

ABILITY

India's cross-disability magazine

July 2019

Simran Chawla

REGRET IS NOT AN OPTION



Understanding
Deafblindness

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WE'D REALLY LIKE TO HEAR FROM YOU

Whether you are a person with disability, or a parent, or a friend, or just someone who cares, we would love to hear from you.

You are just a **click** away!

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Ph: 91 44 2452 0016 / 2452 3013. | Published by Jayshree Raveendran on behalf of Ability Foundation. Email: magazine@abilityfoundation.org

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*Looking Beyond Disabilities &
Breaking Barriers Together*

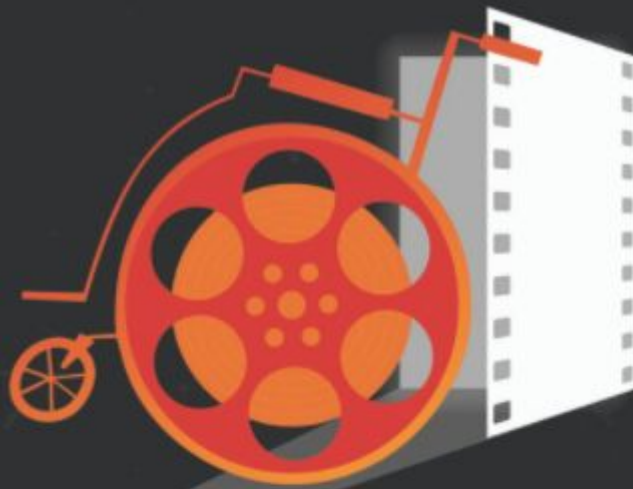
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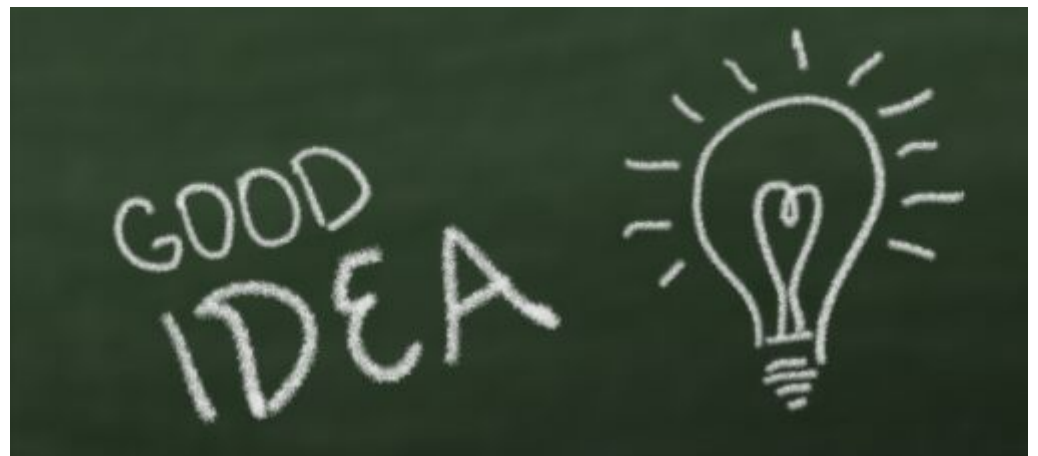
News & Notes

**FUNDING FOR
ASSISTIVE
TECHNOLOGY
START-UPS**

The BIRAC-Social Alpha Quest for Assistive Technologies has been jointly launched by the Government of India's Biotechnology Industry Research Assistance Council (BIRAC), Social Alpha, an initiative working to support India's science and technology start-up ecosystem and Bengaluru-based IT services company Mphasis. This initiative will identify 10 promising innovations that empower education, work and independent living of persons with disabilities and provide funding of up to INR 20 lakhs, besides support their entry into the market and implementation of work orders.

This initiative is expected to chart out a path to overcome the shortage of indigenous, affordable and quality assistive technology solutions in the country. This programme will validate the chosen innovations' product-market fit, fast-track the lab-to-market journey, help with clinical trials where required and bridge gaps in the distribution and service channels. The selected start-ups/innovators will work with implementation agencies within the Social Alpha, BIRAC and Tata Trusts network, interact with potential users of their products, gain exposure to other funders, buyers and CSR initiatives, work with experts on pricing, cost optimisation, market validation, marketing and sales.

Last date for applying is 15 August 2019. For further information and for applying, log on to www.socialalpha.org/assistivetech or <https://atq.innovatealpha.org/>



Government of India's Unique ID for Persons with Disabilities (UDID) card that is being issued to every Indian with disability and valid across India, may be applied online through the UDID portal at <http://www.swavlambancard.gov.in/pwd/application>. One may also renew his or her existing certificate/card on expiration of validity or in the event of loss of card/certificate through this online portal. The UDID Portal also provides information on the various schemes/benefits, procedures to apply for disability certificate/UDID card, manuals, etc.

The Unique Disability Identity card project will help persons with disabilities to easily avail schemes and benefits provided by the Government through its various Ministries and their Departments, help create a National Database for persons with disabilities, encourage transparency, efficiency and ease of delivering government benefits to person with disabilities and streamline the tracking of physical and financial progress of beneficiaries at all levels of implementation – village, block, district, state and national.



Check out this online course on Disability Studies. An All India Council for Technical Education (AICTE) approved Faculty Development Programme (FDP), the course explores disability's capacity to offer special frameworks in the interpretation of knowledge domains such as medicine. The course also explores the ways and means with which disability transpires into an interdisciplinary phenomenon.

The course is formatted as four modules running over eight weeks. In addition to regular lectures, this course includes valuable interviews with specialists around the globe on disability, such as with Reshma Valliappan on her experiences as a schizophrenic writer. The course content may be of great use to students, activists, rehabilitation specialists, and caregivers in general. Students pursuing B.E., B.Tech., B.A./M.A., Medicine and allied courses, Rehabilitation and Special Education might find this course particularly instructive. The course is conducted by

**UDID CARD:
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**DISABILITY
STUDIES:
ONLINE COURSE**

Dr. Hemachandran Karah who teaches English Literature at the Humanities and Social Sciences department of IIT Madras.

While, the course is free, the exam is optional and may be registered for with a fee of INR 1000. Candidates passing the exam will receive a certificate with the person's name, photograph and score (with the break-up) in the final exam. This certificate will carry the logos of National Programme on Technology Enhanced Learning (NPTEL) and IIT Madras and will be e-verifiable at nptel.ac.in/noc For more, log on to https://swayam.gov.in/nd1_noc19_hs58/preview

DISABILITY STUDIES: ONLINE COURSE



Pre-term babies might be facing risk of blindness due to untreated retinopathy of prematurity (ROP), because of not having been screened for it. According to a study done by Dr. Sucheta Kulkarni of H V Desai Eye Hospital in Pune, nearly three-fourth of the children who had become blind consequent to ROP had not been screened for the same and this had led to blindness. Other studies too report similar findings.

Experts advise that every child born before 32 weeks of pregnancy should be screened for ROP. If screening is done of the premature baby's retina, extra blood vessels growing in it, if any, can be spotted and treated and ROP may be prevented. While hospitals in major cities have facilities for screening ROP, the smaller cities and towns don't have this facility. Moreover, awareness on the need for scanning premature babies for ROP is lacking among both doctors and parents. The Indian Retinopathy of Prematurity (iROP) Society of India is to hold a meeting to discuss ways to generate awareness among doctors and parents about this disease.

SCREENING TO PREVENT BLINDNESS

Here's a pan-Indian cooking contest for visually impaired persons. 'Golden Eye Chef 2019' will be held at Agra between 17-20 October. Organised by Antardrishti, an NGO, the contest is being organised to change the common misconception that blind people cannot be independent or cook.

Those who are 18 years old or above and have complete or partial visual impairment are eligible to participate in the contest under the respective categories. The theme of the contest is 'Cooking Beyond Seeing'. The organisers of the contest will also invite designers to help develop accessible utensils, gadgets and kitchen designs. To know more, log on to <http://goldeneyechef.com/> or call +91 63999 00012. ●

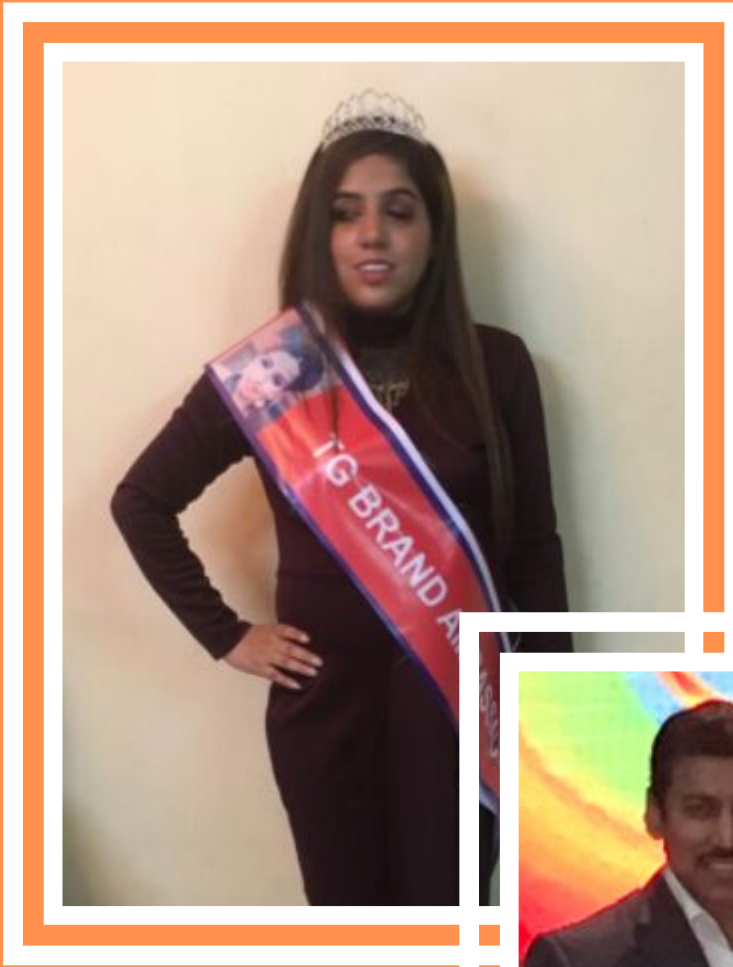
WHAT'S COOKING



Celebrate your friendship this month!

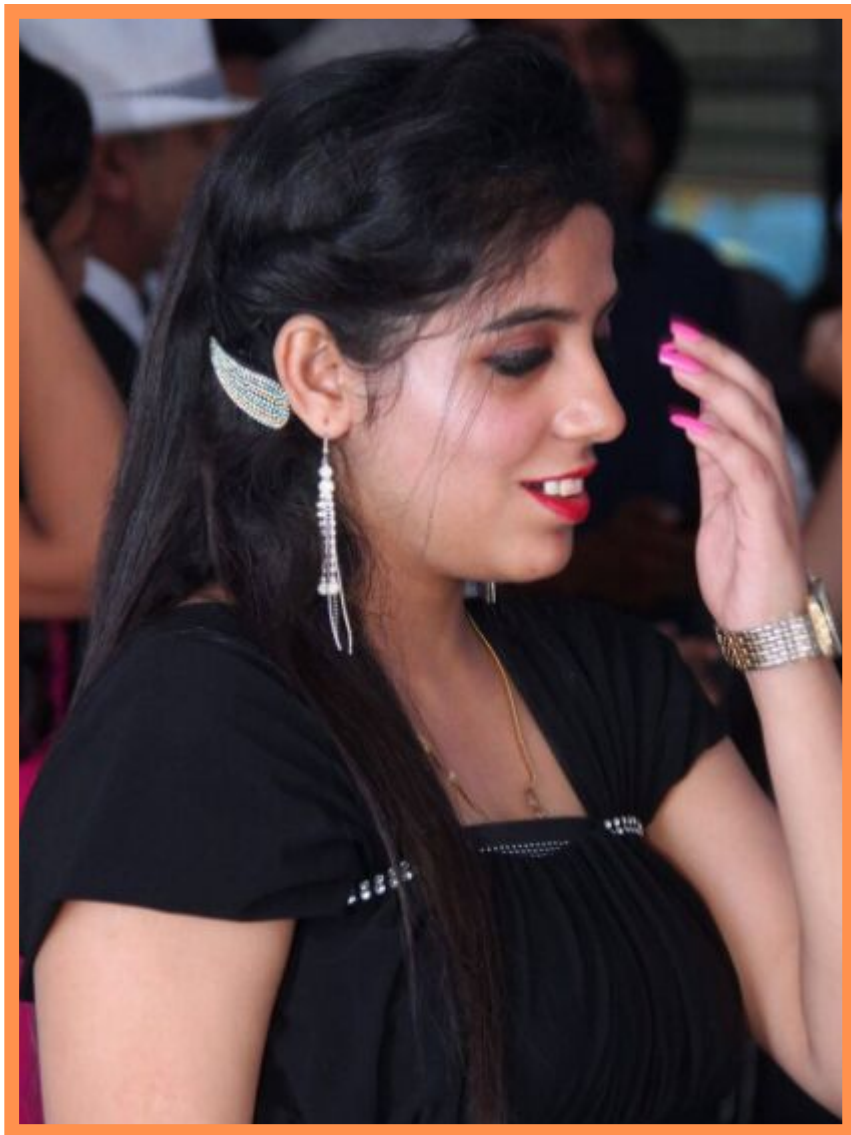
WORLD FRIENDSHIP DAY
30 July 2019

SIMRAN CHAWLA



Top right: Simran posing for a jewellery shoot; Bottom right: Awarded by former Minister of State for Ministry of Youth Affairs and Sports, Rajyavardhan Singh Rathore, for being the President of Enabling Unit, Hansraj College; Bottom Left: Simran in an Enabling Unit T-shirt; Top left: Simran felicitated as Brand Ambassador of Talent Groomers Humanity Club

I, ME, MYSELF



Model, actress, beauty pageant winner, radio jockey, anchor, brand ambassador, writer, founder/admin of Voice Over Bank, user experience architect and marketing executive at an app development company... and, and, and... let me catch my breath, people... this is Simran Chawla for you. Her life cannot be encapsulated. She lives life with a capital "L" on her terms, dreams big and lays it out there... a testimony to the credo that anything that can be imagined and sought out can be achieved. Here is her amazing journey, in her own words...

It was 14 May 2001. My family had returned home after a get-together at my uncle's place. My cousins and I were playing well into the night when our mothers told us it was time for bed. As my mother tucked me in, she touched my



forehead, and found it was very hot. I had 103° Fahrenheit temperature.

It was 3:00 a.m., and all the pharmacies were shut. When my parents finally got through to the doctor, he prescribed Nimulid syrup, which we had at home, as my parents often gave that to my younger brother when he had fever.

After taking the medicine, I slept soundly and didn't wake up in the morning. No one woke me up as they wanted me to rest. When my mom finally woke me to give me food, she noticed that my eyes were totally bloodshot. I was immediately rushed to the doctor and from there to the hospital, where I was admitted.

It was horrifying. Not just my eyes, my whole body had turned red with sores which looked like burning blisters. I was kept on glucose and fed intravenously. I couldn't eat anything at all. My weight dropped to around 15 kgs. My nails were breaking and my hair was falling off in clumps. I was just five years old at that time. My family couldn't bear to see me suffer so much.



Simran with her mother, father and brother



Childhood pictures

A month after getting discharged from the hospital, the marks on my body disappeared, but my eyes had been completely damaged. I had lost my vision. This traumatised me to the extent that I used to hit my head on the wall in sheer frustration when my mom was not around. The whole world around me had turned dark. I didn't know what was happening to me. When I woke up in the mornings, my lips used to be stuck together, and I couldn't speak. My dad used to come home from work just to prise open my lips with some medicine. A lot of blood used to flow out. It was just horrific.

My parents took me to every doctor in India, every pandit... they did everything they could to restore my vision. But my eyes had dried up. There were no tears when I cried. After eight or nine surgeries on my right eye, the only difference it made to me was that I started identifying colours from a very close range. After spending two years at home, of which one year was spent on rushing from one eye specialist to another, my parents arranged a home

Despite securing 93% in my twelfth standard board exams, getting into college turned out to be a huge challenge... my application was rejected on grounds of my disability. I fought tooth and nail with the University before I finally got what I wanted



tutor for me so that my studies would not get affected.

In 2003, I learnt braille at the National Association for the Blind, Delhi. Later, in 2004, they integrated me into Mount Carmel School, New Delhi, where I completed the rest of my school education.

When I was in the eleventh standard, after plenty of arguments with the principal, I was forced to enter the Humanities stream as visually impaired students were not permitted

to opt for science. This was a huge disappointment as I wanted to take the road less travelled.

Once I completed schooling, despite securing 93% in my twelfth standard board exams, getting into college turned out to be a huge challenge and I had to fight tooth and nail before I finally got what I wanted.

I applied for B.Sc. (H) in Computer Science at Hansraj College, Delhi University – my dream college, but my application was rejected on grounds of my disability. When I approached the college authorities, they informed me that my application had been rejected as the course involved plenty of visual elements. They told me that I was the first person with visual impairment to apply for this course at Delhi University and so I needed to get the go-ahead from the University. I then approached the university authorities, assured them that I liked challenges and would ace the course. I also told them that I wished to pave the way for other visually impaired people to take up this course. Finally, after plenty of arguments and convincing, I got admitted into my dream college.

Those three years in college were just awesome. They were unforgettable. When I was in the final year of my college (2017-18), I nominated myself for the post of President of

I want to experience and try out different things. We've got just one life. Why not make the most of it?



Crowned as Princess India 2016-17, Simran with celebrities, judges and the top three winners.

the college's Enabling Unit as I wanted to contribute to society and make a difference. Earlier, in my second year, I had nominated myself for the post of General Secretary but had lost in the elections. This time around, the system of selection for the posts had been changed from the election system to the interview procedure. I was confident of cracking the interview and I did that.

As the President of the Enabling Unit, my focus was to spread awareness about disability and promote inclusion, which we did through events and competitions. We celebrated World Sight Day, World Polio Day, Braille Day and so on. For my work, I was awarded and felicitated by the then Minister of State for Ministry of Youth Affairs and Sports, Government of India, Rajyavardhan Singh Rathore.

I graduated last year, and pursued my Master's in Psychology. You may wonder why I shifted from computer science to psychology. Well, I want to experience and try out different things. I wanted to explore and learn, and psychology has always interested me. We've all got just one life. Why not make the most of it?

Along this journey called Life, I have learnt several things. I have learnt that you have no control over what you've lost; the most you can do is, make the best of things that you have.

If you can't see, it doesn't mean that the world is dark for you. You can illuminate it by your thoughts. You can do anything and everything that you want, you just need to find an alternative way to do it. All that matters is your will and the determination to pursue your dream.

Don't waste life on regretting what you couldn't do or what you don't have. Just go on and live your dreams.

Speaking about myself, I've done many of the things I wanted to and I'm still trying to do the things that are left. I won a beauty pageant, 'Princess India 2016-17', and was crowned by John Abraham. I have always wanted to dance, though I found learning the steps challenging. For the first time ever in my life, I danced – at the talent round of the same contest. In fact, I owe the Crown to my dance performance.

Passionate about acting, I had always wanted to star in a TV series or short film. But being visually impaired, this was very difficult. After winning Princess India 2016-17, I contacted many people for landing a role as an actor, but when they learnt that I was visually impaired, they never got back to me.

But then, I have always had this attitude that if something isn't happening, it means that something better is waiting ahead. As it turned out, last year, I met the director of TVNF India, a YouTube channel that makes short films on social causes. The director loved my confidence, enthusiasm and positive attitude towards life, and hearing that I was keen on acting, he asked me to think of a theme on which we could make a short film. I wrote the script for the same. After filtering out so many scripts, we finalised one, in which I acted too, a film called 'Teen Dost'. The story was of three friends, two visually impaired, one sighted.



With Sudheer Choudhary at Human Library, Delhi

Acting comes naturally to me. I just feel the character and live the character, which helps me understand the character fully. Expressions being important in acting, if you know when to give a happy reaction, when a sad one, when to show disappointment and when to show your anger, you can act well. Acting is just a game of expressions, voice modulations, pauses and living the character's life.

I've served as a Radio Jockey at Radio Udaan and presented a show named "Dilon ki Daastaan", a unique show based on love stories. I've interned with FireMud FM as a Radio Jockey. I do anchoring. I am the Brand Ambassador of the Talent Groomers Humanity Club. I've done a jewellery shoot for the brand 'Design to Attract'. I worked with Robosion INC as Robot Conversation Writer. I'm a founder/admin of Voice Over Bank, a WhatsApp group for professional Voice Over Artists and Lenders/Agents.

I have a channel on **YouTube** in which I present my poetry and another **YouTube** channel I where I post my Ramp Walks and a personal blog on **WordPress** where I write about my experiences and reflections. I also give motivational speeches.

I have walked the ramp as a show stopper and have modelled for Designers Den at DAV Fashion, Lifestyle Week 2018 and Big Bazaar's annual event, Spark 2019, where FBB launched their summer collection. I am now waiting to do the other things in my to-do list. I am much inspired by Dr. Samir Mansuri, who organised Princess India 2016-17. He himself is visually impaired and is an ayurvedic doctor and a beauty consultant for many, including Bollywood stars like Priyanka Chopra. I draw inspiration from him that I too can do path breaking things.

My family, my parents and brother in particular, have always been a source of support for me. Whatever I am today, I owe it to them. They support me in everything I do, be it fashion shows, radio shows, studies, job, or whatever. They are with me throughout. Even today, they travel with me to my office, that is around 45 kms away from home, so that I reach there safely. They've always



Ramp walk as show stopper at Spark 2019, Big Bazaar's annual event

You can do anything and everything that you want, you just need to find an alternative way to do it. All that matters is your will, and the determination to pursue your dream.



pampered me and I'm proud to be born in such a loving family.

I want to enjoy and live my life to the fullest. I want to inspire and motivate people to live their lives fully too, as it is the most precious gift ever. Let me share with you, my conviction: Believe in yourself, stay positive even in the toughest of situations. Keep smiling, no matter what the consequences or the circumstances may be. Your one smile is the solution to all your problems. We've got just one life and it's as short as its spelling. Don't waste it on regretting what you couldn't do or what you don't have. Just go on and live your dreams.●

- Simran Chawla



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Understanding DEAFBLINDNESS





Akhil S. Paul



Sachin Rizal

A lot has changed for the better, nevertheless, ignorance and lack of awareness about deafblindness remains rampant still. In a revisit for the benefit of all stakeholders and family members of children or young adults who are deafblind, Hema Vijay of Success & ABILITY presents an extensive interview with AKHIL S. PAUL, Director and Founder Member, and SACHIN RIZAL, Senior Manager - Training of Sense International India, which has been at the forefront of advocacy on deafblindness, besides early intervention and rehabilitation of persons with deafblindness. So far, around 200 deafblind students from Sense International India's network have become breadwinners of their families - as entrepreneurs, bankers, teachers, software professionals, etc. Every deafblind child who gets early and appropriate education and rehabilitation can become a contributing member of society, say Akhil S. Paul and Sachin Rizal, and they give pointers on how this can be made to happen.



Please begin by telling us about the then and the now. How much has changed where deaf blindness is concerned, and what is imperative that we change now.

When we started, 22 years back, there was no name for deafblindness in Hindi or any regional language in India. Now we call it बधिरांध (badhirandh). Today, deafblindness has found inclusion in the Rights of People with Disabilities Act, 2016, with the Government of India (GOI) recognising deafblindness as one of the unique categories under Multiple Disabilities. Now, there are GOI-accredited teacher training programmes on deafblindness. Earlier, we had to go around convincing parents to take our services and support systems for the deafblind. In the last 20 years, awareness has spread word of mouth, and today, parents, on their own, reach out to our centres asking how and where they can get our service and support. So, now, deafblindness has moved on from being a completely unknown entity to a little-better known entity, though it is still not as well-known as autism, for instance.

When it comes to equal opportunities in education for deafblind persons, we require more than reasonable accommodation. We require curricular adaptation, in the sense of a change in the way we transact a curriculum. The way the teacher teaches in the classroom must not be exclusive. If the system is such that the teacher only speaks or writes on the board, then, this will isolate many children from the classroom. Using gestures, signs, more of play, etc. will help. That's what we look for in the future, for deafblind people.

So far, around 200 deafblind students from our network have become contributing members of their families. We would like to see that every deafblind child who enters school becomes a contributing member of society.

The other change that I would like to see in the next five to ten years is early detection and early intervention. Unfortunately, we are still not catching kids young, we get

to know of children with deafblindness only in their fifth or sixth years. Many a time, the parent recognises only in the child's second or third year that their child is not able to talk, walk or see properly; the next one or two years goes in running behind doctors, and mosques or churches or temples. Once they are tired of this, then they come to centres that provide services for these children. By then, five to six years of early learning has been lost for the child.

Deaf blindness having been recognised by the RPD Act 2016, through its effective implementation, deafblind children should get equal opportunities of education, employment and eventually, they should be empowered to become breadwinners of their families like other young adults.

How do we ensure early and effective identification of deafblindness?

What we would like to see in the future is for every Primary Health Centre (PHC) or district hospital to have an early detection unit as a rule, particularly those hospitals where there is a maternity unit attached, such that every baby will automatically go through it and get screened at the unit – this is what happens in developed countries. And then, once we recognise that any of these children carry a risk for vision impairment, some risk in the learning areas or other issues, then these children can be referred to centres for specific disabilities or to a tertiary centre where they can get more help. There should be referral centres in the vicinity that may take on these children and train the parents on how to bring their child up. It's a most valuable stage in the baby's life and must be maximised upon. Setting up an early detection unit is not an expensive exercise. It is very simple. We have so far helped create eight such units in states such as Gujarat, Bihar, Kerala, Tamil Nadu, and in Goa.

How does a parent recognise deafblindness in their child?

Well, this has been my observation from field experience... Most of the time, parents don't recognize that the child has such a disability, initially. Over time, after around six to eight months, they realise that the child has some challenge. Initially, no parent is ready to accept that their child has a disability and so, even after some indication from the child, they tend to ignore the situation. Because of family pressure, they may not accept the situation and come out in the open about it.

Then, after a long time, the parents begin to accept that the child has an issue and that they need to do something about it, and they reach out for help. They then go to vision and hearing specialists.

Like the immunisation schedule for babies, a system of early identification of disabilities or risk for disabilities should be made part of a mandatory schedule that won't be missed by parents or the government health machinery.

The fact is, soon as the child is born, some of the issues related to hearing can be recognised. Even as of now, there is this Apgar score done soon after birth by doctors to understand the baby's condition immediately after birth. This score can also give us some indications of the issues the child is at risk for, such as for hearing and other issues. But the problem is, the records are not kept properly by the parents, and not followed up with the doctors or paediatric centres the parents take the child to next. So, the at-risk babies are not given appropriate attention, or intervention.

Perhaps, like the mandatory immunisation schedule for babies, a system of early identification of disabilities or risk for disabilities should be made part of a mandatory schedule that won't be missed by parents or the government health machinery.

Once deafblindness is identified in the child, what next? How can we maximise on the child's potential and overall development?

Once the child is recognised to have deafblindness, the earlier we start the intervention, the better it is. Sometimes, we get to start working with babies as young as three months.

We start with the basic things; we start to maximise on the child's residual vision and hearing, through 'play' method and motivate the child to use this residual vision and hearing. We then give stimulation activities involving toys that make sound, toys that enhance sense of touch, smell, etc. Next, we gradually get the child to understand more concepts and take the training from simple to more complex level, give information related to education and other aspects, training on everyday living skills and personal grooming. Each child is assigned an individualised education plan based on her age and current stage of development. And further to this, each activity is split into tasks, and specific objectives are set with time frames.



Tactile sign language has been the age-old mode of communication through which the child is first taught. We realise this - thanks to Helen Keller and movies like 'Black'. However, today, with the advent of accessible technology, is there something more that can be done to break barriers in communication by and with the deafblind?

With tactile sign language, you have the human touch. With technology, we get only the information we feed in. When an interpreter is involved, he has his own mind, and whatever seen or heard and understood by him is directly given to the child or adult with deafblindness. That level of processing and communication cannot be handled by a machine.

Having said that, technology is very important, and in today's life, technology plays a very important and essential role that can make a person with disability independent. But nothing can replace the support of an interpreter.



How does one help the child with deafblindness, and the parents, overcome the initial frustration and despondence, and move ahead in life?

The biggest challenge and the reason for the deafblind child's frustration is in not being able to communicate what she wants, and in finding that the parents or care givers don't understand what she seeks. So, first, we try to teach communication. For instance, if the child wants water, how can she convey it? The untrained child has only one mode of communicating – the child cries. But the parent or care giver might not understand the motive for this crying and may feed the child food instead. This makes the child frustrated and angry and she may start showing temper tantrums. So, when we teach the deafblind child, simultaneously, we teach tactile communication to the parent, so that he or she can communicate with the child.

There ought to be a subject on disability in the school curriculum, with complex aspects of the topic included in the higher classes. This will ensure that every child that passes through the school system understands disability and is sensitive to it.

What are the measures you recommend for sensitising the government, general public, health professionals and even NGOs working in the disability sector on deafblindness and its rehabilitation?

While we have policies in place, we haven't been able to implement it in the right manner, largely because the authorities concerned are not sensitised. Deafblindness has been included under multiple disabilities by the RPD Act 2016. But very few people know about this. In my opinion, the Government should pass regulations and information regarding this to every department under its control; there should be sensitisation at every level. If an NGO provides training, it could be to a limited number of people only. The Government can reach out to everyone.

Doctors, health care providers, and everybody in society must be sensitised about deafblindness. Today, we have entered the era of inclusive education. We believe that every child should go through the inclusive education system. Having said that, there is a huge gap in the human resources required for this. For instance, if the

deafblind child goes into the inclusive education system, then the teacher in the class may not be able to understand the needs of the child and the quality of education imparted to the child will be poor. So, I would recommend inclusion of curriculum on methodology of imparting education to deafblind students in the B.Ed. programme.

Further, there ought to be a subject on disability in the school curriculum, just like mathematics or science, with complex aspects of the topic included in the higher classes. This will ensure that every child that passes through the school system understands disability and is sensitive to it, and the entire country is sensitised to disability.

Every PHC / district hospital must have a detection unit such that every baby gets screened by default and if at risk of disabilities, can be referred to support systems / centres. It's a most valuable stage in the baby's life and must be maximised on.

Some of the highlights are that, we at Sense India have helped around 246 adults with deafblindness come together in the iUdaan network. This is a national network of adults with deafblindness, through which deafblind people from different parts of the country get connected, discuss their issues or come together to take it to the Government. Our Prayaas network has 1563 families connected on it, while our Abhi-Prerna network has 864 educators as members. Not only have our networks grown nationally, they have also developed as strong local and regional networks as well. At present, we have 16 locally registered families' networks in India.

Aided by the advocacy done by us, in the recent general elections, 170 deafblind persons across the country cast their votes. Getting deafblindness recognised as a

Do share with us some of the highlights of Sense International India's successful rehabilitation of children with deafblindness.

disability by the RPD Act 2016 is another achievement for us. Sense India now holds consultative status in the United Nations.

Around 200 adults with deafblindness have been helped into income generating activity by Sense India – into entrepreneurship, banking, software, teaching, office administration, etc. This is what we want for every deafblind person – to be independent, employed, lead a dignified life, and be a contributing member of society. ●



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How I write about disability (and I think you should too)



How may a non-disabled person write about disability such that neither patronising exaggeration is employed, nor divisive vocabulary that perpetuates stigma? YASHASVINI RAJESHWAR has some answers.

As an able-bodied person, writing about disability can be a tricky exercise. You don't know where the line between 'honest' and 'rude' should be drawn, you don't know how forward is too forward, you feel like you are walking on eggshells. Here are a few quick lessons from the last 10 years that dictate how I approach my writing. Some of them are tangible tools while others are changes in mindset, mentality, and attitude. Some are harder than others. All of them need to be followed.



Read

Do your research before you head for your interview. This might seem like really straightforward advice, but it isn't. The more you write on any subject, the more you have the tendency to assume you know what you are talking about. By the 20th food review, a food critic knows what to look out for in a plate. By the 50th movie review, a critic's vocabulary has probably fallen into patterns.



With most forms of interviewing, you feel like you have a sense of the subject, either directly and personally or indirectly and through exposure. As a non-disabled individual writing about disability though, you don't know. The least you can do is read up on the disability before you set out to ask questions. Also make sure you read enough to know the difference in nomenclature (not the euphemisms, the actual terminology). What, for example, is the difference between blind and visually impaired (VI)? (No, these are not used interchangeably. Blind refers to almost 100% or total loss of sight and VI is anything else. Partially sighted is a more self-explanatory way of saying VI).



ASK ANYWAY

Disability is a personal story. It is an individual journey. By definition, this means every individual's story is unique. No Wikipedia page can actually do it justice. Ask questions that only they know the answer to. Try to avoid asking what osteogenesis imperfecta is. That is what the Internet is for. Instead, ask what it feels like, in tangible, everyday terms. Ask them when they knew their lives were changing permanently. Ask them what their support systems were, what their go-to playlist was, at the time. Ask them their story. Ask them questions only they know the answer to.



Disabled person or person with disability?



CLARIFY

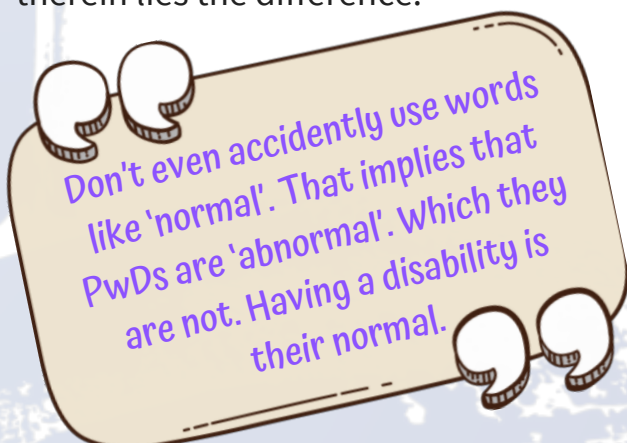
Many times, you need to clarify the details. The publisher you are writing for may demand certain nomenclature (many mainstream newspapers in India insist on 'differently abled' while the international standard is 'persons with disabilities' (PwD). Amongst PwDs themselves, every person has preferences. Check with them how they would like to be identified. Ask them why they feel that way. There is, for example, a big debate in disability writing circles surrounding 'identity first' terminology – should you say 'blind person' or 'person with blindness'? While some believe the former gives due credence to the crucial role blindness plays in the person's identity (think 'tall person,' for example), others think the latter allows for people to look beyond the blindness to focus on the individual (think 'person with the blue t-shirt'). These identity markers are very personal. Always ask. In case your desk has hard and fast rules about terminology, tell them and clarify why it is the way it is.

Disability is a personal story. It is an individual journey, and every individual's story is unique.



THIS IS NOT AN 'US' VERSUS 'YOU' CONVERSATION

Be careful of your vocabulary. We don't realise how the smallest word choices reflect an entire thought process. Avoid phrasing your sentences in ways that suggests that there are two camps – the PwD camp and the able-bodied camp. So, instead of “how do you all feel when you realise you've gone blind?”, try and say, “how does someone who has just then lost his/her eyesight feel?” Don't even accidentally use words like 'normal'. That implies that PwDs are 'abnormal'. Which they are not. Having a disability is their normal. If you want the opposite of PwD, go with able-bodied or non-disabled. It may seem small, but that 'someone' could be any of us and therein lies the difference.

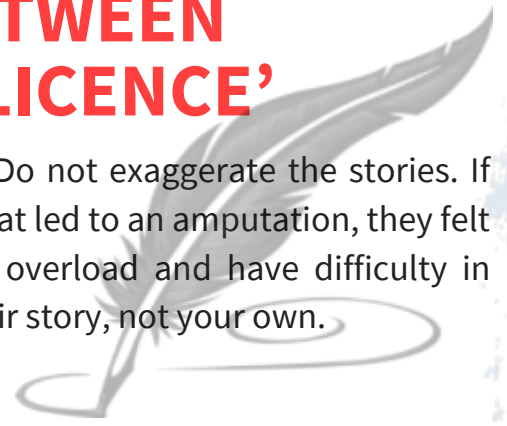


BEWARE OF 'INSPIRATION PORN'

This is a term that has caught the fancy of the Internet, and it is a rather thin line to straddle. When you are pitching a story or writing it, ask yourself why you are writing it or how you are presenting it. Is the only part of this story that is grabbing eyeballs actually peddling disability? Don't fall prey to click-bait titles ('Look how the crowd applauds boy with Down's Syndrome onto stage') or false inspiration ('Blind boy can teach us so many lessons in determination!') Are these stories changing mindsets? Are they focusing on mainstreaming disability? Or are they shining light on behaviour that people should adopt just because they are good people? Ask yourself whether you are including details of disability to add to the pity party, or because you have a larger message to drive home.

KNOW THE DIFFERENCE BETWEEN 'AESTHETIC' AND 'POETIC LICENCE'

The former is okay, the latter is not. This is not a poem. Do not exaggerate the stories. If someone felt numb in the minutes following an accident that led to an amputation, they felt numb. That is all. They did not “freeze from emotional overload and have difficulty in coming to terms with the situation”. It is your job to tell their story, not your own.



GIVE THEM A VOICE

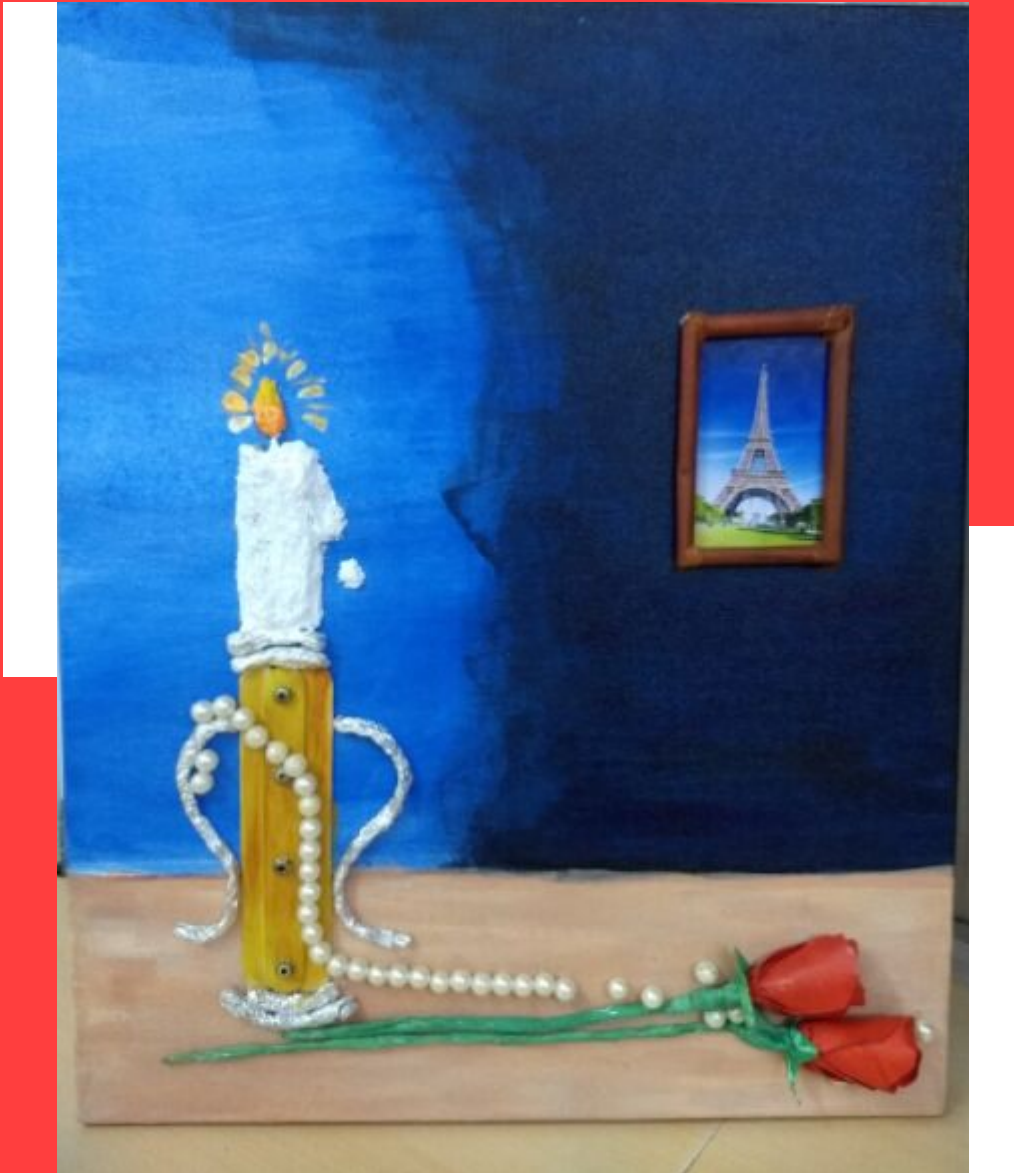
If you are doing an interview, that is an obvious factor, but if you are doing features or opinion pieces about disability, talk to people with disabilities. If you want to understand how accessible theatres are, reach out to a cross-disability audience and ask questions. Again, focus on the story that only they know the answer to. Do not assume that you can extrapolate what a blind person experiences by walking with your eyes closed. If you are writing about or suggesting an innovation/solution/change, ask if that is what they want. Too often, underrepresented communities (including PwDs) are spoken for. You don't get to decide what they want. Ask for their opinion. Represent their voice.



Writing about disability as an able-bodied person is like writing about any other under-represented, marginalised group without belonging to it. Men writing about women, privileged castes/communities writing about Dalit issues... the parallels are endless. This does not go to imply that the stories must not be told or that the articles must not be written. What it does, however, imply is that we must do so with sensitivity, awareness and consciousness of being the outsider. Ask yourself the cardinal questions: Are you perpetuating stigma? Are you adopting divisive vocabulary? Are you exaggerating to suit your interests? Do not assume you know. Always ask those who do. And involve them in telling their story. Remember, you are just the conduit. ●

Too often, under-represented communities, including PwDs, are spoken for. You don't get to decide what they want. Ask for their opinion. Represent their voice.

CREATIVITY UNLIMITED



An evening in Paris

What does vision loss have to do with loss of one's vision? Nothing at all, discovers Aishwarya Pillai, a talented artist and a rehabilitation counselor at LV Prasad Eye Institute, Hyderabad. Take note of her narration, of her journey as a blind painter and the inroads she has made in taking this concept to the visually impaired community.

“Painting has always fascinated me and has been my passion all through my life. Way back in 2008, when I quit painting after losing my sight as a result of a brain tumor, I truly believed that I wouldn’t be able to paint any more. Little did I know how wrong I was! I was then introduced to rehabilitation services at LV Prasad Eye Institute, Hyderabad, and in 2013, I was appointed a ‘Rehabilitation Counselor’ at the same place. Over the years, I became independent and achieved several things which I had earlier thought not possible, as a blind person.

In 2017, I participated in a painting workshop conducted by ‘Anybody can paint’. It was here that I learnt that despite blindness, I could interpret colours based on their meaning. This experience led me to paint two artistic pieces with the help of gun glue, using this as an outline and painting within the circumference. It was at this point that my earlier perception that I wouldn’t be able to paint without sight perished and I proved myself wrong.

In 2018, I visited an art gallery; to my disappointment, I could not experience any of the artistic works on exhibit there, as all of them were two-dimensional. This was when the idea of tactile paintings entered my mind.

I personally believe that art is a form of expression and that it should be experienced by everyone, including blind persons. With this thought in mind, I started exploring different tactile material that I could use in



A tranquil moment



Caribbean Feast

my paintings. The first painting I did was called ‘Happy blossoms’. It is a painting with a blue background (conveying grief) with four big yellow flowers (representing happiness). I used dry leaves for the petals and beads for the centre of the flowers. The message this painting communicated was that, despite sadness, happiness would always bloom.

Soon after, I wanted to use different forms of tactile material. That’s when I started using aluminum foil. With this, I found that I could not only shape round it, but also glue white paper around it. With this innovation, I was able to create four more tactile paintings, namely, ‘An evening in Paris’, ‘Caribbean feast’, ‘Great expectations’ and ‘A tranquil moment’.



Great Expectations

Aishwarya Pillai with 'Happy Blossoms'



So much was my enjoyment of this new-found accessible art that I wanted others to experience this as well. This thus culminated in two workshops that I conducted at the Institute for Vision Rehabilitation.

The first workshop, a theory session wherein I explained the meaning of colours, usage of different tactile materials like beads, aluminum foil, paper, coffee cups, etc., and the process of rendering art on canvas using tactile materials, using brush strokes, gluing material and the usage of garbage bags to cover the areas one doesn't want to be exposed to paint.

At the next workshop, the participants themselves came up with their own ideas and themes. They were provided with material and volunteers' assistance.

Art is a form of expression and it should be experienced by everyone, including blind persons. With this thought in mind, I started exploring different tactile material that I could use in my paintings.

They created their masterpieces which were not only a visual treat, but tactual too. 'The fullmoon night', 'Hillside secret', 'Bloom room', 'You and I'... Not only were the titles interesting, the colors used were vibrant and attractive. All the participants were extremely elated for having created paintings for the first time ever in their lives.

In order to spread awareness among the community about this creative side of theirs, an exhibition was organised in June wherein visitors, both blind and sighted, enjoyed the artwork under one roof. Plans are now afoot to organise more such workshops in the near future. The response so far has been tremendous. ●

16 வகை அனைத்தும் சிறந்த சுவை

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

