most cases is based on self-declaration made by the person concerned.

All public spaces, both internal and external, are made accessible for persons with disabilities and senior citizens. Hence I am able to go the park in my neighbourhood, visit the supermarket and other places of interest such as museums, the local library,etc.

All these services are supported by taxes from the public. Of course all these do not come on a platter; one has to work through the system – but it works! The aim of this article is not to paint a rosy picture, but to attempt to communicate the proactive steps taken by duty bearers that help me to seamlessly blend and be part of everyday life and live with dignity.

I am aware of the fact that it is unfair and unreasonable to compare the high standards evolved by a country such as the United Kingdom with the rest of the world; however when I am benefiting from the system, it makes me ponder about the deprived majority.

According to the World Report on Disability, published by the World Health Organization and the World Bank, there are an estimated one billion persons with disabilities across the globe. They face barriers to participation in society: in accessing development programmes and funds, education, employment, health care and transportation services. Persons with disabilities and their families, of whom 80% live in developing countries, are over-represented among those living in absolute poverty. As of October 2012, 124 countries have signed and ratified the United Nations Convention on the Rights of Persons with Disabilities, a legally binding agreement to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Therefore, the question is: is the person with an impairment limited due to his/her disability, or due to the environment, system, structure and attitudes which make up a society?

HELP! I Need Somebody

DR. VIJAY NAGASWAMI

Asking for help, an absurdly simple thing to do on the face of it, is perhaps one of the most difficult tasks for many urbanised people today, ranking only next to saying 'sorry'. Interestingly, we find it relatively easy to ask for help or apologise for the 'small stuff' ("Could you please hold my place in the line while I go to the toilet" or "I am so sorry, I didn't mean to wake you up from your siesta.") But, when it comes to things that really matter, it's really extraordinary how difficult we find it to say we're sorry ("I'm really sorry that I let you down"), or ask for help ("I simply can't understand my wife, I need you to help me with my marriage.") The more usual modus operandi would be to reach for the nearest excuse or rationalisation, at which we are usually quite adept, and get on with our lives. While a discussion on why we find it hard to apologise is undoubtedly interesting, I shall confine my thoughts to help-seeking behaviour, for the focus of this piece.

The easiest thing to do would be to dismiss this phenomenon as being caused by 'ego problems', a basket term that has been gaining increasing currency in recent times. However, when we see people who are laid-back, self-effacing and far from egoistic, also resorting to the same behaviour, this explanation simply does not cut ice. We need to dig a little deeper.

Looking back at my lengthy time in the 'healing' profession, I realise that I have been able to offer interventions to hundreds of people who required, and were able to find the courage to seek my services. However, I am sharply conscious that those who actually seek services represent a miniscule minority.

There are probably millions who require such services but are not ready to acknowledge that they do, even to themselves - let alone take help from a professional for problems that are as ubiquitous as they are surmountable. When I scrutinise my career a little more closely, I can readily come to the conclusion that people sought my help the easiest, when I was a general medical practitioner, and with much more difficulty when I became a clinical psychiatrist and with utmost awkwardness when I settled down to the practice of 'couples' therapy. In other words, having a physical illness is perfectly acceptable when it comes to seeking help. However, when it comes to a diagnosable mental illness, the stigma associated with having such a problem does come in the way, but eventually when the problem becomes unmanageable, a discreet visit to the mental health professional is still not illegitimate. However, when it comes to seeking help for 'non-illnesses' like relationship problems, active inertia usually sets in.

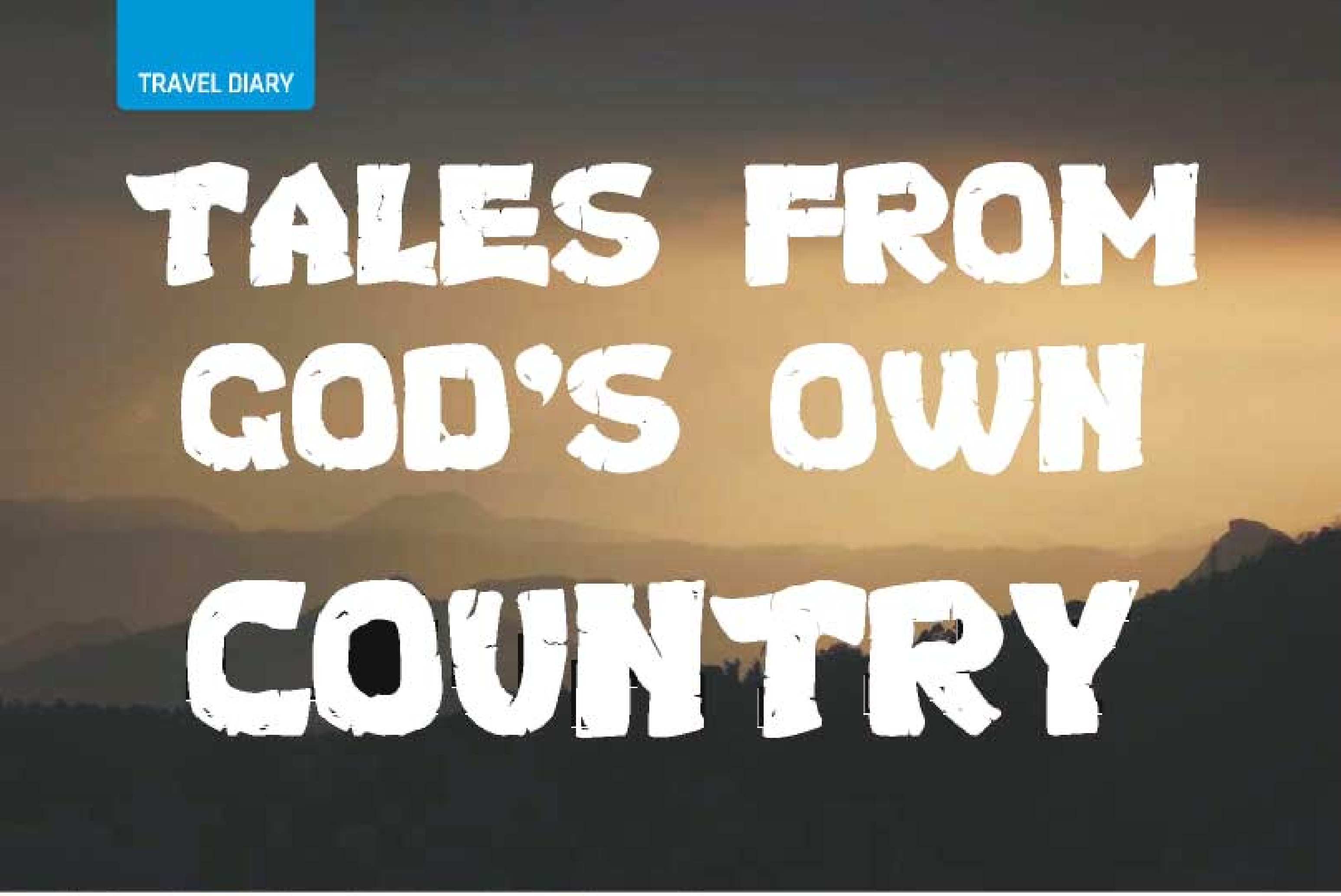
As is well known, men find it hard to ask for help. For instance, how many men do you know, who, when they are lost in an unfamiliar locality, would stop and ask for directions? Or, take a look at gender-specific popular reading matter. Women's magazines are full of advice and tips on a wide variety of things ranging from the kitchen to the boardroom. Men's magazines, on the other hand, usually focus on sport, technology and politics. Put differently, it appears that one of the hallmarks of masculinity, is the capacity to 'handle' everything – emotional or intellectual - by taking these in one's stride; the implication being that, one does so on the strength of whatever one already knows or possesses. If one doesn't know how to handle a situation, or one doesn't possess the wherewithal to deal with a crisis, one somehow bumbles through or 'wings' it. Revealing one's inability is just unacceptable.

Why should this be so? What is wrong with exposing one's inabilities or disabilities? Is it not the imperative first step in managing one's inabilities or disabilities, to acknowledge that these indeed exist, so that one can confront them and deal with them? The answers to these questions centre around a major fear in contemporary life: the fear of vulnerability; and the resultant emotional conflict between dependence and independence. The more vulnerable one is and the more one exposes it, the more dependent one becomes on others in the environment and therefore, the more prone one is to another person exercising control and manipulating. The better option hence appears to be the quest for invulnerability and one of the manifestations of this is the reluctance, even refusal, to ask anyone for help. Although this quest evolved as a masculine trait, contemporary women too have included this in their repertoire, as part of a process of having to acquire masculine tools to enable them to compete in a 'man's world'. The net result: everyone aims to be invulnerable and totally independent. Many people do indeed believe they are.

If truth be told, those who do believe this are deluding themselves. Nobody is truly independent or invulnerable. We are a highly socialised species, and as a result, will always be dependent on each other, whether we like it or not. The process of personal growth and development demands that we accept this reality and come to terms with it; the mature person is one who seeks to get comfortable with vulnerability, not to eliminate it. The sooner we recognise that we are all dependent on one another and that we can comfortably be so, the better we will start performing as a race. Certainly, interdependence does increase the risk of being at the receiving end of 'control games', which people in a position of 'power' may attempt to play. However a game will never be a game if we refuse to play it. For then, the 'controller' loses interest in it. And for the record, all of us play these control games whether in our marriages, our relationships with family and friends or in the work domain. When threatened, human beings try to control each other, and if one of the parties in the relationship stops threatening the other, the games too stop.

So, next time we feel vulnerable, let us not attempt to be one of those strong, silent types. Let us accept that we are indeed vulnerable, as in fact, everyone is. And let us also get on with trying to identify resources in our emotional and social environment, which can assist us with solutions. To do this, we first need to learn to ask for help. Not indiscriminately of course. Let us choose our help-providers with care and discernment, and utilise their experience and expertise as best as we can.

The writer is a Chennai-based psychotherapist and relationships consultant, and is the author of many books including, 'Courtship and Marriage: A guide for Indian couples'.



TALES FROM GOD'S OWN COUNTRY

On a first time visit to India, Jeffrey and Katy Davis share their tales of adventure, exploration and where to find the perfect lassi in beautiful Kerala...

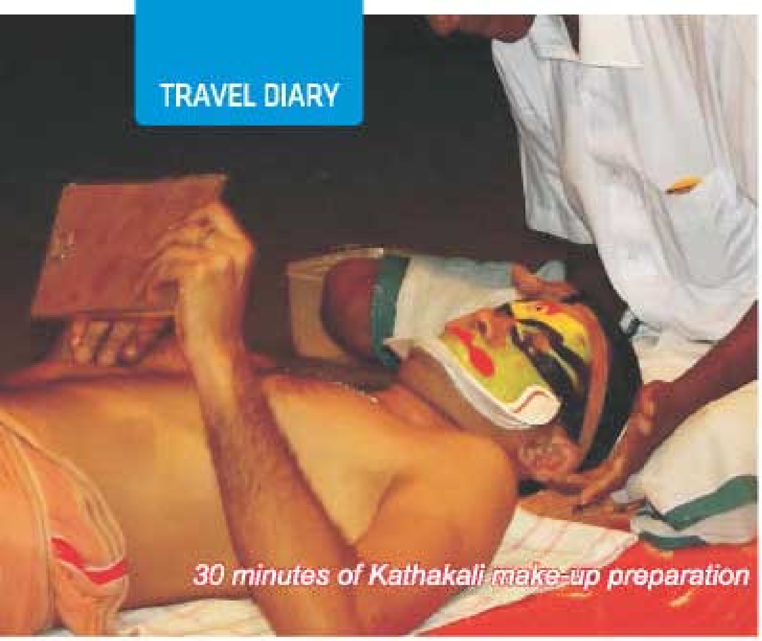
My wife has always wanted to visit India (she is more adventurous than I am) and our twenty-fifth wedding anniversary, along with the fact that our daughter is now working there, provided us the perfect opportunity to finally make the trip.

After a long flight from London Heathrow, we were met by our daughter, waving furiously at Cochin Airport (not that it was difficult to spot her – she was the only European amidst a sea of Indian faces!) We had decided to make Fort Cochin our base, a centre for historical interest, and easy to travel to other hotspots from. Steeped in colonial history, Fort Cochin was one of the first European townships in India, from the time the Portuguese had settled here in the 15th Century. In 1663 the Dutch gained command and then the British in 1795, leaving behind a legacy of trade, culture, architecture and diversity. Now a popular tourist spot, Fort Cochin is flooded with boutiques, book shops, cafes, modern art, spice markets, temples and churches.

Though many quaint home stays are available for accommodation and home cooked food, thanks to the generosity of an Indian family we know in Britain, we stayed in palatial old colonial accommodation – a heritage house right by a tributary of the Arabian Sea – complete with a team of attendant staff... rather like the Indian equivalent of the British TV series 'Downton Abbey'! After trying to catch up with sleep, we explored the local area. I was surprised how similar India was to what I had imagined; incredibly colourful, culturally diverse, vibrant and warm (in every sense).

Along the sea front at Fort Cochin one could marvel at the ancient Chinese fishing nets, in use for the last 500 years and an extraordinary sight rather like pre-historic Pterodactyls, and almost unique to this area. As the days of our visit went by, the fishermen began to recognise us and would allow us to help them haul in the fish by pulling down on the ropes. Remarkably for such large and complex contraptions, they tend to bring in very few fish. Nearby too, was the church of

Bringing in the catch with the fishermen at Fort Cochin


30 minutes of Kathakali make-up preparation

St. Francis, which dated back to the 1500s when the Fort was constructed under the Portuguese. Originally a wooden structure, the church has an eclectic past and was erected as the Church of St. Bartholomew and in 1516, when replaced by a mortar and bricks structure, became the church of St. Antony. Under the Dutch command, it was transformed into a government church, until it was surrendered to the British in 1870, and came to be known as the Church of St. Francis. Now a part of the Church of South India, the weathered building is a tourist attraction, mainly for a site of the original tomb of the Portuguese navigator, Vasco da Gama, who was buried here in 1524, before his body was returned to Portugal. Outside, stands the old military marching ground where we would often take the time to sit and watch children practising their band parades.

Coming from a Jewish background, it was especially interesting to me to be staying near the 'Jew Town' area of Cochin – an extraordinary area containing a mixture of shops (many selling antiques), warehouses and spice/auction rooms. In Mattancherry stands a small synagogue, the oldest one in the British Commonwealth, dating from 1568. Stepping inside was a remarkable experience of light and airiness, partly due to the 18th century hand-painted blue Cantonese ceramic floor tiles, all of them different, and the ornate chandeliers and colourful oil lamps. We wandered bare foot across the tiles and enjoyed the adjoining exhibition which documented the history of Jews in Cochin, through intricate paintings.

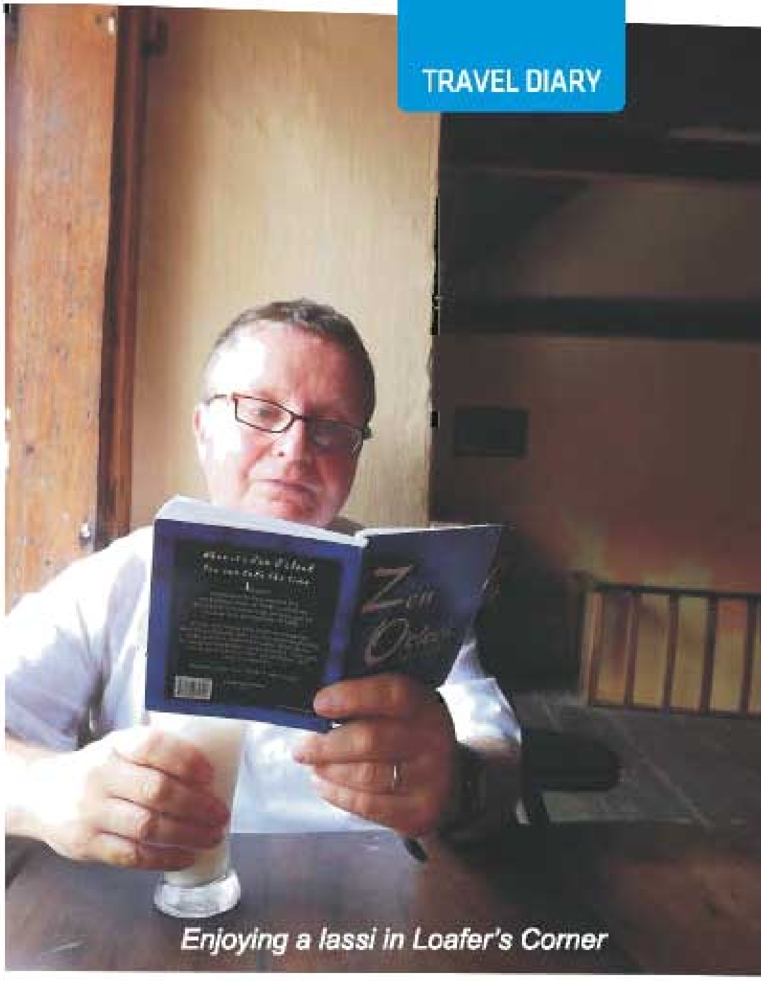

An idyllic spot for lunching & writing postcards

On stepping outside, we went to a riverside restaurant, where we enjoyed appam and stew, a Kerala delicacy, and wrote our postcards whilst overlooking a blissful glistening lake. The calm was soon interrupted by noise in the straet and on joining the local crowds outside we were lucky enough to get a glimpse of an Indian music video being filmed... in full swing with singing and dancing... blocking the road but providing much entertainment!

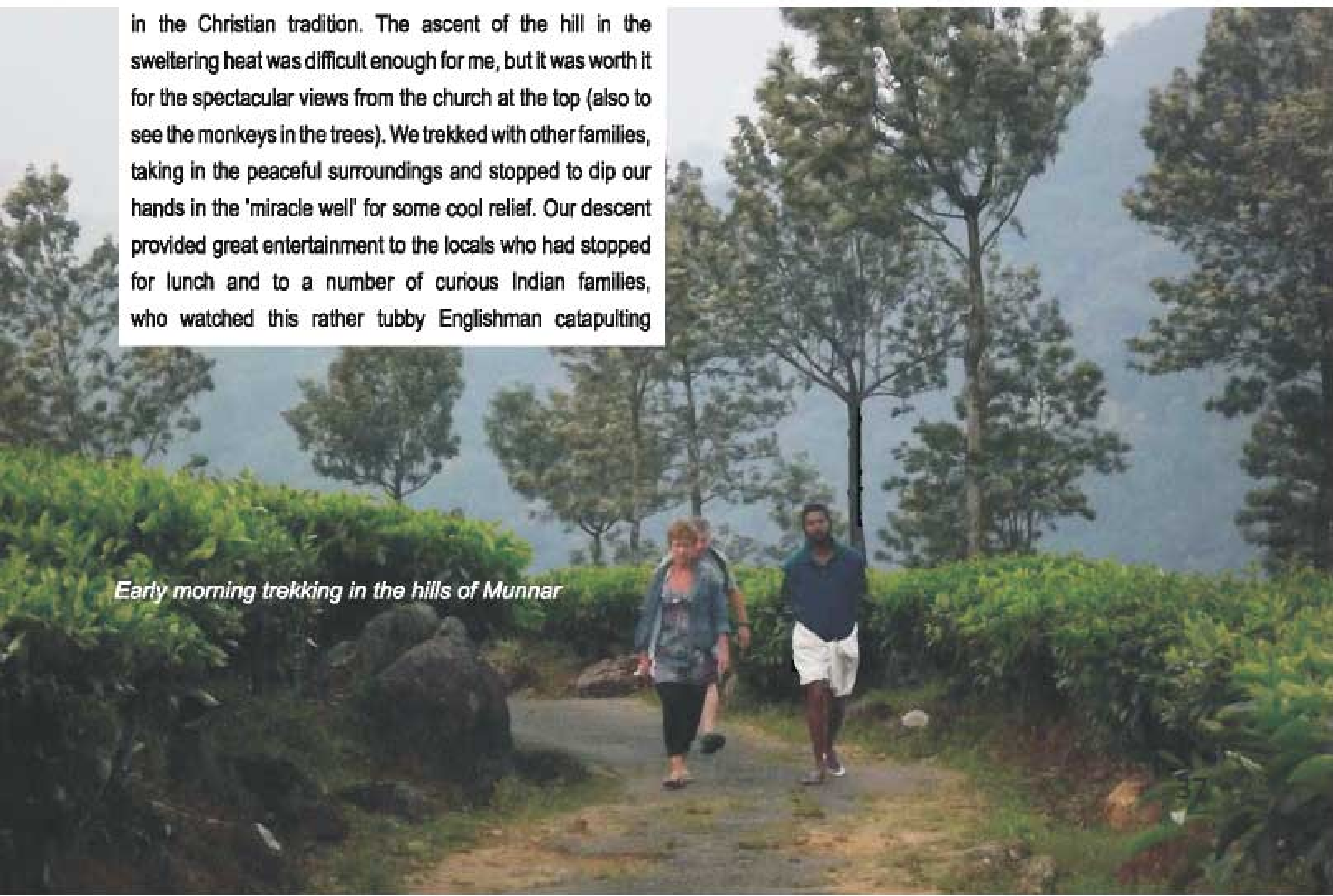
In contrast, watching a traditional Kathakali dance-drama offered a more blood-thirsty entertainment, albeit very effectively choreographed and performed (with men taking both the male and female roles, as in the Elizabethan theatre in England). Geared up for tourists, the show began with a make-up demonstration: half an hour of applying thick green face paint with black, devilish eyes and red clown-like lips with a yellow forehead. This was followed by a demonstration of the nine facial expressions used in Kathakali, each manipulating the facial muscles in such a way that the actor's face appeared to be shaking, or eyes popping out, with each emotion.

Apart from the great wealth of history to be found in India, I was pleasantly surprised to make another discovery – this time food related. The visit allowed me to indulge my predilection for the traditional Indian lassi/yoghurt drink, many of which had to be drunk surreptitiously due to my wife's disapproval of them as being incompatible with my 'weight watchers' programme. The best lassi was the one sampled in the appropriately named (in my case anyway) 'Loafers Corner' in Fort Kochin – a wonderful place to hang out, read, or simply watch the world go by. Other recommended lassis could be found at the Koder House and Kashi Art Gallery, the latter also supplying delicious walnut cakes in the peaceful midst of modern art!

Mid-week, after the numerous lassis and curries had been consumed, we went in search of some exercise and were taken for a rather steep ascent (1269 ' Ft.) of a pilgrimage site at Malayattoor, believed to have been visited by St. Thomas in the Christian tradition. The ascent of the hill in the sweltering heat was difficult enough for me, but it was worth it for the spectacular views from the church at the top (also to see the monkeys in the trees). We trekked with other families, taking in the peaceful surroundings and stopped to dip our hands in the 'miracle well' for some cool relief. Our descent provided great entertainment to the locals who had stopped for lunch and to a number of curious Indian families, who watched this rather tubby Englishman catapulting



Enjoying a lassi in Loafer's Corner

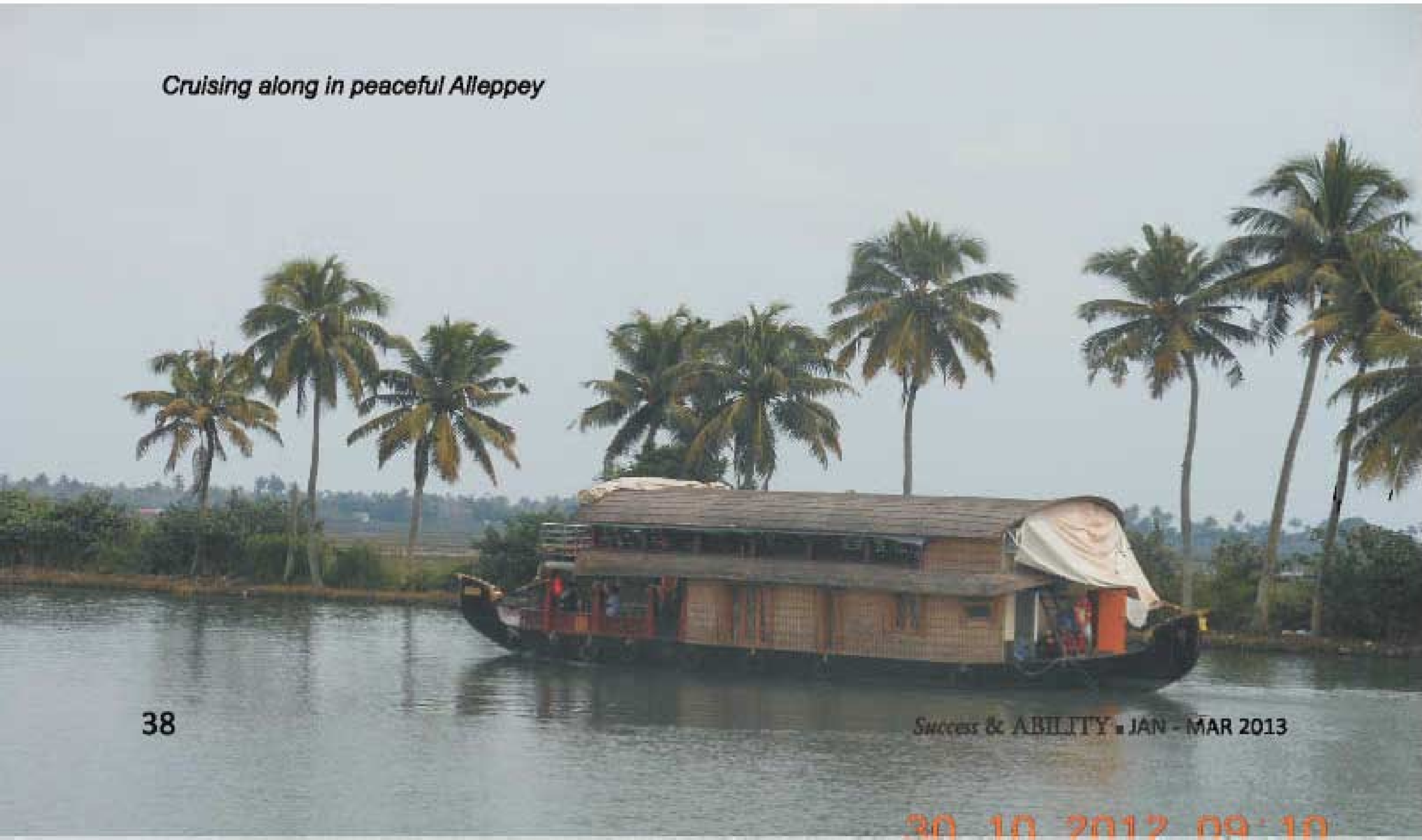


Early morning trekking in the hills of Munnar himself down the steep mountainside, unfamiliar with the rocky terrain.

No doubt, the most beautiful view of the trip was from the balcony of the guest house where we spent two days in the mountainous tea-plantation area of Munnar. Nested in the Western Ghats, this hill station is remarkably cooler in climate and flooded with tree estates and a countryside rich in plants with (ayuredic) herbal properties. Munnar is an absolute must see for anyone wanting to escape the bustling cities and sample beautifully fresh air. Here we wandered along small paths, through villages and enjoyed meeting with other travellers over dinner. Watching the sun going down behind the misty blue distant mountains was unforgettable and worthy of a film setting.

We had not yet sampled the trains in India – and after a visit to the backwaters in Alleppey, we found our opportunity. Planning to journey from Alleppey to Ernakulum (actually we got on a train going in the opposite direction by mistake! Still, it gave us a more extended experience of train journeys in India), the train set off with the doors still open and people sitting on the fire step dangling their feet just above the rails.

In fact, feet remained a prominent feature of this journey, because when I looked down the carriage all I could see were the protruding feet of other passengers, apparently asleep, flat-out on the seats and even on the over-head luggage racks. Yet no account of a trip to India would be complete without a report of the terrifying 'Tuk-Tuk' experience. The drivers of these flimsy vehicles appear to be without any fear. There seems to be no road discipline whatsoever – if there is a vehicle in front of you, the convention was to overtake immediately, regardless of road conditions; so if you are approaching a blind corner – overtake; if you are approaching a busy dual carriageway – pull out anyway, beeping furiously all the while! However, there did seem to be some weird type of logic to it all, as we dodged in an out of the traffic, as we never did collide with another vehicle and always arrived safely at our destination. My wife could not look for many of these journeys and would often be seen laughing nervously, head down with her hands over her eyes! When I pointed this out to our Tuk-Tuk driver during a particularly hair-raising journey, he simply turned and shrugging his shoulders with a broad toothless grin, exclaimed: 'This is India!'



Cruising along in peaceful Alleppey

Usher Syndrome

DIPTI KARNAD

Usher syndrome is the most common condition that affects both hearing and vision. The major symptoms of Usher syndrome are hearing loss and an eye disorder called retinitis pigmentosa (RP). RP causes night-blindness and a loss of peripheral vision (side vision) through the progressive degeneration of the retina. The retina is a light-sensitive tissue at the back of the eye and is crucial for vision. As RP progresses, the field of vision narrows — a condition known as 'tunnel vision' — until only central vision (the ability to see straight ahead) remains. Many people with Usher syndrome also have severe balance problems.

Who is affected?

Approximately 3 to 6 percent of all children who are deaf and another 3 to 6 percent of children who are hard-of-hearing have Usher syndrome. In developed countries, about four babies in every 100,000 births have Usher syndrome.

The causes

Usher syndrome is inherited as an autosomal recessive trait. The term autosomal means that the mutated gene is not located on either of the chromosomes that determine a person's sex; in other words, both males and females can have the disorder and can pass it along to a child. The word recessive means that, to have Usher syndrome, a person must receive a mutated form of the Usher syndrome gene from each parent. If a child has a mutation in one Usher syndrome gene but the other gene is normal, he/she is predicted to have normal vision and hearing. People with a mutation in a gene that can cause an autosomal recessive disorder are called carriers because they 'carry' the gene with a mutation, but show no symptoms of the disorder. If both parents are carriers of a mutated gene for Usher syndrome, they will have a one-in-four chance of having a child with Usher syndrome with each birth.

Characteristics

Type 1: The child is profoundly deaf from birth. There are also severe problems with balance, so a child may be slow to sit unsupported and is often late learning to walk. The child will also have decreased night vision before the age of 10.

Type 2: The child usually has moderate to severe hearing problems from birth. Balance, however, is normal. Decreased night vision begins in late childhood or teens.

Type 3: Hearing and sight are normal at birth, but both deteriorate at a rate that varies from person to person. Problems are usually evident by late teens, and by the time most people with Type 3 have reached their 40s they are blind and have complete hearing loss.

Early intervention

Since Usher syndrome affects hearing, balance, and vision, the diagnosis usually includes the evaluation of all three senses. Evaluation of the eyes may include a visual field test to measure a person's peripheral vision, an electroretinogram (ERG) to measure the electrical response of the eye's light-sensitive cells, and a retinal examination to observe the retina and other structures in the back of the eye. An audiological evaluation measures how loud sounds at a range of frequencies need to be, before a person can hear them. An electronystagmogram (ENG) measures involuntary eye movements that could signify a balance problem.

Early diagnosis of Usher syndrome is very important. The earlier that parents know whether their child has Usher syndrome, the sooner that child can begin targetted educational training programmes to manage the loss of hearing and vision.

The way forward

Early identification is critical so that educational programmes can begin at the soonest. The exact nature of these programmes will depend on the severity of the hearing and vision loss as well as the age and abilities of the person. Typically, treatment includes hearing aids, assistive listening devices, cochlear implants, or other communication methods such as sign language; orientation and mobility training; and communication services and independent living training which may include Braille instruction, low-vision services, or auditory training.

Some ophthalmologists believe that a high dose of vitamin A palmitate may slow, but not halt, the progression of retinitis pigmentosa. This belief stems from the results of a long-term clinical trial supported by the National Eye Institute and the Foundation for Fighting Blindness. Based on these findings, the researchers recommend that most adult patients with the common forms of RP take a daily supplement of 15,000 IU (international units) of vitamin A in the palmitate form under the supervision of their eye care professional.

Crossing the tunnel

Sriharsha Jayanthi

Hello everyone,

I'm Harsha, a rookie writer, writing my first article for *Success* & ABILITY. Hopefully, in the future I'll be back, with more articles for your satisfaction!

My first article, here, is about a special subject that I'm deeply concerned with – Usher syndrome. I found out about my condition – the fact that my disability was even deeper than I knew it to be, only last year. One morning, when I was casually discussing college courses with my dad, he told me that I had Usher syndrome and that my side-sight would degrade. To illustrate this, he mimicked binoculars with his hands, covering his eyes with them. I still didn't understand, for my side-sight had already degraded a small bit and seemed to have stabilised. So, I decided to go online and ask the question (like many others) from Google. There was a page by an Usher's expert that explained everything, from medical, to the future of those afflicted.

We (my dad and I) read it together. For me, it was horrible and intensely painful. The author talked of other young deaf people like me, who were told of their condition during important phases of their lives – before taking up a hazardous job, before marriage – their dreams torn, their futures narrowed. Before all this, I was quite ambitious and a freedom-loving person with dreams of studying in Cambridge. The impending loss of one of my greatest assets – my sight – was a huge set back mentally.

What of my parents? My dad spoke of all this in a causal manner... as if it was something we'd already talked about before... a 'done and dusted' matter. Ever since this discovery, I've come across blogs and forum posts dealing with Usher - the parents in each one of them had great difficulties in telling their children about their condition. They would act as if the poor child had cancer, frightening them out of their wits by the suspense alone. My own parents didn't join me in my 'mourning' – this simple act cut short my sorrow a great deal. Many doctors – retinal specialists had assured my parents, over the years, that breakthroughs were being made, Retinitis Pigmentosa on its own, was not very rare, lots of research was underway in that field. A cure for blindness wasn't a mere theory anymore. Actually, four plausible paths to a cure exist today - stem cells, gene therapy, retinal chips, and bionic eye. In 2011, two women were cured of macular degeneration; more recently, a completely blind woman saw a flash of light. There is indeed hope.

Even as I write this, a matter of debate rises to mind – is all this optimism unfounded? Are my parents harboring false hopes? As a scientific person myself, I know that science is flincy. A treatment could be promised, say for HIV – instead of the promised decade, it takes three decades to find the cure. In addition, most treatments have their own side effects – for instance, tumors due to stem cell therapy and infections from gene therapy. So, a certain period of time has to pass after the discovery for perfection – to ensure the treatment is absolutely safe. Along these lines, I do know that, despite all the optimism, one has not to take things for granted.

Sometimes, I think of what people must have done in the past... on how much worse it must have been, back then. The diagnosis would have been made. Then... that was it! The person had to go figure out how to deal with it. No computer technology existed and most of the jobs were in the factories, so a lonely and impoverished existence was inevitable. Imagine a young working-class man, in his 20s about to join a great workforce – the company doctor tells him, "sorry son, you have Usher syndrome, you cannot work for long. Best spend the time of sight you have left in happiness..." In the middle ages, people would have been affected like a bolt out from the blue – priests, scholars, peasants – maybe, even a knight. It would be dubbed as the effect of some mysterious disease, the victims left to the mercy of quacks and their dubious methods. Inevitably, each one of them would have been thrown out of society to lead a crippled existence with no rights or liberties.

Okay, so far - I've focused just on the blindness part. There are other conditions that come with the syndrome – deafness, night blindness and lack of balance. I have Usher Type-1, which means that I was born with all these things. That's a significant advantage over losing them one-by-one over the years. The difficult thing about being deaf is that there is the potential of missing out on a lot of spoken information. To make up for it, I've got to read a lot. Another thing, no less important, is that I have to do my best to avoid developing a 'disability complex', that is – letting my disability determine how I treat other people. Some of you probably have noticed that disabled people connect better with people who have the same disabilities. This sort of interaction can overshadow the person's connect with the normal world. For me to move forward on this one, I just have to improve on my speech, and I'm off.

The combination of lack of balance and night blindness makes me useless in dark places. As a consequence, there are sacrifices – friends do not call me for a night-out. Even in daytime, I have to rely on others to move around the city. No cars, India isn't America where every 18+ teen owns a car. Besides, there's hardly any space to park one, soon there won't be the fuel, he he. Bikes? Hmm?

Career wise, I have decided not to worry too much over what the future could hold for me and simply carry on and do what I'd been thinking of doing all along. Anyways most modern big-jobs – even flying fighter jets can be done on a computer. I was inspired a lot when I visited CavinKare ABILITY Awards 2012 - where one of the awardees was Azeem Bolar. This man lost his eye sight just when he passed out of college, then suffered a stroke. Yet, he found a job which needed him. This means, that whatever the circumstances, it's certainly possible to manage. You don't have to make compromises and take the easy way out just because of your condition. Just do what you can - in all possibilities, you can become the trailblazer for others... that will be just as well, and you only live once

To sum it all up, I'm putting here a quote from one of my favorite stories – The Last Question by Issac Asimov:

"In a universe, where every star had died out, darkness was the norm; nothing existed to be seen; it was a place of cold chaos. A computer was all that remained – that too in hyperspace. Man used to call it the Cosmic AC. All problems, except the problem of reversing entropy were solved by it.

Man was long gone, but AC never stopped thinking about the issue, until it finally came upon the solution. No one existed to receive the answer, so the Cosmic AC decided to give the answer by demonstration, before releasing his consciousness And AC said, "LET THERE BE LIGHT!" And there was light –

A TRYST WITH THE OUTDOORS

So you're tired. It's an effort to drag yourself out of bed in the morning. There are clear signs you're losing your enthusiasm for your job, your hobbies and your social life. When was the last time you could call a day your own? If you have some vacation time banked, there is only one cure for the onset of ennui. Pack up and head for the great open spaces!

Between budgets and busy schedules, planning a getaway is not as easy as it sounds. Add the travel hassles of packing a wheelchair and accessories, the fear of being stranded because you can't hear the announcements, poor vision that makes it necessary for you to take someone along, and the problems double, triple or quadruple! India's travel-worthy or even must-see places are not always disabled-friendly. Access is always poor, most places have not heard of tactile signs and visual signboards are not in the best of conditions. About public rest-rooms and places needed for breaking your journey, the less said the better. But we know travel can do wonders for our well-being. We really cannot afford not to travel.

Business trips, of course, we are not likely to miss. They build our experience and exposure, and offer an opportunity to temporarily learn other business models and practices. If it's a pleasure trip, we need to make sure we have the right travel companion. A nagging buddy could easily turn a holiday into a stressful experience.

Sometimes going alone may be the best thing to do. Doing so will force us to make connections with others, while giving us the freedom to do whatever we choose. Of course, the nature of the trip makes a huge difference – we must tailor it to our preferences. What does holiday travel mean to you? Beach-combing like Salil Chaturvedi, the poet? Driving at breakneck speed and plunging into ice-cold Himalayan waters like Navin Gulia in his hand operated car? Exploring every side of the globe from Dusseldorf to Darjeeling like Nitin Goel? Savouring the charms of the Shatabdi Express like Anjali Arora? Or checking out every major hotel in the country like Ketna Mehta? Whether for business or pleasure, to an all-inclusive resort or a friend's simple home, travel can offer great gains for your body and mind.

When you're travelling, you'll be out in the fresh air. You'll be breathing more deeply, re-oxygenating your blood. Travel can involve additional activities. Unless you want to rest at all times during your vacation, you'll likely do more walking than you would at home, and generally be much more active than your routine allows you. It is also likely that you'll discover the joys of eating variety. Have you tried sushi, moussaka or couscous?

Once you've set out on your trip, it won't be long before you begin to gain new perspectives. Travel gives you an opportunity to spend quality time with your spouse and children. Travelling gives you a whole new appreciation for different cultures and lifestyles that broaden your horizons. Socialising is great therapy. As SK, our consultant put it, "the more you travel, the more you appreciate the comforts of your home."

In the following pages, you will find a lot of useful travel tips, your rights as a vacationer and perhaps answers to questions you always wanted to ask but didn't know where.

GEETA PADMANABHAN

6 Tips for Travellers

'Vacation' is a magic word. Use it in a conversation and people are likely to momentarily spirit off to their private bit of paradise; disappear to somewhere that exists between fantasy and the world-as-we-know-it. What's the magic formula for conjuring up a charmed vacation?

SCOTT RAINS

First, open up your own personal travel style for inspection. Add a pinch of experience from each of the Six 'Knows' below and you will spice your formula with the wisdom of other travellers with disabilities. Stir it up with a friend or travel agent. Then get out there and see the world!

KNOW YOURSELF

Socrates said, "The unexamined life is not worth living". First off, ask yourself: What would make this vacation a success for you? Try to answer that question even before you decide on a destination, a reservation, or a travel companion. Pare down to the non-negotiables. Are you looking for quiet rejuvenation - or exhilaration? Do you have strict budget limits - or room to splurge? Does success mean having sun, snow, a tropical rainstorm - or are you content with whatever comes along? Do you have 'must includes' for your trip such as a food delicacy, an event or a language?

Secondly, review your physical health. Do it with your physician if necessary. How is your physical strength? Your stamina? Your immune system? Are you in physical pain that would influence your travel plans? Are your medications working correctly and do you have enough to bring on the trip?

What about your mental health? How is your emotional resilience? What's the recent pattern of your moods? Are your dreams or fantasy life telling you something about how you might react to travel right now?

KNOW YOUR SAFETY NET

Life is tough. (That's probably why you want to go on vacation in the first place!) Travelling with a disability can be a test of skill. Expect the unexpected, 'what if' around worst cases, and then strategise about how to deal with what you discover.

Did you leave a copy of your itinerary with friends and family back home? Have you established a schedule for periodically contacting people back home? Do they know what to do if they don't hear from you? If you have friends or contacts at your destination, have you double checked to see that all contact information is up to date and correct? Do you know how your travel companion responds in an emergency? Have you discussed various emergency scenarios with him or her? Does your personal insurance cover you while out of the country? Do you have travel insurance to make up the difference between what the airline will pay if they damage your equipment and the actual replacement cost? Do you have necessary vaccinations, medicine, prescriptions, and letters of medical necessity? Are your money and important documents kept in a secure place?

Do you have multiple copies of information such as contact names and addresses? Do you know what to do if your credit card is stolen? Are those copies distributed between various carry-on and checked-in items?

KNOW YOUR EQUIPMENT

Take responsibility to know your own equipment. Know their equipment too! Do you know it as well as, if not better, than the people who sold it to you? Have you made a toolkit with everything you need for repairs? Do you pack it in carry-on, not checked luggage? Have you prepared an instruction sheet, with illustrations, on assembly and the disassembly of your equipment? How many languages is it in? Did you arrange for an equipment check-up before you left? Have you brought along replacements for items that frequently fail? Do you know of vendors at your destinations that can repair your equipment in an emergency? As preventive maintenance for yourself as well as looking out for others in the disabled community, do you know how to report equipment failures to your vendor and the manufacturer? How to pass along any suggested solutions you may have?

There is a catch to this category. The line between your equipment and their equipment becomes fuzzy when your comfort and safety depends on the transportation company's vehicle. Do you know how to troubleshoot a lift on a van for an inexperienced driver? Can you instruct the baggage crew on how to stow your wheelchair, walker, or scooter? Handle your respirator or oxygen bottle? Have you memorised the accessibility features of various airplanes by make and model of the aircraft? Can you show the flight attendant the location of the button to unlock movable airline seat arms?

Language teachers and travel gurus may tell you that the most important first words to learn in another language are "Please" or "Thank you". I tend to prefer to master words like "Nyet!" ("No!": Russian), "Rollstuhl" ("wheelchair": German), "Kaaga" ("mine": Somali), useful phrases like "De jeito nenhum!" (roughly and in context, "Don't mess with that wheelchair!": Portuguese).

KNOW YOUR RIGHTS AND RESPONSIBILITIES

Laws, policies, business practices and cultural norms change from region to region and country to country. Dont be easily discouraged. Keeping track of the specifics merits an advanced degree in travelling with a disability. Be as knowledgeable as possible.

What responsibility do you have for knowing your rights? For effectively communicating your needs? Are you able to advocate for your own rights in a way that leaves the person you are confronting better educated and more likely to assist the next passenger with a disability? Do you make use of the airlines Complaints Resolution Officer (CRO)? Do you share what you have learned about travelling with others in the disabled community?

KNOW YOUR TRAVEL COMPANION

Be your own best companion first. Know what you expect out of a travel companion.

A travel companion, especially a good friend, can sometimes be a mirror. Don't burden them with the thankless job of reflecting back someone who you don't want to see. There is never a shortage of legitimate reasons to squabble when travelling and in close quarters! What does he or she expect out of you? Can you honestly and clearly communicate your own limits? Do you know each others habits with smoking, drinking, drugs? Each others sleep patterns and pet peeves? Do you have an agreement about borrowing and lending items or money while travelling? Have you established rules for disagreeing? For fighting? Are you comfortable discussing your disability with your potential companion? Have you done so already? Have you started getting to know your travel companion long enough before the trip to allow each of you to evolve a realistic set of expectations for your travel together?

Maybe your fellow traveller is a service, companion, animal companion or a pet.

Have you arranged for the necessary health exams and vaccinations? Do you know the companion animal policies relevant to transportation, lodging, or foreign travel? Have you prepared for the effect of a different climate or a different diet? Can you be certain that your companion will receive adequate exercise and have access to emergency medical care?

KNOW YOUR DESTINATION

Destination research is the least overlooked of the Six Knows. Common holiday spots can be very effective in communicating their image and appeal. The danger lies in being lulled into assuming that the specific accessibility information that you need is as easily available.

Can you read critically through marketing materials for the facts? Have you developed successful strategies for getting the accessibility information you need? Have you researched the accessibility of local hotels and resorts? What about theaters, restaurants, music and sport venues? Are local tourist attractions independently accessible or is accessibility available through prior arrangement? Will you be able to get what you need from car rental agencies? Bus and rail systems and taxi companies? Have you taken the time to find a good travel agent? Can you identify agencies like tourist boards or chambers of commerce that might be of help? Have you located and used online bulletin boards serving people with disabilities?

Travel can be a time of self-transformation. You can grow in confidence and self-esteem while gathering memories that will last a lifetime. One way to guarantee that the memories will be positive is to prepare with the Six Knows.

DISABILITY STUDIES: A PERSPECTIVE

The field of academic study in disability is growing worldwide. Disability studies, a relatively new interdisciplinary academic field, focuses on people with disabilities: how disability is viewed, defined and represented in society. The study refers to the examination of disability as a social, cultural and political phenomenon. From these perspectives, disability is not a characteristic that exists in the person so defined, but a construct that finds its meaning in its social and cultural contexts.

No single academic discipline can claim a comprehensive study of disability issues. The field is informed by the scholars from different disciplines such as history, sociology, political sciences, economics, cultural studies, anthropology, geography, philosophy, gender studies, media studies and more.

So what is meant by 'disability'?

The complexity of defining disability has aggravated because of the indiscriminate and loose use of the term by scholars. Some scholars view disability in terms of culture and identity, whereas others see disability as a label, still others see it as a social construct. In addition, they also use different linguistics related to disability. For example, 'disabled person' is used to focus on the centrality of disability in individual identity, whereas 'person with disability' gives the message that having a disability is secondary to the person's identity.

Within these subgroups, the language and spelling can play a significant role in defining the term disability. The word 'Deaf' (with a capitalised D) conveys the social model and emphasises membership in a cultural linguistic minority whereas 'deaf' typically refers to those who identify and associate themselves with the hearing community. This is in the US and other western countries, whereas in India the most acceptable terminology from right based perspectives is as 'person with disabilities' or 'disabled person' or 'person with hearing impairment' (Karna, 2009).

SANDHYA LIMAYE

Thus, disability studies recognises that disability is a key aspect of human experience, and that the study of disability has important political, social, and economic implications for society as a whole, including both disabled and non-disabled people, as stated in the mission statement found at www.disstudies.org.

Plenty of research, from various perspectives, has been carried out in developed societies, and yet this still remains unexplored in India. Disability studies are ignored in the curricula of schools, colleges and universities. Inadequate attention has been given to address issues related to disability and rehabilitation policies from inter-disciplinary paradigms. As a result, the issue of disability is being studied and analysed as merely part of the syllabi of other disciplines, in a piecemeal fashion.

There is also a far too rigid compartmentalisation of disciplines in the curricula of Indian universities and academic institutions, that has contributed to a reduction of cross-flow between various fields of research and has obstructed progress in the field of disability. Since disability is basically a human rights and developmental issue, its multitudinous dimensions must be approached from an interdisciplinary paradigm.

Ideally, as described by the Society for Disability Studies, that was created in mid-1990, a comprehensive programme should:

- Be interdisciplinary/multidisciplinary.
- Challenge the view of disability as an individual deficit or defect that can be remedied solely through medical intervention or rehabilitation by experts and other service providers. Rather, the programme should explore the various models and theories that examine social, political, cultural, and economic factors and help determine personal and collective responses to differences. At the same time, should work to de-stigmatise disease, illness, and impairment, including those that cannot be measured or explained by biological science, even while acknowledging that medical research and intervention can be useful. It should interrogate the connections between medical practice and stigmatising disability.
- Study national and international perspectives, policies, literature, culture, and history with the aim of placing current ideas in their broadest possible context. This is important since attitudes toward disability have not been the same across times and places, and much can be gained by learning from these other experiences.
- Actively encourage participation by disabled students and faculty, and should also ensure physical and intellectual access.
- Make it a priority to have leadership positions held by disabled persons and at the same time create an environment where contributions from anyone who shares the above goals are welcome.

However, the actual scope of disability studies differs from country to country despite its common core. Some, such as the United Kingdom, tend to see the field primarily as belonging only to disabled people and the disability activism that they might tend to promote, while in the United States, by contrast, a much wider range of professions such as sociology and social work that with both non-disabled and disabled people, may be involved.

> “ Disability studies recognises that disability is a key aspect of human experience, and that the study of disability has important political, social, and economic implications for society as a whole, including both disabled and non-disabled people ”

The disability studies programme has been criticised in several ways. It is said that this study focuses on the academic field and ignores personal experiences of impairment. Furthermore, that the social model of disability separates physical impairment from social disability, and in its most rigid form does not accept that impairment can cause disability at all. This has been argued by others that the socialised model of disability is too restrictive.

There has however been significant growth of courses in disability studies at both initial and postgraduate levels. There has also been an increased number in research centres and groupings specialising in disability research; carrying out participatory action research on issues of contemporary relevance to the disability sector. Therefore increased support for the funding of disability studies research is vital for the growth of disability studies in India. In relation to disabled people, this means giving priority to their voices in terms of the contexts in which they are being expressed, the content of these voices including their possible contradictions and the outcome of such perspectives.

Epilepsy:
AN INVISIBLE DISABILITY

DR. ENNAPADAM S KRISHNAMOORTHY

Epilepsy is the most common and serious neurological condition and affects between five and seven per thousand persons in the community.

Thanks to the developments in medical science, today, epilepsy is eminently treatable. However, about a third of all people with epilepsy do not gain control over seizures, despite the best treatment. Further, the vast majority of people with epilepsy in countries like India experience barriers to healthcare, failing the 'Four A' test of availability, accessibility, affordability and acceptability. Thus, it has been estimated that over 90 per cent of people with epilepsy in developing nations like India experience a 'treatment gap'.

Like many other longstanding neurological conditions, epilepsy can be a very disabling illness. The tendency to have recurrent seizures that often strike without warning in the most inopportune moments, does understandably impose many restrictions on the person thus affected. Research from across the globe has demonstrated amply that persons with epilepsy experience fewer opportunities through their lifespan: being less likely to achieve normal levels of education, find an appropriate job, earn adequate income, get (or indeed stay) married, when compared with her/his peers. Further, epilepsy is a highly stigmatised condition even today, in both eastern and western cultures.

The term 'disabling epilepsy' has therefore been adopted by the International League Against Epilepsy and the Indian Epilepsy Association to distinguish the condition from non-disabling forms of epilepsy. Disabling epilepsy is defined as a 'disorder characterised predominantly by recurrent seizures associated with considerable medical and psychosocial co-morbidity; with a range of adverse consequences; affecting the physical, emotional, social, occupational and vocational functioning of the person affected.' This emphasis, in line with the World Health Organization's bio-psycho-social model of health, moved from the purely medical focus on seizures, to their impact on a person's life domain.

Epilepsy is an invisible disability: in between episodes of epilepsy, the person can function normally; yet, unpredictable and recurrent seizures render him/her disabled. There is a global desire for the development of special legislation that is sensitive to the needs of people with disabling epilepsy. For example, in German law, epilepsy falls within the framework of disability legislation, which is regulated as part of general social legislation 'Sozialgesetzbuch'. Even rare, mild forms of seizures constitute 50-60 per cent disability; more frequently occurring milder forms without loss of consciousness 60-80 per cent; and frequent seizures as 90-100 per cent disability. Even if seizures cease, the person is considered as disabled as long as he continues taking anti-epileptic drugs. Epilepsy in German legislation is considered to be 'healed' only when the person with epilepsy is seizure-free for three years, without medication. Some privileges accorded to persons with disabling epilepsy in Germany include restrictions on employers with regard to terminating services without giving special allowance; more holidays from work, the opportunity to seek early pension, tax reductions and breaks, social obligation for large companies to employ persons with disabilities, the right to adequate work, prohibition against discrimination, the right of inquiry, special facilities and privileges for studying, etc. In the Indian setting, many of these remain a distant dream for people with disabilities.

A problem with Indian legislation on disability is the 'disease and diagnosis focus.' As a consequence, members of the epilepsy movement have had to lobby very hard for its inclusion as a disabling illness. Further, Indian legislation relies heavily on subjective definitions of 'greater than 40 per cent' or 'greater than 70 per cent' disability, which are difficult to validate across clinical settings. Disabling epilepsy thus exemplifies the problems of disability legislation in India. The disease-focused approach favoured by the Indian authorities is leading to the exclusion of people with disorders such as epilepsy. There is a need to shift to a truly social approach using instruments like the World Health Organization's International Classification of Functioning (ICF). Needless to say, disability measurement and the certification for conditions like epilepsy must be voluntary (the person should decide whether she would like to be assessed and when) and repetitive, giving people with this treatable condition the opportunity to become non-disabled, thanks to advancement in medical care.

'Disabling Epilepsy' is thus an illustrative paradigm that the Indian policy maker would do well to draw upon in developing disability legislation for generations to come.

THE KEY FOCUS AREAS THAT RENDER EPILEPSY DISABLING WHICH ARE IGNORED IN TREATMENT:

The fear of seizures and the restriction in activity across a person's lifespan, resulting in the denial of a range of opportunity.

Embarrassment and perceived stigma due to seizures, resulting in a self or family-imposed restriction of social, occupational and vocational functioning as appropriate for age and social station.

Poor educational and occupational attainment across the lifespan resulting in significantly diminished achievement and attendant disability.

Diminished social achievement across the lifespan: limited peer group interactions, lower potential for marriage, normal family life and relationships.

Considerable financial burden of disabling epilepsy across lifespan.

Consideration of these factors should become regular practice in the assessment of people with epilepsy, as should interventions that reduce their impact.

Celebrating National Epilepsy Day with school children.

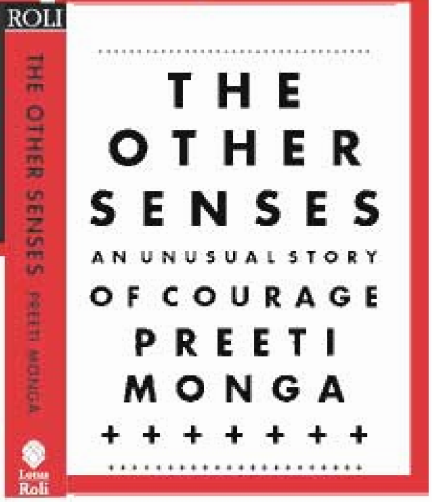
What we can do!

- Early diagnosis: suspect epilepsy not only when a person falls and shakes; think about it even when people have periodic inattention, funny sensations or movements, odd gestures or behavioral problems.
- Initiate treatment with anti epileptic drugs early by seeing a neurologist. Ensure the right drug is given at the right dose. Follow up closely with the doctor. Learn to distinguish symptoms of the illness from side effects of medication.
- Yoga is believed to be helpful in the management of epilepsy. Counselling for the affected person and family can be most helpful. Stress management and a healthy lifestyle - such as sleep and weight management have a role to play in controlling seizures.

Dr. Ennapadam S Krishnamoorthy is a Senior Consultant Neurologist at Neurokrish (www.neurokrish.com) and has founded a novel integrative healthcare concept clinic chain in Chennai, TRIMED (www.trimed.co.in). He is also TS Srinivasan Chair in Neurology at VHS Hospital. Dr. Krishnamoorthy was Chairman of the Commission on Neuropsychiatric Aspects, International League Against Epilepsy and lead the global discussion on disabling epilepsy. The views expressed here are his own. E-mail: esk@neurokrish.com

CHITRA .R

Title: The Other Senses
Author: Preeti Monga
Publisher: Roli Books
Price: Rs 250



A PICK-ME-UP BOOK

Effervescence – that is the tonal quality of 'The Other Senses', a book that is 'an inspiring true story of a visually impaired woman and her road to success.'

Chapter One sets the mood for the book, in which the author, Preeti Monga, speaks of not being recognised as a person with visual impairment. In fact, the only time we get to hear a direct mention of her blindness is when she think s about going through some hard times, courtesy, her first husband.

The reader can actually gauge the mood of the pages by the exquisite writing of the author, who does not fail to recall that her English essay was thrown into the bin by her teacher when she was in school.

ABSORBING CHAPTERS

While one can catch the nebulous quality of her first years and growing up in the loving arms of her parents– father Charanjit and mother Mohini and the conditional acceptance of her younger brother Sandeep (Sandy), whom she later comes to adore – one can also dream alongside her languorous teenage years.

Then came the devastating marriage to Keith which makes you sit up, eyes riveted on the pages, gulping down the misery of Preeti's life, while all along wishing she would fight back. Her graphic description of her first marriage is the most gripping part of the book as she pours out her heart –for the second time– for the sake of her memoirs and makes you go limp with sorrow at what life means for a woman without economic independence and who wants to give her children a better life.

It is a little difficult to believe that bubbly Preeti put up with the torturous marriage, as she returns to her abusive husband more than once – he even threw her out of the house on a cold winter night. But Preeti made the same mistake that many women, not just in India, but world over, do: they think having a child would somehow reverse the situation and make the husband reform. Preeti ends up having two children who suffer along with her, at the hands of the drunkard that Keith was. If you discount the fact that Preeti is blind, her plight would be that of many poor Indian women.

The chapters where she gains economic independence, slowly but surely and, is able to, not just support herself, but also others who need her support and help, elevates the reader's mood and you are willing to join the celebrations.

LITERARY SKILLS

It is however, not just Preeti's life of fighting against odds that makes the book interesting, it is also the easy way it is written and the subtle turn of phrases with which the author achieves this. Like when she talks about showing us the 'glorious pictures stored away in the closet of my reminiscence', during her childhood, or 'remote control parenting' and 'penance of separation' she talks about when her children live separately from her after her second marriage to Ashwani.

PUBLICATION

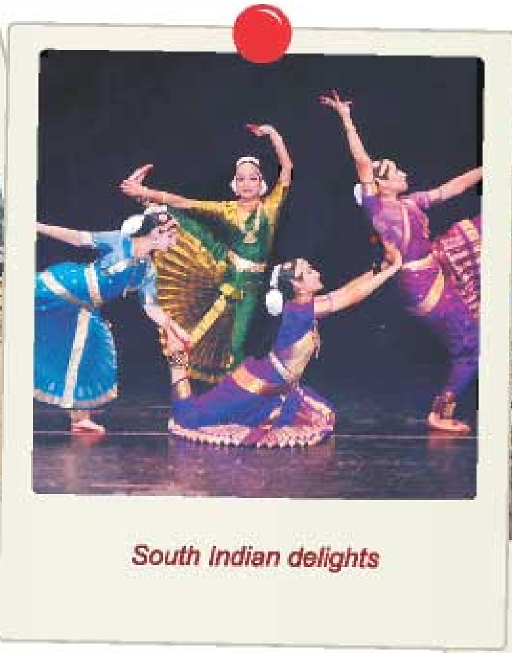
The publishers must be commended for the neat work that they have turned out. The cover design by Bonita Vaz-Shimray (with Braille lettering), the layout by Sanjeev Mathpal (chapter numbers come in Braille script) deserve special mention.

This is a book that every regular reader would want to read, again and again. It is a book that haunts you. Its contents refuse to blur much after you have put it down.

East or West: The Second Leg

Having survived the Indian summer time, Eleanor Davis takes us on her journey as she discovers the twists and turns of life in incredible India...

A first sip of sugarcane juice



South Indian delights

Streets of sugar & spice

How quickly six months have whizzed past, and to think that all I had to come to terms with when I last wrote, was the country's obsessive consumption of buttermilk! Now that the climate is a little more pleasant, the fear of getting body 'heat' is less, which leaves me freer to concentrate on filling up my mind and soul.

In this beautiful, bustling, ever-moving, ever-changing country, that isn't hard. The opportunities to indulge oneself in Carnatic music, get lost in traditional dance performances, practice the art of yoga or simply gorge the eyes on the fabrics, the temples, the pujas and the paddy fields, are endless.

Where to start? I thought to myself, eager to get fully immersed in my new home and surroundings. 'Communication is the key to success', so they say, and an obvious starting point was to get my tongue around Tamil, or perhaps, Tamlish... alright, Inglish, at least! Having come from an office in the UK, which was mostly made up of sign language users, it wasn't a shock to me to be surrounded by colleagues speaking another language. A room full of teachers – I thought with delight as I sat wide-eyed practicing rolling my r's and adding in the odd 'appidiya?', 'saapittiya?' or on a brave day, 'Neen-gaa ep-p-a-dee irr-oo-kin-ga?' causing much amusement to my office 'fellows'. At first I was bemused when my colleague told me her head was 'paining', or she was feeling 'tensed' but I now have to admit that I start most sentences with 'see' and end them with 'no?', and I'm sure the day when I pick up the phone and say 'tell me?' is just around the corner...

Eyeing up firecrackers on Diwali

> “There is nothing more exciting to Indian children than running into the middle of the road, sparkler in one hand, bomb in the other, and sparking a small explosion to the delight of an on-coming car, bike, or goat.”

Outside of the office, knowing a little of the local language comes in handy particularly when it comes to bargaining with auto drivers; known for tripling their prices when spotting a foreign face. For successful bargaining to take place, I soon realised I needed to, not only adopt the local language, but the local fashion also. Putting it to practice one morning I stepped out, donned in a salwer kameez, Bata sandals with plaited hair and dupatta slung nonchalantly over my shoulder, I looked the part, but did I sound it?

Flagging an auto is never a problem; it's avoiding getting run down by them that's the challenge. Spotting my lily-white skin and blonde curly hair, these drivers come bounding towards me, honking, smiling and mounting the curb in their enthusiasm...

"Anna! Besant Nagar beach?"
"ahh, ahh" followed by an inconclusive head wobble, engine revving and gesturing to the back seat.
"Evlow?" deadly serious face, he won't fool me...
"100 rupees Madam...petrol price increase...traffic...evening time...Madam"
"100 rupees??" (Fake stunned and disbelieving face), "Illey! 50 only."

And so it ensued, as it does most days, until finally I am being bumped around in the back as the driver avoids a cow, collides with a rubbish bin and fights his ways through two wheelers. Making sure he knows I'm no fool, I add in the odd "left-a", "right-a" or "straight on, Anna!" for authenticity.

Once able to successfully navigate myself around town I thought it time I engaged myself in some of the fine Indian arts; Sanskrit poetry perhaps? Meditation? Chanting the Vedas? I didn't have long to ponder until I found myself in salsa dance classes, encouraged by my friend who assured me it was all the rage with the young Indian generation.

She was not wrong. The dance studio was filled with suave, well built men, twisting and turning their lean, glamorous partners balanced on kitten heels. In no time I was being flung across the dance floor, desperately trying to look elegant and 'wiggle' my hips whilst reciting 1-7 to keep up with the latino music. My partner, a good 1.5 feet taller than me, remained stony faced when I apologised for stamping on his foot for a second time. Either disinterested or incredibly nervous he refused to 'look into my eyes' as we were instructed, and remained fixated on himself in the mirror, whilst I kept my eyes firmly on my feet, determined not to apologise for a third time...

It was soon apparent salsa wasn't for me, or perhaps I wasn't for it... either way I wanted something a little more experimental, a little more... Indian.

I was a little late for my first Bharata Natyam class, delayed by the purchasing of the coconut, beetle leaf and the flowers that I was instructed to buy for my dance 'master'. Unsure of how

Modelling Ganesha out of clay on the streets of Chennai

to deliver the goods I balanced them tentatively in my hands, entering the room of the beginners' class to be met by a group of gawping five-year-olds, all terribly amused by their new classmate. After chanting some sort of prayer and learning the Namaste (the five-year-olds still gawping) the lesson began; an hour of leg bending, foot tapping and beautiful hand gestures followed, and although it took a good 48 hours after the class for me to regain the use of my thighs, it had me hooked. Finally, I had found a cultural pursuit in which I could lose myself in this big city and connect mind body and soul, for an hour a week at least.

As we entered the festival season, I was able to feast on the cultural delights which keep me so fascinated with India. Ganesha Chaturthi, the birthday of the Lord Ganesha, was a personal highlight for me. Watching the Ganesha idols emerge from clay moulds – ranging from just a few centimetres to a towering 10ft high, I spent the day gawping and 'clicking' photos of Ganeshas painted in bright pink, yellow, black, or gold – sat on his usual carrier, the rat, or a tiger, or a throne. He was lying down, posing with sweets and flowers and all surrounded by offerings from his followers in the temples. A few days later, I managed to watch the processions of devotees setting off firecrackers in Ganesha's path as they paraded him through the streets to the ocean, to be immersed by the waves. The whole spectacle was remarkable, and reminded me a little of how we celebrate Christmas at home, when Father Christmas appears all over the country, just for one night.

Ganesha Chaturthi sparked the perfect mood for Diwali, the second time I was celebrating the 'festival of lights' in India. With memories of the fire crackers, the smog and the war-zone like noise pollution of last year, I made plans to visit a children's home and spend some time playing games, sharing gifts and lighting diyas. No sooner had I arrived, when a box full of sparklers, flower pots, chakrams and bombs were thrust into my arms. I soon learned that my idea of a morning playing organised and well-controlled games, was naivety on my part, and there is nothing more exciting to Indian children than running into the middle of the road, sparkler in one hand, bomb in the other, sparking off a small explosion much to the delight of an on-coming car, bike, or goat. After getting over the initial panic of small children with fire explosives, and the lack of any orderly queue to light the crackers, not to mention the absence of gloves and a safety rope (essentials in the UK), – I relaxed, embraced the experience and thoroughly enjoyed watching families join together on the streets under a sky of fireworks. Lakshmi, the goddess of wealth rose up in splendour outside the temples as the population all over, sporting newly stitched clothes, congregated to pray for prosperity and good fortune. Pollution politics aside, Diwali is a unifying and electrifying occasion in India and one to be treasured.

Entering a new year, I'm ever eager to see what the next few months will bring. Perhaps I'll give Hindi a go? Will I make my Bharata Natyam debut at Kalakshetra? It's safe to say that in India, the land of diversity: the bringing together of cultures, religions, people, food and history under one colourful roof, has something to offer everyone and everything to offer someone like me, who is forever learning from this country. I mean where else in the world can I go to work and hear Tamil, see my friends and listen to Malayalam, arrive home to be greeted in Hindi and finally end my day practicing sign language, or else call home speaking an eclectic mix, which I now call English...

In India, anything is possible...

NEW YEAR RESOLUTIONS, ANYONE?

APARNA KARTHIKEYAN

My New Year resolution was decided for me by a well-meaning friend. Just as I was complimenting her on her smart New Year's Eve attire. I also bemoaned the fact that I couldn't dream of wearing half of what I had in my cupboard (they don't fit, you see), when she said, 'so, let that be your New Year resolution.... lose weight!'. As if it was the easiest thing in the world!

Yet, I promised her I would try... just as I had promised myself the last 6 or 7 years. Every January it was the same story – stand on weighing scales on the morning of the 1st, tell the daughter to check weight, scold her for pointing and laughing, make a note of weight, and bribe daughter to never repeat the number to anybody... ever.

Now begins the difficult part – undoing the damage of all those slabs of plum-cakes and cups of payasams. What do I do... heaven help me... because, come December, all my feeble resolves usually brake down, or have been broken down by others! Could it be because as per the New Year philosophy – the logical idea is to 'wipe the slate clean and start afresh'? Besides, what, as I asked myself, is one more bite of cake or one more gulp of payasam?

Apparently, they all add up. To the inches piling on around my waist; to the knees, when they make old-lady noises when I sit or stretch; and to the back, which feels as stiff as a board first thing in the morning. Now... this calls for a concerted effort to get me back to the happy place where my weight was its acceptable best and my fitness was robust. Thankfully, there's enough support online; and a quick browse brings me up to speed with healthy food stuff...

The first thing I learn is to keep one eye on nutrition and the other on calories. Which is why I'm scribbling on a piece of paper as I type this. I'm pencilling in sprouts, oats and fat free milk. On another scrap, I make a note of the vegetable list for tomorrow; it reads like a conscientious rabbit's breakfast – crisp orange things, green leafy stuff.

However, the whole dieting game, I understand, is a grand waste of time unless it's supported by exercise. Experts say that just going backwards on carbs will perhaps get rid of the flab for a bit; but then again, the body will go into 'starvation mode' and stop burning the fat. So walk, they say, or better still, run. I prefer Pilates, so I've begun to set the alarm for 5:45 a.m, hoping that I can carve out those fifteen extra minutes from an otherwise busy morning and spend it flat-out on mat.

The trouble though is not just the initial enthusiasm... there's plenty of that... it's the will to sustain it beyond January. To this effect, I receive plenty of advice from friends, and family. Here's some of it –

- Pin-up a slim picture of yourself on the fridge; it motivates you; and acts as a deterrent when you want to whack the daughter's chocolates.
- Keep a food diary. And be honest.
- Rope in somebody; you'll motivate each other; but remember to set realistic goals.
- Don't rely on massages to lose weight; only the masseur does, if at all.
- Don't skip your walk. Even if your legs hurt.
- Don't skip Pilates. Yes, your butt will hurt.
- Eat plenty of chocolates... in your dreams. When you're awake, limit yourself to an occasional nibble.
- If it makes you feel better, tell people your weight in stones. If they're very clever with numbers, say it in Swahili. Whatever makes you happy—because, sometimes, there are more important things than being slim...

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