

Newsletter

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Editor's note

Dear friends,

As we travel through life, we encounter different people, different perspectives and various levels of perseverance. But my personal champagne toast goes to those who take extra steps to make this world a better place. The one quote which comes to my mind while I share this edition is "It is our decisions and not our conditions that determine our quality of life". -John C. Maxwell.

Isn't life all about trusting our feelings, grabbing opportunities and realizing that change is inevitable with sustained effort? The edition collates a few human endeavours in bringing about change in the society.

Happy reading!

Regards,

Bhavna Botta
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From the heart

The Tryst with Stage-

Mrs. Jeeja Ghosh

I had least expected that I could act on stage. So when Esha, the director of Katha Kalam, an inclusive theatre group, asked me to act, I was somewhat skeptical. Yes, I had performed on stage for school concerts. But that had been some 30 years back. I said to myself – me and acting? Somewhere it really doesn't fit! Anyways, with Esha's persuasion, I reluctantly agreed.

The play conceived by Esha was based on the gruesome gang rape that shocked not just India but the entire globe in December 2012. I had to play the role of Nirbhaya, the glorious name given to the girl who became the victim of lust. Esha wanted to portray two images of Nirbhaya – the first one, an enthusiastic young woman with her aspirations in life, while the second one – a battered body, yet with an undaunted soul decrying for justice till her last breath. Esha had chosen me for the second character. I found it challenging and that perhaps prompted me to accept the new dimension of creative art.

"Black Holes are Not Black", as Den had named the production, was much more than just acting in a play for us. As a theatre group, we were standing at zero balance. Thus we were also the people who had to look for funds so that we could stage the first show. This was not an easy task and we were literally gallivanting all over the city, knocking at doors, asking for support to put up our first show. Thankfully we did manage and we launched our debut show on 8 March 2016 coinciding with the International Women's Day.



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Thus this was our beginning! Acting on stage has the potential to be intoxicating. Once you got over the initial apprehensions of facing the audience, you kind of enjoy the presence of being on stage and witness the responses of the audience. Every performance is a challenge. Once you have built up the expectations then it becomes your onus to live up to them. Thus each show was a new learning.

Esha as a director was tender yet firm. Her constructive feedbacks helped us to sharpen our acting skills. She helped us to appreciate the importance of identifying with the character we were to enact. This had the potential to craft the characters so that they seemed to come alive. Establishing an invisible communication with the audience was significant in capturing their absolute attention and thus engrossing them completely



Undoubtedly the rapport with the co-actors was a vital ingredient in the curry. The chemistry was critical. Of course we are all humans and somehow cannot avoid obliging in unintentional errors. The art however lies in the technique the performers are able to manipulate thus saving situation from the impending disaster. Frankly speaking we did have quite a few moments when one of the actors committed a blunder and left the co-actor to swim in the deep sea helplessly clattering for an anchor. All these added to the flavor of live performance. There are no options of takes and re-takes unlike the silver screen.

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Reliving on stage the agony of Nirbhaya has made me delve into the horrific experience of gender based violence that mostly women have to face by the virtue of being the “lesser gender”.

I find it strange writing this article just after the Supreme Court verdict proclaimed death sentence for the accused. Isn't this an irony that some of them esteemed intellectuals are questioning this judgment? Capital punishment is unacceptable in a “civilized society”.

I earnestly question them was it civil on the part of those savage men who ripped apart an innocent girl?



Jeeja Ghosh believes in the rights based approach and dignity of all human beings and this is reflected in her work as the Head of Advocacy and Disability Studies at the Indian Institute of Cerebral Palsy, Kolkatta. A documentary film named *I'm Jeeja* (on her life produced by PSBT & Doordarshan of India and directed by Swati Chakraborti) won the National Film Award 2016 from the Govt. of India as the best film for social issues in the non-feature film category.

Attitudinal change

Attitudes are associated beliefs and behaviors towards something Ms.Pavithra explains why there needs to be a change in this society towards employment of people with disability. **'Pavithra, you already have a master's degree in mass communication, what interested you to pursue human rights**

I am a strong believer of “**No person with disability shall be discriminated on the grounds of disability**”. I am a person with cerebral palsy and have been in inclusive schools and colleges .There are many barriers in this society which create limitations to persons with disability. It is every citizen's right to have equal opportunity,so I realized I needed more knowledge in Human Rights to create awareness among public to make our society inclusive.

What is your opinion on the new Rights Of people with disability act which states that there will be no discrimination in infrastructure, transport facilities? Promises are many,the reality is different –access is the biggest drawback for a person with physical disability like me. If public transport is accessible, more opportunities would come our way. Our dependency will come down, but I guess it is a long drawn battle. The tragedy is generations are going by without much change.

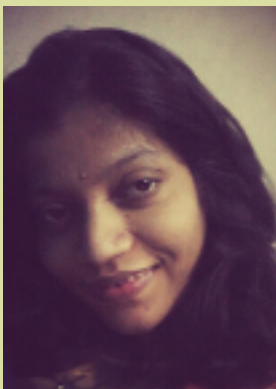
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What is your opinion about employment of people with disability?

There is a lot of hesitation in the employment sector when it comes to people with multiple disabilities.

Be it engineering or arts, the job sector is not willing to give us opportunities to prove our abilities against the disabilities. I am qualified; willing to work hard all I would need is a speech to text software to work independently. But how many potential employers interview me with this reasonable accommodation in mind? There are thousands like me raving to prove our abilities and talents but lack of mindset to create and accept accommodations, is still making us sit at home. **So what are your future plans?**

As I wait for a job opportunity in the field of content writing I want to create awareness as a human rights activist regarding many issues. It was a great struggle in the disability sector to bring the reservation for various levels of disabilities. So many human rights activists, disability rights activists fought to bring the reservations for the various categories of disability. But where is the implementation, so the struggle continues.



Ms. Pavithra Swaminathan, is a final semester student pursuing Masters in Human Rights. She is passionate about inclusion and equal opportunities.

Creating Opportunities

Aparna Das, founder director of Aurnima shares her vision about Independent living

Madam you have started Aurnima, India's first assisted living centres for teenagers and adults with autism and now recently, you extended its vision to launch a new initiative, The Independent Living Program. Could you tell us a little about it?

The Independent Living Program is a very exciting initiative indeed. We found that some of our residents had lower support needs, and also the ability to develop good life skills. Continuing to live in a group setting was restrictive to their development, and not fair on the others who had higher support needs.

So we decided to "take the plunge" and move the more independent individuals into two bedroom flats, along with a staff member. These young men and women live fairly independently, go out to work, engage in activities of personal development (like fitness/music) look after their own flats, do their own shopping and a lot of their cooking - like many other people their age.

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Who is eligible to join the Independent Living Program?

In our current setup, anyone who can manage his or her activities of daily living independently, and is interested and able to go out into the community with minimal support.



What is the profile of the current residents?

How do you equip these youngsters with skills that will help them get a job? The current residents enrolled in the Independent Living Program, all in their late 20s and early 30s, have fairly good expressive and receptive language. Everything in their environment works towards equipping them to be successful in the workplace as well. Doing a task from start to finish, working quietly,

staying on task, only having conversation related to the task – these are some of the aspects incorporated into their daily routine. Apart from this, very specific training related to the job itself, is required before someone joins the workplace. So for example, two of our young men, who work at a restaurant, also attended a 45 day hospitality course before they applied for their job.

How does one create an autism-friendly workplace?

Awareness is the key. So, while we work hard to prepare our residents for the work place, preparing the workplace for them is important too. Most importantly, the job must be very specific, and the same each time. The employer must be made aware that the expectations they have of their employee have to be structured, not casual and constantly changing.

What was the biggest challenge for you in setting up the Independent Living Program?

The most challenging aspect is finding the staff who will be appropriately supportive of our residents. This means, most importantly, knowing exactly when to step back, not over instructing, and always being aware that independence is our foremost goal. We are fortunate to have some staff who are constantly aware of the need to think each action through, but it continues to be a work in progress.

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What kind of self-advocacy and independent living skills is imparted at the Program?

Making one's own choices, be they in the colour of the curtains, to the weekly menu and learning that these choices will be respected. However, this is not isolated to the Independent Living Program only. All our service users are taught about the power of independent choices. That does not mean that one gets to do whatever one wants. But decision making is informed, and discussion based.

Why are we not able to build more provisions or inclusion in employment, schools and universities for people on the autism spectrum disorder?

Why are women targets of sexual abuse? Why are minorities discriminated against? It is all the same basically. Unless people change their mindset and accept the fact that each of us, as members of the human race has an equal right for opportunities anywhere, we will keep struggling with these issues.

Lastly, how do you see the campaign or struggle for the future of autism advocacy in India?

We are very hopeful. There is a strong movement for awareness raising and equal opportunities and one celebrates tiny victories that are achieved through groups of people working together. Good things will happen in the future.



Aparna Das founded Arunima, one of India's first assisted living centres for adults with autism. Located on the foothills of Himalayas in Dehradun, Arunima's vision is to provide a life of dignity and maximum independence to people on the Autism Spectrum.

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Human ingenuity

**Meet Arun Cherian, founder ,
Rise legs, world's first prosthetic
legs of cane.**

**Arun , it is a brilliant and game changing
concept, please tell us a about your
company and the idea**

Rise legs is a start up company with just four employees based in Bangalore. We make high quality, cost effective mobility aids for the masses not only for India but also for countries in Asia, Africa and South America. Right now, we make sports wheelchairs for basket ball and Tennis and prosthetic legs made out of cane, which is like bamboo

I am a robotics engineer in bio-mechanical locomotion .I studied how animals and humans walk and run. Essentially legs of any animal be it elephant or giraffe or spider or human, mathematically we all walk and run the same way. The leg is like a spring with acute stiffness .You have sports people running with these funny looking legs possibly better than able bodied people .These are springs, which is the reason why they run faster.

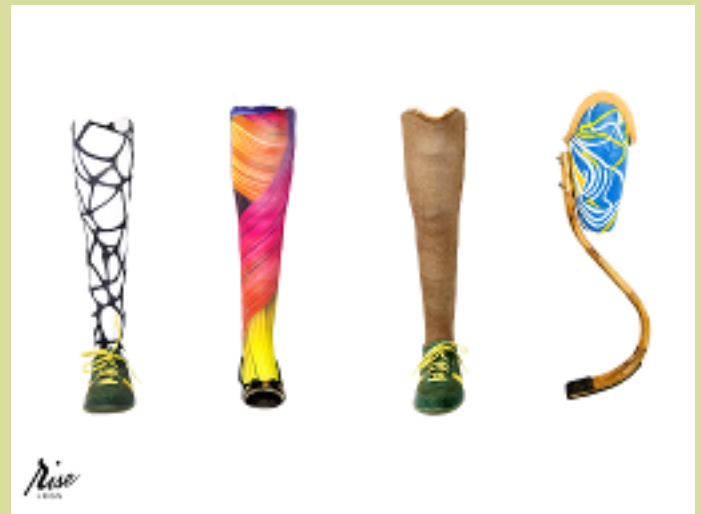
What I have done is introducing cane, with a unique fibre property, a special kind of cane, which makes it like a spring. It is not like springs we have in cars –spiral or helical .This is a different class of spring called compliant spring. This is very cost effective prosthetic leg which allows people to

walk, run and dance too. We have amputees with Rise Legs fitted in who have done marathons, crossed obstacles, climbed walls, and dancing.

Can you share with us the success and challenges?

In terms of success, the proof is in the pudding. We have Rise Legs users as fitness trainers for able bodied, as body builders, as marathon runners, as dancers.

One of the amputees who had lost both her legs was previously fitted with other prosthetic legs and used a walker for mobility. But now with Rise Legs she no more uses a walker but in fact has become a good dancer.



Tell us about the team for cybathlon, Zurich

We went on to compete at The Cybathlon 2016, in Zurich, Switzerland. It is an international competition organised for disabled competitors using bionic assistive technology, such as robotic prostheses,

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brain-computer interfaces and powered exoskeletons.

We had the honour of being the only team from India and from Asia along with Japan. We competed with the best in the world. Otto Bock came with a hundred thousand dollar prosthetic leg. While we had two boys participating in three races, using Rise Legs which was just costing a few hundred dollars (the cost was higher due to the sports need). Our boys stood first in 2 races and second in the third race.

Arun, how is the feedback of the field tests outside the sports arena

Outside sports we also have a 42 year old farmer who was previously using a Jaipur leg. This weighed 7 kg and due to this he could feel tired within 3 hours. But with Rise Legs, which is 2.5 to 3 kgs and also has a spring like effect, he is able to work for 13 hours as a wine yard supervisor.

There are many small sweet success stories like this person who was using an American prosthetic leg which needed him to wear foot ware all the time. This restricted him from entering temple. After Rise Legs were fitted he went to a temple after 6 long years, and the first thing he did after coming out is calling me and thanking

There are many challenges too—the perception that since it is made of wood it will break. We actually test it with three times the person's weight and encourage the users to try and break it. The medical community also doubts the

reliability of a product made of cane. But with the steady success; the hospitals are reaching out to us. Yes, sourcing the cane is a challenge but it is something which is solvable.



What has been the experience at Cybathlon?

As said earlier, our performance was appreciated by The International Committee for the Red Cross and is looking at Rise Legs as a portfolio product. With their reach in 80 countries, we are hopeful for a quick access.

In fact the founder of Cybathlon on seeing our performance, commented – "Rise Legs shows it is important to develop appropriate technology than just power technology" That was my happy moment as a robotologist on being able to create an affordable cane leg which allows a person to walk, run, dance, work and live a life as he or she wishes to the fullest.

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What is the response for the cane sports wheel chair?

Till now we have a very positive feedback on sports wheel chairs too. A regular motorised sports wheel chair made in US and assembled in China weighs around 23 kgs while the cane one is 9 kgs. The person can hold the ball in hand and turn the wheel chair by wriggling the hip. It is custom built and is sought by ICRC and other sports associations.

The challenge is to find talented human resource to make the high quality wheel chairs. We hope to solve this in the next couple of months.



What has been the learning so far

Many learnings in our journey so far, there has been some challenge with the waterproofing of the prosthetic legs, one of our Rise Legs user is a paddy farmer when countered this problem, so we worked on it. Even though the end users were very happy with the affordable and light weight cane leg they wanted it to look more realistic. So again we started working on the cosmetic appearance, giving it a skin texture and tone. Prosthetic manufactures from US are inquiring on this. We are looking at help from NIFT to add more artistic value and custom made art work on the prosthetic leg society

What are your future plans?

There is some fine tuning to be done which is why we are still doing end to end work and prototyping and working on a small scale. Our priority is to build a team, overcome

the challenges and spend on automating the process –be it measuring or fitting. We would be working on Arvind Eye Hospital model of mechanising the process as there are very few prosthetic makers for a geographically vast India. We are partnering with MIT, Boston, ICRC, multiple partners in US and Europe, CMC Vellore, St John's Hospital, Bangalore to automate the production.

We are in people's business and Rise Legs improves the quality of life with prosthetic legs and sports wheelchairs so the need for mechanization to maintain high quality.

We will continue to support the users with Rise Leg program of sports and dance. We create awareness; provide world class coaches, fitness trainers, nutritionists to our end users. We are looking at affordable, accessible, high quality device throughout India and countries in Asia, Africa and South America.



Arun Cherian quit his PhD in Mechanical engineering at Purdue University, USA and founded Rise Legs. Previously, he had been a researcher at University of California, Berkeley developing wearable exo skeletal suits to help the paralyzed people walk.

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Experts Advice

We are continuing the discussion on various issues that parents of children with special needs have to tackle on an almost every day basis and possible solutions.

Q. Are there differences between a mother and a father? Does the anxiety in both manifest themselves differently?

Naturally, there is stress and anxiety in both the parents. Grief and disappointment do not get processed as parents hardly find any time for these issues. Parenting is hard no matter who your kid is – and no matter who you are.

The manifestation may, of course, be different. The mother often always has to take the bigger brunt. She has to take maximum responsibility in taking care of the child and often feels guilty if she wants to take time off for herself. Due to lack of respite from the 24/7 challenge of caring for these children, she faces huge challenges for herself and the family.

Another source of stress is that often one parent is generally more effective in managing the difficult behaviours. The man, in my experience, often has the liberty to take a break from parental responsibilities without feeling the same level of guilt. But the younger generation is different. They are definitely more hands on.

Families with disabled children experience poor mental

health such as anxiety, depression or breakdown. They are often unwell -- and so they ask their GP for medication and often even choose to see a counsellor, which is a welcome step.

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is a Senior
Consultant in
Clinical
Psychology,**

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